

**EXPERIENCES OF SPOUSES CARING FOR THEIR DEMENTIA OF ALZHEIMER'S TYPE  
PARTNERS: A SOUTH AFRICAN PERSPECTIVE**

by

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**Key terms:**

Dementia of Alzheimer's Type, activities of daily living, phenomenology, interpretative phenomenological analysis, spouse caregiver, retrogenesis.

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### **Abstract**

Dementia of Alzheimer's Type is a degenerative neurocognitive disease accounting for majority of Dementia's. It affects millions of people worldwide and thousands of people in South Africa. Apart from the economic burden this illness places on the country, it has detrimental effects for those who provide care for individuals with this illness, who are mostly spouses. The spousal caregivers bears great financial, social and emotional burden which worsens as the disease progresses. The aim of this study is to phenomenologically explore and describe the lived experiences of spousal caregivers in caring for the spouses with Dementia of Alzheimer's Type. This South African study was therefore qualitative in nature and was conducted in the province of KwaZulu- Natal, in the city of Pietermaritzburg. Eight participants were interviewed using a semi-structured questionnaire. Data was analysed using interpretative phenomenological analysis (IPA). The main findings of this study are the negative emotional affects that the caregiving role creates. Caregiver stress and strain is experienced as well as the experiences of various losses including lack of intimacy and ruined expectations for the future as the disease progresses. The caregiving role also created negative implications for the social lives of caregivers and coping mechanisms were seen to be very important.

Keywords: Dementia of Alzheimer's Type, activities of daily living, phenomenology, interpretative phenomenological analysis, spouse caregiver, retrogenesis

**THE EXPERIENCES OF SPOUSES CARING FOR THEIR DEMENTIA OF  
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## **Chapter 1: Introduction**

### **1.1 Rationale of the study and problem formulation**

Dementia refers to a progressive loss of one's memory (Poirier & Gauthier, 2011) and Alzheimer's disease is seen as part of the large family of the various Dementias. The disorder contributes greatly to interdependency and disability (Prince, Bryce, Albanese, Wimo, Ribeiro & Ferri, 2013) and also produces a sense of vulnerability in the care recipient (Hill, 2015).

Dementia of Alzheimer's Type is the most common with sixty to seventy percent of known and medically diagnosed cases (Poirier & Gauthier, 2011). Dementia of Alzheimer's Type has been very often dismissed as being part of old age. However, over the last decade or two this disease has recently come to the fore (Weiler, 2010). In some countries Dementia is therefore receiving more attention by society, health care professionals, social care professionals and policy makers than previous years (Ablitt, Jones & Muers, 2009). Countries in Europe, for example Netherlands and the France have very powerful Alzheimer's societies where campaigns are regularly implemented in order to raise public attention on Dementia (Moniz-Cook & Manthorpe, 2009). This disease impacts on relationship in such ways to cause declines in communication and overall happiness of individuals (Ablitt et al, 2009).

From a worldwide perspective, there is a large increase in the amount of people that are aged sixty and over (Pillay & Maharaj, 2012). This is further shown by Pillay and Maharaj (2012) as in the year of 1980 the ageing population was 378 million, three decades later this figure doubled to 759 million and in terms of the future, the ageing population is expected to rise to two billion people. Turkington and Mitchell (2010) state that in the year 2008 there were approximately 507 million older people that were over the age of sixty five in the world. The bulk of these individuals were found in developing countries. By the year 2025 it is expected that at least seventy percent of the world's population that are aged over sixty will be residing in developing countries (Turkington & Mitchell, 2010). These authors further add that Asia, Latin America and Africa will see the biggest rise in the ageing population. Similarly, Pillay and Maharaj (2012) state that amount of the ageing population in developing countries will quadruple from the year 2000 to 2050. Taking this into account, the African continent will be mostly affected as most countries in Africa fall within the less and least developed categories (Pillay & Maharaj, 2012).

In comparison to developed countries, the older population in developing countries is growing at a faster pace. Pillay and Maharaj (2012) state that the population of Africa is growing at a rate of 2.27 percent and the fastest growth of the ageing population will occur on northern and southern Africa (Pillay and Maharaj, 2012). In terms of growth of Dementia in South Africa, Clarke, Wilkinson, Keady and Gibb (2011) reveal that South Africans aged sixty and over will rise to fourteen percent by the year 2050. In South Africa, there is an estimate of 250 000 elderly individuals with Dementia and an estimate of 35 000 individuals with Dementia of Alzheimer's (Potocnik, 2013). South Africa is therefore experiencing a growth in the number of older people (Munthre & Maharaj, 2012).

One of the reasons that there has been an increase in the ageing population is due to medical advancements and medicines which have increased the life expectancy of individuals (Lu & Bludau, 2011). Furthermore, these authors state that baby boomers that were born in the decade after World War II have now become the ageing population. However, currently the worldwide fertility rate is projected to decrease from five children per woman in 1950-1955 to 2.6 children in 2045-2050 (Pillay & Maharaj, 2012). This trend is also seen in less developed countries where the fertility rate is projected to decrease from 6.6 and 6.4 children in 1950-1955 to 2.6 and 2.3 in 2045-2050. Similarly, Munthre and Maharaj (2012) attribute the increase of older people to the decline in fertility. They state that more than one in eight persons are aged fifty and over and nearly seven percent are aged sixty and over. The effect of a decrease in the fertility rate in less developed countries in the African region together with decrease in the mortality rate will create an ageing population for the future (Pillay & Maharaj, 2012).

With the increase in ageing in South Africa, the risk of developing Dementia of Alzheimer's Type disease becomes more prevalent. This is confirmed by Scherder (2012) who states that prevalence of Alzheimer's disease increases with age. Age is therefore seen as the main precipitating factor of Alzheimer's disease. According to this author, ageing results in changes in the central nervous system. This makes the central nervous system more vulnerable to neurodegenerative diseases like Alzheimer's disease.

With an increase in Dementia of Alzheimer's Type there is a need for a greater amount of informal caregivers that need to provide the necessary care. Due to this neurodegenerative disease, the individual suffering requires constant care. In addition to the memory loss associated

with Alzheimer's disease and various cognitive dysfunctions Dementia of Alzheimer's Type patients also experience various behavioural and emotional problems as well as conditions where the need for constant special personal care and supervision is of utmost importance (Croog, Burleson, Sudilovsky & Baume, 2006). The majority of the adults with Alzheimer's disease are cared for in a home environment by unpaid family caregivers (Quinn, 2013) as many terminally ill older individuals prefer to be cared for in their own homes as opposed to been placed in a nursing home (Visser, Klinkenberg, Van Groenou, Willems, Knipscheer & Deeg, 2004). Taking this into account informal caregivers are placed with the huge responsibility as they have to provide care more often and for a longer duration (Visser et al, 2004).

With regards to caregivers, six in ten caregivers provide care to an elderly family member or friend and one fifth of caregivers providing care for five years or more (Dupuis, Epp & Smale, 2004). They further add that, "the median length of in-home caregiving before nursing home placement is 6.5 years." (p. 15). Dupuis et al. (2004) also add that in terms of hours in a week, an average of sixty hours per week is spent on caregiving activities. Caregivers who reside with the care recipient provide more hours of caregiving tasks than those living in a separate residence (Dupuis et al, 2004). Without this valuable support from informal caregivers the thought of Dementia of Alzheimer Type patients remaining at home remains an impossibility (Visser et al., 2004). This therefore emphasises the important role played by the informal caregivers.

Spousal caregivers are a very special group of informal caregivers. The relationship with the individual with Dementia of Alzheimer's Type is one of intimacy and special commitments (Croog et al., 2006). Furthermore these authors add that spouses have a responsibility associated with their bond of marriage. Due to the level of the longstanding relationship experienced by the spousal caregiver and the Dementia patient, the experience of giving and receiving precedes the onset of Dementia (Ablitt et al., 2009). The relationship between the spousal caregiver and the spouse is therefore seen as very important and can greatly affect the caregiving situation. For example Ablitt et al. (2009) describe that a lower relationship quality results in a lower emotional well-being in both the carer as well as the spouse with Dementia. The caring role is therefore experienced negatively leading to feelings of frustration which further decreases the quality of the caregiving relationship. The relationship prior to the diagnosis of Dementia of Alzheimer's

Type is therefore seen as very important for the spouses as this influences the approach they take to the caring role (Ablitt et al, 2009).

According to the Family Adjustment and Adaptation Model developed by Patterson (1988), family members dealing with chronic illnesses experience a continual cyclical adjustment crisis adaptation process. Throughout this process, family members are always trying to maintain a balanced level of functioning by creating and using their current resources and coping mechanisms to deal with the demands of their situation. Due to family members having different perspectives of both the demands of the situation and their coping mechanisms, the way in which they respond to the situation will be different (Patterson, 1988). Taking this into account, the less aware people are of Dementia of Alzheimer's Type disease, the less coping mechanisms they possess and the more distressed they become.

To make caregivers more aware of the disorder, non-profit organisations such as Alzheimer's South Africa are available to provide the necessary assistance. Kalula and Petros (2011) also add that individuals are also prone to neglect and abuse in households where families are not supported. They further add that, "the policy on ageing in South Africa promotes deinstitutionalisation and limits state subsidised residential care to no more than two percent of frail older persons who are in need of 24-hour nursing care" (p. 36). Potocnik (2013) also adds that in South Africa there seems to be a move away from residential institutions. Fewer beds are available and this comes at a very high price, therefore many family caregivers have to rely on their own resources. With this been said, more individuals with Dementia of Alzheimer's Type will have home-based care and therefore the number of family caregivers can also be expected to increase. This however can pose a problem as distress found amongst caregivers due to their caregiving role is one of the most important predictors of institutionalisation (Lawlor, 1995). Caregivers are found to place their relative in an institution when depression or anxiety arises (Lawlor, 1995). This is also confirmed by Croog et al. (2006), in that due to the burdens associated with caregiving, caregivers move the Dementia of Alzheimer's Type patient from the home environment to a nursing home. This therefore means that caregivers will experience different levels of distress while caring for their spouses at home if they are unable to place their spouse in a nursing home.

Furthermore, if a caregiver does choose to place their spouse in a nursing home they experience high emotions and financial costs (Croog et al., 2006). This is another important aspect to consider regarding the caregiving role. In Europe the costs towards Dementia amounts to fifty two billion euros a year. This is a startling amount and does not even include the losses in productivity and the economic impact of the disease on the informal caregivers (Poirier & Gauthier, 2011). These authors state that there are also costs associated with the work missed by the caregivers who are employed.

Caring for a spouse with Dementia can be viewed as stressful. Emotional stress will continue for as long as the disease progresses. According to Weiler (1987) research shows that for every American suffering with Dementia of Alzheimer's Type there are possibly up to three times the number of close family members that are impacted by the caring role. This impacts them emotionally, physically and financially. Due to Dementia of Alzheimer Type patients' brain failure, this eventually leads to the point where total care will be required by the caregiver who will eventually assist in all basic activities like dressing, bathing and eating (Weiler, 1987). The care shown by the caregiver is constant and they do not get complete relief even when the decision is made for the patient to be placed in a nursing home.

The stress experienced by caregivers is emphasised by Alpert (2014) as he states, "the situation can be viewed as an unrelenting chronic stressor, which ultimately has a negative impact on the caregivers psychological, physical and behavioural being, which can ultimately lead to poor health and less than optimal quality of life" (p. 1). Keeping this statement in mind Kalula and Petros's (2011) finding that lack of awareness and chronic stress leads to distress. Therefore, the current study aims to understand the experiences of the caregiver as they care for their Dementia of Alzheimer's Type spouse.

In South Africa, Kalula and Petros (2011) carried out research in an isiXhosa speaking township in the Cape Town area which found that there was little awareness or even understanding about Dementia. Lack of awareness in South Africa is attributed to minimal media coverage regarding Dementia. As such the only major form of media coverage is linked to a day in the year (21st September) which is World Alzheimer's Day. Kalula and Petros (2011) state that an absence of understanding can lead to stigmatisation and misunderstanding in relation to Dementia. The behaviour of individuals that possess Dementia is poorly understood and this not only leads to

stigma and blame but also leads to distress in the caregiver. This is also consistent with Clark et al. (2011) as they describe research undertaken in Cape Town, South Africa. The finding of this research was a lack of awareness regarding Dementia amongst the black and coloured communities.

Understanding spousal caregivers' experiences can potentially lead to better ways of helping them cope. Studies show that caregivers experience less stress if they are flexible and able to cope with stress (Alpert, 2014). The current research is to focus on understanding the experiences of caregivers as they care for their Dementia of Alzheimer's Type partners within the context of South Africa.

## **1.2. Problem Statement**

From these introductory remarks, a research problem was derived. The research problem is the foundation of this research and will direct the research from here on.

The problem statement for this research was postulated as follows:

Due to the increasing number of the ageing population, there is a direct increase in diseases such as Dementia of Alzheimer's Type (Potocnik, 2013). The majority of those suffering from this neurodegenerative disease are cared for by their spouse (Vikstrom, Josephsson, Stiggsdotter-Neely & Nygard, 2008). Due to the various stresses and demands of the caregiving situation, spouses experience a continual cyclical adjustment crisis adaptation process (Patterson, 1988). This in turn negatively affects the spouses' mental, emotional and physical health (Alpert, 2014).

Therefore the goal of this research was to describe and explore the experiences of spouses within the city of Pietermaritzburg, KwaZulu-Natal, South Africa as they care for their Dementia of Alzheimer's Type partner.

## **1.3 Research question**

The research question for this research was as follows:

What are the experiences of spouses as they care for their Dementia of Alzheimer's Type partner?

## **Chapter 2: Literature review**

### **2.1. Definition of Dementia**

Derived from Latin origin, *de* meaning “from” and *mentis* meaning “mind” (Kaplan, 1996) dementia is a term that is used to describe a variety of disorders of the brain that usually result in progressive and severe loss of memory (Cayton, Graham & Warner, 2002). There are over a hundred forms of Dementia.

For the individual to be diagnosed with Dementia there should be verifiable evidence of the severe impairment of short-term and long-term memory (Thompson, 2006). Thompson (2006) adds that impairment to an individual’s short-term memory is shown, briefly, by an inability to remember three objects within a five minute period. On the other hand, impairment of long-term memory is indicated by an inability to remember personal information from one’s past or facts of common knowledge (Thompson, 2006). It is also important to know that there are certain conditions that appear to imitate Dementia. These conditions include alcohol and drug abuse, minor head injuries, depression as well as a lack of nutrition (Biernacki, 2001). Dementia can also be triggered by a variety of other disorders, which can be reversed if diagnosed and treated early. A few of these conditions are brain tumours, reactions and other metabolic diseases (Kaplan, 1996). Sometimes delirium is often confused as been Dementia. This is due to the very similar symptoms of confusion, disorientation and impaired memory. However, the difference between the two being that unlike Dementia, delirium causes a state of consciousness that shifts between restlessness and drowsiness (Kaplan, 1996).

#### **2.1.1. Dementia of Alzheimer’s Type**

Cayton (2007) states that, “Alzheimer’s disease is seen to be the most common form of Dementia accounting for about half of all cases” (p. 4). This is also confirmed by Thompson (2006) who states that Alzheimer’s disease accounts for more than fifty percent of cases of Dementia in those who are over the age of sixty five. The following is quoted by Chapman and Marshall (1993) who explains the reason why Dementia of Alzheimer’s Type is increasing, “The baby bulge born at the turn of the century and before the Great War are now very old and from 65 onwards, the proportion of people in each age group grow with dementia doubles every

year” (p. 5). The disease is a detrimental and fatal condition resulting in the impairment of the brain and eventually the death of the individual (Granello & Fleming, 2008). Alzheimer’s disease is characterised by the slow yet progressive decline in cognitive functioning which begins with the loss of short-term memory. People may encounter difficulty in recalling recent events and numbers (Biernacki, 2001).

Memory is therefore seen as the main loss associated with Dementia of Alzheimer’s Type. Kelsey, Newport and Nemeroff (2006) state that if it is only memory that is affected then the disorder is not seen as Dementia but rather it is amnesia. These authors emphasise that there are other losses associated with Dementia. One of these losses is the use of language (aphasia). Language can be disrupted when the individual is not able to construct sentences to the point of being unable to converse with others. Kelsey et al. (2006) also describe the loss of co-ordinated physical ability (apraxia). For some Dementia patients, gait apraxia is apparent which involves a complete loss of mobility. The ability to recognise family members (agnosia) is another loss associated with Dementia (Kelsey et al., 2006). The loss of planning and being able to carry out complex activities (executive functioning) is a further loss which begins in the early stages. The loss of executive functioning is apparent when the Dementia patient cannot complete activities in the order that they are meant to be completed. These symptoms of Dementia not only divide families but they can be extremely exhausting for the caregivers to the point where institutionalisation becomes an option.

Craig, Meiland, Passmore and Drees (2010) find that the main difference between age-related cognitive decline and that of dementia is the clear impairment in activities of daily living (ADL) which can be basic such as eating and dressing oneself or it can be instrumental such as handling money or using a telephone. Other features of the disorder are disorientation and self-neglect and even psychiatric symptoms such as depression, apathy and psychosis (Aziz, Leelavathi, Tohid & Hamzah, 2009).

## 2.2. Prevalence, incidence and age

Prevalence is defined as how common a condition is in the community (Rabins, Lyketso and Steele, 2006). Dementia is typically found to be a condition that affects older people as the main risk factor for Dementia is seen to be one's age (Craig et al., 2010). Even though one's age is seen as a risk factor the disease can also affect people as young as thirty, however, this is not found to be common (Cayton et al., 2002).

The statement that Dementia affects older people is supported by Montgomery and Williams (2001). These authors found that in a national survey in 1993 in the United States of America nineteen million individuals reported a family member with the disorder and thirty seven million knew someone with Dementia of Alzheimer's Type. Nearly one-half of adults over eighty five years of age suffer from this disease. Among people aged over sixty five years old, the prevalence of moderate to severe dementia is estimated at between 1.3 and 6.2 percent (Thompson, 2006).

One of the reasons for an increase in Dementia is due to lowering birth rates and this directly results in a higher proportion being aged sixty five and older (Bowie & Takriti, 2004). Disease eradication programmes and the availability of public health care also greatly increased the life expectancy in the second half of the twentieth century. Therefore from 1900 to 1950 people in the developed countries were able to add twenty years or more to their life expectancy (Bowie & Takriti, 2004). Incidence is defined as the number of new cases of a disorder in a given period of time (Rabins et al., 2006).

From a worldwide perspective regarding the incidence of Dementia, more than thirty million people worldwide are currently living with Dementia. This figure, however, is expected to rise to one hundred million by the year 2050, when more than one in five individuals will be over the age of sixty (Rabins et al., 2006).

From a South African perspective, it is anticipated that by 2030 the proportion of the South African population aged sixty and over will rise to eleven percent, this is directly related to a rise in Dementia (De Jager, Joska, Hoffman, Borochowitz & Combrink, 2015). Similarly Vally (2010) states that South Africa's population is rapidly ageing and a large proportion of ageing individuals who are likely to develop Dementia can be expected over the next forty years. There

is very little known about the prevalence of Dementia and the impact on older individuals. De Jager et al. (2015) describe a research undertaken by the University of the Free State and the 10/66 Group. In this research, Dementia in the urban black community was investigated. The results of this research found that was a six percent prevalence of Dementia in a small sample of two hundred older people.

There is therefore a very critical need to investigate these factors in South Africa as the research on prevalence and risk factors is needed to estimate the public health burden of Dementia (De Jager et al., 2015).

### **2.3. Diagnosis of Dementia of Alzheimer's Type**

Detection of Dementia in the early stages is very important as this will allow the individual to access specialist services such as doctors and neurologists and it will also allow them and those close to them to start planning for a future living with Dementia (Biernacki, 2001). In these early stages, there should be encouragement to seek help rather than to put memory difficulties down to old age (Bierbacki, 2001).

Disclosing the diagnosis can also be an issue. According to Biernacki (2001) disclosing the diagnosis could bring on anxiety and distress which will in turn create worry amongst the family as to how to cope with the distress. Disclosing the diagnosis could also trigger depression and even suicidal thoughts but there is no evidence to support this. However, although there are these fears of disclosing the diagnosis, there are also advantages to this. Biernacki (2001) highlights the following advantages:

- It is “the universal right of the individual to medical information about themselves and the obligation of professionals in possession of that information to pass it on to the individual (p. 58).”
- Disclosing the diagnosis also allows the individual to settle outstanding issues and problems in life and to consider the future and to also make practical arrangements when it comes to finances as well as accommodation.
- Disclosing can also help the individual to come to terms with Dementia as knowledge of the disease will offer the opportunity to come to terms with the diagnosis and begin to live with the disease.

- Disclosing the diagnosis will also allow the individual to seek help or treatment.

Through the use of mental status evaluation and neurological tests which evaluate language, memory, reasoning and physical condition an individual can be diagnosed with Alzheimer's disease (Granello & Fleming, 2008). These authors state that diagnosing Dementia of Alzheimer's Type tends to be a difficult task as low-level confusion and memory loss is very similar to what is experienced as part of the ageing process. People who have memory difficulties need to be encouraged to seek advice early as this will enhance the possibility of early diagnosis and treatment (Biernacki, 2001). According to Vally (2010) when cognitive deficits are severe enough to cause impairment in occupational or social functioning and when there is a decline from previous higher level of functioning, then Dementia of Alzheimer's Type is diagnosed according to the Diagnostic Statistical Manual of Mental Disorders Fifth Edition (DSM-5) (Black & Grant, 2014) (*See Appendix F*).

Gallo and Paveza (2006) describe the Revised Memory and Behaviour problem checklist as a diagnostic tool for Dementia of Alzheimer's Type. Observable problem behaviours are assessed and the checklist also takes into account the caregivers responses and assesses the caregiver's distress (*See Appendix H*).

In terms of diagnosis some individual's exhibit psychosis which includes paranoid delusions (Kelsey, Newport & Nemeroff, 2006). Psychosis can often lead to violent episodes as the care recipient might mistake their family member for an intruder. Individuals displaying psychosis feel that their family members have turned against them and this makes them more paranoid (Kelsey et al., 2006). These authors also describe personality changes which can aid in diagnosing an individual with Dementia of Alzheimer's Type. Personality changes include withdrawn, introverted behaviour which is a change from one's personality previously.

#### **2.4. Stages of Dementia of Alzheimer's Type**

According to Kovach (2012) there are three stages of Dementia. These stages are the early stage, mid-stage or moderate stage and late or severe stage of Dementia.

The following are characteristics of each stage as outlined by Kovach (2012). In the early stage memory loss, time, spatial disorientation and poor judgment become more prominent and observable. The individual with Dementia of Alzheimer Type's visuo-spatial skills are affected, and whilst driving the individual with Dementia may become lost in a surrounding that should be very familiar. In terms of language, the disturbance starts with a low level of word list generation and progresses to anomia (disorder causing problems with recalling words or names of everyday objects). Delusions of a persecutory nature are also common at this stage. In the early stage, Dementia patients should not be living alone however twenty- four hour supervision is not required (Kelsey et al., 2006). The loss of grooming is also seen as one of the early signs of Dementia, however, this is probably associated to forgetting how to take care of themselves (Turkington & Mitchell, 2010). Similarly, Shamy (2003) refers to this stage as the forgetfulness stage. According to this author, other characteristics of this stage include the inability to complete mathematical problems, constantly forgetting appointments which were made and a zest for life is no longer displayed.

In the mid or moderate stage of Dementia, those with Dementia are disoriented to place and time and may no longer recognise family members. Their conversations become empty and apraxia (the inability to execute learned, purposeful movements) affects the ability to perform activities of daily living (ADL). Wandering and pacing become more evident as well as hallucinations. According to Kelsey et al. (2006) at this point the care recipient needs help dressing and to maintain their personal hygiene. Furthermore, having a conversation at this stage becomes very difficult. Shamy (2003) also refers to this stage as the confusional stage. Further characteristics of this stage include aggression and agitation.

In the late/severe stage of dementia, the individual becomes bound to the bed and this progressively worsens and the individual develops increased rigidity. Their appetite decreases and due to apraxia the patient loses the ability to ingest food. Weight loss is also inevitable. Some individuals with late Dementia are unable to communicate, others become mute whilst others scream repeatedly. Their sleeping cycle is also very disturbed as forty percent of time in bed is spent awake with many of the daytime hours spent sleeping. Infections such as pneumonia or urinary tract sepsis may result causing death in the patient. Kelsey et al. (2006) also state that

at this stage there is loss of control of their bowels and their bladder. Furthermore, other present illnesses and their treatment can overstress incontinence (Coon, Gallagher-Thompson & Thompson, 2003). An example of this is diuretics. With the impaired mobility which develops at this stage and other muscular problems, this leads to an even greater impact on incontinence (Coon et al., 2003).

Furthermore, nursing homes become an option in this stage. This is also consistent to Coon et al. (2003) as they describe incontinence as a reason for nursing home placement. Caregivers are unable to manage this process and the costs associated with this together with skin problems formed from incontinence motivate them to consider nursing home placement.

The characteristics of the last stage in Dementia are also consistent with the Dementia stage described by Shamy (2003). However at this stage Shamy (2003) describes the immune system as compromised thereby making the patient vulnerable to infectious diseases. Chapman and Marshall (1993) state that all individuals experience these stages differently and the speed from one stage to another is different for everyone.

## **2.5. Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL)**

Assessing the functional capabilities is an area which is important for the individual with Dementia of Alzheimer's Type and also the caregiver. This is beneficial for the caregiver because when there are changes in a person's capabilities, appropriate resources can be looked into to remedy the situation (Gallo & Paveza, 2006). Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) fall under an individual's functional capabilities. To understand how Dementia impacts an older person and the family, functional assessment is the cornerstone (Gallo & Paveza, 2006).

Activities of Daily Living are seen as the foundation to independent living. Some aspects of ADL include dressing, bathing and eating (Gallo & Paveza, 2006). These authors describe the Katz Index of ADL which was published in 1963. The Katz Index of ADL allows one to assess the ability to live unaccompanied. In the event that there is a shortcoming, a remediation will then be found. This intervention will be focused on the ADL where the individual is lacking, thereby also assisting the spousal caregiver.

Gallo and Paveza (2006) state that if an intervention is created for the Dementia of Alzheimer's Type individual but they are still unable to adequately perform on or more of the ADL's, they are more likely to be hospitalised or placed in a nursing home.

On a more complex level, Gallo and Paveza (2006) describe IADL. These activities are more demanding in nature. It includes skills like using the telephone, travelling, preparing meals and shopping to name a few. If these tasks cannot be performed, these tasks will then need to be undertaken by the caregiver (Gallo & Paveza, 2006).

## **2.6. Formal care services**

### **2.6.1 Respite programmes**

Respite programmes which assist the caregiver include services like adult day care, in-home services and institutional respite. Some caregivers' experience role captivity as they progress in their caring role, as such a feeling of been trapped in their situation which often leads to psychological ill health and caregiver burden (Brodaty & Donkin, 2010). Respite functions to alleviate role captivity can in turn prevent negative effects associated with caregiving (Gottlieb & Johnson, 2000). The aim of respite programmes is therefore intended to provide relief to the caregivers (Stephens, 1993).

The most widely used respite programme is centre-based day programmes, as this offers care for a certain amount of hours per week, however, this will depend on availability of space for the care recipient (Gottlieb & Johnson, 2000). In-home respite provides relief to the caregiver in the home of the care-recipient. Once again a scheduled amount of weekly hours per week of care is provided. Gottlieb and Johnson (2000), finally, describe institutional care which offers short-term stay in situations when the caregiver becomes ill or when the caregiver goes on holiday.

Comorbidity and increasing frailty increase as Dementia progresses, therefore health, social, home and community care services are required (De Jager et al., 2015). In terms of the environment in which the Dementia of Alzheimer's Type patient finds him/herself, it needs to be able to support the remaining ability of the individual and not allow it to be disintegrated. The environment therefore also needs to support the development and maintenance of relationships (Innes, Kelly & Dinscarslan, 2011).

According to Rabins (1998), most individuals reside at home, however as Dementia of Alzheimer's Type becomes progressively worse it becomes difficult to be managed by family members. There are two options that are available to caregivers when this difficulty arises. The options available to the caregiver are nursing homes and assisted-living facilities (Miller-Day, 2011). Miller-Day (2011) defines nursing homes as facilities that have three or more beds and routinely provide nursing care services. By placing a loved one in a nursing home, powerlessness arises in the caregiver as they no longer play a role in decision making regarding their activities of daily living.

Ultimately, individuals are admitted to nursing homes because their families can no longer provide the appropriate level of care needed or because there is no other family member available to provide care (Rabins et al., 2006). This is also consistent with Light and Lebowitz (1990) as they state that the journey of the caregiver is a prolonged and strenuous process as they try to keep the individual in the community. Due to all non-institutionalised Alzheimer's patients residing with a caregiver, caregiver strain increases as Dementia of Alzheimer's Type progresses. It is only when this becomes overbearing for the caregiver, that they decide to place their family member in a nursing home. A reason why the journey for Alzheimer's caregivers becomes overwhelming is due to the cognitive impairment which takes place in their spouses. It is this cognitive impairment which is an important factor leading to admission in a nursing home (Hope, Keene, Gelding, Fairburn & Jacoby, 1998). These authors add that psychological functioning, incontinence and aggression are seen as some of the cognitive impairments found in patients.

Furthermore, Hope et al. (1998) add that the caring environment can also play a role in admitting the spouse to a nursing home. An example of this is the death of the principal caregiver. Another reason for institutionalisation is due to the use of formal services such as day-care or overnight respite care. Spruyette, van Audenhove and Lammertyn (2001) add that these formal services are intended to delay institutionalisation but instead there is evidence suggesting that it creates institutionalisation. The relational dynamics between spouse and caregiver is also an important factor to consider for institutionalisation as it was found that poor relationship quality was predictive of a caregiver's higher preference for institutionalisation (Spruyette et al., 2001). These authors therefore state that the relationship quality between family caregivers and their

patient's needs to be taken into consideration to improve the quality of life. Even though there are the factors of caregiver strain, cognitive impairment and the caring environment often make it necessary for nursing home placement. Spruyette et al. (2001) add that majority of older people prefer to live as long as possible in surroundings which are familiar to them.

Feelings of guilt and shame of the family members begin to surface as the decision to handover care comes to the fore (Kraijo, Brouwer, De Leeuw, Schrijvers & Van Exel, 2011). This guilt can also be due to family responsibility and societal expectations (Miller-Day, 2011).

Furthermore, Turkington and Mitchell (2010) describe guilt experienced by caregivers who believe that they should visit their family member every day and when they do not they feel guilty. In a study by Chene (2006) twenty carers were recruited from an aged care facility based in northern Melbourne in Australia. In this study guilt and shame was experienced by family carers in relinquishing care of their loved one. The participants felt the painful emotions of loss and sadness after having made the difficult decision of relinquishing full-time care. In the study by Kraijo et al. (2011) which was undertaken in the Netherlands, it became clear that caregivers wanted to retain control of the care process for as long as possible. In the study by Chene (2006) handing over care was something that the majority of participants did not want to do as they viewed the nursing homes as depressing. The idea of having control of the situation is further emphasised by Chapman and Marshall (1993) as they add that carers need to feel a sense of control, by having professional help it means letting go of that control and in turn this makes them feel diminished.

Rabins (1998) also adds that placing a relative in long-term care is distressing for most individuals and therefore many decide to delay the decision for as long as possible. Vally (2010) argues that it is a better option to delay institutionalisation for as long as it is within the caregiver's capacity to do so as the life expectancy of the individual with Dementia is longer when not institutionalised.

Having to trust others with care was a theme which was produced in study undertaken in Australia by Shanley, Russell, Middleton and Simpson-Young (2011). The spouse carers in this study discussed difficulties in having to trust that paid workers will provide good quality care to their loved one. Some carers found themselves constantly at the nursing home, providing care themselves or complaining to management about the level of care. In this study, it was important

for spouse carers to feel they were still seen as the primary caregiver. They also genuinely wanted to be involved in decisions about the care of the person with Dementia. Consistent with research by Shanley et al. (2011) is research undertaken in Australia by Chene (2006). Participants of this research still made great attempts to visit their Dementia relative in the nursing home even if it meant travelling long distances. During this time the carer's spent a lot of time with their relative. This therefore shows the need to still care and be there for their family member.

In another study by Gillies (2012) the carers of this study believed that they were unable to leave their relative alone for any length of time. As Miller-Day (2011) states, "when caregivers in a nursing home interact with residents it is controlling and task oriented and condescending" (p. 367). Placement in a nursing home was also perceived as a place of finality. This was seen as a place where carers would be placing their relative for the final time or it was seen as the place where they would remain for the rest of their lives (Chene, 2006).

The health of the caregiver was also another important factor in the decision to relinquish full-time care. In the study by Chene (2006) many of the elderly caregivers indicated in the interviews that they could no longer provide the daily tasks of caregiving to their family member due to their own health. Due to caregiver burden there is a lowering of patient well-being and this fosters the risk of institutionalisation (Fernandez-Ballesteros, 2003). Similarly, Michon, Weber, Rudhard-Thomazic and Giannakopoulos (2005) state that the health of the caregiver, specifically, the experience of burnout is seen as a strong predictor of institutionalisation.

As the disease of Dementia of Alzheimer's Type progresses, the person may have increasing difficulty finding their way through the home environment (Coon et al., 2003). Coon et al. (2003) state that troublesome behaviours that are generally associated with Dementia, such as agitation, wandering and incontinence may be increased by the demands of the physical and social environment of the home therefore the home environment needs to be adjusted and adapted in order to accommodate these behaviours. This is related to Gogia and Rastogi (2009) who argue that safety precautions need to be taken into consideration in order to improve their quality of life and to also prevent or lessen their potential for accidents for the Alzheimer's patient. According to these authors, a home safety evaluation and recommendations for prevention can be performed by physical and occupational therapists that are professionally

trained in safety assessment. After safety problems have been identified, home modifications should be performed.

From a South African perspective, De Jager et al. (2015) state that the policy on ageing promotes deinstitutionalisation and limits state-subsidised residential care. Therefore not more than two percent of frail older persons who are in need of twenty four hour nursing care are catered for. In South Africa, there have been problems accessing care for older persons in urban areas. This situation is worse in rural areas where more than forty percent of the South African population reside. It is in these areas that service provision is disintegrated and severely under-resourced (De Jager et al., 2015). The promotion of deinstitutionalisation in South Africa is consistent with Spruyette et al. (2001) as these authors add that governments in Belgium are embracing home care rather than promoting residential care for those that are cognitively impaired.

In terms of a diagnostic tool to determine nursing home placement, Gallo and Paveza (2006) describes the Texas Tech Functional Rating Scale for the symptoms of Dementia. This is a Dementia scale which allows one to measure the severity experienced. This can be seen as a valuable tool in predicting when nursing home placement is needed.

#### 2.6.2. Psycho-educational Programmes

Another form of formal service available to the caregiver is psycho-educational programmes which include counselling, psychotherapy and support groups. These programmes are intended to improve the caregiver's abilities to deal with the demands of the caregiving situation (Stephens, 1993). This is also confirmed by Zheng, Hill, Gardner (2013) as they state that these programmes help to teach caregivers skills that will not only help caregivers increase their understanding but also assist in managing the problematic behaviours displayed by Dementia spouses. These interventions are seen as important for the short-term and long-term well-being of the caregiver (Zheng et al., 2013). Furthermore by improving the knowledge of the caregiver, they are better able to manage problem behaviours exhibited by their demented spouse and in turn this delays nursing home placement (Zheng et al., 2013). Therefore these interventions not only improve the well-being of the caregiver but it also improves the well-being of the Dementia patient.

One of the negative aspects of caregiver interventions is the indirect financial costs associated to this. Caregivers who attend support groups or counselling have to travel to where the intervention takes place resulting on money been spent for petrol (Zheng et al., 2013). Furthermore these authors state that time away from work to participate in interventions also leads to indirect financial costs. Telephone based interventions to support the caregiver decrease the travelling but scheduling times for this to take place that will be suitable for all parties, becomes very difficult. Zheng et al. (2013) provides evidence that some caregivers see telephone interventions as helpful but evidence also shows that caregiver stress was not improved by using this intervention.

Another form of support for the caregiver is dyadic interventions which incorporates the caregiver and the individual with Dementia (Zheng et al., 2013). This intervention allows both parties to discuss their planning for the future. The individual with Dementia is therefore able to talk about their illness and also discuss their preferences for care (Zheng et al., 2013). Not only does this intervention create a shared understanding between both parties but it also helps to assist in alleviating the burden with caregiving.

Internet interventions are alternative interventions which can be used by Dementia caregivers. In a research undertaken in the Netherlands by Blom, Zarit, Groot Zwaafink, Cuijpers, & Pot, (2015) an internet intervention called the Mastery of Dementia was tested on family caregivers. The Mastery of Dementia internet intervention was designed to reduce caregivers' symptoms of depression and anxiety. Majority of the caregivers in this research were female spousal caregivers. Results of this research found that caregivers' symptoms of depression and anxiety were significantly reduced after receiving Mastery of Dementia (Blom et al., 2015). These authors state that this type of intervention will also be feasible for older people that have never grown up with knowledge or use of the internet.

Internet interventions for Dementia caregivers have many advantages. This intervention can allow participation at a time which is most suitable for the caregiver and it also prevents travelling thereby saving money. Furthermore internet support may be easier for caregivers to accept because there is a stigma associated with seeking help from a professional health care provider (Blom et al., 2015).

There are very few caregiver interventions towards the later stages of Dementia of Alzheimer's Type however Hospice planning can play a valuable role in helping the family plan for care in a way that also respects the individual with Dementia (Zheng et al., 2013).

### **Chapter 3: The Dementia of Alzheimer's Type spousal caregiver**

#### **3.1. Definition of the caregiver**

Dementia is a neurological disease that greatly affects the life of the individual afflicted and also the lives of the entire family who must gather their resources to provide a high level of care to the person as the disease progresses (LoboPrabhu, Molinari & Lomax, 2006). These authors state that seventy five percent of frail elders residing in the community rely solely on informal resources (e.g. family and friends), while the other twenty five percent rely on a combination of family care and paid assistance.

Kasuya, Polgar-Bailey & Takeuchi (2000) define informal or lay caregiving as “the act of providing assistance to an individual with whom the caregiver has a personal relationship” (p. 199). According to Ferrara et al. (2008) the caregiver is the person who on a daily basis takes care of the patient. The reason why care is given is due to positive and negative reasons. Some of the positive reasons include having a sense of love for their partner or relative, it provides them with some form of spiritual fulfilment and it also provides them with feelings accomplishment (Brodaty & Donkin, 2010). Brodaty and Donkin (2010) describe the less positive outcomes as caring due to the pressures of cultural and social norms.

Navon and Weinblatt (1996) state that the burden of caregiving is often taken on by the spouses who are also elderly. “The most common person to support a person with Dementia in the home is a cohabiting person who is often the spouse” (Vikstrom et al., 2008, p. 253). This is further confirmed by Brodaty and Donkin (2009) as they add that in 2007 there were at least ten million Americans that were providing care for a Dementia of Alzheimer's Type person. From this ten million, spouses were the largest group of caregivers. Caregiving involves the relationships between people and includes the psychological and practical implications (Jansson, Nordberg & Grafstromm, 2001). However there are certain groups of individual's that are more likely to have a spouse available. According to Hill (2015) older people in the rural areas are more likely to be married than urban people therefore the chances of them having a spouse to care for them are greater. In terms of practical implications, the tasks of caregivers are frequently measured by the number of ADL's. Practical implications also refers to the number of hours that they report providing care, their ability to leave the care recipient alone for periods of time, the presence or

absence of other caregivers and the length of time that they have provided care (LoboPrabhu et al., 2006). These authors further state that the tasks of caregiving differ depending on the stage in which the dementia is present. In the last stage or severe stage the patient with Dementia is completely dependent on the caregiver.

### **3.2. Profile of the caregiver**

Research was undertaken in developing countries such as Bangalore and Chennai in India and Nigeria in Africa by the 10/66 Dementia Research Group (2004). In this research it was found that the caregivers are mainly women who live with the person with Dementia. This is similar to a national survey in the United States of America (1996) on family caregiving with 1500 caregivers where it was found that the profile of the caregiver tended to be female spouses that were retired (Schulz, 2000).

Kaplan (1996) states that the older the caregiver, the more likely they are to have their own medical conditions that increase the stress and health risk of caregiving. Due to neglecting their own health problems, Kaplan (1996) states that elderly caregivers are more likely to die than their Dementia partners.

In terms of gender, as a consequence of demographic and societal role expectations in industrialised countries, there are a greater number of woman as caregivers than there are men (Michon et al., 2005). Similarly, Fernandez-Ballesteros (2003) states that caregiving is largely assumed by wives and daughters placing significant burden on woman. According to Fernandez-Ballesteros (2003) this is generally considered their “natural work”. Another possible explanation for woman assuming the role of the caregiver is that woman are responsible for raising children therefore this experience of caregiving makes them more able to care for a spouse in old age. On the other hand, Brodaty and Donkin (2009) describe an increase in men as caregivers over a period of twelve years. These authors state that in 2008 men comprised forty percent of family caregivers in the United States of America. This is a considerable increase from a study done in 1996 by the Alzheimer’s Association where there was an increase of twenty one percent. Furthermore, Brodaty and Donkin (2009) add that in the United Kingdom, men aged over seventy five years are more likely to be caregivers. Caregiving is not seen as a masculine role but due to one’s culture or the role of the husband, this results in men taking on the role of the

caregiver (Hill, 2015). In terms of one's culture, taking care of a woman is seen as having authority over the woman. Furthermore Hill (2015) states that caring for their wife is seen as abiding to their wedding vows and therefore is something that a husband is expected to do. Men who are also not strict in their traditional roles will find the caring much easier (Hill, 2015).

In a study by Adams, McClendon and Smyth (2008) female caregivers reported greater loss of intimate exchange and spouses were more susceptible to loss of self than other relatives were. Female caregivers experienced a greater sense of role overload than males. Burnout also seems to be related to gender of the caregiver, this is correlated to the Swedish study by Almberg, Grafstrom and Winblad (1997) where fifteen females reported a risk for developing or had symptoms of burnout, whereas only two males had symptoms of burnout.

The irony is that although females tend to suffer from depression more than males, they are the ones that actually continue the responsibilities of caregiving over a longer time (Lubkin & Larsen, 2013). These authors add that women also are less likely than men to engage in preventative health behaviours such as resting, exercising or even taking medications while caregiving.

Male caregivers appear to display better patterns of utilising support that is readily distinguished from those employed by their female counterparts (Pretorius, Walker & Heyns, 2009). Males also depend on their daughters more often to assist with caregiving. They are also more inclined to make use of practical support services. On the other hand, females report experiencing greater levels of emotional stress and are therefore more likely to make use of therapeutic services from professional services (Pretorius et al., 2009).

### **3.3. The role of the caregiver**

The patient with Dementia displays very unpredictable behaviour such as wandering and aggression (Michon et al., 2005). These authors state that patients with Dementia need permanent care and this is stressful for the caregiver. In a study carried out by Vikstrom et al. (2008) in Stockholm, Sweden, twenty six cohabiting couples were interviewed. The spouse was the primary caregiver of a partner diagnosed with mild to moderate Dementia. In this study it was found that the responsibility for care in general lay on the caregiver. Some of these responsibilities were bills being paid and groceries being bought. They took the responsibility of

completing necessary day-to-day chores and obligations. Agronin (2008) states that there is a reversal of gender roles as husband and wife have to assume tasks that were once handled by their spouse. This is similar to Lubkin and Larsen (2013) as they add that in role reversal wives that provide care to their husband are required to make financial decisions or performing tasks in terms of home maintenance and it is these tasks that have always been the responsibility of the husband.

The care of the person includes a range of duties from daily management of the individual to handling incontinence (Emmatty, 2009). In a study which took place in Stockholm, Sweden by Jansson et al. (2001) these researchers aimed to understand the various activities spouses have to perform as part of their everyday routine when caring for a partner with Dementia. It was found that all of the people with Dementia needed help with personal hygiene. Similarly, in another study undertaken in Northern Ireland where family carers emotional and coping strategies were explored, the carers reported carrying out tasks ranging from simple to complex and covering all ADL (Chambers, Ryan and Connor, 2001). For example, getting up and putting the patient to bed, daily grooming, toileting and coping with incontinence, giving the spouse with Dementia medication and keeping them company. Some participants of this study reported that the level of physical effort involved in these activities was great and that they experienced fatigue and exhaustion regularly.

According to Stephens, Crowther, Hobfoll and Tennenbaum (1990) when there is an increase in role overload amongst caregivers, there is a decrease in the quality of the spousal relationship and in turn the feelings of stress increase. With the increased stress, the quality of the relationship is also further negatively affected.

### **3.4. Caregiver burden**

It is well known that caregivers of persons with Dementia experience increased mental and physical burdens due to the challenges that they face (Vikstrom et al., 2008). George and Gwyther (1986) defined caregiver burden as the “physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults” (p. 253). Similarly, Kasuya, Polgar-Bailey and Takeuchi (2000) define caregiver burden as the deep struggle faced by the person who cares for an elderly, chronically ill and disabled

family member. Therefore as the caregiving demands are introduced into the caregiving situation, they intensify the burden of the caregiver (Papastavrou, Kalokerinou & Papacostas, 2007). Papastavrou et al. (2007) carried out a study in Cyprus with 172 caregivers. In their study they found that with the demands of the caregiving situation, various strategies such as emotional coping strategies, problem-solving strategies and social support were used to cope but when the caregiving situation became overwhelming they were unable to cope even with the mechanisms available to them. It is then that burden was experienced.

According to Talley and Montgomery (2012) caregiver burden can be broken down into two aspects, this been objective burden and subjective burden. Objective burden refers to behavioural aspect associated with caring. In terms of caring the average number of hours spent providing care for care recipients with Dementia related needs is 56.5 hours per week (LoboPrabhu et al., 2006). This is correlated to a study conducted by the National Alliance for Caregiving and the American Association of retired persons where it was found that a higher percentage of Dementia caregivers provided forty or more hours of care and constant care than did non-dementia caregivers (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999). Brodaty and Donkin (2009) provide similar results in terms of hours of caregiving per week. They further add that caregivers maintained this commitment for more than a year and one third for five years or more. Agronin (2008) also states that Dementia caregiving is seen as a full-time job and can have a huge toll on the caregiver's health including their lifespan. For many woman that are spouse caregivers they are expected to do what is needed and find it difficult to see a limit to the amount of care they provide (Bauer, Maddox, Kirk, Burns, Kuskowski, 2001).

In terms of developing countries, caregiving is also very high. Interviews carried out by seven hundred and six informal carers in developing countries such as Bangalore and Chennai in India and Nigeria in Africa show that an average of between three hours a day is spent assisting Dementia patients with ADL's (The 10/66 Dementia Research Group, 2004). Unlike the developed world, households in developing countries consists of three generations however this does not decrease caregiver burden as there is actually only one person providing the care in a hands on manner (Brodaty & Donkin, 2010).

Talley and Montgomery (2012) add that the second aspect of burden is subjective burden which refers to the feelings and the emotions that arise in family members as they fulfil their caregiving

functions. With this in mind caregivers also experience rapid burnout as a consequence of the burden experienced (Michon et al., 2005). It is this burden that sometimes leads to physical and psychological decline in the caregiver and/or an increased degree of symptoms related to depression and loneliness (Vikstrom et al., 2008). In a study in Sweden, seventeen out of the forty six caregivers either reported a risk for developing burnout or experienced symptoms of burnout in their caregiving situation (Almberg et al., 1997). When caregivers do not have any sense of mastery over the caregiving situation, the resultant is increased strain and burden (Brodaty & Donkin, 2010).

Risk factors for burden include the worsening of the relationship between the caregiver and patient, being a spouse is also considered as being a risk factor as well as poor caregiver health (Fernandez-Ballesteros, 2003). One of the reasons as to why the spouse is considered to be a risk factor for burden is due to the marital dyad (Feld, Dunkle, Schroepfer & Shen, 2006). The spouse is seen to be the best individual to be a caregiver due to their long standing relationship with each other and they are seen as the best individuals to take on the tasks of caregiving. These researchers further add that with increasing age and marital duration, couples will turn more to their spouse for support and an emotional connection. Therefore in times of illness the spouse is seen as the main form of support. Taking this into account, the individual with the illness will prefer receiving IADL care from their spouse (Feld et al., 2006). This not only makes them feel needed but negative emotions linked to dependence will be avoided.

Craig et al. (2010) add that further risk factors include the age and the gender of the carer. They also add that when the carer is functionally or behaviourally impaired this also adds to the caregiver burden. In terms of gender, females are seen to display higher levels of burden when compared to men. This is probably due to females experiencing social restrictions because of their caring role (Papastavrou et al., 2007). One of the reasons why some woman experience more burden than men is because it is socially imposed on them, therefore this role is not undertaken by choice (Papastavrou et al., 2007). Furthermore, these authors state that women are expected to fulfil the caregiving role without having any informational knowledge as the expectation is that a female should understand this due to their female nature. In terms of male caregivers, one of the reasons that males experience low burden is due to another informal helper that supports them (Papastavrou et al., 2007).

Papastavrou et al. (2007) also describes the education levels of the caregiver as playing a role in the levels of burden experienced. Caregivers that have a higher education level and have better remuneration have lower levels of burden.

Another factor which increases burden is lack of information from professionals and poor informal social support (Michon et al., 2005). This is also confirmed by Brodaty and Donkin (2010) as they state that when there is lack of knowledge regarding the disease, carer's experience poor psychological health. When there is a lack of coping skills from the caregiver this also increases the burdens faced (Craig et al., 2010).

The behavioural problems of patients have a greater effect on caregiver burden than their cognitive impairment or functional limitations (Michon et al., 2005). Papastavrou et al. (2007) found that the behaviour that was most strongly linked to burden was aggression. Examples of aggression exhibited by the spouse with Dementia of Alzheimer's Type are suspicious behaviour and communicating aggressively to their partner. Furthermore Papastavrou et al. (2007) state that due to the behaviours of the spouse with Dementia the caregiver provides constant vigilance which leads to burden. LoboPrabhu et al. (2006) describe caregiver vigilance as providing surveillance and control over the spouse with Dementia.

Caregiver burden not only has consequences for the caregiver but also for the family and the care recipient as it disrupts the affective relationship between them (Fernandez-Ballesteros, 2003). Caregiver burden was also found to be the key factor for institutionalising their partner (Michon et al., 2005). However it is important to note that burden does not leave the caregiver even after institutionalisation takes place (Papastavrou et al., 2007). This therefore communicates that there is a strong emotional bond in the caregiving dyad which does not end even with the physical separation.

### **3.5. Depression and health of the caregiver**

#### **3.5.1 Depression of the caregiver**

Oxington (2005) states that Dementia of Alzheimer's Type caregivers are different from caregivers who care for elderly individuals. In comparison with other types of caregivers, those caring for Dementia patients possess higher rates of depression, anxiety and emotional distress (Michon et al., 2005). This is affirmed by data from an Alzheimer disease research centre as it was found that Dementia caregiving spouses reported higher levels of loneliness and depression than non-caregiving spouses (Beeson, Horton-Deutsch, Farran and Neundorfer, 2000). Similarly, Lubkin and Larsen (2013) add that caregivers for spouses have reported higher incidences of depression and stress than those caring for a disabled person. Zarit and Talley (2012) also state that many Dementia caregivers experience an episode of anxiety or Major Depressive Disorder for the first time during their caregiving years. The longer dementia caregivers are in the caregiver role, the more burdened and depressed they become.

Depressive symptoms are also increased as the caregiving spouse bears witness to the decline of the family member's cognitive disintegration as well as changes in behavioural and personality changes (Beeson et al., 2000). Data from an Alzheimer disease research centre found that the loss of emotional attachment between married couples resulting from the cognitive changes in one spouse often led to depression in the caregiving spouse (Beeson et al., 2000).

In terms of gender, the research by Beeson et al. (2000) found that being a wife caregiver and reporting a greater loss of self were associated with higher levels of loneliness and depression. Furthermore, they add that the loss of self refers to loss of identity and self-concept. Spouses also experience couple identity before the diagnosis of Dementia disintegrates the relationship but due to the illness there is also a loss of relational identity in the caregiving spouse (Beeson et al., 2000).

According to Beeson (2003) loneliness and depression overlap with each other and also contribute to each other. When a person is lonely they tend to display symptoms of depression, however the reverse does not apply. Therefore when an individual is depressed they are not necessarily lonely. An example of this can be seen in a study by Beeson (2003) as loneliness and depression were positively related for Dementia of Alzheimer's Type caregiving husbands and

wives. This means that as they experienced more loneliness, they also experienced more depression.

The caregiver's mind-set is also been found to place them at risk for depression. Brodaty and Donkin (2010) state that when a caregiver has negative and repetitive thoughts they are at a higher risk for depression. However, if carers display neutral repetitive thoughts then they are less at risk for depression. A further finding by Papastavrou et al. (2007) is that even after institutionalising the Dementia patient, depression in the caregiver remains.

### 3.5.2. Health of the caregiver

In terms of the health of the caregiver, providing caregiving for an extended period of time results in a decrease in health (Hill, 2015). Furthermore, with an increase in activities of daily living there will also be a decrease in the caregiver's health (Schulz, 2000). However, caregivers provide care even though they are not in good health (Hill, 2015). There is a higher risk of contracting cardio-vascular diseases and there is a decrease in their immune system (Brodaty & Donkin, 2010). Furthermore, these authors note that caregivers use more medications and their healing of wounds is much slower. Although caregivers have more physical health risks, they are less likely to engage in activities that would prevent this (Brodaty & Donkin, 2010). For example, caregivers are more likely to smoke and drink and less likely to be involved in exercising. There is also evidence which shows that a lack of social support is also directly related to the decrease in caregiver health (Schulz, 2000). At a certain point caregivers decide to stop caring as it negatively affects their health (Hill, 2015).

### **3.6. Loneliness, grief and isolation in the caregiver**

According to Beeson et al. (2000) caregivers experience loneliness when one's life is deprived of relationships that are desired. Loneliness is experienced when relationships in the present differ greatly of those from the past. Beeson (2003) states that the psychological loss of an individual as one knew them as the important person in one's life is seen as the most common cause of loneliness. The loss of a close relationship is therefore seen as important factor related to loneliness. Marriage represents the most important sustained relationship in one's life (Beeson, 2003). Beeson (2003) adds that sharing experiences with a spouse over a lifetime helps to define

and maintain one's individual need for human intimacy. The loss of a partner in the marital dyad therefore contributes to loneliness.

Caregivers in the study by Vikstrom et al. (2008) provided descriptions of loneliness. This loneliness arose from them having lost the intimate relationship they used to have as husband and wife. In a qualitative study carried out in Michigan, USA, eighty two caregivers were interviewed. The cognitive impairment of patients with Dementia of Alzheimer's Type and the changes in communication between themselves and their spouse contributed to the caregivers perceptions that they had lost a sense of intimacy in their relationship with their partner (Collins et al., 1993).

Apart from loneliness that comes about from loss of the relationship, having to observe the slow death of a loved one's memory and their personal identity brings a unique form of grief associated with present and anticipatory losses before the actual physical death (Chene, 2006). Rabins et al. (2006) state that with grieving process comes the emotion of sadness. This comes and goes when the spouse is reminded of the person that has been lost. According to Papastavrou et al. (2007) this type of grief is referred to as disenfranchised grief. Disenfranchised grief refers to the caregiver not been able to express their grief as happens when a person physically dies. The loss cannot be recognised publicly (Papastavrou et al., 2007).

Specifically, the caregiving spouse also becomes socially isolated when Dementia erodes the ability of the ill spouse to communicate effectively (Zarit & Tally, 2012). The carer has the responsibility to initiate at least ninety five percent of communication as those with Dementia tend to be apathetic (Chapman & Marshall, 1993). Semantic memory (the system through which the individual's knowledge of the world is stored) and episodic memory (memory storing autobiographical details) is adversely affected by Dementia (Biernacki, 2007). This disruption in memory by Dementia influences the individual's ability to communicate effectively (Biernacki, 2007). In a study by Jansson et al. (2001) the participants with Dementia could not have a continuous conversation any longer. In this study, despite the memory loss the spouses were found to still provide the patience to their demented spouses as they had to repeat questions

Lack of social activities also contributes to loneliness. According to Ekwall, Sivberg and Hallberg (2003) social isolation is referred to as social loneliness which relates to social

networks and contacts with friends. The social networks of many elderly people have decreased in size due to death of friends and relatives (Zarit & Talley, 2012). However the size of the social network prior to caregiving plays a role in determining the support or assistance the individual receives. The bigger the social network, the more likely the caregiver is to receive assistance (Hill, 2015). These authors state that spouse caregivers may have placed a greater reliance on companionship and emotional support of their husband or wife with Dementia. However, according to Hill (2015) men confide in their spouses more than women. Women confide more in their friends. Hill (2015) therefore adds that wives experience more intense losses as the caregiving role isolates them from their friends while husbands are better able to deal with having less time with friends. Men also have smaller social networks (Hill, 2015) therefore making the adjustment easier.

Lack of social activities can be seen in an Australian study by Shanley et al. (2011) where the participants found that they do not have time and energy to pursue interests and network outside the home. This contributed to a sense of loneliness. Another factor contributing to loneliness was that of friends and also other family members who experience great difficulty in dealing with the situation and withdraw from both the friend or family member with Dementia (Shanley et al., 2011).

In the findings of the study by Vikstrom et al. (2008) social engagements outside the relationship as well as within it had diminished. The caregivers in this study found that being so much at home reduced their possibilities to develop and/or maintain their social contacts. Another reason for caregiving spouses losing social commitments was due to changing their social habits deliberately. For example, they no longer hosted dinner parties since they felt that they were unable to cook and they could not appear as hosts in the manner they used to. In comparison with other caregivers, caregivers that care for patients with Dementia spend more time in their caregiving role and report a more severe impact on their work, financial situation, family relationships and social and leisure activities (Michon et al., 2005).

### 3.7. Stress and the caregiver

De Jager et al. (2015) describe a research study undertaken in Cape Town, South Africa. In this research it was found that seventy nine percent of a memory clinic's clients were being cared for by family members. Some of these family members had given up their jobs to take on the caregiving role as the tasks of caregiving were demanding. Stress can be defined as the response to change (Olsherski, Katz & Knight, 2012). Caregiver stress is therefore seen as important in understanding the role of caring for a spouse with Dementia. This also applies to traditional cultures where family care is regarded as the norm. For example, in some traditional families, family care is seen as the norm (Olsherski et al., 2012). This context in which caregiving takes place is there important and refers to the relationship between the spousal caregiver and their partner with Dementia, the resources which are available to the family and also includes the social and cultural beliefs of the family (Whitbourne, 2016).

In terms of the caregiving context the patient caregiver relationship is adversely affected by stress (Stephens et al, 1990). Similarly, Potgieter and Heyns (2006) add that the quality of the patient caregiver relationship between spouses is affected when there is a lack of sense of coherence. Potgieter and Heyns (2006) state that one has sense of coherence when one is able to understand as well as cope with the stressor that they are confronted with. This is also consistent with Brodaty and Donkin (2010) as they state that the type and quality of the relationship between the caregiver and the care recipient can have an impact on carer distress. They further add that if the current and past intimacy between caregiver and care recipient is low there will be a higher level of negative emotions directed to the individual with Dementia and there will be higher levels of carer distress. In research by Ablitt et al. (2009) it was found that lower relationship quality before the diagnosis of Dementia of Alzheimer's Type was related to depression, burden as well as emotional reactivity. Therefore couples whose relationships lack intimacy and love before their partner can be diagnosed with the illness are more likely to experience negative affects when caring. However these authors also describe that high relationship quality does have a protective factor but there is also evidence high levels of closeness in the past can increase distress in carers.

According to Oxington (2005) stress can be viewed from two perspectives, this being primary and secondary stress. Primary stressors refer to difficult caregiving demands such as many hours

of care provision per day or being confronted with difficult behaviours of the care recipient. Whitbourne (2016) also describes this type of stress as a daily stressor. Some of these behaviours include dependency, sleep disturbance and anger. Tasks that are physically demanding like moving the patient from one room to another is considered a primary stressor. Tasks that are emotionally demanding are also seen as primary stressors. These tasks involve the ability to deal with the cognitive and behavioural problems displayed by Dementia patients (Whitbourne, 2016).

Secondary stressors refer to impairment of care recipients with Dementia of Alzheimer's Type (Oxington, 2005). Whitbourne (2016) further describes these stressors are those that emerge as a consequence of the disease. Examples of the stressors experienced are marital conflict and conflict amongst other family members. Finances also play a role in creating this stress (Whitbourne, 2016). These can result in less time for family and friends and also decreased social activities (Oxington, 2005).

A third aspect of the stress process refers to the subjective appraisal of the situation. The number of stressors experienced and meaning attached to these events impacts the stress experienced by the caregiver (Whitbourne, 2016). Furthermore, these authors add that the caregivers self-esteem play and the availability of social support available to the caregiver increases or decreases the stress they experience. Taking this into account caregivers may not be able to control the caregiving situation they can control their reaction to change (Olsherski et al., 2012). Olsherski et al. (2012) argues that stress involves not only the stressful event but also how the event is evaluated. Similarly, Stephens et al. (1990) state that the way in which the family responds to stress can either have a negative or positive influence with future interactions within the family.

According to Shamy (2003) caregivers occupy four affective positions. The affective positions are as follows:

1. Commitment- In this position the caregiver is able to come to terms with the Dementia of Alzheimer's Type of their spouse. They are still able to maintain a positive of the relationship.

2. Obligation- Due to social expectations, spouses feel that they are obligated to provide care. In having this obligation the relationship with their Dementia of Alzheimer's Type spouse is very distant.
3. Dissociation- This position describes an even greater distancing from their spouse with Dementia.
4. Repudiation- The relationship between the spouse and the caregiver is one where the caregiver gains no pleasure from the caring role. Instead, caring is seen as been a burden.

Taking into account the affective positions described by Shamy (2003), the commitment position can provide positivity in a stressful situation. Stress can be positive in the sense that it is a motivating factor that stimulates better performance and also accomplishment (Olsherski et al., 2012). Positive stress can be in the form of finding meaningfulness in caregiving. Kaplan (1996) adds that, "for some, the caregiving role may replace other diminished or vacated roles and provide the satisfaction of attending to the needs of a loved one and performing the job well" (p. 57). This is also confirmed by Quinn, Clare and McGuinness (2012) as they state that meaning can be found during the stressful situation of caring for their loved one. For example, in a study by Potgieter and Heyns (2006) caregivers found fulfilment and a sense of meaning in caring for their loved one with Dementia. They wanted to make the life of their loved one as comfortable as possible.

Meaning found in caregiving is seen to have a motivational component as finding meaning helps motivate the caregiver to sustain coping (Quinn et al., 2012). According to these authors there are two types of motivation, intrinsic motivation and extrinsic motivation. Intrinsic desire refers to the desire to care for the Dementia of Alzheimer's Type patient while extrinsic motivation refers to the external pressures to provide care. The findings of the research by Quinn et al. (2012) found that caregivers with higher intrinsic motivations were associated to low burden and role captivity and a higher sense of competence while those with extrinsic motivation were associated with higher burden. Furthermore, caregivers who experienced higher meaning in their caregiving role also experienced better outcomes.

Positive stress or meaningfulness in caring can be seen in another study by Kellet and Mannion (1999) wherein seven family caregivers were interviewed. These caregivers experienced a sense

of engaged involvement in terms of creating meaning and responsibility through the development of caring practices. Another uplifting aspect of these caregivers was the sense of structure in their everyday lives. This gave them a sense of being in control and having accomplished things during the day. A further positive element was a sense of worth which was experienced. This sense of worth was experienced in terms of possessing special knowledge about the older relative. In another study by Ablitt et al. (2009) highlights the concept of reciprocation as carers voiced that they knew their spouse had changed but were still motivated to provide the necessary care because their spouse had provided care for them in the past. Furthermore, carers believe that their spouses would have done the same for them.

Oxington (2005) states that the feeling of being a valuable aid to the individual with Dementia, appreciating the closeness to the care recipient and also experiencing a sense of pride in one's abilities to handle crisis can be seen as positive events or positive stress. Furthermore, a caregiver with a positive outlook on caregiving may experience less stress and physical ailments and it is this that allows the caregiver to be hopeful (Qualls & Zarit, 2009). Qualls and Zarit (2009) also found that depression was also less likely reported in these instances.

In a national survey on family caregiving with 1500 caregivers in the United States of America in 1996, respondents were asked to state the one feeling that best describes their experience of caregiving. The result was that more than half of the caregivers in this study reported positive feelings with regards to caregiving (Schulz, 2000).

In terms of gender differences towards finding meaning in caring, husbands who care for their wives have more positive feelings than wives caring for their husbands (Hill, 2015). A possible explanation for men viewing the caregiving as more meaningful is possibly due to the attention and admiration they receive for their caring role. For a woman this caring role is expected of them and therefore their efforts to care go unnoticed (Hill, 2015).

Negative stress occurs when the outcome is not constructive (Olsherski et al., 2012). Olsherski et al. (2002) states that in terms of negative stress, the caregiver does nothing to try to counter-balance the stress, and in turn, frustration increases. When negative stress is extended and is a constant the caregiver experiences a wearing down on the entire body, and eventually, can cause

permanent damage and disease (Olsherski et al., 2012). Furthermore negative stress can cause the caregiver to become violent thereby leading to abuse of the care recipient (Hill, 2015).

Also related to stress is the concept of burnout. For the caregiver, burnout can be seen as the physical, mental and/or emotional exhaustion (Lubkin & Larsen, 2013). Burnout can result when primary and secondary stressors are high. Figley (1998) developed a model of burnout which begins with a caregivers stress response which is compassionate stress. According to Figley (1998) compassionate stress refers to “the stress connected with exposure to a sufferer” (p. 21). When compassion stress is accompanied by prolonged exposure to the suffering, then compassionate fatigue sets in. It is this that leads to burnout. For a Dementia of Alzheimer’s Type partner, prolonged exposure to suffering would occur due to the progressive nature of the disorder.

In terms of gender, women are more likely to experience greater levels of stress than men. This is due to their levels of mastery over the situation which is very low (Papastavrou et al, 2007). Furthermore the coping strategies used by women were not found to be effective, unlike, men who used problem solving approaches. Papastavrou et al. (2007) further add that men were better at coping with stress as they had a wider range of stress management techniques in comparison to woman. As such male caregivers used mechanisms where a psychological distance was created from the care recipient (their spouse with Dementia), therefore reducing the personal stress experienced.

### **3.8. Coping mechanisms and the caregiver**

According to Whitbourne (2016) the coping mechanisms use by the caregiver will depend on the way in which the caregiver subjectively appraises the caregiving situation. Whitbourne (2016) states that coping mechanisms can either be problem focused or emotion focused. The coping mechanisms described below are emotion focused as they aim at decreasing emotional distress and allow the caregiver to vent negative emotions (Whitbourne, 2016).

#### **3.8.1 Social Support**

When behavioural changes and incontinence takes place for the individual with Dementia, it becomes very difficult for patient and carer to maintain contact with their social environment.

This is also emphasised by Miller-Day (2011) as it is stated that time spent with the Dementia of Alzheimer's Type care recipient causes distance between caregivers and their social network. Due to this, it makes it less likely that the caregivers will receive the support that is needed. At this point people in the social environment are important as support for the carers (Kraijo et al., 2011). The family's informal support system determines its degree of involvement with relatives, neighbours, friends and religious and social groups (Kaplan, 1996).

Rabins (1998) states that negative impact of caring for a person with Dementia can be less distressing when there is emotional support. Relatives sometimes feel a form of bereavement as they feel that they have "lost" the person they used to know and this form of loss also requires social support (Thompson, 2006). This is emphasised by Schulz (2000) who states that caregivers with a great deal of social support cope better with the demands of caregiving than those with little support, while restriction of social contacts contributes to a sense of loneliness (Ekwall et al., 2003).

Social support is one of the factors that have also been seen to protect one against depression (Qualls & Zarit, 2009). According to the stress-buffering hypothesis applied to social support, "individuals exposed to high levels of caregiving stress benefit from social support received from others, but individuals who are not stressed as a result of caregiving exhibit no beneficial effects attributable to social support" (Schulz, 2000, p. 47).

In a study by Shanley et al. (2011) carers valued psychosocial support in the form of acknowledgment of their role, help with the difficult decisions or just having someone to talk to who understood their situation. These carers valued interactions with others who were non-judgmental and provided unconditional support and understanding. Shanley et al. (2011) found that instrumental needs, such as showering and dressing the individual with Dementia, were seen as very important. There is a need for the family members to provide assistance by maintaining an active involvement in life of the carer. Kaplan (1996) states that services frequently provided by other family members are meal preparation, light house-keeping, assisting with bathing, dressing and grooming.

In a South African study in Bloemfontein, it was found that the lack of experience, knowledge and insight into the realities of caregiving prevented willing family members from providing relief to caregiver by temporarily caring for the patient with Dementia (Potgieter & Heyns, 2006). Information on Dementia of Alzheimer's Type is very important and should ideally be presented to the caregiver at an early stage of the diagnosis been made (Meyer, McCullough & Berggren, 2016). These authors further add that it is the responsibility of the health care system to provide this invaluable knowledge to caregivers as this will serve in ensuring that all parties are satisfied in their roles.

Carer support groups have also been found to play an important role in terms of helping them cope with the difficulty faced in caring for a Dementia of Alzheimer's Type spouse (Chapman & Marshall, 1993).

### 3.8.2. Faith in coping

Prayer as well as religious coping is seen as coping mechanisms for caregivers (Stolley, Buckwalter & Koenig, 1999). These two areas of coping are seen as providing the caregivers with the psychological energy needed to overcome their caregiving responsibilities. The carer's personal faith and religious beliefs are incorporated to form the activity of religious coping while prayer is seen as a private form of communication with God (Stolley et al., 1999). According to the research by Papastavrou et al. (2007) it was found that prayer was a coping strategy used to deal with the situation by high-burden caregivers.

## **3.9. The impact of Dementia on marriage**

### 3.9.1. The decrease in intimacy and sexuality

As Dementia develops, the intimacy between spouses decreases. Intimacy and sexuality are important aspects in a marriage. These two concepts are the foundation of a marriage as it is seen as the physical expressions of love and care between two individuals (Wright, 1998). This author further explains that affection amongst older individuals increase as they get older and while interest in sexuality might be high, sexual intercourse itself is very low.

The one area in any individual which sustains the quality of affectionate expressions is cognitive ability. It is one's cognitive ability that allows individual's to perform sexual activities in a

manner where their partner's feelings and needs are taken into consideration (Wright, 1998). Taking this into account, this therefore becomes a problem for Dementia of Alzheimer's Type patients where their cognitive ability is severely impaired. Sexuality in a marriage is not eliminated with the onset of Dementia of Alzheimer's Type, rather it is altered. There is now a change in the way love is shown and received (Davies, Zeiss, Shea & Tinklenberg, 1998). On the other hand, Hanks (1992) states that there is actually an increased need for emotional and sexual reassurance in a marriage impacted by Dementia.

Results from the research of Wright (1998) found that when a spouse has Dementia of Alzheimer's Type there were evident changes in their affection as well as their sexual intimacy. For a spouse with Dementia of Alzheimer's Type remaining sexual active allows them to preserve their role identity and provide something of meaning to their partners (Davies et al., 1998). One of the reasons for a decrease in affection and sexuality is due to the caregiver's responses. Ballard (1995) describes the spousal caregiver as being unable to see their partner in a sexual manner once Dementia of Alzheimer's Type progresses. They now view them as been 'sick'. In recent research by Meyer et al. (2016) the participant's role to their spouse changed to that of a caregiver. This change became more prominent as they personality of the spouse with Dementia changed. Furthermore poor hygiene and incontinence which is brought about by the disease creates unattractiveness in the spouse with Dementia. This further creates anger, physical and emotional fatigue which in turn creates a negative consequence for the relationship (Ballard, 1995).

Sexual impairment in a Dementia of Alzheimer's Type patient can take different forms. Davies et al. (1998) state that erectile dysfunction amongst male patients can be one form of sexual impairment as well as cognitive sequencing impairment during sexual intercourse. Mood disturbances and decrease in libido in both male and female dementia patients occurs (Hanks, 1992).

In terms of the caregiver, they are also faced with a huge challenge. Davies et al. (1998) describes spousal caregivers as feeling discomfort about sexual advances from their spouses who are unable to recognise them or know their names. Furthermore, there are frequent sexual overtures from their spouse with Dementia as they are unable to remember a sexual encounter which occurred earlier in the day, which troubles the spousal caregiver. As the Dementia

progresses the spouse with Dementia can no longer make decisions and this in turn can affect the intimacy in the relationship (Davies et al., 1998). One area of concern for male caregivers is that their female counterparts can no longer consent to sexual intercourse (Davies et al., 1998). These caregivers therefore feel that they are raping their spouses. Spousal caregivers are therefore faced with dealing with the losses and changes in their spouse as well as losses in their marriage while at the same time having to deal with their own ageing.

Central to the caregiver in dealing with intimacy and affection is the concept of guilt. Hank (1992) adds that during the early stage of Dementia of Alzheimer's Type, caregivers isolate themselves when they can have sexual closeness with their spouse. The reason for this is that the caregivers feel that their spouse no longer understands or consensually welcomes the sexual intimacy therefore guilt arises when touching their spouse (Hank, 1992). In experiencing this guilt, initiation of any sexual activity is decreased, which eventually results in all sexual closeness ending. Hank (1992) adds that caregivers compensate for this guilt by overcommitting to care for the patient and refusing respite care. Apart from guilt experienced with intimacy and affection, caregivers also experienced guilt in general. According to Turkington and Mitchell (2010) caregivers experience guilt as they feel that they could have possibly contributed to the disease and guilt arises in feelings that they could have done something more to assist their spouse. Lastly, spouses experience guilt as they feel that they are enjoying their life and their spouse is not.

Caregivers still retain an interest in sexual activity, even though there is a loss of this in their marriage. Hank (1992) states that in this situation there has been an increase in spousal caregivers initiating extra-marital relationships. The loss of the expressed spousal affection and sexuality also creates some caregivers to have secret thoughts of wishing their spouses would die so they could find affection in a new relationship.

Hank (1992) describes the concept of desexualisation which is a psychological strategy used by caregivers to deal with their own sexual frustrations. In using this strategy, spouses do not identify with their spouses as a husband or wife, instead they are labelled a patient, brother or sister. This makes the duties of handling their spouse's incontinence or bathing their spouse easier.

Even though there are various difficulties which are found to impact the marriage, caregivers still want to maintain some form of intimacy with their spouse as the intimacy provides them with reassurance and a means of coping with the illness (Davies et al., 1998). In the face of these difficulties caregivers strive for marital commitment which is greatly influenced by how they perceive the bond with their spouse (Hank, 1992). Hank (1992) further states that the spouse caregiver's cultural values including their sense of loyalty also influence their marital commitment. Further Davies et al. (1998) states that when the spouse caregivers receives some form of reciprocity from the relationship, the spouse with Dementia is more likely to remain in the home setting.

### **3.10. Retrogenesis and Dementia of Alzheimer's Type caregiver**

Rogers and Lasprilla (2006) state that, "retrogenesis involves functional, behavioural, cognitive and neurological degeneration as well as neuropathological changes that occur in Alzheimer's Disease" (p. 260). The theory of retrogenesis describes how an individual changes in terms of their functional and cognitive abilities as the progression of Dementia of Alzheimer's Type takes place (Carson, Vanderhorst & Koenig, 2015). Carson et al. (2015) state that the brain of an Alzheimer's patient degenerates in the reverse order that the brain develops from birth, this therefore means that the last area that was completely developed is the first area to be damaged. The family caregivers of individuals suffering with Dementia of Alzheimer's Type describe their family member with this illness as becoming 'child-like' as the disease progressed (Rogers & Lasprilla, 2006). This child-like behaviour can be explained by means of the theory of retrogenesis.

#### **3.10.1. Cognitive retrogenesis**

In terms of cognitive retrogenesis, it was found that the deterioration of certain capacities in Dementia of Alzheimer's Type appeared to be in reverse of Jean Piaget's theory of intellectual development which was founded in 1952 (Rogers & Lasprilla, 2006). In this theory of intellectual development four stages were identified which described the relationship between internal operations and the environment in the attainment of knowledge. The development of cognition and behaviour in children and loss in people with Dementia of Alzheimer's Type were seen to be similar (Rogers & Lasprilla, 2006). This therefore means that individuals with this

Dementia of Alzheimer's Type move in reverse through the stages created by Jean Piaget (*See Appendix K*).

### 3.10.2. Functional retrogenesis

In the late 1980's Dr. Barry Reisberg who coined the term 'retrogenesis' created the functional assessment staging tool (FAST). The FAST is an assessment tool that allows an individual to identify where someone is in their progression through Alzheimer's. This assessment tool also provides an intervention for each stage (*See Appendix G*). The FAST in reverse describes the various capacities which an infant develops over the course of life (Rogers & Lasprilla, 2006). For example, an infant would first learn to keep their head up without the help of an adult, they would then start to learn to use vocabulary and then learn to control their bowels. Due to the functional deterioration of an individual with Dementia of Alzheimer's Type, the order of acquisition of the same functions is reversed (Rogers & Lasprilla, 2006). Furthermore, these authors state that the amount of time that it takes for a child to acquire these abilities is approximately the same amount of time that is needed for an individual with Dementia of Alzheimer's Type to lose the same capacity.

Each FAST stage can be translated into a developmental age (DA) and it is through this DA that many emotional changes in Dementia of Alzheimer's Type can be explained. Obtaining the DA of the patient will then allow one to anticipate other changes and furthermore identify ways that management of Alzheimer's can take place (Rogers & Lasprilla, 2006). Another important reason for obtaining the DA is that it helps in arranging developmentally appropriate tasks, in turn this will provide the Alzheimer's patient with a sense of accomplishment (Rogers & Lasprilla, 2006). In terms of the caregiver the results become a valuable tool which will provide ways in which to deal with their spouse with Dementia of Alzheimer's Type.

### **3.11. Finances and the Dementia of Alzheimer's Type caregiver**

The costs that are associated with Dementia are very high. The direct costs to the couple associated with Dementia include consultations with doctors, the use of medications, use of nursing care and towards the later stage the costs that are associated with residential care (Brodaty & Donkin, 2009).

According to LoboPrabhu et al. (2006) about sixty four percent of family caregivers are employed and this will continue to rise. The statistics between the year 2000 and 2010 show an increase from 6.4 million to 10.1 million. There are at 14.4 million caregivers that are full-time or part-time employed (LoboPrabhu et al., 2006). This large group of caregivers have the difficult task of having to maintain their job as well as seeing to the needs of the care recipient. The task of juggling these two activities is very difficult and in turn caregivers cut back on their hours at work. By cutting back on their working hours this will have a direct effect on their financial stability as therefore there is a loss in wages (LoboPrabhu et al., 2006). Furthermore, these authors state that a cut in finances not only impacts the current situation but also impacts retirement savings. Apart from the caregivers reducing their workload, caregivers also stop working completely (Brodaty & Donkin, 2009). This was also seen in research which was undertaken in developing countries such as Bangalore, India and Nigeria. Caregivers were found to devote less time to their jobs and some of them stopped working altogether to care for the person with Dementia (The 10/66 Dementia Research Group, 2004).

In terms of the countries in the developing world, the costs of Dementia are greater and the economic disadvantage is more significant than when compared to the developed world however despite there been an economic disadvantage, caregivers from poor countries tend to use more expensive services as the public services which are available are undesirable (Brodaty & Donkin, 2010).

LoboPrabhu et al. (2006) further states that there has been a lack of focus on families and their present and economic future stability. The main focus has been to the formal system however with regards to institutionalisation, the cost to the family still exists when the care recipient is placed in an institutionalisation. According to LoboPrabhu et al. (2006) residents and their families finance at least thirty one percent of all nursing home expenditures, this is considered to rise by forty eight percent by the year 2030. In terms of institutionalisation, if an individual is employed and they balance too many caregiving responsibilities this can lead to the care recipient been placed in a nursing home (Brodaty & Donkin, 2009).

## **Chapter 4: Research Methodology**

### **4.1. Epistemology**

Epistemology specifies the nature of the relationship between the research and what can be known (Terre Blanche, Durrheim & Painter, 2006). The epistemology for this research is phenomenology, and interpretative phenomenological analysis (IPA) was used as the analysis method in this research. According to Braun and Clark (2006), there is a direct relationship between IPA and the epistemology of phenomenology.

The main principle of phenomenological inquiry is that experiences should be examined in the natural way in which it occurs (Smith, Flowers & Larkins, 2009). Phenomenology is a philosophy without an assumption. All judgements are terminated about what is real until they are founded on a more accurate basis (Creswell, 2012) therefore conscious experience as experienced from the subjective or first person point of view is the essence phenomenology aims to study (Smith, 2011). This statement is also confirmed by Braun and Clark (2006) as they state that phenomenology gives an individual's experience priority and what is of importance is been able to comprehend people's everyday experience of reality in absolute detail. When this comprehension and understanding is evident, a better understanding is gained of the phenomenon in question. In this research, more knowledge was gained by understanding how spouses experienced their reality of caring for their Dementia of Alzheimer's Type spouse. This reality can only be recognised within the meaning which is held by the experiences of an individual (Creswell, 2012). Phenomenology therefore shifts from a positivist cause-effect focus to individualism (Penner and McClement, 2008).

In the early twentieth century, phenomenology was created by the works of philosophers such as Husserl, Heidegger, Satre, Meleau-Ponty and others (Smith, 2011). For the philosopher Husserl, phenomenology involves studying the experiences of humans (Smith, Flowers & Larkin, 2009). Husserlian phenomenology is descriptive. In descriptive phenomenology the researcher makes no interpretations, and in not making any interpretations, the most fundamental meaning of a phenomenon of interest is made clear (Penner and McClement, 2008). Eatough and Smith (2008) state that the world which unfolds within one individual is different from that of another's world. Experience is seen as been subjective because what individuals experience is phenomenal

rather than a direct reality (Eatough & Smith, 2008). These authors state the reality individuals live in is seen as experiential and it is experienced through interaction with things in their world. In Husserl's view, it can be seen that there is a signification and relevance of a focus on experience and what is perceived.

According to King and Horrocks (2010), Husserl was of the opinion that "science needed to try and set aside preconceptions and closely describe how phenomena appeared to human consciousness" (p. 175). In order to describe how phenomena appeared to human consciousness, the researcher needs to set aside his/her own presumptions about the research and in doing so the researcher will not influence the object of study (King & Horrocks, 2010). This statement by King and Horrocks (2010) is further supported by Dowling (2004) who adds that, for Husserl, phenomenology was about identifying and constraining our judgements. King and Horrocks (2010) add that setting aside one's own assumptions is known in phenomenology as *epoche*. The term *epoche* means abstention or self-restraint. *Epoche* can be broken down into two types. The first of these is *epoche* of the natural science which involves putting aside theories, hypotheses and prior knowledge. With the use of bracketing, prior knowledge or judgements are eliminated and this allows one to focus on what Husserl called lifeworld (Wertz, Charmaz, McMullen, Josselson, Anderson, McSpadden, 2011). The term "lifeworld" means that experiences should be seen as concrete and accurate experiences as it is lived by people and not seen as abstractions (King & Horrocks, 2010). King and Horrocks (2010) add that "understanding the lived experience of the life-world is the main goal of most research the interpretative phenomenological tradition" (p. 179).

By using this method of bracketing or otherwise known as phenomenological reduction, the researcher's preconceptions are extracted and we are able to see a situation as it is. Dowling (2004) also describes bracketing as the removal of all biases and beliefs of the phenomenon being researched which the individual carried with them before even data is collected. Bracketing allows one to take a new perspective of the phenomenon under investigation. A reflective diary is a useful tool which can be used for bracketing and was used in the current study (*See Appendix I*) (King & Horrocks, 2010).

The second type of *epoche* is *epoche* of the natural attitude which is sometimes also referred to as phenomenological reduction, this refers to the researcher abstaining "from the natural

tendency of consciousness to unreflectively posit and focus on the existence of objects independent of experiences” (p. 125). This allows one to closely evaluate how various situations present themselves through experience (Wertz et al., 2011).

Central to phenomenology is the notion of intentionality, which involves having the knowledge of human consciousness (King & Horrocks, 2010). King and Horrocks (2010) state that consciousness is never an abstract state but rather consciousness is something that is constantly connecting individuals to the world that they live in. The feelings that are experienced in the consciousness of the individual is the focus of phenomenological inquiry (Smith et al., 2009). When individuals speak of experience, this refers to conscious experience. An experience is seen to be conscious when there is a certain level of awareness that one has of the experience while live or are engaged in it (Eatough & Smith, 2008). When the word experience is used, it does not only includes passive experience as in vision or hearing but Smith (2011) states that it includes active experience in activities such as running or perhaps drilling a bolt.

While with Husserl there was a focus with the psychological processes found in the individual such as perception awareness and consciousness, Heidegger is more perturbed regarding the ontological question of existence itself (Smith et al., 2009). While Husserl’s work is referred to as eidetic, descriptive or objective hermeneutics, the work of Heidegger is referred to as interpretative phenomenology. The aim of interpretative phenomenology is uncovering meanings which are latent in nature (Dowling, 2004). The concept of inter-subjectivity is central in Heidegger’s view as it refers to the mutual, overlapping relationship to our engagement to the world (Smith et al., 2009). In Heidegger’s view, our being in the world is always perspectival and our being is always in a relationship with something else. Our relationship to the world is paramount (Smith et al., 2009).

In IPA research, attempts to gain an understanding of other people’s relationships to the world are interpretative and will centre upon their attempts to make meanings out of their activities and to things happening to them (Smith et al., 2009). Heidegger’s role in hermeneutics is therefore essential as IPA is influenced by hermeneutics (Eatough & Smith, 2008). These authors state that hermeneutics is the theory of interpretation. The interpretative paradigm stresses the significance of interpretation and observation in understanding the workings of the social world.

Hermeneutics is based on the assumption that people experience their world by using language

and it is this language that provides understanding and awareness (Dowling, 2004).

Hermeneutics is a considerable part of qualitative research (Hennink, Hutter & Bailey, 2011).

Originating in the seventeenth century, hermeneutics began with interpreting biblical texts. The aim was to illuminate the meaning of texts (Dowling, 2004). Hermeneutics has now evolved to establish a more general concern with the process of interpretation. Our access to lived time and connection in the world is through interpretation (Smith et al., 2009). According to these authors, Heidegger sees phenomenology as concerned in part with examining something which may be masked as it emerges into the light, but phenomenology is also interested in examining that which appears at the surface or on the outer because this is integrally connected with what is hidden.

For Heidegger, uncovering the meaning of being or bringing to light the normal process of understanding for humans was vital as he felt that this was disregarded in the past by other approaches which were seen as reductionist. According to Heidegger, the concept of *Dasein* (being-in-the-world) is important (Dowling, 2004). Heidegger believed that understanding results in the awareness of *Dasein* (Dowling, 2004). Hermeneutics is seen as a method of interpretation that directs one to being (presence in the world).

According to Dowling (2004), the work of Heidegger was continued by Gadamer. Gadamerian or philosophical hermeneutics has two key positions, these been pre-judgment and universality. Pre-judgment refers to one's preconceptions or biases that are part of our language and makes understanding possible achievable. Universality refers to an increased understanding due to the connection between the person that expresses themselves and the person who comprehends what was expressed. They are linked together by a common human conscious (Dowling, 2004).

For Gadamer, hermeneutics is seen a dialogical method where the interpreter and the thing been studied are merged. In order for this to occur, one must accept the meaning held by another person while at the same time we need to be aware of our own prejudices. Gadamer is also linked to critical hermeneutics (Dowling, 2004). Critical hermeneutics involves revealing individuals to the meanings that they themselves are unable to see.

Merleau-Ponty emphasises the situated and interpretative quality of individual's knowledge about the world (Smith et al., 2009). This is similar to Heidegger's views. Merleau-Ponty suggests that as humans we see ourselves as unique and different from everything else in the world. An individual's sense of self is holistic and is engaged in looking at the world, rather than being subsumed within it (Smith et al., 2009). According to these authors, Merleau-Ponty's view is that even though individual's can observe and experience empathy for another, one can never truly comprehend and be a part of their experience as that experience is solely theirs and it is their position in the world.

Sarte stresses that the self is not a pre-existing unity to be discovered but rather a continuous journey to be discovered (Smith et al., 2009). Sarte argues that things that are vague are as important as those that are existing in defining who individuals are and how they view the world (Smith et al., 2009).

Heidegger, Merleau-Ponty and Sarte all see the person as immersed in a world of objects and relationships, language and culture, projects and concerns (Smith et al., 2009). For these philosophers, there is a complex understanding that experience invokes a lived process with various perspectives and meaning, which is distinct to the persons embodied and situated relationship to the world (Smith et al., 2009).

#### **4.2. Qualitative research approach**

The research that was employed was a qualitative research in terms of its methodology. One of the key strengths of qualitative research involves the comprehensiveness of perspective it gives the researcher. By interacting directly with the social phenomenon under study and by observing it completely, a deeper understanding can be developed. Qualitative research is associated with the term phenomenology, which was described earlier. Phenomenology is a key philosophical paradigm chosen for conducting qualitative research (Rubin & Babbie, 2009).

Qualitative research incorporates the idea that individuals build their reality when connecting and engaging with their social worlds (Merriam, 2009). Qualitative research therefore functions from the interpretive paradigm where people are building their own realities socially and symbolically (Klenke, 2008). Social interaction meaning is constructed, as such qualitative researchers are concerned in understanding the meanings people have constructed, that is, how people make

sense of their world and the experiences they have in the world (Merriam, 2009). The way in which people interpret experiences and the way in which they construct their worlds as well as the meaning they attribute to their experiences are important in qualitative research (Merriam, 2009). This is also confirmed by Hesse-Biber and Leavy (2011) as they state that qualitative research is focused on the social meaning that people bring to their experiences and situations. Apart from this, the focus of qualitative research is also the meaning that people place into texts and other objects. This meaning is extracted from data which can be obtained through the technique of interviewing participants. Interpretation of meaning-making is thus vital in qualitative research, this is accounting for how individuals experience and make meaning from their lived experience (Hesse-Biber & Leavy, 2011).

Merriam (2009) outlines key characteristics of qualitative research. The first characteristic of qualitative research which is outlined by Merriam (2009) is the emphasis on meaning and understanding. She states that the main purpose of qualitative research is to acquire an understanding of how people make sense of their lives, describe the process of meaning-making, and describe how people shed light on what they experience. In this research an understanding was achieved as to how Dementia of Alzheimer's Type spouse caregivers make sense of their situation. Related to this is also the concept of subjectivity which is a characteristic of qualitative research. An individual's inner state as outer expressions of human activity is therefore the interest in qualitative research (Hatch, 2002). This author further states that inner states is not something that can be directly noticed therefore qualitative researchers depend on subjective judgements to make them comprehend the situation.

Merriam (2009) outlines a second characteristic which is the researcher been the primary instrument. An advantage of this is that the researcher can expand their non-verbal as well as verbal communication, process information as soon as it occurs, summarise the information, check with respondents for validity of interpretation and explore uncommon or unanticipated responses. In this research I was the primary instrument as information was collected via semi-structured interviews. Orb, Eisenhauer and Wynaden (2000) state that qualitative researcher's concentrate their research on exploring, studying and describing people in their natural environments. This is confirmed by Hatch (2002) who states that in qualitative research the

primary objective is to explore human behaviours within the contexts of their natural environments.

Another important characteristic of qualitative research is that the process is inductive, that is, researchers gather information to build concepts or theories (Merriam, 2009). As Hatch (2002) states qualitative researchers collect thorough information from the research setting then go through the process of looking for patterns of the relationship among this comprehensive information. In this research data was gathered and analysed. By analysing interview transcripts, themes were developed.

Finally Merriam (2009) states that the end product of qualitative research is richly descriptive. Instead of numbers, words are used to convey what the researcher has learnt about a phenomenon. In this research, the spouses' words were gathered through the use of semi-structured interviews. Through these words more knowledge was gained as to how spouses experience caring for their partners who have Dementia of Alzheimer's Type.

In terms of qualitative analysis, Klenke (2008) states that that it "involves the non-numerical organisation of data in order to discover patterns, themes, forms and qualities found in field notes, transcripts, open-ended questionnaires, diaries, case studies and so on" (p. 33).

The goal of this study was to describe and explore the experiences of spouses as they care for their Dementia of Alzheimer's Type partners. In view of the above characteristics of qualitative research, this research approach was well suited to achieve the required goal.

#### 4.2.1. The Interpretivism Paradigm and Phenomenology

Qualitative approaches are generally founded upon theoretical perspectives ingrained in interpretivism and are described as hermeneutics, phenomenology, ethnography (King & Horrocks, 2010). King and Horrocks (2010) also describe interpretative research as idiographic which means describing aspects of the social world by offering a comprehensive account of specific social settings, processes or relationships. To better understand the interpretative paradigm, one needs to differentiate between understanding and the concept *Verstehen* (Hennink et al., 2011). When a researcher is using their own frame of reference on a matter this is known as understanding. When matters are identified from the participant's perspective then this is

referred to as *Verstehen*. (Hennink et al., 2011). The German term, *Verstehen*, is a significant phenomenological principle (Rubin & Babbie, 2009). Hennink et al. (2011) state that *Verstehen* means studying people's lived experiences which occur within a certain social setting.

Furthermore, understanding social phenomenon is not the sole purpose of qualitative research but rather the main aim of the approach should be attaining *Verstehen*.

*Verstehen* therefore refers to understanding the issues from the interpretative framework of the population been studied, or from the insiders' viewpoint (Hennink, et al., 2011). The current research study aimed to achieve *Verstehen* by understanding the spouses experiences from their perspective as they cared for their Dementia of Alzheimer's Type partner. *Verstehen* is also referred to as the emic perspective where the main aim is achieving an understanding of the phenomenon of interest from the participants' viewpoint and not the researchers own perspective.

As described earlier, the epistemology for this study was phenomenology. Merriam (2009) describes phenomenology as aiming to understand the core and the underlying structure of the phenomenon. Furthermore, unique to this type of research is the concept known as phenomenological reduction which is the process of continually returning to the core of the experience to acquire the inner structure or meaning in and of itself (Merriam, 2009).

Phenomenological inquiry utilises a naturalistic approach that strives to understand phenomena in context-specific settings (Hoepfl, 1997). In this research, the context specific setting was spouses caring for Dementia of Alzheimer's Type spouses in the home environment within KwaZulu-Natal, South Africa.

#### 4.2.2. Self-reflexivity

In phenomenology, the Husserlian approach promotes the concept of bracketing which refers to suspending the researcher's own biases beliefs regarding the phenomenon being studied (Dowling, 2004). When researchers have stripped away all their personal pre-conceptions and judgements about a phenomenon, the main parts of that phenomenon remains. In contrast, Heideggarian approach suggests that these should not be eliminated (Dowling, 2004). Being the primary instrument in research, the researcher's personal reflexivity is increased. Personal or self-reflexivity involves the researcher being able to reflect upon the various ways in which their

own values, experiences, interests, beliefs, have played a role in moulding the research (Willig, 2013). It can also include an understanding of the greater social context and to consider how this context could have shaped or constrained the research (Hennink et al., 2011). Similarly, Lambert, Jomeen and McSherry (2010) explain reflexivity “as an integral process in qualitative research whereby the researcher reflects continuously on how their own actions, values and perceptions impact upon the research setting and can affect the data collection analysis” (p. 322). Reflexivity can be confusing and daunting process but by the researcher possessing reflexivity it opens up various possibilities of understanding people’s lives and experiences (King & Horrocks, 2010).

Similarly, King and Horrocks (2010) state that the idea of reflexivity is used to indicate the awareness within the research process. Researchers are involved and implicated in the entire research process through reflexivity and in doing so the experiences that take place are co-constructed (King & Horrocks, 2010).

Self-reflexivity can be documented by keeping a diary, research notes or even keeping notes during the data analysis process (Hennink et al., 2011). However, the notes kept during this process are not seen to be a confessional of the researcher’s experiences throughout the research process, instead, the researcher’s notes should provide an honest and accurate account of the interactions between the researcher and the participant’s (Lambert et al., 2010). By recording one’s thoughts and feelings associated with the research process it allows the development of self-awareness and it also allows one to see to go back to the start of the research and see initial thoughts and feelings (Lambert et al., 2010). In this research a journal was kept throughout the research process, which was used to document my thoughts and feelings (*See Appendix I*). The following extract is taken from the journal I kept:

*“I feel sympathy for participant five as she spends most of her time caring for her husband who is unable to communicate much and he is unable to walk. I see her as a strong woman, emotionally and physically. She doesn’t seem to quit despite all the pain she is currently going through. The interview went well. An environment was created where participant could talk, even though at times she would get a bit emotional...”*

Willig (2013) also states that self-reflexivity also involves thinking about how the research may have possibly changed and shaped us as researchers and people. As Hatch (2002) states

researchers are connected to the world that they study, the knower and the known are taken to be directly related to each other and always inseparable.

Hennink et al. (2011) see reflexivity as important as it shows understanding and awareness of the interpretative paradigm which is an important aspect of qualitative research. Reflexivity is also seen as important as it shows how the researcher managed their own subjectivity throughout the research process. Lambert et al. (2010) states that when researchers remain sensitive to the ways in which the research process moulds the information gathered, it enables an honest interpretation of the data.

Reflexivity also takes into account multiple selves (King & Horrocks, 2010). These authors state that during the research process, we, as researchers bring various 'selves' into the process. Not only do we bring our role as the researcher but we also bring our caring roles such as that of a mother or father and we also bring our professional roles into the research process. It is these 'selves' that play a role in the co-construction process. Each one of these 'selves' has a part to play in building knowledge (King & Horrocks, 2010). Due to my grandfather being diagnosed with Dementia of Alzheimer's Type, I brought my own role of an individual whose grandfather was diagnosed with Dementia of Alzheimer's Type. I was exposed to the various stages of Dementia of Alzheimer's Type, the emotions which came with it and the physical tasks which came with the caring role as I witnessed my grandmother become the primary caregiver for my grandfather. The care which I had for my grandfather during his stages of Dementia of Alzheimer's Type was brought into the current research.

### **4.3 The research design**

#### **4.3.1. Sampling**

One of the reasons that sampling takes place is that better information can be generated from carefully drawn samples than information from an entire population group related to the topic under study (Monette, Sullivan, Dejong & Hilton, 2013). A vital aspect regarding sampling is how representative they are of the population from which they are taken from. According Gratton and Jones (2010) the population refers to everyone who shares certain characteristics defined by the researcher as being relevant to the research question.

To prevent undependable and ambiguous conclusions the population needs to be clearly defined from which to draw the sample (Monette et al., 2013). These authors add that the definition of a population should specify four things. The first refers to the content of the population which refers to the unique characteristic that members of the population have in common. In this research the characteristic that members of the population had in common was that they were stay-at-home caregivers for their Dementia of Alzheimer's Type partners. For the sample to be representative, the partners who were diagnosed with Dementia of Alzheimer's Type were in the second stage (moderate) or third stage (severe) of the disorder.

The population should also specify the unit which refers to the unit of analysis. The unit of analysis for this study were spouses. The third aspect, Monette et al. (2013) state is that the population should specify the geographical area to be covered for the research. In terms of this study, the research was undertaken in the Pietermaritzburg area in the province of KwaZulu-Natal in South Africa. The participants were sourced from an old age home based in Pietermaritzburg. This old age home provides Alzheimer support group meetings once on the first Friday of every month. By attending the support group an explanation of the research was given and an information letter outlining the research and its goals was also provided (*See Appendix A*). This letter was signed to allow access to the potential participants.

The last aspect which the population should specify is the time factor (Monette et al., 2013). This refers to the period of which the spouses should possess the appropriate characteristics to qualify for the sample. In terms of time factor, the spouses should be stay-at-home caregivers of their spouses during the moderate and severe stages of Dementia of Alzheimer's Type.

From this population a sample was then selected. A sample is defined as a section of a population selected for study (Mark, 1996). The criteria for inclusion in the sample were male or female spouses who were stay-at-home caregivers for their Dementia of Alzheimer's Type spouses. A second criterion for inclusion was that the spouses must have Dementia of Alzheimer's Type partners in the second and third phase of the progression of the disorder (*refer to p. 84 for sample profile*).

The method of sampling that was used for this study was purposive sampling. Hoepfl (1997) states that purposive sampling is seen as the main method used in qualitative research. Penner

and McClement (2008) add that purposive sampling is the best suited method for a study using a descriptive phenomenological approach as the aim is to understand and describe a phenomenon from the perspective of those who have experienced it. The advantage of using this type of sampling method is that it allows the researcher to 'hone in' on people which are best suited for this type of research (Denscombe, 2007). Denscombe (2007) further states that with purposive sampling, the research participants are chosen with a specific purpose in mind. This purpose is found in the particular qualities of the people or events chosen and their relevance to the topic of the investigation. This is also echoed by Ritchie, Lewis, Elam, Tennant and Rahim (2003) who state that "sample units are chosen because they have particular features or characteristics which will enable detailed exploration and understanding of the central themes and questions which the researcher wishes to study" (p. 113). These characteristics are socio-demographic characteristics and may also be related to specific experiences or behaviours.

According to Ritchie et al. (2003) purposive sampling has two principal aims. The first aim is "to ensure all key constituencies of relevance to the subject matter are covered" (p. 113). The second aim is ensuring that "enough diversity is included so that the impact of the characteristics concerned can be explored" (p. 113). Taking into account these aims as outlined by Ritchie et al. (2003) the sample took into consideration all key constituencies of the subject matter and in terms of diversity, two race groups were also taken into account. Due to the unavailability of other race groups, this could not be included in the research.

According to Holloway and Wheeler (2010) six to eight participants are seen as sufficient when the sample consists of a homogenous group while between fourteen and twenty participants might be needed for a heterogeneous sample. Smith and Osborn (2007) state that some studies using Interpretative Phenomenological Analysis (IPA) have been published with samples of up to fifteen participants. In terms of sample size, eight participants were selected for this research. The sample size for the research was also dependent on the method of data analysis which took place. Interpretative Phenomenological Analysis was used for this research and generally Smith and Osborn (2007) state that IPA studies are conducted on small sample sizes, with six to eight participants being a recommended sample size.

Ritchie et al. (2003) provides four reasons as to why qualitative samples tend to be small in size. The first reason is that if the data is analysed in detail, eventually that data will not yield new

evidence. Similarly, Hoepfl (1997) states that when the decision is made to stop sampling, the goals of the research must be taken into account. With this in mind, once enough information on the experience of spouses caring for their Dementia of Alzheimer's Type partners has been collected then sampling should stop. The number of research participants that is selected are guided by a theoretical principle called saturation (Hennink et al., 2011). Theoretical saturation is defined as the point when one stops collecting new information because it no longer adds anything new to the information that is already obtained (Terre Blanche et al., 2006).

The second reason of having small samples in qualitative research is that in this type of research incidence and prevalence are not of concern. With this statement in mind, Ritchie et al. (2003) state that, "there is therefore no requirement to ensure that the sample is of sufficient scale to provide estimates or to determine statistically significant discriminatory variables" (p. 117). Qualitative data generates information that is rich in detail (Ritchie et al., 2003). Due to this, sample sizes need to be kept small so that data can be thoroughly analysed. Lastly, Ritchie et al. (2003) state that qualitative research can generate in-depth information therefore small sample sizes are more manageable. Smith and Osborn (2007) also state that there is no right answer to the question of the sample size. It partly depends on several factors, this been the degree of commitment to the case study level of analysis and reporting, the richness of the individual cases, and the constraints the researcher is operating under. In the current research a small size of eight participants was used due to the constraints of limited Alzheimer support groups in Pietermaritzburg. Furthermore, hospitals were not keen to provide access to their participants.

#### 4.3.2. Ethical considerations

Denscombe (2007) states that researchers need to respect the rights and dignity of those participating in the research. Harm should be avoided to the participants and the researcher needs to operate with honesty and integrity.

Marshall and Rossman (2010) state the following regarding respect for persons, "respect for persons captures the notion that we do not use the people who participate in our studies as a means to an end and that we respect their privacy, their anonymity and their right to participate" (p. 47).

Respect for participants takes place with the informed consent form. With this form, the researcher ensures that the participants are fully aware and that they understand what the research requires, they understand that their participation is voluntary as well that their identities have been protected (Marshall & Rossman, 2010). In this research, participants were respected as they were given the informed consent form in writing (*See Appendix C*). By abiding to the informed consent, research participants give their permission that they have full knowledge regarding the purpose of the research and the consequences for them of taking part (Piper & Simons, 2005). All participants in this research were read the information letter (*See Appendix B*). By reading this information letter they were carefully informed of the nature of the research. Participants were free to ask questions before signing. Once participants were comfortable in knowing the nature of the research, they could sign.

Participants also had the right to withdraw consent. According to Denscombe (2007) and King and Horrocks (2010) the consent form does not bind the participant to help with the research. Participants should be made aware, should they wish to do so, that it is their right to withdraw their consent at any time without any subsequent consequences for them. In terms of the consent form, simple language was used in order for the participant to understand, and if there were any difficulties in the understanding of the form, this was also explained to them (Tappen, 2011).

Interests of the research participants were also protected by ensuring confidentiality of information. According to Klenke (2008) by ensuring confidentiality the researcher agrees not to divulge private data that identify participants. Information that easily identifies participants must be removed or not gathered at all, therefore in terms of tape recording; names should be removed to conceal identities of participants. In this research, participants were protected by ensuring confidentiality of information. Anonymity was also afforded to participants in that when publishing results, care was taken not to disclose the personal identities of the research participants (Denscombe, 2007). Hennik et al. (2011) state that it is of utmost importance to inform those participating in the research that information will be collected, analysed and also reported anonymously, they therefore will not be identified in any research data. In the current research names were not used, rather personal identifiers were given to each participant (e.g. P1, P2). Prior to audio-recording, participants were made aware that the recording would start and therefore to not mention any names. Although respect for individuals in terms of anonymity was

taken into consideration, participants were comfortable in disclosing their names. Yet, caution has been taken in reporting the research and experiences have been reported without identifying details.

In terms of confidentiality, Hennik et al. (2011) state that when interviews are carried out in the home environment of the participant, it becomes very difficult in the sense that family members may over-hear the interview. In this case, Hennik et al. (2011) adds that, in this situation the researcher can ask the participant to stop the interview for a while or perhaps move to another place that will be better suited.

In terms of beneficence, avoiding harm to research participants, Denscombe (2007) states that care needs to be taken to avoid psychological harm which results from the research. He further states that the research should not be intrusive or indiscreetly touch on sensitive issues or threaten the beliefs of the participants. Research participants were informed that they could refuse to answer questions should it be distressing for them. Participants were also informed that debriefing contact details would be made available to them should the interview become distressing for them (*See Appendix B*). Apart from harm to research to participants, benefits to participants also results as the potential to enjoy participation in the research can occur as it allows them to discuss their lives and experiences (Hennik et al., 2011). In talking about their situation and their lives, Hennik et al. (2011) adds that participants become more aware of what they think and feel about themselves and their situation.

Hesse-Biber and Leavy (2011) state that the relationship between the researcher and the participant is vital in constructing meaning. In terms of the role of the researcher, theoretical sensitivity was displayed which is the personal quality of the researcher. It refers to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and the capability to separate the applicable from that which is not (Hoepfl, 1997). As a qualitative researcher, capturing one's lived experience becomes very important and this can be done by creating a comfortable and warm environment for participants in which they are free to disclose (Hesse-Biber & Leavy, 2011). A comfortable environment was created by making participants fully aware of the purpose of the research. A climate of mutual respect was created thereby making participants aware that they are free to express their thoughts and feelings to the extent that they are comfortable.

#### 4.3.3. Research procedure

Telephonic contact was made with Alzheimer's Association KwaZulu-Natal. This organisation provided details via email of various old age homes that would be potentially willing to assist in the Pietermaritzburg region. Contact was then made with old age homes. One of the homes was willing to assist and allowed the research to be presented in an Alzheimer's support group. The facilitator of the Alzheimer's support group was contacted to arrange a suitable date and time for the research to be presented to the Alzheimer's support group.

In the Alzheimer's support group meeting potential participants that were present read the documents provided. These documents being the information letter (*See Appendix B*), the consent form (*See Appendix C*) and the consent to audio-recording (*See Appendix D*). Potential participants were free to ask any questions during this recruitment meeting and were allowed to take these forms home to read through. Interested potential participants provided their contact details (phone numbers and residential addresses).

Contact was then made with the potential participants via telephone. Ethically, participants cannot be required to be involved and therefore all contacted individuals were informed that their participation would be voluntary and that they had the right to withdraw at any time (Blaikie, 2010). From this call, it was determined whether they were willing to participate. Those potential participants whom were willing to partake in the research were paid a home visit. The home visit was made at a time that was most convenient for them. Eatough and Smith (2008) state that people often feel most comfortable in a setting that they are most comfortable with, for example their home, after all the participants were the stay at home spousal caregiver for their Dementia of Alzheimer's Type partner.

During the first home visit, respondents had the opportunity to ask questions pertaining to the research. Respondents were requested to sign the information letter (*See Appendix B*) as well as the consent form (*See Appendix C*). Permission was also granted from the respondents to tape record the interview. Participants were then asked to sign the letter of consent to audio-recording (*See Appendix D*). They were also informed who would have access to the information given and what would happen to the information after it has been transcribed. Eatough and Smith (2008) state that for IPA, it is necessary to record (on audio tape or by using digital recording equipment

which gives a much clearer recording), and transcribe the whole interview, including the talk of the interviewer. Recordings have the advantage of capturing data more faithfully than hurriedly written notes might, and can make it easier for the researcher to focus on the interviewee (Hoepfl, 1997). Smith and Osborn (2007) also state that attempting to write down everything during the interview interferes with the interview running smoothly and with establishing rapport with the participant. In the current research no notes were taken while the interview took place. Terre Blanche et al. (2006) add that when tape recording the interview it shows the interviewee that the researcher takes what participants say seriously and desire it also shows the interviewee that the researcher wants to document their thoughts accurately.

#### 4.3.4. Method of data collection

The primary strategy for data collection was with the use of semi-structured questionnaires. This type of data collection was well suited to method of data analysis. This is echoed by Eatough and Smith (2008) who state that a large amount research involving IPA have been conducted on data obtained from semi-structured interviews.

When using a semi-structured questionnaire, a certain set of questions are depended on in order to guide the conversation (Hesse-Biber & Levy, 2011). Participants been interviewed are given the freedom to talk about any other aspects which are of interest to the topic being researched and through this a meaningful conversation is developed (Hesse-Biber & Levy, 2011). Smith and Osborn (2007) add that semi-structured interviews allow the researcher to gain comprehensive knowledge of the thoughts and beliefs of the individual been interviewed. Apart from this advantage of gaining richer information on the topic, semi-structured interviews also facilitate rapport and empathy as well as allowing the researcher to enter novel areas, as the researcher remains flexible to feedback from the participant (Smith & Osborn, 2007). Face-to-face interviews would be best suited for the research, this is confirmed by Penner and McClement (2008) who add that, phenomenological research data are commonly collected through face-to-face interviews which allows the researcher to gain a deeper insight into the experiences of the participants through more personal contact and non-verbal cues.

With the semi-structured questionnaire, the researcher was guided by the interview schedule (*See Appendix E*). Eatough and Smith (2008) endorse the researcher having the freedom to examine

and probe interesting areas that arise and can follow the participant's interests. In terms of the interview schedule, Smith and Osborn (2007) state that when questions are too difficult or too vague for the interviewee, prompts need to be used for these questions. Smith and Osborn (2007) recommend when conducting the interviews, general and easier questions should be first on the schedule. The reason for this is that it allows the respondent to disclose more information. In the current research general questions were asked first in the interview to prevent the interviewee from being overwhelmed.

Semi-structured interviews usually take place for an hour or more (Smith & Osborn, 2007). In this research the interviews took place for an hour. These authors further state that when interviewing participants, the interviews should take place with them alone, this is to avoid interruptions. In the current research, one participant's spouse with Dementia interrupted the interview. The interview stopped for four minutes and then resumed when the spouse with Dementia left the room.

In terms of the interviewing process, building of rapport is very important. To build rapport, mutuality of trust needs to be created (Klenke, 2008). This author further adds that to establish mutual trust, one needs to display empathy and a relationship displaying equality between interviewer and interviewee needs to be created. To maintain rapport throughout the interview process, the interviewee needs to display understanding and create an environment that is non-judgemental and without biases (Klenke, 2008). To establish trust as a basis for rapport, Klenke (2008) identified the significance of informing interviewee's fully about the length of the interview. In this research, the duration of the interview was highlighted in the information letter (*See Appendix B*). This was also discussed with interviewee prior to them signing the consent form. Inviting clarifying questions is also seen as a way by Klenke (2008) to establish trust. In this research, interviewees were free to ask for clarification at any stage.

#### 4.3.5. Method of data analysis

The method of data analysis which was used for this research was Interpretative Phenomenological Research (IPA). According to Eatough and Smith (2008) the aim of IPA is to explore in detail the individual personal and the lived experiences of how people make sense of their personal and social world. Lived experience which is also known as *Erlebnis*, is

encompassed by the individual's history, culture and society (Eatough & Smith, 2008). IPA therefore attends to aspects of this lived experience such as the individual's thoughts, desires and feelings (Eatough & Smith, 2008). IPA stresses that our ability to gain information to events and information is only gained through the eyes of the person describing the event (Shaw, 2010).

IPA is influenced by both phenomenology and hermeneutics. In terms of phenomenology which is a concept of IPA initiated by German philosopher Husserl, the aim is to understand human experience while in hermeneutics which is associated with Heidegger, close attention is paid to interpretative activity (Shaw, 2010). Similarly, Pringle, Drummond, McLafferty and Hendry (2011) state that phenomenology reveals meaning and hermeneutics interprets and explains the meaning. These authors also add that IPA involves a two-stage process. In the first stage, researchers uncover the meaning and lastly they try to interpret the way in which the participant makes sense of these activities. Shinebourne (2011) echoes the previous statement as she states that, IPA is interpretative as it recognises the role of the researcher in making sense of the experience of participants. Shinebourne (2011) adds that, researchers need to critically assess how these pre-understandings and pre-judgments influence the research. This is described as double hermeneutic. Therefore in the current research not only were the participants trying to make sense of their world but I was trying to make sense of them trying to make sense of their world. A process of interpretative activity therefore took place to create a double hermeneutic (Smith & Osborn, 2007). For Heidegger, the meaning of phenomenological description as a method lies in interpretation (Shinebourne, 2011).

IPA is particularly well suited to exploring topics in the fields of health, social and clinical psychology where the need is to distinguish how people comprehend important events in their lives. It is an approach to qualitative analysis with an interest in how people make sense of their experiences (Larkin & Thompson, 2012). IPA, therefore, fits with current research as Dementia Alzheimer's Type falls within the above mentioned sub-discipline and this research sets out to discern or make sense of how spouses experienced caring for their spouse with Dementia of Alzheimer's Type. An idiographic approach therefore needs to take place. This allows a detailed focus on the phenomenon been studied (Larkin & Thompson, 2012).

IPA requires questions that are open ended. Using open ended questions facilitates a focus on experiences and understandings. Open ended questions therefore provide exploration of a topic

(Larkin & Thompson, 2012). In this research a semi-structured questionnaire was used. Research questions were present in the questionnaire. Open ended questions provided a focus on experience and understanding. IPA also requires a verbatim transcript of a first person account (Larkin & Thompson, 2012). Verbatim transcripts were produced in this research after individual face-to-face interviews took place.

With regards to the research stage of analysis, the researcher also plays an important role. This is confirmed by Dalby, Sperlinger and Boddington (2011) as they state that the researcher plays an active role in the research process. Pringle et al. (2011) emphasises the active involvement of the researcher as the researcher is the individual that brings information to light. The active role which researchers play occurs by first co-creating the social interaction within which the information are gathered, and then through interpretation the information, a set of themes and conclusions are arrived at. Smith and Osborn (2007) argue that the researcher also plays the role of interpreting and describing people's mental and emotional state from what they say as sometimes participants may not wish to discuss their underlying emotional meanings in their spoken words.

The main interest in the analysis of IPA is identifying what matters the most to participants and thereafter exploring these meanings with the participants. Once we have this understanding, an interpretative synthesis of the analytical work can be developed (Larkin & Thompson, 2012). Analysis of data using the method of IPA, takes place in different stages. In the first stage of data analysis, interviews were transcribed verbatim from a digital recording. Any personal identifiers were removed to protect the anonymity of participants. As part of the coding system, a personal identifier number was given to them (e.g. P1- participant 1/P2 – participant 2). The digital recordings were transcribed in full. King and Horrocks (2010) state that, “approaches that seek to examine personal experience in depth, like phenomenological approaches will require full verbatim transcription” (p. 143).

The next stage of data analysis started with an iterative process of reading and re-reading the transcript. The reason for doing this was to get an overall “feel” for the interview. This is confirmed by Smith and Osborn (2007) who state that the reason for reading and re-reading the transcript is to become very familiar with the experiences of the participant. Similarly, Shaw (2010) concurs that the first stage of analysis is getting to know the data. Shaw (2010) also states

that if the interview is tape recorded, this should be gone through with the transcript to pick up meanings beyond the text transcribed. King and Horrocks (2010) emphasis that the transcript should be read through in full before proceeding with the analysis as phenomenological analysis should be holistic. In this research, the audio-recording was listened to carefully twice, the transcript was read through numerous times to fully understand the information presented. The transcript was also checked against the audio-recording to make sure the interview was transcribed correctly.

When reading through the data, the left-hand margin was used to jot down notes and ideas. Smith and Osborn (2007) state that there are no rules about what is commented upon. The notes that were taken down attempted to summarise or paraphrase the transcript. The use of language was commented on, as well as similarities and differences amongst transcripts. According to Storey (2007) these observations are set aside as useful information that might be used later. Larkins and Thompson (2012) refer to this stage as free coding. At this stage the researcher's preconceptions came to the fore. This was an ongoing reflexive process with each transcript.

The second stage of data analysis involves using the notes made in the left-hand margin to produce emerging themes in the right hand margin. Klenke (2008) makes a distinction between two different types of thematic coding. In manifest coding, the content of a phenomenon is already quite clear. Whereas, in latent coding, the researcher is seeking hidden content that represents a higher level of abstraction.

In the second stage, the notes made were used to form brief statements which aim to capture what was found in the text (Smith & Osborn, 2007). These authors state that the skill at this stage is finding expressions which are at a high enough level to allow theoretical connections within and across cases but which are still grounded in the actual words been said by the participant. Importantly, when progressing between these two stages, the researcher needs to ensure a balance between the richness of what is said, the themes that are gathered and the theoretical connections that are created (Jones & Watt, 2010). This step of identifying significant statements, sentences or quotes is called horizontalisation (Creswell, 2012). The quotes and metaphors used by participants can also be used in the theme titles or in descriptions to further root the analysis directly in their words. IPA aims to therefore go beyond a standard thematic analysis (Pringle et al., 2011).

Shaw (2010) also adds that when identifying initial themes, the transcript needs to be broken down into smaller sections and to describe what is been said in each section. Shaw (2010) states, that in this stage, descriptive summaries need to be written about what the participant says and initial interpretations need to be made about what issues and feelings might mean.

The third stage of data analysis involved finding connections between preliminary themes. The themes listed were put down on paper and from there connections between themes were made (Smith & Osborn, 2007). Willig (2013) points out that some of the themes will form natural clusters of concepts that share meanings, whereas others will be characterised in terms of a ranking order. According to Jones and Watt (2010) in this stage some themes will immediately be evident as superordinate themes (overarching themes under which other themes naturally cluster). This stage takes on an idiographic approach which aims for a commitment to detailed analysis. In an idiographic approach, the analytical process begins with a comprehensive analysis of each transcript, moving to careful examination and scrutiny of similarities and differences to produce a thorough account of patterns of meaning and reflections on experiences (Shinebourne, 2011).

The fourth stage of data analysis involved producing a summary table of the themes, together with quotations that illustrate each theme. This is also echoed by Smith and Osborn (2007) who state that the analysis becomes extensive and distinct, as themes are explained and illustrated. The summary table, in the current study, only included those themes that captured something about the quality of the participant's experience of the phenomenon (Willig, 2013). Willig (2013) further states that the summary table needs to include the cluster labels together with their subordinate theme labels and brief quotations (*See Appendix J*).

#### 4.3.6. Limitations of Interpretative Phenomenological Analysis

IPA opts for a smaller sample as according to Pringle et al. (2011). This can allow for a richer depth of analysis that might be inhibited by a larger sample. By having a deeper, richer and more interpretive analysis, it draws the researcher away from the original meaning. Pringle et al. (2011) adds that IPA is very tied to its theoretical roots. However, the theoretical roots can add a sense of depth which generic thematic analysis, arguably, lacks.

The effectiveness of an IPA study is judged by the light it sheds in a broader context. Therefore if the sample group is too specific then IPA will not be very effective. However, if the research account is descriptively rich and transparent enough then the researcher should be able to estimate and evaluate transferability.

#### 4.3.7. Trustworthiness of data

Before a research study is undertaken, it is important to note how a paradigm influences their inquiry, data collection and data analysis (Miles & Jozefowicz-Simbeni, 2009). For this research, the naturalistic paradigm is well suited. This paradigm is hermeneutic and phenomenological in nature, placing emphasis on lived experience. According to this paradigm, multiple realities are constructed and the goal of research is to understand how individuals construct their reality within their social context (Miles & Jozefowicz-Simbeni, 2009). The researcher and the participant are interrelated.

The naturalistic paradigm introduced the concept of trustworthiness. Trustworthiness is the term that is used to describe the processes and the product of qualitative research (Tappen, 2011). Trustworthiness in qualitative data analysis is of high importance in order to maximise the potential for meaning-making (Klenke, 2008). Trustworthiness of the study is what persuades others that the findings of a study are credible, dependable, confirmable and transferable to other situations. Credibility, transferability, dependability and confirmability therefore comprise the concept of trustworthiness (Klenke, 2008).

##### 4.3.7.1. *Credibility*

According to Guba's model of trustworthiness (1981), one of the aspects relevant to qualitative research is called truth value. Krefting (1991) defines truth value as how confident a researcher is with the truth of the findings. Through the human experiences of participants, truth value is created.

Credibility is the criterion for truth value (Krefting, 1991). Krefting (1991) adds that, "a qualitative study is credible when it presents such accurate descriptions or interpretations of human experience that people who also share that experience would immediately recognise the description" (p. 216). Credibility also refers to whether the participants perceptions of the setting is the same as what the researcher portrays in the research report (Lodico, Spaulding & Voegtle,

2010). Similarly, Klenke (2008) adds that credibility is the degree to which findings of the research are believable from the standpoint of the participants and professionals in the field.

When aiming at credibility, Klenke (2008) highlights the theoretical positioning of the researcher. The researcher's values, motives and personal history play a role in influencing the research. Lodico et al. (2010) state that researchers need to engage in analysing how their thoughts change when conducting the research. Krefting (1991) states that reflexivity involves the researcher assessing one's own backgrounds and perceptions when entering a new environment. Researchers therefore need to monitor their own subjective perspectives and biases (Lodico et al., 2010). The researcher should reflect on their own characteristics and pay attention to how they influence the data gathering process and analysis. These authors add that this can be done by keeping a journal of one's thoughts throughout the process. Krefting (1991) outlines that this journal could include information like feelings and thoughts of the researcher and also problems and frustrations that the researcher encounters in the process of conducting the research. In this research, a journal was not only kept for the interviewing process but was also kept throughout the data analysis process. This was critical to prevent my personal experiences in 'contaminating' the themes found. The following is an extract from the data analysis stage:

*"In reading through the interviews, there were many similarities with my experiences of having a grandfather with Dementia of Alzheimer's. Some of these examples are being bed-ridden due to immobility and aggression. I need to take care when analysing themes to not focus on these issues because I have had a personal experience with them but rather focus on them as they appear in the other transcripts as well."*

With regards to credibility, Shenton (2004) states that specific procedures employed such as line of questioning pursued in the data gathering sessions and the method of data, should be derived from those that have been used successfully in previous research that are similar. In this research, questions for the semi-structured interview have been alluded to in previous studies of Dementia of Alzheimer's or have been taken from previous studies related to caregiving (*See Appendix E*).

Shenton (2004) states that participants of the research should be given the opportunity to refuse to participate in the project thereby ensuring that the data collection sessions involve only those

that genuinely want to take part and offer credible data. In this research, participants were given this opportunity, as indicated by their written informed consent (*See Appendix C*).

To enhance credibility, a detailed description can be important for promoting credibility as it helps to convey the actual situations and to an extent the context that surrounds them (Shenton, 2004). The semi-structured interview provided a detailed description of the situation as the questioning explores experiences and concerns that were expressed by the Dementia of Alzheimer's Type caregiver participants in an in-depth conversation of an hour duration.

Krefting (1991) states that credibility in a research is threatened when participants of the research respond with what they think would be the best social response, therefore the data given is based on social desirability and not their personal experience. Krefting (1991) also adds that the closeness of the relationship between the participant and the researcher can also be seen as a threat to credibility. This author does see some degree of closeness as important, but the ability to interpret findings should not be lost. To ensure that there is no overinvolvement, the issue of self-reflexivity is important (Krefting, 1991). Self-reflexivity is seen as important in qualitative research as it can affect the situational dynamics between the researcher and the participants (Hesse-Biber & Leavy, 2011). In the current research self-reflexivity was maintained through the journal which was used to document each interview. Each journal entry was a space for reflection and through this any pre-conceptions about the research were noted. This allowed me to keep track of my personal experiences of having a grandfather with Dementia Alzheimer's Type and to also keep track of how it impacted the interviews. The journal allowed me to express my thoughts but also keep influencing thoughts on the research process at bay (*See Appendix I for journal entries*).

#### 4.3.7.2. *Transferability*

The second aspect in Guba's model of trustworthiness (1981) is applicability. Applicability refers to the extent to which the research findings can be applied to various contexts (Krefting, 1991).

There are two different perspectives regarding applicability. The first perspective suggests that generalising is not important in qualitative research as qualitative research is conducted in a naturalistic setting with limited emphasis on controlling variables as such, therefore each

situation is seen as unique and in turn less susceptible to generalisation (Krefting, 1991). The second perspective presented by Guba (1981) refers to transferability which refers to having a fit between the two contexts (Krefting, 1991).

It is therefore important that qualitative researchers provide plenty background information about the research context and setting to allow others to assess how transferable the findings are (Krefting, 1991). By providing a detailed description of the sample and the context in which the study was conducted, this allows one to decide the extent the findings may be transferred to other individuals (Tappen, 2011). In this research, the sampling methods and the sample were discussed in detail in the research design. In this research, purposive sampling was used. The criteria for inclusion in the sample were male or female spouses who were stay-at-home caregivers for their Dementia of Alzheimer's Type spouses. The Dementia of Alzheimer's Type spouses were also in their second and third phase of the progression of the disorder.

Participants were sourced by contacting the Alzheimer's Association in KwaZulu- Natal. The Alzheimer's association provided contact details of various retirement homes or old-age homes in the Pietermaritzburg region. An old age home based in Pietermaritzburg allowed me to source participants from their Alzheimer's support group. In terms of the research setting the interviewing took place in the home of each participant for their convenience. This research could be easily replicated in other provinces in South Africa as the future researcher could follow the same process of contacting the Alzheimer's Association which has branches throughout South Africa. The Alzheimer's Association of South Africa will have contact details of various old age homes in provinces. This could be used to contact support groups and thereby source spouse caregivers in a similar situation.

Krefting (1991) adds that another strategy used for transferability is to consider the data. This means that the researcher needs to analyse if the behaviours are typical or atypical of lives of the participants. This was achieved by carefully comparing each transcript with the other transcripts of the participants, for similarities and differences of the current study as well as findings of previous studies.

According to Krefting (1991), transferability is not seen to be the responsibility of the researcher of the original study, rather it should be the responsibility of the researcher that wants to transfer

the findings. If the original researcher provides ample descriptive data, then they have succeeded in addressing the problem of applicability.

An audit trail details the thoughts and actions of the researcher throughout the research process (Holloway & Wheeler, 2010). In terms of an audit trail for the current research, all thoughts and actions made throughout the research process were documented in a journal (*See Appendix L*). The various activities were kept safely with the researcher, no individuals had access to this. Telephone numbers and names of all participants were saved on the researcher's personal computer which could only be retrieved by the researcher via a password. Furthermore, the semi-structured questionnaire, signed consent and information forms were kept safely with the researcher in a file which could only be accessed by the researcher itself. All interview recordings were saved on a recorder and were stored away safely after transcriptions were completed. No individuals had access to these recordings and the recordings were transcribed by myself as the researcher. The analysis of the transcripts and the findings of the research were saved electronically on the researcher's personal computer which could only be accessed by the researcher via a password.

#### 4.3.7.3. *Dependability*

Dependability refers to the technique to show that if the research were repeated in the same context, with the same methods and with the same participants, it would yield similar findings (Shenton, 2004). Shenton (2004) adds that to address dependability, the process of how the study was conducted should be reported in detail, from the research design, implementation and the data gathering of the research. Smith and Osborn (2007) state that in order to enhance dependability, the researcher should stay very closely to the interview schedule and they should also behave with as little variation as possible between the interviews. Closeness to the interview schedule was closely followed in the current study.

For dependability, an audit trail becomes an important. An audit trail is a record of the conduct of the study itself, the researcher's thoughts and decisions that were made along the way. (Tappen, 2011). There are six types of raw material that can be compiled throughout the research. Tappen (2011) outlines the following:

- Raw materials: This been field notes and tape recordings.
- Data synthesis products: Summaries or ideas that occur to the researcher during the process.
- Data synthesis products: This being coding schemes, themes found (*See Appendix J*) and interpretations made.
- Process notes: Description of how data was obtained and how analyses were done (*See Appendix L*).
- Reflections of the investigator - This refers to a personal reflexive diary (*See Appendix I*).
- Surveys or questionnaire guides – This being semi-structured interview guides (*See Appendix E*) or any document which collects information.

In terms of this research, an audit trail of raw materials was formed as tape recordings were completed. Themes were found and interpretations made from verbatim transcripts of the interviews. A reflexive journal was kept and a semi-structured interview guide was used to collect all the data in each interview (*See Appendix I*). These procedures were implemented to contribute towards the dependability of the study.

#### 4.3.7.4. *Confirmability*

The final aspect of Guba's trustworthiness model (1981) is that of confirmability. Krefting (1991) states that confirmability refers to "the degree to which findings are a function solely of the informants and conditions of the research and not other biases, motivations and perspectives. (p.217). Lincoln and Guba (1985), however, moved the emphasis away of neutrality from the researcher to the data. The audit strategy is therefore an important technique to establish confirmability.

Audit trails are also useful in ensuring confirmability as understood by the qualitative researcher. Macnee and McCabe (2008) refer to audit trails as constant documentation regarding the researcher's decisions about data analysis as well as the collection process. This assists the researcher in being consistent. Audit trails also assist in ensuring the data reflects participants' descriptions (Miles & Jozefowicz-Simbeni, 2009).

The reflexive journal also adds in creating trustworthiness as personal experiences of the researcher are recorded as well as the expectations before data collection begins (Tappen, 2011).

Tappen (2011) further states that, the researcher needs to record their expectations and their preliminary ideas about what is going to be studied. This becomes important as the researcher may want to refer back to these thoughts during or after the study has been completed. The journal also assists in keeping the researchers' subjectivity and pre-judgments at bay (*See Appendix I*).

#### 4.3.7.5. Enhancing quality

According to Klenke (2008), one way to enhance quality is through the process of verification. This author defines verification as “the process of checking, confirming and making sure that data collection procedures, analysis and interpretation are monitored, reflected upon and constantly subjected to confirmation or disconfirmation” (p. 42).

To enhance quality measures in this study, the various tools used in this research were checked if they appropriately apply. Therefore there needs to be a fit between sampling, data collection and the analysis stage (Klenke, 2008). This was checked constantly throughout the research process. Purposive sampling was used as this is seen to be the key method used in qualitative research (Hoepfl, 1997). The current qualitative research study was informed and as such regulated using the paradigm of phenomenology (Rubin & Babbie, 2009) therefore IPA was used to explore and make sense of the participant's lives (Larkin & Thompson, 2012). The sampling of the participants took place using purposive sampling. This sampling is well suited to the IPA technique as it was used with various IPA research in the past (Eatough & Smith, 2008). There was therefore a fit between all stages in the research process. This enhanced the quality of the findings.

The semi-structured questionnaire was further checked to ensure that it would appropriately answer the objectives of the research, this being the lived experiences of the spouse caregivers. Each question was checked to ensure that it would generate the appropriate level of detail in understanding these experiences. Furthermore, these questions were arranged in such a manner so as to not intimidate the participant. General questions were placed first leading to more specific. The semi-structured questionnaire was also communicated in clear and simple language which made it easy for the participants to understand. This ensured that participants could answer questions without constantly clarifying the question asked.

In the stage of data collection, ethical procedures were implemented which further enhanced trustworthiness. Participants were given an information letter which outlined the objectives of the research. This letter was given to participants in advance of the interview taking place. In receiving this letter in advance, participants were fully aware of the aims of the research and were more comfortable in participating. Furthermore, participants signed a consent form and a form consenting to audio-recording.

The building of rapport with participants further enhanced trustworthiness. In creating a warm environment, participants felt more comfortable to disclose their feelings. One way in which rapport was built is through offering debriefing resources if an interview was distressful. This showed concern for their feelings and created an environment built on trust. Furthermore, in terms of the audio-recording, participants were informed when the recording was starting and when it ended. This communicated respect to the participants and further added to rapport building. According to MacNee and McCabe (2008) participants need to be able to share their thoughts and feelings without feeling pressurised and they should not want to censor information which they share. In this research participants felt comfortable sharing information and did not feel pressured. All participants did not mind their identities being revealed.

The recorded information was stored on a recorder which was kept safely with the researcher. There were no other individuals which had access to this information therefore recordings were not able to be tampered with. Once transcribed, the transcript was checked at least twice against the recording. This was done to ensure that the information was accurately transcribed.

Throughout the data collection process, self-reflexivity was practised. This prevented any personal biases from impacting the research (Klenke, 2008). A journal was kept when conducting interviews (*See Appendix I*). Thoughts and feelings were written in the journal before the interview began and when the interview was completed. Through this process thoughts were tracked to see if any personal subjectivity was negatively affecting the research.

After the analysis of each transcript was complete, this was read through at least twice. This was done to ensure that adequate themes were generated and that the themes were relevant to the objectives of the research which is the understanding the experiences of the spouses. Once the main themes were produced, this was further checked to see if it produces a detailed exploration

of the participant's experiences. Reading of the transcript occurred again to ensure that appropriate quotes were used in discussing the findings. These techniques ensured quality of the research.

## Chapter 5: Findings and Discussion

The current research aimed to answer the following question: What are the experiences of spouses as they care for their Dementia of Alzheimer's Type partner within the South African context? The following table below provides the themes and sub-themes which were produced from the analysis of the data. Below are the findings and discussion of the data.

Themes	Sub-themes
The Loss	<ol style="list-style-type: none"> <li>1) Ruined expectations</li> <li>2) Loss of the spouse               <ul style="list-style-type: none"> <li>- Changes in personality</li> <li>- Loss of communication</li> <li>- Loss of hobbies previously enjoyed</li> <li>- Loss of roles</li> </ul> </li> <li>3) Loss of marital intimacy / companionship</li> <li>4) Loss of self</li> </ol>
Caregiver Stress	<ol style="list-style-type: none"> <li>1) Assisting with activities of daily living               <ul style="list-style-type: none"> <li>- Assisting with dressing</li> <li>- Assisting with bathing</li> <li>- Assisting with eating</li> <li>- Assisting with toilet use</li> </ul> </li> <li>2) More time spent on caregiving               <ul style="list-style-type: none"> <li>- Hours spent on caregiving</li> <li>- Worry over wandering</li> </ul> </li> <li>3) Lack of knowledge of Dementia of Alzheimer's Type</li> <li>4) Impact on employment</li> <li>5) Financial implications</li> <li>6) New roles for caregiver</li> </ol>

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Strain of caregiving	<ol style="list-style-type: none"><li>1) Distress in witnessing degeneration of spouse</li><li>2) Fear of the worst</li><li>3) Caregiver death</li></ol>
Love as a motivating factor	No sub-themes
Retrogenesis	No sub-themes
Decrease in social activities	<ol style="list-style-type: none"><li>1) Behaviour of the spouse</li><li>2) Seeing to the needs of the spouse</li><li>3) Losing friends</li></ol>
Coping mechanisms	<ol style="list-style-type: none"><li>1) Need for relaxation / alone time</li><li>2) Support<ul style="list-style-type: none"><li>- External</li><li>- Emotional</li><li>- Financial</li><li>- Faith</li><li>- Practical</li><li>- Institutionalisation</li></ul></li></ol>

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The demographic table, as such sample profile, below provides a biographical description of the participants that participated in this study.

	<b>Age of caregiver</b>	<b>Age of spouse</b>	<b>Home language</b>	<b>Ethnicity</b>	<b>Years married</b>	<b>Years diagnosed with Alzheimer's</b>	<b>Stage of Alzheimer's disease</b>
<b>Participant 1</b>						4 years, 6 months	
<b>(Female)</b>	71	72	English	Indian	43 years		Severe
<b>Participant 2</b>						5 to 6 years	
<b>(Female)</b>	82	82	English	White	56 years		Severe
<b>Participant 3</b>						12 years	
<b>(Female)</b>	71	77	English	White	52 years		Severe
<b>Participant 4</b>						1 year, 2 months	
<b>(Female)</b>	66	78	English	White	36 years		Moderate
<b>Participant 5</b>						5 years	
<b>(Female)</b>	72	85	English	White	35 years		Severe
<b>Participant 6</b>						3 years	
<b>(Male)</b>	70	58	English	Indian	14 years		Severe
<b>Participant 7</b>						± 2 years	
<b>(Male)</b>	90	82	English	White	30 years		Moderate
<b>Participant 8</b>						5 years	
<b>(Female)</b>	75	83	English	White	50 years		Severe

## 5.1. The Loss

### 5.1.1 Ruined Expectations

Some participants expressed the hope that the course of life would be different, however, with the onset of Dementia of Alzheimer's Type, their expectations were now ruined and lost.

Dementia of Alzheimer's Type now brought a new path to their married lives where they now

had to adapt to the changes. Participant six hoped that in the future his wife would be the one caring for him as he is twelve years older than her:

*Participant 6 – “I am actually...I am now...I am twelve years her senior, so I was anticipating that when I get old she will look after me, so that was my pre-planning...acceptable to both of us and it just turned out the other way around...completely the other way around.”*

Participant four was hopeful that life was going to be better as both of them were doing well in terms of their health. A new path to life now had to be taken with the onset of Dementia:

*Participant 4 – “Because you know, I was enjoying my life and I was healthy...much better than I was...not healthy...and he was getting better and better every day because he had a heart attack, he had a bypass. Ya (Yes), and all of a sudden this happened and I just couldn’t come to terms with it.”*

On the other hand, participant two hoped things would go according to the norm that they would grow old together. She also admits to not wanting to face reality that this was happening to her:

*Participant 2 – “You don’t really want to accept it. You just think, he’s getting older, I’m getting older, we’ll go together type of thing.”*

In this research, expectations for the future were lost. Some participants spoke of how they thought life would be. They expected life to go according to the norm, by them growing old together without major cognitive decline. However, due to Dementia of Alzheimer’s Type, growing old together without neurocognitive impairment was now an impossibility. The theme of ruined expectations is supported by research undertaken in the United States of America by Butcher et al. (2001). In their research, carers experienced the loss of realising that dreams for the golden years were no longer tangible. Consistent with the theme of ruined expectations is research by Lewis (2015) which was also undertaken in the United States of America involving twenty eight states. In this research, apart from missing their loved one, they also missed a future that they would have had. The disease had stolen their anticipated future and this was now shattered. Understanding of this theme is important because not only is the loss of the person a difficult task but this is now exacerbated with the loss of their own future.

### 5.2.1. Loss of the Spouse

With the onset of Dementia of Alzheimer's Type, the disease slowly started to 'eat' away at the participant partners. All participants therefore expressed that they "lost" their spouse. The person they once knew, no longer existed. The following losses in their spouse were noted:

- **Changes in personality**

The personality of the individual changed drastically. Participant one describes her husband as a very caring and loving man but as Dementia of Alzheimer's Type progressed, his personality changed to that of someone who was unaware of anything:

*Participant 1 – "Before Dementia came into the picture, he was a very caring and loving person...but as time went on, all that went off...he didn't know anything..."*

Participant five reminisces when her husband was a different man before the Dementia of Alzheimer's Type took control. She finds comfort in describing the holidays they went on and how he had made her feel special and loved:

*Participant 5 – "I remember it was five years ago we went to the Berg and that's the last time I can remember him being a little bit alright. He was very...it was our 30<sup>th</sup> anniversary, he was very sweet and gave me a present and said nice things...ya (yes), it's all gone really."*

Participant three also expresses the changes in her husband's personality. He was a man of a friendly nature who was able to easily get along with people but with the onset of Dementia of Alzheimer's Type he became withdrawn:

*Participant 3 – "The main thing was that he withdrew, he was a very friendly person, mixed with people easy and then he withdrew."*

A further change in personality was the aggressive behaviour which was brought on by Dementia of Alzheimer's Type. Two participants experienced this change. This was also a cause of stress amongst these participants.

Participant eight described her husband as very violent. This behaviour was something she never experienced from him before. Not only was it stressful for her, but she also felt it would impact her health:

*Participant 8 – “Yes, we moved...well because he was getting so violent. I couldn’t take in anymore, because I felt I was going to have a heart attack or something...he’d never touched me in his life but he hit me quite a few times.”*

Participant six described aggressive tendencies of his spouse. He sees this as part of the disease and something that needs to be overcome. He describes intense moments of aggressiveness where he would have to physically leave the house so his wife would be more comfortable:

*Participant 6 – “She became very aggressive and nothing can be done about it, we just have to see it through...at the moment, she recognises me throughout the day...night, except for just now and again, maybe like five minutes here and five minutes there. Previous to that she used to chase me out the house, she didn’t know who I was and then it comes to a period where she recognises me and then it’s not so heavy.”*

The experience of the loss was an important theme which was felt by all participants. The most common loss which was experienced was the loss of the person they once knew. It was these changes in spouse with Dementia’s personality which were the most difficult for spousal caregivers to witness.

The caregivers reported that their spouses with Dementia no longer enjoyed hobbies which they used to be passionate about. They became withdrawn. One of the spouses with Dementia became aggressive when in fact he was a very loving and caring individual prior to the onset of Dementia. There was therefore a drastic change of the person that she knew and loved for a number of years. This is supported by previous research undertaken by Butcher et al. (2001). The research by these authors was similar to the current study as the aim was to determine the experiences of caring for a family member with Alzheimer’s. Much like the current research, this study was a phenomenological in nature however it was carried out over a four-year period. In their research, carers found it difficult to come to terms with the changes in their spouse. Their spouse was still physically the same person but in many ways, they were very different due to the changes brought on by Dementia of Alzheimer’s Type. Using a comprehensive database search

on qualitative research, research by Evans and Lee (2014) also provide findings that support the current research. In their research, spouses felt that their partner was now a stranger, they doubted whether the person they married was still present. It is this slow deterioration of their loved one that brings about a deep sadness and extended leave-taking from the people they once were. Understanding the various losses which are brought about by Dementia of Alzheimer's Type is important as it will provide future caregivers with the knowledge to deal with the situation. Future caregivers will not walk blindly into the caregiving role but will know what to expect. They will not see it as their spouse been difficult but rather as a natural process of the disease.

- **Loss of communication**

Most Alzheimer spouses in the current research could no longer have a conversation with their spouse. The spouses of the participants below could still talk however forgetfulness of their partner with Dementia was very apparent and this made it difficult for them to hold a conversation.

The spouse of participant four was in the moderate stage of Dementia of Alzheimer's Type. He was still able to speak however due to memory loss it was difficult to hold a conversation with others:

*Participant 4 – “Ja (Yes), and as I say the conversation...that's just gone, you know...he'll mention a couple of little things to me but nothing serious.”*

Similar to participant four, the spouse of participant seven could not hold a conversation due to the memory loss. He expresses the desire to have a conversation with her. He also described himself in playing a role trying to make her talk but his efforts were in vain. Behind the comments of this participant, one sensed social isolation as he yearned to have a conversation with her:

*Participant 7 – “...I also miss sitting and chatting. There's nothing to chat about anymore. I wish there were, not like there's anything wonderful to talk about. I do sometimes talk about the paper...what I see in the paper. But she will forget it straight away.”*

The spouse of participant six could not hold a conversation. She would use words to express how she felt.

*Participant 6 – “She relates what she is feeling...but she relates it...you can’t actually pick up what she’s saying. But you pick up a word or two. She complains...she calls me ‘Ana’ because of Anna the maid that works here so she repeats the name all the time, but if she uses the name ‘Ana’ then she’s referring to me basically.”*

For half of the caregivers, the loss of communication was apparent. This caused difficulties in their caregiving role as spouses with Dementia could not express how they felt and caregivers could always not have any adult interaction with their spouse. Similarly, Lin et al. (2011) documented the loss of communication in their research which was undertaken in the United Kingdom. The spousal caregivers of this research reported that meaningful communication between themselves and their spouse was non-existent. The loss of communication was also seen to be related to caregiver stress as caregivers have only one-way communication with their spouses with Dementia. Therefore another possible explanation of caregiver stress is the loss of communication. However in this research, although loss of communication was described, the caregivers who experienced this did not describe increased levels of stress due to this. Evans and Lee (2014) found in their research that the impact on conversation between the couples was also related to changes in companionship occur. As changes in communication worsened so did the changes in the companionship. Similarly, in the current research, the three of the caregivers expressed that they could no longer talk about each other’s day with their partners and therefore that sense of companionship was no longer present in their marriage.

- **Loss of hobbies previously enjoyed**

A further loss to the personality of their spouse with Dementia was the fact that the participants noticed that their spouse with Dementia no longer enjoyed hobbies that required basic skills. The activities which they loved doing, now became dormant. All participants expressed this loss.

Participant four described her husband as someone who loved to cook but this was something that no longer interests him:

*Participant 4 – “He used to be a very good chef, when I was sick he used to make all our meals for us. And now he doesn’t even want to peel a potato. Can’t even peel a potato.”*

The spouse of participant eight enjoyed working on the car and being able to fix things. A basic tool like a screwdriver was something he could now not use:

*Participant 8 – “Well he used to love fixing things and going out to the car but all that went. He couldn’t even use a screwdriver.”*

The extract below shows the extent of the spouse with Dementia losing the ability to do things he enjoyed. He was a motor mechanic by profession but towards the end he would start a job and not know how to complete it:

*Participant 3 – “...and that also he couldn’t complete the jobs, he was a motor mechanic and other motor mechanics used to come to him because he was so good and he had such a wide variety of experience, you know been old and been all over, and then him starting a job and not know how to finish it.”*

Further loss and deterioration of the individual’s abilities is seen in the following extract:

*Participant 5 – “So, he was not able to do stuff, like he used to do woodwork, he stopped his hobbies, he gradually got more and more...he couldn’t do things he wanted to do. Then...I think now he’s completely lost interest in everything but at first he was trying to do things and making a bit of a mess of them...”*

- **Loss of roles**

The loss of traditional gender roles was also apparent. Participant five and participant six lost the protectiveness of having a husband. Their husbands could no longer provide the safety which they previously could.

Participant five expresses her loss of safety at night. Her spouse with Dementia is unable to assist if something should happen:

*Participant 5 – “In the night I feel a bit afraid, if something happens to me...I mean...he can’t tell anyone, or get an ambulance or even phone my daughter, he can’t even do that.”*

In the extract below, participant eight describes how she now has to take the lead. Her husband with Dementia no longer possessed this role, he now depended on her:

*Participant 8 – “And our car parks right outside here and he’d always be seeing people sitting in it and he wouldn’t go say anything to them...I had to go and I had to go in front which wasn’t like him at all...and I used to say, they going to hit me instead of you...and he used to say...”no, you go first...you talk to them”. And, we’d go there and of course there was no one there.”*

In terms of a male, the expectation a female taking care of domestic tasks was lost. In both extracts below, the spouses of participants six and seven could no longer cook:

*Participant 6 – “She stopped cooking totally...”*

*Participant 7 – “...I mean she was a fantastic cook...she would run the house. I’m the cook now...I do the best I can.”*

Participant eight also described how she missed her husband being the man of the house:

*Participant 8 – “Well, he used to be the man of the house. He made all the decisions and that changed completely.”*

### 5.1.3. Loss of Marital intimacy / companionship

With the progression of Dementia of Alzheimer’s Type came a loss of intimacy and companionship. Some carers expressed this loss.

Participant six expresses the complete loss of the relationship they once had. Romantic sexual advances shown to his spouse with Dementia are no longer accepted:

*Participant 6 – “Our relationship was a developed relationship...every year was a better success than the previous. We had no problems...but, now we have no relationship at all. There can’t be a relationship because she can attack me as if I’m attacking her. She won’t look at it as romance or anything of that sort so that’s totally cut off.”*

The loss of the companionship is seen in the following extract:

*Participant 8 – “That’s what I miss...the companionship I think...telling him about my day and he telling me about his day and he’d understand what I was talking about and we had mutual friends...and the children...but he couldn’t even talk about the children because he didn’t even know who they were.”*

Participant five expressed missing the intimacy once had with her spouse:

*Participant 5 – “Well, it’s everything really. You miss him being a normal human being, you miss the intimacy, you miss the holidays...”*

A further loss to intimacy and companionship can also be due to the spouses with Dementia no longer remembering who their partners are due to the memory loss. The spouse of participant eight would always ask for her even though she was with him:

*Participant 8 – “He used to say to me, ‘where’s Jen, where is Jen...I want Jennifer...I want her now’. I would say she’s coming and I’d say... ‘I’m here’.”*

This is also emphasised by participant six:

*Participant 6 – “She complains...she calls me Ana because of Anna...the maid that works here so she repeats the name all the time, but if she uses that name Anna then she’s referring to me basically.”*

A second loss which was very apparent in this research was the loss of marital intimacy or companionship. For five of the caregivers in this research, they did not state explicitly that intimacy was lost although it became obvious that intimacy or companionship no longer existed due to the changes which took place in the spouse. The loss of marital intimacy is supported by various researchers. Research by Vikstrom et al. (2013) found that participants from their research described feelings of loneliness. These feelings of loneliness stemmed from the loss of the intimate relationship once experienced with their spouse.

In similar research in the United Kingdom undertaken by O’Shaughnessy, Lee and Lintern (2010) the spouse carers described a deep sense of being separated from their partners. This was due to the loss of doing things to together and the loss of having shared experiences. The current research has in common with other studies, the change from the attachment relationship with

equal adult partners to one where dependency on one partner was now needed, a dependency that has parallels with the parent-young child relationship. Research by Evans and Lee (2014) found that as physical intimacy decreased, husbands and wives reported an increase in emotional intimacy. None of the caregivers in the current research expressed an increase in emotional intimacy, however previous emotional intimacy did play a valuable role in allowing the caregivers to provide the care they did for their spouse. An interesting result from the research by Evans and Lee (2014) was that companionship decreased due to not being able to go out together. Spouses with Dementia often displayed disturbing behaviours which made it impossible to pursue enjoyable social outings. This could be another possible explanation for a decrease in companionship in the current research. Caregivers in the current research expressed that they could no longer go out due to embarrassing behaviours. They also expressed that they missed doing things together. The companionship of doing things together was therefore lost.

However, in research by O'Shaughnessy et al. (2010), the one aspect which helped reinforce their longstanding relationship as well as the commitment to the caring role was the participants' desire to maintain the continuity in their relationships. This continuity was maintained when the spouses with Dementia were able to remember memories of the caregivers. Caregivers felt pleasure when these were observed. In the current research the Alzheimer spouses with Dementia would want their spouses near them as this helped to reinforce their longstanding relationship.

#### 5.1.4. Loss of self

Participant one described changes in herself due to the caregiving role:

*Participant 1 – “It has changed me completely, I wasn't the person I was...more tearful, it was always...you know...in me, I had no happiness or anything like that...”*

Although other participants did not express that there was a loss within them, they did describe how they stopped doing certain activities. These activities played a large role in their lives.

Participant six decided to step down as a senior pastor due to the caregiving role:

*Participant 6 – “...it came to a stage when I couldn't manage and I called in the counsel and I resigned as a senior pastor...”*

O'Shaughnessy et al. (2010) found similar results in their research where carers found their sense of self being engulfed in the role of caring. With the demands of caring, there was a decrease in their personal and social identities. In the current research, participants described how they wished they could be doing other activities. This implies that they are losing touch with themselves and their main focus is that of the caring role. An example of this can be seen by participant five:

*Participant 5 – “And you know, your whole life is changed. I can't go out much. I used to like my work. I'm sure that I would have been doing voluntary stuff if it wasn't that I had to stay here all the time, day and night.”*

## **5.2. Caregiver Stress**

### **5.2.1 Assisting with activities of daily living**

All spouses with Dementia could no longer see to their own basic needs. The activities of daily living such as eating, bathing and dressing were now the job of the spouse. This activity created added stress for the spouse.

#### **- Assisting with dressing**

The spouse of participant three could still dress himself in the early stages but as Dementia of Alzheimer's Type progressed he was unable to dress himself:

*Participant 3 – “...round about ten o' clock or half past ten I'd get him out of bed and I'd have to sometimes help him dress...but he could more or less dress himself in the beginning. It was towards the end that he couldn't dress himself.”*

Participant one describes herself as been responsible for his dressing. Her spouse was unable to choose any clothes:

*Participant 1 – “I was responsible to take him to the loo...and his clothes, he didn't know how to choose anything of his own. I had to take all those things, that was my responsibility.”*

The spouse of participant eight shows clear confusion which is characteristic of Dementia. Not only was her spouse with Dementia unable to dress himself, but he also could not identify his own clothes:

*Participant 8 – “No, I had to dress him. He couldn’t get his socks and shoes on...and one day I came in...I’d been outside...I came in and he’d been putting on one of my jerseys and he didn’t know whose jersey it was.”*

- **Assisting with bathing**

All participants also assisted their spouse with showering. Although two participants were still able to shower themselves, they still needed the assistance of their spouses as confusion was apparent.

The spouse of participant four did not know how to use the shower. This is where the spousal caregiver now had to intervene:

*Participant 4 – “You know, he always has a shower at night and, maybe, during the day as well and he didn’t want to go into the shower and he couldn’t open the shower. He couldn’t...he didn’t know how to open the taps and how to regulate the water and then he’d stand there and use all the hot water.”*

Participant seven would direct his spouse to the bathroom and guide her to what needs to be done:

*Participant 7 – “And, then eventually I get her into the bathroom and I just say...you must take your clothes off and get into the shower and that’s when I leave her to it and she does it...”*

Participant eight also described confusion by her spouse when he entered the shower. This was not an easy task for her:

*Participant 8 – “I’d have to get him up in the morning and sometimes he would be willing to shower and sometimes he wouldn’t. Sometimes he would just stand in the shower, he didn’t know what he was doing, he couldn’t find the soap or whatever...but I had to battle at the end to make him shower, he didn’t think it was necessary.”*

On the other hand, participant two was unable to get her spouse to the shower. A bed bath therefore became necessary:

*Participant 2 – “It got to the point where I couldn’t even...couldn’t even get him into the shower so he had to have a bed bath, so, I’d sponge him down nicely, put his pyjamas on and sometimes change the bed...well, mostly change the bed every day.”*

- **Assisting with eating**

Participant two assisted her spouse with eating. She would also buy him soft foods that would be easier for him to eat:

*Participant 2 – “And, then he was...and then he couldn’t eat properly, he could only just swallow. My daughter-in-law was buying the baby foods. And I said, ‘we will make our own soups, you know, how we used to make them’ ...”*

Participant one described how she would assist her spouse with Dementia by feeding him at all meals. This also further emphasises the amount of time spent caring for the spouse with Dementia:

*Participant 1 – “As time went on, he couldn’t walk, so we had to get him into bed and feed him his porridge. That I did every morning and after that, it went on to lunch and so forth.”*

- **Assisting with toilet use**

Six participants experienced the issue of incontinence. This was something which they found most difficult in helping their spouse with.

Participant one described that she needed to change his diapers often as sores would develop:

*Participant 1 – “So I had to check him you see, then when I felt that he needed a change, I used to change him quite often because I didn’t want him to be with, you know, the same diaper all the time which meant that he might get some sores or rash, so I had to very careful about this.”*

Participant six also describes having to see to cleaning up his spouse with Dementia after she made use of the toilet to prevent bed sores. However, he also described the emotional effects of this as an embarrassing feeling experienced by the spouse with Dementia in having one’s spouse assisting with one’s own toilet needs:

*Participant 6 – “Certain times it’s embarrassing for her or even cleaning up after the toilet...it’s something we have to do because we don’t want her to develop sores or anything of that sort so we do the maximum that is like...I found it hard because she found it embarrassing.”*

Participant two also describes having to assist her spouse with his toilet use by changing his diapers:

*Participant 2 – “...he’d got a catheter, but then the bowels gave way and you’d have to get the nappies and you’d have to change him.”*

Participant five also had to deal with a spouse that was incontinent but she then knew when he needed to urinate and she would give him a bottle:

*Participant 5 – “No, I give him a bottle. You know, in the night he goes a few times but in the day he hardly goes...I don’t know why, but anyway, I understand when he needs to wee and I give him a bottle and you have to be patient.”*

Time spent on caregiving was used to not only supervise their spouses with Dementia but to also assist in activities of daily living. Activities of daily living include the ability to bath, dress or feed oneself. With the progression of Dementia of Alzheimer’s Type the ability to do these activities for oneself becomes diminished. The caregiver spouse plays a huge role in assisting their spouse with Dementia with basic activities that they are no longer able to perform. All caregivers in this study assisted with activities of daily living, some to a greater extent than others. This was a time-consuming job which took place mostly in the mornings as they had to get their spouse ready and started for the day. In a research which took place in Italy by Ferrara et al. (2008), a survey was carried out on two hundred caregivers. The results of this research found that thirty nine percent of the patients with Dementia of Alzheimer’s Type have to be constantly supervised and forty two percent needed help with washing, dressing and eating. This is therefore in support of the results of the current research. Cahill and Shapiro (1998) found the same results from their study in Brisbane, Australia, where caregivers provided on-going assistance with daily activities to the care receiver such as dressing, feeding, medicating, bathing and grooming.

The constant supervision needed for the Alzheimer's spouse as well more time spent on activities of daily living can leave the caregiver feeling overwhelmed. Potgieter et al. (2006) found that been overwhelmed can lead to a decrease in the carer's self-confidence. In contrast, this was not something found in the analysis of the current research.

#### 5.2.2. Increased time spent on caregiving

##### - **More hours spent on caregiving**

The caregiving role brought on more responsibility for the spouse. More hours were now used for the caring role. Caregivers expressed that their spouse constantly wanted them by their side even with an external carer present:

*Participant 2 – "...I had my son's maid here because he liked her. He liked Thandi, she made him tea...she fed him biscuits and she sat on the bed. That was fine. She was happy with him. If he slept, she'd do some ironing or something like that. But, don't let me be longer than two hours. He was fretting...and where's Michelle gone and what's she doing. She can do it in two hours."*

This is also emphasised by the following participant:

*Participant 5 – "You see, he doesn't like me to go out much. He want me to get back quickly. He doesn't me to stay out for more than an hour and half. Even if there's somebody with him, he wants me here."*

The spouse of participant eight would always be by her side, making it difficult for her to continue her own activities:

*Participant 8 – "...and also towards the end I couldn't go anywhere without him and I'm the chairlady of the residence home, so he came to all my meetings and I run the library, he used to just sit in the library but if I got up, he would follow me."*

##### - **Wandering**

Due to the spouse with Dementia's behaviour of wandering, there was a need for increased supervision by the caregiving spouse. Participants' spouses would need to be closely watched as

they could sometimes take the car and drive off or wander off when in a busy area. Having to constantly watch their spouse was perceived as added stress by the participants. Reportedly, it became even more stressful for participants when their spouses with Dementia would leave unannounced and participants would have to find them:

*Participant 1- “Malcolm, I’m just going to take this vacuum cleaner back. I got back to the car and there’s no husband there. So, what do I do now? I got visions of him going on the main road...on Victoria road and getting knocked down. And, then the car guard came up to me and said, ‘have you lost him?’ I said, ‘I have’. He said, ‘I know where he’s gone, he’s gone to Foodpak. You know where I mean?’ He’d gone round the back where cars park. He said he’s gone to Foodpak and he’s gone to find you. I went to Foodpak and he was there in the office. Anyway...that’s how things go.”*

Participant six and participant three would prevent their spouse with Dementia from wandering by making sure that no areas were accessible:

*Participant 6 – “We didn’t give her the opportunity. We’ve got the gate locked there and we keep that back door locked all the time or closed and if it’s closed she doesn’t have the tendency of opening.”*

*Participant 3 – “While he was here he could still walk but he used to also wander. But luckily our yard is secured and I used to hide the remote for the gates so he couldn’t get out. Then he would just stand at the gate.”*

Carers in this study found themselves spending more time in the caregiving role. It was seen as a time consuming role that often created more stress for the participants because it also prevented them from doing things for themselves or going places. Participants expressed that they could no longer do the things they liked, and if they did go out they would have to rush home quickly to see to the needs of their spouse. The current study shows that more hours spent per day on caregiving is an important theme with regard to caring for spouses with Dementia. This is supported by other studies which show that the caregiving role is a time consuming task. Research on the impact of caregiving by Marcia, Hoffman, Yee, Tennstedt and Schulz (1999) found that dementia caregivers spent more hours per week providing care than did non-Dementia

caregivers. In terms of hours, Dementia caregivers provided forty hours or more than non-Dementia caregivers. This is a considerable difference.

### 5.2.3. Lack of knowledge on Dementia of Alzheimer's Type

Four of the caregivers expressed that they had very little knowledge on the course of Dementia of Alzheimer's Type. These participants were not prepared for what was to come and due to this there was added stress which was reported to be brought on as they watched their partners deteriorate.

Participant one had no knowledge of Dementia of Alzheimer's Type, but the behaviour she witnessed affected her:

*Participant 1 – “No, I didn't know what it was...I really didn't know, but the way he was carrying on was really painful.”*

Participant five did not have knowledge on the early signs of Alzheimer's, she therefore saw his behaviour as strange and felt he was being nasty to her:

*Participant 5 – “...he was doing weird things and he wasn't very...he wasn't very nice to me at times, like saying hurtful things and you know, uhmmm...you don't know, but, now I know it was his brain but then at the time you don't, you don't know why he's been nasty. So, now it's well and truly obvious that it's the Dementia.”*

Two of the caregivers accessed reading material to understand more on Alzheimer's. This helped them to understand Dementia of Alzheimer's Type better and to identify with what was happening with their spouse:

*Participant 3 – “No...uhmmm...quite close to when he'd been diagnosed my own doctor told me about the Alzheimer's support group....And then I went there and they lent me some books to read so I could understand it better...”*

*Participant 4 – “I actually went onto the internet and I'd get a little Alzheimer's email every now and again, but, it's an American one and we sort of...I try and read as much as I can and it gave me very clear markers on the research that they did and I identified with all of them...everything and the signs were there.”*

A theme which was found to be a contributing factor to stress in this research was the lack of knowledge associated with Dementia of Alzheimer's Type. Participants did not have much knowledge on what to expect as the disease progressed which added to the emotional effects when strange behaviour from their spouse did occur. Potgieter and Heyns (2006) describe comprehensibility as the level of understanding that an individual has of a stressor. In this case it would refer to the understanding of Dementia of Alzheimer's Type. It refers to understanding all aspects of the disease, from the aetiology, symptoms and progression of the disorder. Such information allows for a better understanding of the spouse's behaviour and will also assist the spousal caregiver in dealing with their emotional reactions in the caregiving situation. In the current research, comprehensibility was limited for most carers. In the South African research by Potgieter and Heyns (2006) which took place in Bloemfontein, findings were similar to that of this research. The caregivers' experiences were linked to the level of comprehensibility that they experienced. In their research, many of the carers experienced the time before a diagnosis was made, as very difficult as they reported bizarre behaviour which they did not understand. In the current research, one participant reported not understanding what was happening to her husband as he was behaving very strangely prior to his diagnosis.

Two of the caregivers in the current research did educate themselves by reading articles and books on Dementia. Four of the participants were also part of an Alzheimer's support group. This was something that contributed to their sense of overall psychological well-being. In support of this is Potgieter and Heyns (2006) as they note that caregivers received education of the disease by means of support group discussions, individual psychotherapy and reading available literature on the subject. This contributed to their sense of coherence.

Comprehensibility therefore becomes an important aspect in the caregiving situation as a lack of this can possibly lead to a loss of control amongst caregivers. The need for comprehensibility was also documented in research by Butcher et al. (2001) as the caregivers from this research reported wanting to find out as much as they could about the disease as permanence of Alzheimer's became apparent.

#### 5.2.4. Impact on employment

Three caregivers were working at the time of their spouse being diagnosed with Dementia of Alzheimer's Type. Their work was greatly affected.

Participant four expresses that her start times for work have been affected as she now has to see to her husband in the morning:

*Participant 4 – “...I’m just used to getting up, dressing, eating and off I got to the office. Where I used to be at the office around 8:15am, but now I get in at 09:30am. Now, I have to try and get him out of the bed, get him dressed because I know he won’t get dressed if I...if I just leave him. So I’ve got to spend more time with him to make sure that...you know...that he’s sorted before I go.”*

Participant six also describes that his work environment has been affected:

*Participant 6 – “My clients all know her because she was the accountant, so they all knew her, it wasn’t a problem. She leaves when a client comes through, she walks around, but, my production is affected drastically.”*

One participant was forced to leave her job so she could be with her husband more to care for him:

*Participant 5 – “But, I found it was just impossible to leave him on his own anymore, so I left my job. I mean I was already 70 two years ago but I left my job so I could be with him more.”*

One participant was not employed but was involved with various activities which kept her occupied. These activities were negatively affected by the caregiving role as her spouse would constantly want to be near her:

*Participant 8 – “...I couldn’t go anywhere anymore without him and I’m chairlady of the residence home, so he came to all my meetings and I run the library but if I got up, he would follow me.”*

Disruptions in the caregivers’ employment is another important aspect adding to caregiver stress. Four of the caregivers in the current research were impacted in this regard. Due to the time consuming nature of the caregiving experience, caregivers spent more time in the mornings in assisting with activities of daily living, in doing so, their work was affected as they would get to work later than usual. Furthermore, one participant who was self-employed experienced a decrease in the production of his business due to the constant care which was needed by his

Dementia spouse, this in turn lead to financial implications. In a research by Marcia, Hoffmann, Yee, Tennstedt and Schulz (1999) Dementia caregivers reported more problems related to employment than did non-dementia caregivers. Some of the caregivers of the current research study reported that they had to take on less demanding jobs so they could spend more time with their spouse, others opted for an early retirement and some gave up work entirely. In a Northern Ireland study Chambers and Ryan (2001) found that the younger carers felt that their lives were now at a stand-still due to the caring role as they were now making unexpected sacrifices. In the current research one participant stated that she would have being doing voluntary work but now she cannot. There is the underlying feeling that her life is now at a stand-still.

#### 5.2.5. Financial Implications

Financial costs were also incurred due to the behaviour of the spouse with Dementia. In the following two extracts, the participants' spouses still wanted to regain some independence by getting behind the wheel to drive. However, due to the memory loss, they could no longer drive and the cars were now written off. This created an unexpected dire financial situation for the caregivers as well as medical costs for their spouses involved in the accidents:

*Participant 2 – “The major thing is that you’ve got to tell them to stop driving a car. That is a major thing because somebody that’s been driving a car since he was a teenager, to try and say, “you’re not to drive that car anymore” ...well it was getting to be an impossibility. So, I thought well, clever me, let him get the car out the garage. Get the car out for me and I’ll take you to the shops, I know the roads better. And, what did he do? One day, he backed it out the garage, straight down where your car is, down the slope and into the river... What do you do? He couldn’t drive the car then. Smashed it to smithereens.”*

*Participant 5 – “...then I went to Pick ‘n Pay and I went into the...I parked and went into the bank...to the ATM...I got the number wrong anyway, so I came back and he’d already got into the driver’s seat and driven off and the car guard said to me, “he’s gone down there”. I went down there and he’d gone into a parking place and knocked this other person’s car completely out into the roadway there and there was a crowd of people around and uhmmm...ja(yes)...he put his foot on the accelerator instead of the brake. He’d just gone and wrecked this poor lady’s car and ours as well.”*

The caregiving role also brought on financial implications. Financial implications in this regard where due to medical costs (visiting to doctors / neurologists). Due to incontinence adult diapers were needed. This was a further financial implication:

*Participant 6 – “Well, I went to the specialist to analyse what’s happening...and then having derived the answer, I needed to make a decision, which I did. I said, “I’ll see it through”, but in the meantime I have taken every precaution to try and allow it not to develop...so it did cost a lot of money, but the money wasn’t a criteria...it was the need and I went all the way through. Spent a lot of money and realised that most of it is a waste of time.”*

*Participant 5 – “And those nappies, just for a week cost me R806.00. And the medical aid won’t pay for it and, I don’t blame them really. He needs them basically.”*

Another expense for the caregivers was having to buy equipment that would make their spouses’ mobility easier:

*Participant 2 – “I did get a wheelchair, this was a long time afterwards. Somebody said, “oh, ...you have to pay about fourteen thousand for a wheelchair”. I said, “we don’t have that, because I’m not paying fourteen thousand for a wheelchair”. Well, I went to the chemist in the mall, the big chemist at the end and I saw one for two and a half, which I bought brand new...”*

Having external help also brought on financial implications for the couples. Four participants had an additional caregiver that would come in weekly to assist them:

*Participant 7 – “The carer only comes on Mondays to Fridays. There may come a time where I’ve got to have her longer or more days...I don’t know, but we only just started so we’re just feeling our way. It’s not cheap either, you know, fortunately, at this stage she can afford it.”*

Due to the spouse’s immobility, the participant’s homes became a problem. Two participants expressed selling their home for something that would accommodate their spouse with Dementia:

*Participant 6 - “...I find that this property is a hindrance to her because of the stairs. I’m negotiating selling it and buying something that’s suitable.”*

Financial problems brought on by the caregiving situation were due to a variety of issues. Caregivers now had to buy adult diapers for their spouses with Dementia as they were now incontinent. These had to be bought almost weekly and were an added but very necessary expense for their spouses with Dementia. Furthermore, some of the caregivers received extra help in the form of domestic workers or professional nurses. This was an added expense as well. Sometimes a caregiver had more than one individual assisting. With the onset of immobility, the caregiver's invested in commodes or wheelchairs. Two participants from this study made use of a commode and a wheelchair. Two participants also were deciding on moving out of the house they currently lived in as they felt that their house was a hindrance and this would also involve financial implications.

Another aspect of concern for one participant in the current study was the cost of placing her spouse with Dementia in a home. She found the cost too high and knew that she would not be able to survive financially if she did place him in a home. In research undertaken in the United States of America by Chenoweth and Spencer (1986) involving 289 participants this was also a concern as participants worried about financial constraints, especially when it came to placing their loved one in a nursing home. Due to lack of finances, care at home often is the only option available for the spouses with Dementia. Consistent with the findings of the current research regarding finding suitable accommodation for the spouse with Dementia of Alzheimer's Type, participants from the research study in Sweden by Meyer et al. (2016) also found that several participant's found a smaller place to live as this would be more suitable for their caregiving role.

#### 5.2.6. New roles for spouse as caregiver

Due to the "loss" of the spouse with Dementia, the spousal caregivers now had to adopt new roles which they previously never did. For caregivers, almost everything now fell onto them.

Participant four described the extent of the new roles she had taken on:

*Participant 4 – "He used to go to the shop for me, he used to go and buy the bread and milk. He would get some meat for us for supper. He used to garden. I mean...I don't worry about the pots he's got around, it doesn't concern me because it makes him happy. The gardener comes, I've got to tell the gardener what to do. I never used to do that, he used to supervise him and be*

*outside with him. Absolutely everything I've got to do. I can't rely on him to do anything. So basically, everything has fallen on me."*

Participant one also described now having to take over everything as her spouse with Dementia could no longer continue these activities:

*Participant 1 – "Before Dementia came into the picture, he was a very caring and loving person...but as time went on, all that went off. He didn't know anything, he used to do everything. I never used to do a thing, even shopping and all that, he used to do. I had nothing to worry about. He was a very good husband and very caring."*

The following participant expressed frustration with having to assume full responsibility for tasks and also to now learn to do tasks previously done by one's partner, for example, manage payments of healthcare which she never bothered about previously:

*Participant 5 – "Everything's on me. And, the medical aid is a terrible strain because they keep not paying things and I'm permanently trying to fight with them to pay stuff. No, he used to deal with all that, but I mean, he's been in hospital a lot so there's a lot of medical aid problems. And, that stresses me a lot. Just having total responsibility stresses me. And, you get used to somethings. Like I do, he can't even get into the car now, but I do all the driving and the cooking and this and that and the other and the bills...uhmmm...I suppose I'm getting more used to it but it's...it's not nice you know, to suddenly do it when you had a partner who did it."*

The following participant's wife worked for him as an accountant, but due to Dementia she could no longer fulfil her work responsibilities. He relayed now being responsible for this:

*Participant 6 – "Ja(Yes), and I couldn't expand. I had the opportunity but I didn't. I had to be very active because she was doing the balance sheets and I had to take over that responsibility as well and still keep the financial planning going...that you can't pass the responsibility on to anybody else because..."*

Furthermore apart from new roles, the spousal caregivers now had to make more decisions on their own. Some caregivers were never involved in decision making and they were now placed in a position where all decisions now had to be made.

Participant four described her inability to make decisions and needs help from her adult children regarding this:

*Participant 4 – “I think so and that they can come here and see what’s happening and, maybe, help me make decisions because I can’t make decisions...I’ve got general power of attorney...he signed it and I’ve got a friend whose an attorney, he’s going to register that for me, so, that if I’ve got to take decisions on his behalf, like his pension...I can sign them.”*

A further theme which was an added contributor to the stress was the adoption of new roles by the caregiver as the spouse with Dementia could no longer perform certain activities. The assuming of new roles was also gender specific. For example, female spouses with Dementia could no longer see to the running of the house or they could no longer make a meal. Male spouses with Dementia on the other hand were no longer involved in home repair or they could no longer drive the partners as this ability was lost. The caregivers were now responsible for all duties in the household. The caregivers in this study expressed stress in now having complete responsibility and further stress was created by not knowing how to carry out their new role. Role change is also seen as difficult due to the fact that one spouse (now with Dementia) is letting go of roles which defined their place within the marriage and the other spouse is now accepting unknown territory (Evans & Lee, 2014).

Research by Butcher et al. (2001) found that caregivers were affected by having to take on a new role that their partners could no longer meet. These caregivers now had to learn new skills such as managing finances, having power of attorney, taking care of a home and repairing items in a home. Further research support regarding the adoption of new roles was undertaken by Vikstrom et al. (2013) where all responsibilities now lay on the caregiver. In a recent research by Evans and Lee (2014) the individuals with Dementia often helped their spousal caregiver adjust to the role change or role reversal. In the current research the individuals with Dementia did not play a role in supporting their spousal caregivers with their new roles due to the memory loss which consumed them. However, in the earlier stages, some male spouses with Dementia were accepting of the fact that their spouses now had to drive, but, there was no actual help from the spouses with Dementia.

### 5.3. Strain of caregiving

#### 5.3.1. The strain of witnessing deterioration of spouse

Some participants expressed the sadness in having to witness their spouse with Dementia deteriorate. One of the aspects which put a strain on caregivers was to now see them incapable of doing anything for themselves.

Participant one described the pain in seeing her husband with Dementia bed-ridden and unable to be independent:

*Participant 1 – “The hardest thing was like, you know...err...to see him like that in bed and not, you know...he couldn’t do a thing, and for me to do all those things was very very hurtful and painful.”*

Strain was created for participant seven in knowing that his spouse was aware that she was losing her memory. His spouse with Dementia’s awareness of her deterioration was most traumatic for him:

*Participant 7 – “Anyway, I hate to see her like that because it distresses me to see her distressed. I don’t know when the time will come when she won’t realise...she realises what her problem is. She knows it. I’ve always tried to avoid the word Alzheimer’s...I’ve just always referred to it as being a memory loss. But I think, I’m sure she knows it...but that’s the distressing part, that she knows it. If it gets to the stage where she doesn’t know it anymore, it won’t be so traumatic.”*

The following extract shows how a participant had to witness first-hand the deterioration of her husband with Dementia:

*Participant 5 – “...he’s condition is getting very bad and he’s stiff and his legs...I know one of them is so sore, but, the other one is alright but he will still have it stiff as a board.”*

For carers four, one and eight, they described their personal frustrations and sadness:

*Participant 4 – “Monday, I just felt I couldn’t cope. I went off to work, I left him here on his own and I went off to work and I just stayed there for two hours and I just felt that I am at my wits end. I can’t cope anymore.”*

*Participant 1 – “I felt really downhearted and I didn’t know what to do. That was the worst days of my life. I couldn’t just believe that he really had it.”*

*Participant 8 – “I felt it was the beginning of the end, because I think I grieved more than I did now because I knew what the end was going to be like.”*

One participant expressed the impact on her own health and the possibility of depression:

*Participant 5 – “I’ve lost 9kg and I’ve just recently been to the doctor and he’s sent away a lot of blood tests, you know, he’s concerned that I might have something wrong with me...the reason why I’m losing so much weight and I’m finding it difficult to swallow. But, it has affected my health and certainly, I think I’m depressed really...”*

Research by Shanley et al. (2011) found that caregivers experienced extreme difficulty in having to witness their spouses decline physically. The findings from this research support the findings from the current research. Caregivers in this study witnessed the physical deterioration of their spouses. The caregivers reported having had capable spouses that could walk and perform duties to now having spouses that were completely dependent on them. They witnessed the decline of mental changes in their spouses’ behaviour ranging from the loss of communication to no longer having the skills to drive a vehicle. Most of the carers expressed their sadness and distress in now having to witness their spouses change for their worst. This is supported extensively by other researchers. The witnessing of the deterioration of their spouses is described by Butcher et al. (2001) as a form of grief. Sadness was ascribed to witnessing their spouses losing the ability to do things that they were able to do before.

However, despite the frustrations experienced by the spouse caregivers regarding the caregiving situation, in the current study, none of the caregivers spoke of wishing that their suffering would end. The participants never wished a quicker death upon their spouses in order to be free of their caregiving duties. On the other hand, participants would do everything they could do see to them to the end. In recent research by Lewis (2015) the yearning for escape was apparent as caregivers wished that their loved one would die, as the death of the spouse with Dementia seemed to free them from the caregiving role.

### 5.3.2. A fear of the worst

Participants would often fear leaving their spouses on their own for too long and as a result their time spent away from home was minimal. Two participants expressed the need to always check up on their partner or not leave them for too long. Fears were that participants might do something to harm themselves.

Reportedly, participant four was scared to leave her spouse with Dementia on his own for fear that he might interfere with appliances in the house. Leaving her husband alone for too long was seen as dangerous:

*Participant 4 – “You know, when we had load shedding he went into the bathroom, brought the candle out...and I said to him...where’s the candle...no, he doesn’t know. He had it inside the cupboard, he put it inside the cupboard and closed the door. So you know, I’m scared to leave him here, because we’ve got a gas stove, I’m scared to leave him here too long...you know, with things like that.”*

Participant three also described her fear in leaving her spouse with Dementia on his own for too long:

*Participant 3 – “My youngest son used to come every second weekend and he still comes every second weekend. And, then that weekend, he would stay with my husband, so, I could go and do grocery shopping, otherwise, I would just run and grab a loaf of bread and milk and come home because I was too scared to leave him long at home.”*

Two participants described constantly checking on their spouses with Dementia when noises were made as they feared something had happened to them:

*Participant 2 – “I couldn’t tell you how many times, I’d been working in the kitchen or doing something and I could hear a noise...and...it’s a short distance along that little passageway. I used to run, because I really thought something was going to happen.”*

*Participant 5 – “...half the night I’m awake anyway, listening to him, he sort of stops breathing and I keep prodding him to start him breathing again, although, I’m sure he would start by himself, but, you know, it’s a worry...”*

One participant expressed the fear of losing their partner with Dementia:

*Participant 5 – “Ja(Yes), and then, you know the fear of actually losing him which, you know, I don’t know which way things are going to go.”*

Caregivers often described the fear of leaving their spouses alone for fear that they could harm themselves. Reportedly, they would rush home quicker than usual to see to their needs and this also was implemented to prevent their spouses from doing anything that would harm themselves. Apart from this, caregivers reported running to address the needs of their spouses if any strange noises were made by their spouse. They feared something would happen to them in their sleep. They were therefore always constantly checking up on them and spending increased time on supervision with their spouses with Dementia. There seemed to be a fear from the participants that the worst could happen. A similar result was found in Vikstrom et al’s. (2013) research, using thematic analysis, the analysis found that issues of safety were a concern for spousal caregivers. There was a fear of the spouses with Dementia doing certain tasks in case they harmed themselves.

### 5.3.3. Caregiver death

The other concern which placed a strain on caregivers was what would happen if they had to pass away. The caregivers already had plans of what could possibly happen should they pass away or fall ill. The children seemed to play a pivotal role in caring for their parent with Dementia if the spousal caregiver should no longer be there:

*Participant 6 – “The other thing...the problem will arise because of my age...If I get sick then that becomes a major problem. The children will step in, my eldest daughter will step in, she will be able to tolerate that. If I am deceased, the whole circumstances change, that can change the future. That is a worry, if you see the age difference, that’s why I’m trying to keep fit...eating well.”*

*Participant 7 – “...we’ve got family who would support if necessary and James, if anything happened to me...she could go and stay with him, but, they both work, him and his wife. It might be better if she went into a home...but, he would be supportive.”*

Caregiver death was also a concern for participants in the research by Chambers and Ryan (2001). The future welfare of their partner was important if they were to die.

#### **5.4. Love as a motivating factor**

Love played a role in motivating spousal caregivers to provide the care to their husbands/wives with Dementia. The following extracts from participants two and eight emphasise love as a motivating factor to provide care:

*Participant 2 – “And then you just nurse them...it’s love that you doing it for. You still love each other...uhmmm...there’s nothing I can say. You have to love them to do the things you have to do.”*

*Participant 8 – “I don’t know...I never really thought about it. He would have done the same for me if our positions had been reversed. So I just did it.”*

Participant five reported that she does not want to place her husband with Dementia in a nursing home even though it will be difficult for her to cope. She knows she will provide him with better care. The love for her husband is shown in the extract below:

*Participant 5 – “I want to keep him at home, but I don’t know whether it’s...I’m going to cope. But, I want to do my best to try because his experience in hospital has been awful. You know, with people with Dementia...they don’t...they don’t deal with them nicely. So you don’t want your loved one to be stuck in a place like that where no one will be bothered about them.”*

*Participant 5 – “So, I mean, I really do want to know what’s happening to him, I don’t want to put him in anybody else’s care. I mean, if he goes to hospital, I go in like three times a day, I stay longer because he’s confused, and, you can’t just leave him. So, I’d rather see it through. It might get difficult, I might need to get more help.”*

Similarly participant seven expressed the same sentiments in not wanting to send his wife with Dementia to a nursing home:

*Participant 7 – “Because I’m not getting younger you know, I’m ninety years, so I’m just fortunate I’m able to get around because I’ve got to be here for her, because if I’m not here then*

*she'll probably have to go into a home and I wouldn't like that...at least this is her home and familiar surroundings."*

Love for their spouse was also shown in smaller ways, for example, some caregivers would allow their spouses with Dementia to behave in ways that was not the norm. All they wanted was for their spouse to be happy:

*Participant 4 – "...the other day I got home, he still had his pyjamas on and Sunday...Sunday...I went out, came back, I thought he changed but he was still in his pyjamas and he stayed in this all day. I didn't worry him because I didn't want to make him unhappy."*

The theme of love presented itself in all the interviews. There was a deep sense of commitment by the participants to their spouses with Dementia to persevere and do the best they could do even in times of stress. None of the caregivers expressed the caring role as a burden but rather it was something that they should be doing for their spouse. Love can be seen as a factor which motivates them to provide the care which they do. Related to the concept of love as a motivating factor were the findings of a study by Lin et al. (2011). Lin et al. (2011) defined commitment as the desire for caregivers to care for their relatives, this also includes the happiness which is brought from the caring role. The carers as such possessed the emotional commitment of being a family carer. In the current research, being the spouse (the commitment of marriage) motivated them to provide the care they did to their spouse with Dementia. Consistent with the current research is the results of the research by Chambers and Ryan (2001) where carers had strong emotional bonds and had an in-depth knowledge of the person accumulated over a number of years. This strengthened the commitment between the carers and their spouse with Dementia as it allowed them to provide the care that an institution would not be able to provide. One participant expressed that she would not want her loved one in an institution and would care for him as best she could till the end of their life.

In research by Butcher et al. (2001), the caregivers found joy in caring for their spouse and caring for them also increased the bond shared. This is also in line with the research by Lin et al. (2011) as they describe the happiness brought from the caring. Finding joy in the caregiving role was also found in the research by Lewis (2015). The caregivers opted to live in the moment rather than focusing on the end stages of Dementia of Alzheimer's Type. In doing so, they

focused on being together with their spouse with Dementia and that the caregiving role was not seen as a job. This created a deeper form of love and understanding. On the other hand, in the current research, none of the carers expressed any sort of happiness which was brought about from the caring role.

Lin et al. (2011) sees the process of love as dynamic and they describe the degree of commitment to the cared for person as changeable. The degree of commitment depended upon their perception of love and also with their satisfaction with their relationship. This can also explain the differences in commitment found amongst the caregivers in the current research.

### **5.5. Retrogenesis**

All participants' spouses became dependent on them. They changed from very able people to people that could not do without their spouse. The behaviour of the spouses was similar to the behaviour of a child. Two participants described the childlike nature of their spouses:

*Participant 4 – “So you know, ja(yes)...it’s like having a child in the home again and the routine is like a child’s routine because it’s got to be at certain times.”*

*Participant 3 – “He was incontinent, he was in nappies while I was looking after him. That was the most difficult because I was looking after my two grand-daughters. And the little one was three or four so she was out of nappies and then I got to wash and change granddad.”*

The following extract describes the participants spouse with Dementia as having to eat food that an infant would eat. Her spouse's dentures also had to be removed towards the end, similar an infant with no teeth:

*Participant 2 – “My daughter-in-law was buying the baby foods. And, I said we will make our own soups, you know, how we used to make them Malcolm. Yes, he’d like that, so...big spoon and I was pouring it down his throat. But, then we got to the point he got a denture here and he couldn’t...the denture didn’t hold in. It was loose in his mouth and I had to take that out.”*

The following extract describes the spouse with Dementia' inability to use the toilet or communicate, similar how a young child would be:

*Participant 1 – “No, he couldn’t communicate as time was going on and even to go to the toilet he couldn’t go himself, I had to take him and as time went on I had to get him into diapers.”*

Participants also described how they prevented their spouses with Dementia from having access to certain places, similar to having a child in the house and preventing them from entering certain areas. Participants below described measures taken to prevent their spouses with Dementia from wandering:

*Participant 6 – “We didn’t give her the opportunity. We’ve got the gate locked there and we keep that back door locked all the time or closed and if it’s closed she doesn’t have the tendency of opening.”*

*Participant 4 – “He used to wander off in the park but now he’s been banned...He’s not allowed to go, although he’s not a danger to anybody but I mean that is the rule for six months, he’s not allowed to go in.”*

In majority of the spouses with Dementia there was a very obvious regression. They behaved more like young children than adults. From been very capable and independent adults, the spouses with Dementia now displayed child-like behaviour. Incontinence was the main behaviour which was displayed. The use of adult diapers therefore became necessary. The inability to perform all activities of daily living is a clear indicator of regression. One participant expressed that caring for her husband with Dementia is now similar to caring to that of a child. This concept of retrogenesis is echoed by different researchers. Research by Butcher et al. (2001) undertaken in the United States of America found a similar finding in his study. Having interviewed over a hundred participants, they found that several participants felt that even though they saw their loved one as an adult, the care which was given to them was very much the care for a child.

In line with the current research, regarding retrogenesis, is research by Evans and Lee (2014). Participants in their research also saw the husband and wife relationship change to that of parent and child. A participant described her husband as a child and she saw herself as the mother of her spouse with Dementia. An interesting result from the research of Evans and Lee (2014) was the fact that the child-like behaviours from their partners led to a decrease in marital intimacy. The spousal caregivers could no longer have an intimate relationship with their spouses because they

now saw them in a different way. Two spouses in the current research expressed that there was no longer any intimacy, the result from Evans and Lee (2014) could also provide a possible explanation as to why intimacy decreased in the couple relationships.

## **5.6. Decrease in social activities**

### **5.6.1. Behaviour of the spouse**

Due to the caregiving role, all spousal caregivers experienced a decrease in social activities. Outings and hobbies were seen as a thing of the past. One of the reasons there was a decrease in activity was due to the Dementia spouse's behaviour. This is described by the following participants:

*Participant 8 – "...both of us played croquet, but, I had to stop that because he started to irritate other people because he couldn't remember which was his ball or where he was supposed to be going, so I stopped that."*

*Participant 5 – "It was accepting the fact he couldn't do things for himself. That he was a different person really. And, also we couldn't really go anywhere, because he would just cry all the time if we went anywhere. And, I couldn't leave him on his own because there was no one to look after him."*

A further reason for the spouses with Dementia's behaviour resulting in a decrease in social activities was due to the spouse with Dementia not wanting to be around people to socialise. Participant eight described her spouse has been very uneasy when they would go out for lunch:

*Participant 8 – "But, we used to go out to lunch, he used to sit next to me, he never spoke to anyone else. I used to talk to them and he'd keep saying to me... "when are we going home?...where's the car?...how did we get here?"*

Participant four described her spouse with Dementia as wanting to stay at home rather than venturing out:

*Participant 4 – "I miss the times that we went out...could go walk with him. He doesn't like to do that anymore, he just wants to stay in his own surrounding."*

### 5.6.2. Seeing to the needs of the spouse

For other participants whose spouses with Dementia were immobile, decrease in social activities was attributed to constantly being at home seeing to the needs of their spouse:

*Participant 5 – “And, you know, your whole life is changed. I can’t go out much. I used to like my work. I’m sure that I would have been doing voluntary stuff if it wasn’t that I had to stay here all the time, day and night.”*

*Participant 7 – “I used to go Durban quite a bit because I had family down there and I’m very keen...I used to be very keen on boating. I had a small boat on the bay...and, now I can’t do that but now I can’t leave her for too long.”*

### 5.6.3. Losing friends

Another reason why social activities ceased was due to friends distancing themselves and no longer visiting. Participant three described losing her friends due to her spouse having Dementia:

*Participant 3 – “I feel that they didn’t know how to communicate. It’s difficult to know how to handle something when a person is so different. So it’s easier just...they would say, you know, “we’ll come, we’ll come”, but, nobody ever came.”*

*Participant 3 – “...and then also...because people were embarrassed by it, who didn’t know how to communicate because, all the friends that used to visit, never visited anymore, so we were very isolated.”*

Caregivers in the current research expressed the decrease in social outings which was brought by advent of Dementia and the caregiving role. Activities which the couple used to enjoy doing together were now non-existent due to the never ending job of caring for their spouse and the incapacity of their spouse. Participants from a study by Vikstrom et al. (2013) expressed that their social engagements were now diminished and caregivers also felt trapped in their caregiving role. The feeling of been trapped was also echoed by Cahill and Shapiro (1998) as the participants of this research reported having excessive tiredness and they also experienced adverse effects regarding their social lives and this made them feel trapped. In the current research, some participants seemed to feel the same. Although not explicitly stated, the

participants did express that they would like to do certain things but cannot anymore due to the caring role. In their statements was an underlying feeling of being trapped and not been able to do their own activities. This is also consistent to recent research by Meyer et al. (2016) as participants wished to meet friends and travel as well as simply been able to sleep more. Caregiving demands resulting in a decrease in personal and couple social activities can be seen in research by Chambers, Ryan and Conner (2001). In their research, the carers disclosed that the need for constant care and supervision caused a decrease in their social lives. Another possible explanation for a decrease in social activities is due to the caregiver changing their social habits, deliberately, for example they may stop giving dinner parties. This was a result found in research by Vikstrom et al. (2008).

In terms of losing friends, the participants in the research described how friends and family distanced themselves. Friends stopped visiting and therefore activities with friends no longer existed. However, not all participants felt this way. Two participants described having friends and going for lunch at certain times. Research by Chenoweth and Spencer (1986) confirm the distancing of friends from the caregiver as sixty percent of the participants expressed the loss of friends and families as they no longer creating isolation the caregivers. Research thus emphasises the important role placed on family and friends for a couple facing Dementia. This is also consistent with the findings from a recent study by Meyer et al. (2016) were spouses felt isolation from friends, this was mainly because they stayed indoors caring for their spouse with Dementia. However, some caregivers did receive support to a certain extent but others reported not receiving the support required. This created feelings of abandonment.

## **5.7. Coping mechanisms**

### **5.7.1. Need for relaxation / alone time**

The caregiving role was verbalised as time consuming and participants expressed the need for relaxation, to be removed from the situation for a short respite:

*Participant 8 – “...I wanted to go away for a week...that was my...I felt if I could just get away for a week and think about things and...you know...”*

*Participant 5 – “...in the evening, I get irritated sometimes because I’m tired and I feel like saying, “I’m off-duty now, you know, that’s it”, but you can’t.”*

Some caregivers saw time for themselves as simple as going to the shop alone. Time alone was expressed as something which was much needed:

*Participant 4 – “I think it’s just to give me a little bit time for myself. Not that I’m been selfish but time that I can just go and do shopping at my leisure...”*

One caregiver expressed that his relaxation pursuits were seriously affected:

*Participant 6 – “I came off active duty in the church although still active, but, not in the same capacity and it affected me relaxing time...like, you know,...we liked to go for drives.”*

In the following extract, one participant described that work in their house needed to be completed quicker than usual in order to have more time to see to her spouse with Dementia.

This further emphasises the time pressure and lack of relaxation:

*Participant 2 – “My routine for the day is getting up very early, so I could get the bedroom looking a bit tidier when my son came in at six because he starts his work at seven. Then it would be stop and clean up the bedroom, clean up this and clean up that, get yourself showered...do this...doing everything in double quick time.”*

The need for relaxation was an important sub-theme which was found among several participants. Some participants expressed that their need for relaxation no longer existed and some expressed that they wish they had more time for relaxation. Relaxation was seen as important as it allowed the caregivers time away from the caregiving role and therefore provided time to de-stress. The caregiving role created feelings of been trapped, and an escape was therefore needed. In research by Lewis (2015) the caregivers exhibited the same feelings as some of the participants in the current study. They felt bound to the spouse emotionally, physically and mentally. The need for relaxation was also documented in the research by Vikstrom et al. (2008) as spouse caregivers found that not having enough restoration of the mind in solitude was something that could negatively affect them in their daily engagements with their spouse with Dementia. This also provides a possible explanation why the need for relaxation is so important for spouse caregivers.

### 5.7.2. Support

Support can be further broken down into the need for external support, emotional support, practical support and financial support. Support was seen as very important for spousal caregivers. Participants expressed the inability to deal with the situation on their own:

*Participant 4 – “Support is very important to me because I just can’t do it on my own. I really can’t.”*

*Participant 1 - “...it makes a lot of difference, because when they are supporting me there, I know I got people around me, no matter how heartbroken I am...but they are always there for me...to comfort...and it helps so much...it’s so much better in that way.”*

However, one participant appeared ambivalent to support from others due to being used to living more of a solitary life with just her husband and herself:

*Participant 8 – “Very important in some ways...it’s hard to say because Jacob and I have always been comfortable, just the two of us.”*

#### - **The need for external support.**

Seven participants in this study had help from an external caregiver. Some spousal caregivers received assistance from a professional caregiver while other spousal caregivers had a domestic worker that would assist with caregiving duties.

All participants stressed the importance of having external support and to many this was seen as a coping mechanism. By having an external carer help in the home, relieved spouse caregivers from caregiving duties for a time period:

*Participant 2 – “I had a carer. Very close to the end. Two weeks...it gave me a break. I could do something else. And, he was quite relaxed with her there”.*

The extract below further emphasises the relief brought about by external help:

*Participant 7 – “...I had trouble in the mornings in getting to do what’s necessary to start the day...to get up...to have breakfast...to have a shower...to get dressed. And, once that’s done, and that’s where the carer has been a great help...we’ve had a carer now for a couple of weeks. She*

*comes at 8'o clock in the morning and stays till twelve...my wife...we get up...get breakfast and when this person comes in...she's still in her pyjamas or nightie or whatever...then she takes over...takes her into the bedroom...gets her started and everything. "*

When participants were unaware of how to carry out an activity, the external help would step in to assist. They therefore assured the spouses to not worry. This can be seen in the following extract:

*Participant 2: "One day, I said to her, "his hair needs shampooing, how are we going to shampoo his head?" "I know how to do that", she said. And, she did, she did in bed. Laying down, with towels behind him. Yes...she was very, very good".*

Having a carer also allowed spouses to leave the house. This allowed spouses to cope better with the situation:

*Participant 5 – "...I'm coping better because at least I can get out to the shop while the maid's with him, you know".*

Having external support was seen as important for providing the caregivers respite time. The external support relieved them of caregiving duties for a time period and allowed them the time to focus on something else other than the role of being a caregiver. Within the South African context, the current study found that external caregiver support was mainly provided by a domestic worker as opposed to hiring a professional nurse. The majority of participants employed a domestic worker to help them care for their spouse. Some participants had multiple domestic workers to assist in the home and with caregiving duties. The importance of respite care was also found in research by Shanley et al. (2011) as this was found to be the most frequently mentioned form of instrumental support. In a similar vein, the current study highlights that respite care was something which was much needed to give spouse caregivers a break from the caregiving role. They also found that even though the caregivers had respite care, the available time was then used for house hold chores. This is also similar to this research as one participant expressed that the available time was used to see to the house. On the other hand in the current research, the domestic workers were also responsible for seeing to the house hold chores as well.

- *Emotional support*

In this research, family and friends were seen as providing emotional support to the spousal caregivers. Family and friends allowed sharing of feelings to take place. Emotional support allowed caregivers to vent their feelings thereby relieving some stress.

Reportedly, participant four would receive emotional support from a friend who is an Alzheimer's caregiver for her mother. Not only did this allow the participant to express herself but there was also a sense of been understood as her friend knew her situation as she was experiencing the similar circumstances in caring for her mother:

*Participant 4: "I think my biggest support at this time is Jessica...for me. She's got her mother...not as bad as Steve...but she's pretty bad. She's my support in sharing."*

*Participant 6: "My children are very, very good...they help us through...they take us through."*

Apart from family and friends, participants were part of an Alzheimer's support group. This group provided emotional support as participants were able to share experiences and also learn from other participants who were in similar situations:

*Participant 4: "And, I find...the support group, well it's only the second time I've gone there, but, at least I see I'm not always on my own. Other people are having the same problems."*

*Participant 3: "And, then I went there and they lent me some books to read so I could understand it better, and from hearing the other ladies...well it's mostly ladies...there are some men that come discuss it, you know, sort of prepared me and it also helped me to understand what was happening."*

The Alzheimer's support group became a source of empathy for half the participants in this research. This was reported to provide a forum for spouses to share their experiences on the caring role. Not only did the support group provide this empathic role but it also allowed the caregivers to be part of conversation which for some was different from the one-way interaction which pervaded their life. This was consistent with the research from Chambers and Ryan (2001) where many participants regarded communication as important and they expressed a desire to have contact with other carers in the same position.

The support group also allowed the caregiver to learn more about the caregiving situation from listening to others. This added to their comprehensibility of Dementia of Alzheimer's Type. This is also consistent with the results from the research by Chambers and Ryan (2001) where carers felt that they needed more information and training as reassurance that they were doing the right things. Furthermore, spouse caregivers were not taught skills to care, and as such they had to learn this through trial and error. The support group thus provided them with the information needed to also provide the correct care. On the other hand, one participant did express that caring for her spouse with Dementia came naturally to her because she had always been like a "mother hen" around her husband. Chambers and Ryan (2001) add that family carers needed to be provided with information, education as well as practical advice to cope in their caregiving role. Research by O' Shaughnessy (2010) found that caregivers attending support groups receive emotional validation. Apart from emotional validation, the support group also facilitates control over the caregiving situation. The support group can be seen as a link to other carers and it served as an important lifeline. Within South Africa, Potgieter et al. (2006) also found that when other family members attended the support groups, it allowed a deeper awareness of the caregivers' journey. However, no family members in the current research attended the support group with the caregiver.

Apart from the support groups, family and friends also provided the opportunity for the caregivers to express themselves. In terms of family, children and siblings were seen as providing an instrumental role in providing the emotional support structure. Support from family allowed caregivers to release their feelings and to share emotions with other members of the family who they were close to and who their spouse with Dementia were also close to. This is also supported by research by Lin et al. (2011).

The findings from the current research regarding the family as an emotional support system are vastly different from the research by Ferrara et al. (2008) where they found that the Alzheimer's situation created misunderstandings within the family. In their research it was found that fifty five percent of caregivers argue with other members of the family and they also felt criticised. Research by Upton and Reed (2006) also provided results which are in contrast to the current study. In their study caregivers expressed being forgotten by family and friends to different degrees. Furthermore, they also did not receive support from their children as they did not visit

them. Research by Chambers and Ryan (2001) found that the collective response from the group interviewed was that they had little emotional support. They felt abandoned with no help from anyone. In the current study one participant did express that she felt cut off from everyone however this seemed to also be practical in nature, on the other hand, the majority of the participants expressed receiving support from family and friends. All caregivers expressed that their children were very supportive, as such, none of the spousal caregivers expressed being neglected by their children.

- **Practical Support**

The participants found it helpful when family members and friends helped in practical activities which they found difficult doing.

The extract below shows how the spousal caregiver's son assisted practically:

*Participant 2 – “Michael came in at six just to see that everything was alright. We'd sit him up or turn him up...”*

Some of the neighbours of the spousal caregivers also played a role in assisting with practical duties:

*Participant 1 – “My children, my grandchildren and sometimes my neighbours too, you know, when the children are not around because they are not with me all the time, they got their own things to see too, so my neighbours will always find out like, you know, if I need anything, or whatever it is. They really, you know, support me in that way, like...it helps a lot.”*

On the other hand, one participant described herself as feeling very cut off from people when asked how important social support is for her. She described not having much support practically:

*Participant 3 – “I did feel very cut off. Because I never had help in my home or anything. I didn't even have somebody I could leave him with to go to the shop or something.”*

Spouse caregivers saw practical support as important and as something that really helped them. Practical support included taking the caregiver to the shop to buy groceries or providing respite while they were able to go to the shop themselves. Practical support can also be seen as helping

around the house in terms of home repair or also helping the caregiver with activities of daily living for the spouse with Dementia. In research by Upton and Reed (2006) psycho-social distancing was described where carers expressed that their family and friends did not offer any practical help in terms of helping the caregiver or helping the spouse with Dementia. Instead they acted more as co-ordinators informing the carer that they need extra help. Therefore the friends and family of carers would urge the carer to find nursing home placement or find a formal caregiver but they would not do anything to help find this. In contrast, the current study found that family members were very supportive when it came to the practical duties of caregiving. The majority of the participants expressed the help which they received from their family, mainly their children.

The concept of psycho-social distancing described by Upton and Reed (2006) is also described by Vikstrom et al. (2008) where carers reported losing their friends. In the current research four participants also described a loss of friends. The caregivers could not explain why they had lost their friends; one caregiver felt that it was possibly because they did not understand the disease. Vikstrom et al. (2008) found that carers lost friends due to missed telephone calls and disproportionate anger outbursts by the spouse with Dementia during social encounters. This could be a possible explanation as to why spousal caregivers in the current research also lost friends. Studies, thus show, that the caregiver experiences isolation which stems from the caregiver-spouse relationship as they can no longer relate in the same way to their spouse with Dementia however, when there is psycho-social distancing from family and friends, isolation becomes more apparent. Upton and Reed (2006) argue that the isolation should not be seen as a negative factor but is seen as something that will allow one to cope better as they will be able to extend more energy to the caregiving role. However, this was not the case in the current research, as the support from family and friends were deemed as very important.

- **Financial support**

Some carers also received financial support from their family members, however, this was not something that participants saw as necessary:

*Participant 6 – “He’s also very supportive financially although I never asked him for it, but he insisted on financial support to me.”*

*Participant 2 – “...I have a very nice daughter-in-law and she would bring a load of things in from the shops...and I would say, ‘how much was that?’...she never wanted to say, which was a bit embarrassing for me because I’d always pay for everything.”*

In the current study, financial support was not seen as a need by the carers. They reported not depending on anyone to help them financially. The participants of the current study were of a middle class socio-economic status, however, their children would step in to assist financially but carers would not ask for this support despite the costly nature of caregiving. Chambers and Ryan (2001) also found that caregivers did experience financial hardships as they had to provide a substantial amount of care resources. For those caregivers that were incontinent, adult diapers were being bought on a regular basis, wheelchair and commodes also created an added expense for the caregivers but financial support from external structures was not seen as important. Lin et al. (2011) provides a similar result from their research as the main source of financial support was provided by the carers themselves. A further finding by Cahill and Shapiro (1998) found that very few carers received additional financial support.

- **Faith**

Two participants also described their faith in God as a coping mechanism:

*Participant 3 – “Well, being a Christian, through that it enabled me to cope and, although, I couldn’t go to church very often because I couldn’t leave him and in the last few years I couldn’t take him either.”*

*Participant 7 – “And, I mean let’s face it...I mean I’m not going into religion, I am religious. I mean I am not fanatic, but, I am religious...and that is also a support for me.”*

Participant three also described faith as a coping mechanism even after her spouse with Dementia was placed in a home:

*Participant 3 – “But, then he was at Riverside, then at least I could still go to church on a Sunday morning and then on a Wednesday morning we’d have a ladies meeting, so I was able to do that. That helped me over the last four years.”*

The current study shows that religion played an important role as a coping mechanism as expressed by three spouse caregivers. In times of stressful negative life events or when they felt over-whelmed by their spouse's Dementia, they would turn to their faith to help them cope with the situation. This is prevalent in research by Potgieter et al. (2006) where the coping mechanism of faith was seen as something that allowed control to be regained. Further support of this is found in research by Lin et al. (2011) where religious belief was drawn upon as a source of support for some participants who expressed that their faith in God helped them to overcome their frustrations and their stresses and they reported that the powerful nature of prayer in helping participants cope through the situation. In research by Stuckey (2001) during negative life events participants would turn to their religious and spiritual beliefs. When in need of support these caregivers would turn to God and prayer was seen as an important aspect for coping with a spouse with Dementia which increased one's spiritual growth.

- **Institutionalisation**

Institutionalisation was an option for two participants in this study. For some participants this was reported as not an option and others did not mention anything about institutionalisation.

The doctor of participant three recommended that her spouse with Dementia be placed into a home for the sake of her own health:

*Participant 3 – “That’s why my doctor told me I must put him into Riverside, because he said if I didn’t, I was going to land up somewhere in hospital.”*

Participant eight placed her spouse in a home in the end stages of Dementia due to her spouse's violent behaviour as she could not handle the behaviour:

*Participant 8 – “...well because he was getting violent, I couldn’t take in anymore, because I felt I was going to have a heart attack or something...so we moved him into Victoria homes.”*

On the other hand, participant five did not want to place her husband with Dementia in a home as she felt she could provide better care:

*Participant 5 – “You see, I don’t want to do that because I also know what goes on in those frail care places. And you know, say you put him in a decent one, I would have no money to live on at all.”*

Research by Chenoweth and Spencer (1986) found that one of the main reasons for institutionalisation was the angry outbursts of the spouse with Dementia as participants could not handle the aggressive or violent situation. Furthermore, due to spouse caregivers not having enough sleep, this became a contributing factor to placing their loved one in a home. In the current research the spouses of two participants displayed aggressive behaviour. Of the two spouses, one spouse decided to place their partner in a home as the aggressive behaviour was too much to cope with. The second participant reported needing to deal with the issue as placing their participant in a home was not an option. Further research by Chenoweth and Spencer (1986) found that thirteen percent of the families said that due to a doctor’s recommendation, this convinced them that it was time to consider institutionalisation. This was found to be true by one participant in the current research. The doctor played a role in convincing her to place her spouse in a home as her own health was deteriorating. Spruyette et al. (2001) found that those individuals with a low commitment to the caregiving role decided to place their spouse in a nursing home during the early stages of the disease. The possible reasoning behind this is that if the spouse is functioning at a very low level, the caregivers feel it is too risky and they did not want to challenge their adaptation capacities. In contrast, two caregivers in the current research placed their spouses in residential care when there was a very serious cognitive impairment.

## **Chapter 6: Conclusion**

### **6.1. Overall findings**

From a worldwide perspective regarding the incidence of Dementia, more than thirty million people worldwide are currently living with Dementia. This figure, however, is expected to rise to one hundred million by the year 2050, when more than one in five individuals will be over the age of sixty (Rabins et al., 2006).

In South Africa there is an estimate of 250 000 ageing individuals with Dementia (Potocnik, 2013). Taking these estimates into account, Dementia is seen as one of the most common causes of death in ageing individuals and Alzheimer's disease is the most common form of these Dementias (Thompson, 2006; Poirier & Gauthier, 2011). These statistics not only pose a social and economic burden but creates stress and burden for many family members. The majority of individuals with Dementia of Alzheimer's Type are cared for by a member of their family (Connell, Janevic & Gallant, 2001). Spouses are seen to be the largest group of people that provide care to those diagnosed with Dementia. Connell et al. (2001) further add that these spouses are more likely to experience negative physical and mental health problems. Consistent with the following statement from Jansson et al. (2001): "Dementia caregivers provide more care and assist with a greater variety of tasks than non-Dementia caregivers, resulting in employment complications, family conflict, mental and physical health problems and decreased time for leisure activities" (p. 179).

The current South African study was undertaken in the province of KwaZulu-Natal in the city of Pietermaritzburg. The aim of the study was to explore and describe the various challenges and experiences that spouses succumb to as they care for their spouse with Dementia of Alzheimer's Type. The study sought to answer the following question: What are the experiences of spouses as they care for their Dementia of Alzheimer's Type partner?

The findings of this study show the negative emotional and physical effects that are experienced by spousal caregivers in their caregiving role. All caregivers in this study assisted their spouses with ADL's (bathing, eating, dressing) and IADL's (decision making, preparation of meals etc.). The caregivers' subjective appraisal was a deciding factor in how much stress they experienced (Whitbourne, 2016). Some caregivers in the current study experienced these activities, such as

managing the incontinence of their spouses as extremely stressful while some spouses found activities not as stressful. Understanding the ADL's and IADL's is critical to having an understanding as to what challenges spouses experience.

There is a relationship between ADL's / IADL's and the time spent on caregiving. ADL's need to be completed on a daily basis and as the disease progresses to the moderate and severe stage, the ADL's become the responsibility of the caregiver. Increased time spent on caregiving was therefore another result of the study as many spouses experienced more time being taken away from their own activities in order to care for their spouse. Furthermore, as more time was spent on caregiving this impacted them personally. Employment was affected for half the caregivers in the study. Caregivers either gave up their work or decreased their production or their working times were affected due to having to care for their spouse.

Participants also voiced a relationship between ADL's / IADL's and a decrease in social activities. All caregivers expressed that they could no longer do the things that they enjoyed. Any social activity was a thing of the past as the main priority for them was caring for their spouse. This finding becomes critical as social activities can also be seen as a form of respite for the caregiver. Due this not materialising the caregivers were home constantly with their spouse and this added to the negative emotional affects they experienced.

In South Africa, there is a lack of awareness of Dementia of Alzheimer's Type (Steyn, 2010; Khonje, Yako, Mabelane, Borochowitz, & de Jager, 2015). In looking at these findings, it is important to note that half of the caregivers in this study had a lack of knowledge regarding Dementia of Alzheimer's. This is a very point to take into consideration as Tremont and Davis (2014) state that if the caregivers have more knowledge on the illness they are better able to deal with the caregiving role. They will experience less depression and furthermore, they will have more control of the situation facing their marriage (Tremont & Davis, 2014). Awareness and knowledge of the illness therefore becomes an important factor to take into consideration in order to help prevent the negative emotional affects that were found in this research.

There is evidence which shows that an early diagnosis can be very helpful for both the patient and the spousal caregiver as this will allow both parties to discuss their future planning and also their short-term planning (Tremont & Davis, 2014) but for many families receiving a diagnosis

can be a difficult time. These authors further add that families do not see the seriousness of this illness and many see it as being part of old age. Furthermore, there is a stigma surrounding this illness which prevents the families from understanding more about the illness. A research in the township of Mangaung, South Africa found that black African research participants viewed Dementia as being linked to witchcraft (Steyn, 2010).

One way of providing education about Dementia to caregivers is through the doctors that diagnose the individuals. Tremont and Davis (2014) state that after the diagnosis is made, there should be a time where knowledge is shared to the caregiver including removing any myths that the caregiver may have about the disease. In a South African newspaper article it was found that one of the myths associated with Dementia of Alzheimer's Type is that the disease is only linked to European individuals and not found amongst the black communities (Steyn, 2010). Aspects that could possibly be discussed at this stage to educate the caregiver include the different stages of the disease, the effect that this will have on the caregiver and also options should be provided regarding different interventions that can assist the caregiver as the illness worsens. This should be addressed so the caregiver will know what to expect and they will have more control over the situation.

A further finding of this study was the caregivers' difficulty in accepting that their spouse could no longer provide care for themselves, they behaved more like children than that of adults. Caregivers viewed themselves as the parent. This was distressing for the caregiver. Further education can be provided to the caregiver to assist in understanding what to expect of their spouse as the disease progresses. The Functional Assessment Staging Tool (FAST) can be used in this situation to educate the caregiver on how to appropriately care for the spouse as he/she progresses through the various stages. This will not only assist the caregiver but the individual with Dementia as well. Rogers and Lasprilla (2006) add that when using the FAST tool positive outcomes can be seen in both behaviour and cognition and the speed of decline is also reduced in the patient.

More than half of the participants in the current research experienced their spouses' decline in mobility as the illness progressed. This created huge physical demands for the caregiver and in turn created added stress. Martin and Sabbagh (2011) state that caregiver's need to be educated in the loss of mobility of their spouses which arises in the last stage of Dementia. The FAST tool

can help to predict these future needs. These authors further add that caregivers should be educated in strategies for anticipating needs promoting mobility within a safe setting and providing comfort with mobility difficulties' (p. 132).

However, apart from educating the caregiver, health care workers or external/employed caregivers (assisting with nursing in the home environment) also need to be educated on the symptoms of Dementia. In a study in Mangaung, South Africa, under-diagnosing of patient was found due to health care workers not knowing the symptoms (Steyn, 2010) and this in turn can negatively affect the spouse caregiver and the spouse with Dementia.

The results of the study show that apart from educating the caregivers on this illness, there also needs to be greater public awareness. Some caregivers were not aware what this illness entailed before their partner was diagnosed with it. People need to be aware of this illness before a visit to the physician is even made. This awareness needs to be prioritised by the health care system. Furthermore, awareness-raising can take place by educating younger generations, so they are aware of the illness when they reach old age (Ames, Burns & O'Brein, 2010). Dissemination of Dementia of Alzheimer's Type information needs to be a co-ordinated effort by government, the media as well as urban and rural communities. In a newspaper article in South Africa it was stated that leaders in the community, pastors in the church and various community programmes need to make the community aware of this illness (Steyn, 2010).

A further important finding of this study was the need for support. All caregivers stressed the importance of having support. Support can be seen as external support in the form of professional caregivers, emotional support which was provided by family and friends, practical support which was provided mainly by family members, faith provided by prayer, institutionalisation and, finally, financial support. The main idea voiced by participants was having support which included a respite from the caregiving situation and to be able to vent their challenges and frustrations with the situation. External, emotional and practical supports were seen as the most important forms of support in the current study. This finding highlights the importance of family and friends in the life of the spouse caregiver. Social support, as such, plays a pivotal role in helping the spouse caregiver deal with the stresses of caregiving. Taking this into account, educating the immediate family of the caregiver could also assist in positive well-being for the carer.

However, there is a lack of support service in South Africa for Dementia caregivers (Clarke et al., 2011). There is hope that the Older Persons Act, No. 13 of 2006 in South Africa will be able to address these shortcomings. The aim of this act is to “deal effectively with the plight of older persons by establishing a framework aimed at the empowerment and protection of older persons and at the promotion and maintenance of their status, right, well-being, safety and security and to provide for matters connected therewith.” (p. 56).

In terms of institutionalisation, in the current study two participants opted for this in their spouse’s final stages of the disease. For other spouses this was a possible thought in the future and for some this was not a thought at all. The main reason for participants needing to place their spouse in a nursing home was due to the increase in stressors. One spouse in the current study was against placing her spouse in a nursing home due to the lack of care which takes place in some retirement homes. However, according to the National Action Plan of South Africa, the Protection and Promotion of human rights of 1998 urges the state to provide enough funding for caring for older persons (Harding, Powell & Gwyther, 2015). This involves funding for nursing homes and also funding for home based care. Ames et al. (2010), on the other hand, state that there is a lack of regulation and training amongst staff at nursing homes and this is a notable concern in both developing and developed countries. Nursing homes need more trained caregivers and also inspection of homes need to be done on a regularly basis by government.

## **6.2. Limitations of the study**

In terms of limitations of the study the sample size was small. A small sample was due to the nature of qualitative research which requires an in depth understanding and exploration of the topic. Eight participants were interviewed in this research. Therefore the findings do not claim to be representative of a larger spousal caregiving group but the findings from this research should provide an indication of what could arise from a larger and more representative or countrywide research sample.

A second limitation was a lack of ethnic diversity amongst the participants. The study comprised of six white participants and two Indian participants. There were no black participants or coloured participants due to availability constraints. According to Schulz (2000) ethnic differences have an impact on the attitudes towards caregiving.

Furthermore, a third limitation was an imbalance in the ratio of gender. In this study there were six females and two males. Caregiving has different meanings for men and woman (Hill, 2015) therefore this could have impacted the results of the research. An example of this can be seen in the current research where women seemed to take on more responsibilities such as finances, home repair and home maintenance. This created more stress for female participants whereas these were the usual tasks for male participants. Male participants only had the added responsibility of cooking and cleaning of the house which they at times received assistance from either a domestic worker or family members.

A fourth limitation was that three of the spouses' partner's died a few months before the actual interviews could take place. The participant's still agreed to participate but their emotional status of losing their partner could have also possibly affected the findings of the research.

### **6.3. Future recommendations**

It is recommended that future research should incorporate a larger sample. Furthermore, different ethnic groups should be included in future studies to gain a better understanding of the experiences of spousal caregivers in a country like South Africa which is culturally diverse.

A second recommendation would be that future research be longitudinal in nature as this will provide better understandings of the experiences of caregivers. A longitudinal study will allow one to identify the various factors affecting caregiving and can also differences in caring between gender and ethnic groups (Zarit, Todd & Zarit, 1986).

Dementia of Alzheimer's Type is an illness which will continue to increase and have an impact on family members. It is therefore, within the South African context, hoped that there will continued research in this field to uncover further experiences of elderly caregivers. Continued research in this field will only serve to create better awareness of Dementia of Alzheimer's Type and help those couples placed in this difficult situation.

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## **Appendix A: Letter to Organisation/Hospital**

To Whom it may concern:

### **RE: RESEARCH STUDY CARING FOR PARTNERS WITH DEMENTIA**

My name is Melissa Valoo. I am currently completing a qualitative study in fulfilment of my master's degree in research psychology at the University of South Africa under the supervision of Christine Laidlaw (clinical psychologist PS0112887). This research aims to describe the experiences of spouses as they care for their Dementia of Alzheimer Type partner. The study will contribute to the discipline of psychology to gain an in-depth understanding of the challenges and experiences that these spouses face.

My choice of topic is based on the fact that there is a general lack of research in South African literature which focuses on the experiences of spouses caring for partners with Dementia Alzheimer Type. Current research indicates that although many studies focused on spousal caregiving of Dementia, have been carried out internationally; far fewer have been carried out in South Africa.

I hereby ask permission to access 8 of your patients spouses who are willing to participate in my study and who are primary caregivers of those with Dementia of Alzheimer's Type. All volunteering participants in the study will remain anonymous in that, while their test results will be made known, their identities will remain confidential. The participants will be interviewed via a semi-structured questionnaire for 60 minutes each. Interviewees may refuse to answer any question and may withdraw at any point that they wish. Non-participation or withdrawal in the study will not have any negative consequences for you in any way.





Debriefing information resources will be provided to the hospital should it be required. The anonymous results will be included the final work with all identifying remarks and names changed. Feedback regarding the study's outcomes will be made available to all those interested.

You are in no way required to participate in this study. If you have any queries do not hesitate to ask me. It is necessary for me to obtain your informed consent in order to conduct the study at your organisation.

Your support is greatly appreciated.

Yours faithfully

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**Researcher: Melissa Valoo**



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**Supervisor: Christine Laidlaw**



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**Chair of Department of Psychology Ethics Committee: Prof. Piet Kruger**

Tel: 





## **Appendix B: Information Letter to Participant**

Dear Potential Participant

My name is Melissa Valoo and I am currently completing a research report in fulfilment of my Masters degree in Psychology at the University of South Africa. This research aims to describe spouses' experiences as they care for their partners who have Dementia of Alzheimer's Type.

All participants that are willing to take part in this study will remain anonymous in that, their identities will remain confidential. The interviewing process will take place for approximately one hour. The interviewees may refuse to answer any question and withdraw at any point they wish. If you do not participate in this study or if you feel the need to withdraw, this will not have any negative consequences for you.

Debriefing contact details will be made available to participants should debriefing be necessary. Each interview will be tape recorded and then transcribed. The transcriptions will be included in the appendix of the final work with all identifying remarks and names changed. Feedback regarding the study's outcomes will be made available in the form of a report to all those interested.

You are in no way required to participate in this study. If you have any queries, please feel free to ask me. It is necessary for me to obtain your informed consent before I can begin the study.





Yours faithfully

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Researcher: Melissa Valoo



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Supervisor: Christine Laidlaw

Tel: [Redacted]



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Chair of Department of Psychology Ethics Committee: Prof. Piet Kruger

Tel: [Redacted]





### **Appendix C: Letter of participant consent**

Dear Participant

Participation in this study is allowed strictly and only on the explicit understanding of the following conditions:

I will undertake to maintain confidentiality and anonymity as far as possible, as outlined by my governing body, the Health Professions Council of South Africa.

**You are in no way compelled to participate in this study and you may withdraw as you wish. The interview will be audio-recorded and transcribed. It is imperative that I obtain your informed consent before I can begin this study. Your signature below indicates that you understand and consent to the above conditions.**

Thank you for your support.

Yours faithfully

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Researcher : Ms Melissa Valoo

Email: [REDACTED]





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

Signature of Participant: \_\_\_\_\_

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**Supervisor: Christine Laidlaw**

Tel: [REDACTED]

[REDACTED]

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**Chair of Department of Psychology Ethics Committee: Prof. Piet Kruger**

Tel: [REDACTED]

[REDACTED]



### **Appendix D: Consent to audio-recording**

Dear Participants

The interview which you will be participating in will be audio-recorded. The recordings are intended to allow the researcher to transcribe what was said during the interview. All facts that may lead to the identification of a participant will be changed in the final transcription. This will apply to names and any identifying statements made.

Once transcriptions are completed all recordings will be deleted.

**You are no way compelled to participate in this study and you may withdraw as you wish. The interview will be audio-recorded and transcribed. It is imperative that I obtain your informed consent before I can begin this study. Your signature below indicates that you understand and consent to the above conditions.**

Thank you for your support.

Yours faithfully

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 Researcher : Ms Melissa Valoo

Email: 



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 Participant

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**Supervisor: Christine Laidlaw**



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**Chair of Department of Psychology Ethics Committee: Prof. Piet Kruger**



## **Appendix E: Semi-structured guide**

### **The Grand-tour question:**

1. What are your experiences caring for your spouse since they have had Dementia?

### **Prompts:**

2. How old is your partner?
3. How long has your partner had Dementia of Alzheimer's Type?
4. Can you describe to me the feelings you experienced when you found out that your spouse was diagnosed with Dementia of Alzheimer's Type? (Meuser & Marwit, 2001).
5. Can you describe the changes in your spouse's behaviour as Dementia of Alzheimer's Type progressed? (Gillies, 2011).
6. What is your routine for the day with your spouse? (Cahill & Shapiro, 1998).
7. What is it that you miss the most about your spouse? (Butcher, Holkup & Buckwalter, 2001).
8. What do you find the hardest about being a caregiver? (Ferrara, Langiano, Di Brango, De Vito, Di Ciocci & Bauco, 2008).
9. How has your life changed ? (Cahill & Shapiro, 1998).
10. Describe your social support system. (Upton & Reed, 2006). How important is this support system to you? (Upton & Reed, 2006).

11. What coping resources would have been helpful to you, or will be helpful to you in the future? (Chambers, Ryan & Connor, 2001).

**Appendix F- DSM-5 diagnostic criteria for Major or Mild Neurocognitive Disorder due to Alzheimer's disease**

(Black, D.W., & Grant, J.E, 2014, p. 373-374)

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

*For major neurocognitive disorder:*

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

- 1. Evidence of a causative Alzheimer's disease genetic mutation from family history or genetic testing.
- 2. All three of the following are present:
  - a. Clear evidence of decline in memory and learning and at least one other cognitive domain (based on detailed history or serial neuropsychological testing).
  - b. Steadily progressive, gradual decline in cognition, without extended plateaus.
  - c. Evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological, mental, or systemic disease or condition likely contributing to cognitive decline).

*For mild neurocognitive disorder:*

**Probable Alzheimer's disease** is diagnosed if there is evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history.

**Possible Alzheimer's disease** is diagnosed if there is no evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history, and all three of the following are present:

1. Clear evidence of decline in memory and learning.
  2. Steadily progressive, gradual decline in cognition, without extended plateaus.
  3. No evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological or systemic disease or condition likely contributing to cognitive decline).
- D The disturbance is not better explained by cerebrovascular disease, another neurodegenerative disease, the effects of a substance, or another mental, neurological, or systemic disorder.

**Coding note:** For probable Major Neurocognitive Disorder due to Alzheimer's disease, with behavioural disturbance, code Alzheimer's disease first, followed by Major Neurocognitive Disorder due to Alzheimer's disease. For probable Neurocognitive Disorder due to Alzheimer's disease, without behavioural disturbance, code Alzheimer's disease first, followed by Major Neurocognitive Disorder due to Alzheimer's disease, without behavioural disturbance.

For possible Major Neurocognitive Disorder due to Alzheimer's disease, code possible Major Neurocognitive Disorder due to Alzheimer's disease (**Note:** *Do not use* the additional code for Alzheimer's disease. Behavioural disturbance cannot be coded but should still be indicated in writing.)

For Mild Neurocognitive Disorder due to Alzheimer's disease, code Mild Neurocognitive Disorder due to Alzheimer's Disease (**Note:** *Do not use* the additional code for Alzheimer's disease. Behavioural disturbance cannot be coded but should still be indicated in writing.)

## Appendix G – Functional Assessment Staging (FAST)

### Reisberg (1988)

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	--	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0

**Appendix H: Revised Memory and Behaviour Problem Checklist (Teri, Truax, Logsdon, Uomoto, Zarit & Vitaliano, 1992)**

**Revised Memory and Behavior Checklist**

**Instructions:** The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened Use the following scale for your reaction. Please read the description of the ratings carefully.

Has it occurred in the past week:

0 = No  
1 = Yes

Reaction Ratings:

0 = not at all  
1 = a little  
2 = moderately  
3 = very much  
4 = extremely

*Please answer all the questions for both frequency and reaction.*

(RC11)

Problem	Has it occurred? (in past week)		Reaction (how much it bothered you)
	NO	YES	
1. Asking the same question over and over	NO	YES	
2. Trouble remembering recent events (i.e. items in newspaper or TV)	NO	YES	
3. Trouble remembering significant past events	NO	YES	
4. Losing or misplacing things	NO	YES	
5. Forgetting what day it is	NO	YES	
6. Starting, but not finishing, things	NO	YES	
7. Difficulty concentrating on a task	NO	YES	
8. Destroying property	NO	YES	
9. Doing things that embarrass you	NO	YES	
10. Waking you or other family members up at night	NO	YES	
11. Talking loudly and rapidly	NO	YES	
12. Appears anxious or worried	NO	YES	
13. Engaging in behavior that is potentially dangerous to self or others	NO	YES	
14. Threats to hurt oneself	NO	YES	
15. Threats to hurt others	NO	YES	
16. Aggressive to others verbally	NO	YES	
17. Appears sad or depressed	NO	YES	
18. Expressing feelings of hopelessness or sadness about the future	NO	YES	
19. Crying and tearfulness	NO	YES	
20. Commenting about death of self or others	NO	YES	
21. Talking about feeling lonely	NO	YES	
22. Comments about feeling worthless or being a burden to others	NO	YES	
23. Comments about feeling like a failure, or about not having any worthwhile accomplishments in life	NO	YES	
24. Arguing, irritability, and/or complaining	NO	YES	

## Revised Memory and Behavior Checklist

### RMBPC Scoring

**Frequency Scoring:** Sum items on subscales and total

**Reaction Scoring:** Sum scores on items that had a frequency rating of 1 or greater on subscales and total

Memory:	7 items (#1, 2, 3, 4, 5, 6, 7) Possible range: 0-28 Frequency: mean = 18.33, sd = 7.02, range 0-28 Reaction: mean = 11.12, sd = 6.34, range 0-28
Depression:	9 items (#12, 14, 17, 18, 19, 20, 21, 22, 23) Possible range: 0-36 Frequency: mean = 11.40, sd = 9.28, range 0-36 Reaction: mean = 18.73, sd = 8.47, range 0-36
Disruption:	8 items (#8, 9, 10, 11, 13, 15, 16, 24) Possible range: 0-32 Frequency: mean = 5.64, sd = 6.44, range 0-28 Reaction: mean = 14.85, sd = 8.34, range 0-32
Total:	24 items Possible range: 0-96 Frequency: mean = 33.59, sd = 16.56, range 1-87 Reaction: mean = 22.69, sd = 15.60, range 0-77

## **Appendix I– Extracts from journal**

### **Participant 1**

*“The interview went very well. She described her challenges that she experienced. She cried a lot too. I felt deep sorrow for her as she lost her husband two months ago and she was still grieving.*

*She has taken on a lot since his Dementia worsened and she has learnt to do so many things on her own. She is a strong woman. She tears a lot but tries to hide it when she speaks about the person he was before he had Dementia. I can see from this that she really misses him and it’s difficult for her to move forward.*

*Even though she has family and friends at her side, she still seems to have a sense of loneliness and although it has been almost four years that he was diagnosed she still seems shocked that all this has happened because she said he was never someone that had any form of sickness.*

*She places a lot of emphasis in speaking of his incontinence. I think this was a very difficult time for her.*

*It seems she has come out a stronger woman from this and she is content in knowing that she was able to care for him at home till the very end”*

### **Participant 2**

*“She was very welcoming and was eager to be part of the research. She felt it is important to assist in the research as her son told her to do it. She was very happy to share any information to help. Her husband passed away a few months ago. She is doing well though and is able to move on but still keeps his memory strong. She showed me a picture of him which made me connect even more with her.*

*She provided a lot of detail of how the Dementia took over to the point where he became immobile. It seemed very difficult for her as she lived alone with him but she tried her best. In the interview she always brought up the issue of love. This was why she cared for him till the end. It was difficult for her but thankfully the support gave her some relief. It is disheartening for me especially hearing how she still wishes him goodnight. This is a bond that will never leave her.*

*I admire her for always trying to make him feel comfortable even though it took a toll on her as she is very old. The descriptions she gave of how he changed as a person, from stopping driving to not knowing how to use his cheque book, these were things that made this illness a reality. I could see how this impacted her life.*

*However, she finds joy in reminiscing about the past especially how she was able to take him on a ship cruise which he loved. She has come out a stronger and independent woman*

### **Participant 3**

*“She is a lovely, independent woman. She lost her husband two months ago. Towards the very end her husband was placed in a nursing home as she felt that it would be negative for her health. It was surprising that her husband had Dementia for so long, twelve years. I admire her as she cared for him through majority of those years on her own.*

*She never had an external help before placing in a nursing home. It did take up a lot of her time but thankfully it seems that she has her grandchildren to keep her busy.*

*Like participant two, she also found the incontinence a problem and it seems this was very stressful for her as she never had any assistance. It seems that emotional support was not something she really had yet it was something she really hoped to receive from people. This was disheartening as it seems she really wanted to connect to people in this difficult time. Thankfully the support group seemed to provide that emotional support.*

*This interview was very heart-warming for me as she was still a loving and caring wife. The Alzheimer’s which existed for a period of twelve years did not change their relationship.”*

### **Participant 4**

*“Her spouse was more in the moderate stages of the illness. He was communicating when I was there but it was evident that he would forget very easily as he was speaking to me and then forgot what he said. This showed me what this participant probably goes through daily and also showed me that a conversation between them is probably very limited.*

*I feel that for this participant this stage is probably heart-breaking as she will slowly witness her husband stop talking and stop doing things that he can do now. There is no doubt that she will*

*do what she can so make sure if he is happy, even if he does strange things like planting things in pots constantly. She will leave him as this makes him happy. She also was interested in the adult colouring books to add some sort of creativity to his life. She is giving him the space to be the person that Dementia is making him be.*

*She is still young and working and I think the impact that this is having on her own life is something that is getting to her. She is spending more time in the mornings seen to him and this is impacting her work.*

*My fear for her is when he gets to the severe stage. The hope is that she will develop appropriate coping mechanisms when he gets to this stage”*

### **Participant 5**

*“I feel sympathy for participant five as she spends most of her time caring for her husband who is unable to communicate much and he is unable to walk. I see her as a strong woman, emotionally and physically. She doesn’t seem to quit despite all the pain she is currently going through.*

*The interview went well. An environment was created where the participant could talk, even though at times she would get a bit emotional but she was very honest with her feelings as she told me how she sometimes feel frustrated and needs time for herself. It was not hard to see where her stress comes from.*

*Before the interview began she needed to put him into the room. It was difficult to move him, I assisted her. Eventually, with much effort we managed to place him in a wheelchair. This gave me an eye opener into what her life is like on a daily basis, thankfully she does have caregivers during the week to assist.*

*It seems like she is really losing who she is in this caregiving role. She wishes she could do things like voluntary work as she was a nurse but this is non-existent. Her life is devoted to him and I also think that she wouldn’t want it any other way as placing him in a nursing home is out of the question”*

### **Participant 6**

*“Out of the participants interviewed, their Dementia spouses were in their seventies. This interview was very touching for me as his spouse was much younger and in the severe stage of Dementia. He was twelve years older than his wife and he always expected her to care for him as he got older. This was disheartening as there was an expectation but Dementia changed this. Despite this, his love is unfailing. In fact, he is trying to stay healthy and look after himself for her, so he can be with her longer.*

*He does things to make her happy. Even through her aggression when she would chase him out from the house, he would wait for her to calm down. Placing her in a nursing home was not an option even through the aggression.*

*Even though his business suffered, money was not his motive. She is important to him. A caregiver assists in the week and, thankfully, their children offer great support.*

*I think it’s seeing her personality change and she is becoming someone he doesn’t know. This is very disheartening for him. I admire him for not giving up on her and still having faith that she will remember him”*

### **Participant 7**

*“His spouse with Dementia is in her eighties and he is in his nineties. He is already very old and is the caregiver for her. He has only recently had support from a maid that comes in during the week but on the weekend he is alone with caring for his wife. The thing that distresses him the most is seeing her worried about what’s going on with her. He cannot take this. It is evident that this creates a lot of strain on him.*

*He is a very intellectual man and it seems that conversations are very limited because she cannot have a proper conversation. He also likes to go out and do things but this is something he can no longer do. However, he is very caring and loving to her.*

*During the interview, he stopped to assist her with her oxygen mask. He made sure she was seen too. Furthermore, he has taken on the role of cooking. He expresses that this is hard for him but*

*he really tries his best. I can see that he tries his best and this seems to have caused him strain as well because he doesn't know how to cook.*

*He was very honest in saying how the situation frustrates him and he does get very angry. I admire him as he only came into his wife's life in his sixties, but, despite the disease, he will not give up on his wife. He will be there for her till the very end"*

### **Participant 8**

*"Her spouse died a few months ago. Towards the end he was placed in a nursing home because he was becoming very aggressive. I think that this was something that really took a toll on her. They obviously had a relationship built on respect and love and he never hit her and now suddenly he became a changed man and started to become aggressive.*

*She is definitely a very strong woman, but she seemed to be a very independent woman before Dementia came into the picture. She describes many incidences of confusion and hallucinations which gave me an inside view of what her life was really like.*

*She also had a good support system such as friends and their children but for her, the support wasn't very important. They lived on a farm at one stage and she describes this as an isolated life so they never had much friends coming over. She is okay even without the support. This further showed me that was a very strong woman.*

*What I gathered from this interview is that apart from missing him being the man of the house, she also missed the space between them. With the Dementia, she was constantly with him. She missed him having the independence. She also needed time for herself and she wished she could get away from the caring role. It was not easy for her despite her independence and she admits that when hearing of the diagnosis, she grieved as if he already died because she knew in her heart it was the end. This was very painful for me to hear and maybe this could have affected the caring role"*

**Appendix J: Summary table of themes**

Theme and subordinate themes	A key extract
<b>The Loss (Theme)</b>	
Ruined Expectations	<i>Participant 6 – “I am actually...I am now...I am twelve years her senior, so I was anticipating that when I get old she will look after me, so that was my pre-planning...acceptable to both of us and it just turned out the other way around...completely the other way around.”</i>
Loss of spouse	
- Change in personality	<i>Participant 3 – “The main thing was that he withdrew, he was a very friendly person, mixed with people easy and then he withdrew.</i>
- Loss of communication	<i>Participant 4 – “Ja (yes), and as I say the conversation...that’s just gone, you know...he’ll mention a couple of little things to me but nothing serious.”</i>
- Loss of hobbies enjoyed	<i>Participant 4 – “He used to be a very good chef, when I was sick he used to make all our meals for us. And now he doesn’t even want to peel a potato. Can’t even peel a potato.”</i>

- Loss of Roles *Participant 5 – “In the night I feel a bit afraid, if something happens to me...I mean...he can’t tell anyone, or get an ambulance or even phone my daughter, he can’t even do that.”*

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Loss of marital intimacy/companionship *Participant 6 – “Our relationship was a developed relationship...every year was a better success than the previous. We had no problems...but, now we have no relationship at all. There can’t be a relationship because she can attack me as if I’m attacking her. She won’t look at it as romance or anything of that sort so that’s totally cut off.”*

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Loss of self *Participant 1 – “It has changed me completely, I wasn’t the person I was...more tearful, it was always...you know...in me, I had no happiness or anything like that...”*

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**Theme and subordinate themes**

**A key extract**

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**Caregiver Stress (Theme)**

Assisting with activities with daily living

- Assisting with dressing *Participant 1 – “I was responsible to take him to the loo...and his clothes, he didn’t know how to choose anything of his own. I had to take all those things, that was my responsibility.*
- Assisting with bathing *Participant 2 – “It got to the point where I couldn’t even...couldn’t even get him into the shower so he had to have a bed bath, so, I’d sponge him down nicely, put his pyjamas on and sometimes change the bed...well, mostly change the bed every day.”*

- Assisting with eating *Participant 1 – “As time went on, he couldn’t walk, so we had to get him into bed and feed him his porridge. That I did every morning and after that, it went on to lunch and so forth.”*
- Assisting with toilet use *Participant 2 – “...he’d got a catheter, but then the bowels gave way and you’d have to get the nappies and you’d have to change him.”*

### **More time spent caregiving**

#### **(Theme)**

Hours spent on caregiving *Participant 5 – “You see, he doesn’t like me to go out much. He want me to get back quickly. He doesn’t me to stay out for more than an hour and half. Even if there’s somebody with him, he wants me here.”*

Worry over wandering *Participant 2 – “Allan, I’m just going to take this vacuum cleaner back. I got back to the car and there’s no husband there. So, what do I do now? I got visions of him going on the main road...on Victoria road and getting knocked down. And, then the car guard came up to me and said, ‘have you lost him?’ I said, ‘I have’. He said, ‘I know where he’s gone, he’s gone to Foodpak. You know where I mean?’ He’d gone round the back where cars park. He said he’s gone to Foodpak and he’s gone to find you. I went to Foodpak and he was there in the office. Anyway...that’s how things go.”*

**Theme and subordinate  
themes**

**A key extract**

**More time spent caregiving**

**(Theme)**

Lack of knowledge of Dementia of Alzheimer's	<i>Participant 1 – “No, I didn't know what it was...I really didn't know, but, the way he was carrying on was really painful.”</i>
Impact of employment	<i>Participant 6 – “My clients all know her because she was the accountant, so they all knew her, it wasn't a problem. She leaves when a client comes through, she walks around, but, my production is affected drastically</i>
Financial Implications	<i>Participant 5 – “And those nappies, just for a week cost me R806.00. And, the medical aid won't pay for it and I don't blame them really. He needs them basically.”</i>
New roles for caregiver	<i>Participant 4 – “He used to go to the shop for me, he used to go and buy the bread and milk. He would get some meat for us for supper. He used to garden. I mean...I don't worry about the pots he's got around, it doesn't concern me because it makes him happy. The gardener comes, I've got to tell the gardener what to do. I never used to do that, he used to supervise him and be outside with him. Absolutely everything I've got to do. I can't rely on him to do anything. So basically, everything has fallen on me.”</i>

**Strain of caregiving (Theme)**

Distress in witnessing degeneration of spouse with Dementia	<i>Participant 5 – “...he’s condition is getting very bad and he’s stiff and his legs...I know one of them is so sore, but, the other one is alright but he will still have it stiff as a board.”</i>
Fear of the worst	<i>Participant 2 – “I couldn’t tell you how many times, I’d been working in the kitchen or doing something and I could hear a noise...and...it’s a short distance along that little passageway. I used to run, because I really thought something was going to happen.”</i>
Caregiver death	<i>Participant 7 – “...we’ve got family who would support if necessary and James, if anything happened to me...she could go and stay with him, but, they both work him and his wife. It might be better if she went into a home...but he would be supportive.”</i>
<b>Love as a motivating factor (Theme)</b>	<i>Participant 8 – “I don’t know...I never really thought about it. He would have done the same for me if our positions had been reversed. So I just did it.”</i>
<b>Retrogenesis (Theme)</b>	<i>Participant 4 – “So you know, ja(yes)...it’s like having a child in the home again and the routine is like a child’s routine because it’s got to be at certain times.”</i>
<b>Decrease in social activities (Theme)</b>	<i>Participant 8 – “...both of us played croquet but I had to stop that because he started to irritate other people because he couldn’t remember which was his ball or where he was supposed to be going, so I stopped that.”</i>

Theme and subordinate themes	A key extract
<b>Decrease in social activities</b>	
<b>(Theme)</b>	
Seeing to needs of spouse	<i>Participant 5 – “And you know, your whole life is changed. I can’t go out much. I used to like my work. I’m sure that I would have been doing voluntary stuff if it wasn’t that I had to stay here all the time, day and night.”</i>
Losing friends	<i>Participant 3 – “...and then also...because people were embarrassed by it, who didn’t know how to communicate because, all the friends that used to visit, never visited anymore, so we were very isolated.”</i>
<b>Coping mechanisms (Theme)</b>	
Need for relaxation/alone time	<i>Participant 6 – “I came off active duty in the church although still active but not in the same capacity and it affected me relaxing time...like you know...we liked to go for drives.”</i>
<b>Support</b>	
- External support	<i>Participant 2 – “I had a carer. Very close to the end. Two weeks...it gave me a break. I could do something else. And he was quite relaxed with her there”.</i>
- Emotional support	<i>Participant 6: “My children are very, very good...they help us through...they take us through.”</i>
- Financial support	<i>Participant 6 – “He’s also very supportive financially although I never asked him for it, but, he insisted on financial support to me.”</i>

- Faith *Participant 7 – “And I mean let’s face it...I mean I’m not going into religion, I am religious. I mean I am not fanatic, but, I am religious...and that is also a support for me.”*
  - Practical support *Participant 2 – “Michael came in at six just to see that everything was alright. We’d sit him up or turn him up...”*
  - Institutionalisation *Participant 3 – “That’s why my doctor told me I must put him into Riverside, because he said if I didn’t, I was going to land up somewhere in hospital.”*
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**Appendix K: Jean Piaget's Developmental Levels and corresponding stages of Alzheimer's disease (Rogers & Lasprilla, 2006)**

<b>Piaget Developmental Stage</b>	<b>Alzheimer's Disease Stage</b>
<b><i>1. Sensorimotor period (Birth - Age 2)</i></b>	
Substage 1: Use of reflexes	Speech and motor dysfunction
Substage 2: Primary Circular reaction (PCR)	Few words spoken Incontinence Unable to walk or eat
<b><i>Moderate stage AD</i></b>	
Substage 3: Secondary Circular reaction (SCR)	Recent memory loss
Substage 4: Co-ordination of SCRs	Remote memory preserved
Substage 5: Tertiary Circular Reactions (TCR)	Unaware of surroundings
Substage 6: Invention of new means through induction	Personal hygiene problems Agitation, wandering, obsessive symptoms Difficulty counting to 10
<b><i>2. Pre-operational Period (Age 2-7)</i></b>	
Stage 1: Pre-conceptual Stage	Difficulty choosing proper clothing
Stage 2: Perceptual or intuitive Stage	Bathes only with coaxing Cannot subtract three repeatedly starting at 20

**3. Concrete Operational Stage (Age 7-12)**

***Early AD stage***

Decreased ability to perform in job  
Increased difficulty in social interactions  
Deficit in memory and concentration  
Difficulty with counting up by 7

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**5. Formal Operational Stage (Ages 12+)**

***Preclinical***

Normal forgetfulness - No impairment  
Possible subjective worry about memory  
loss

## **Appendix L: Process notes on research process**

### **28 July 2015 - Tuesday**

*Made contact with the Alzheimer's Association telephonically today. The social worker who assisted me was very helpful and gave me the contact number of another social worker who provided me with contact details of retirement or old-age homes in Pietermaritzburg. I contacted the social worker via email.*

### **29 July 2015 - Wednesday**

*I received a response from the second social worker. She gave me the contact details of ± 5 old-age homes. I contacted these old-age homes by email*

### **3 August 2015 - Monday**

*One of the old-age homes responded saying they will not be able to assist. I called the three of the other old-age homes and there was no answer. I called --- old-age home and I was put through to matron. The matron gave me the number of a Sister as she was the one who ran the support group. I could only get hold of her next week as she was in training.*

### **10 August 2015 - Monday**

*Contacted the sister. I managed to get hold of her. She asked me to come through for the Alzheimer's support group which was taking place on the first Friday of next month at 10:00am. I agreed I could make it at this time. I mentioned to her that I only need at least 20 minutes to present my research to the group. I will also bring any documentation.*

### **3 September 2015 - Monday**

*I prepared for the meeting with the Alzheimer's support group which was taking place the following day. All information letters printed. I prepped myself for the presentation I would give them regarding the research.*

### **4 September 2015 - Friday**

*The Alzheimer's support group meeting was at 10:00am. I took some time off work to attend this meeting. When I reached the old-age home I was immediately reminded of my grandfather as this was the same place where we sourced his caregiver. I found my way to the room where the meeting took place. There were a few ladies waiting for the meeting to start. They were all very*

*warm and welcoming and seemed very comfortable in this group. I introduced myself to a few ladies and some ladies were having small talk regarding their spouses with Dementia.*

*The facilitator of the group came in and greeted all present. Before we started members of the group were free to go and make some coffee and grab some biscuits. She asked me to present my research after everyone introduced themselves.*

*I presented my research. This took about 20 minutes. I explained to them my reasons for undertaking the research and why the research is important. The members of the support group were very interested. Some of them asked questions. They were all given information letters to take home to read. Those that agreed to take part in the research gave me their contact numbers and addresses. I told them I will be contacting them soon via telephone.*

#### ***20 November 2015 – Friday***

*Transcripts were transcribed today. This took me a few hours to transcribe one interview. Had to check this twice to make sure the correct information was transcribed.*

#### ***24 November 2015 - Tuesday***

*I transcribed transcripts over the past four days. I was very successful. Transcripts are very long.*

#### ***28 November 2015 – Monday***

*Today, I will start analysing the transcripts and immersing myself in transcripts. It will be a long process. I will have to read through transcripts a few times to have a good understanding with what I'm working with.*

#### ***29 November 2015 – Tuesday***

*In reading through the interviews, there were many similarities with my experiences of having a grandfather with Dementia of Alzheimer's Type. Some of these examples are being bed-ridden due to immobility and aggression. I need to take care when analysing themes to not focus on these issues because I have had a personal experience with them but rather focus on them as they appear in the other transcripts as well.*

*It took a long time to work through one transcript, but, various themes were found. I reminded myself to work independently through the second transcript and not let the themes from the first*

*transcript influence me in anyway. However, I still needed to mentally look for similarities and differences.*

***1 December 2015***

*I'm trying to condense themes and put them under one as they are many themes. I also need to find similarities and start linking interviews together. This is a very interesting process as I can see how they experience so many of the same feelings.*

***9 December 2015***

*I read through themes again to check again if this is a good reflection of transcripts.*

***10 December 2015***

*I'm happy with main themes and sub-themes. I need to work through transcript again to source information for each theme.*

***20 December 2015***

*I've identified various quotes and extracted to suit each theme. This will be used in the findings and discussions. Data analysis was a long process but findings have being very interesting.*

***23 December 2015***

*I've identified various quotes and extracted to suit each theme. This will be used in the findings and discussions. Data analysis was a long process but findings have being very interesting. It's interesting to see that participants are so different in terms of their background but their experiences are so similar. Some of their experiences were the same. I began to see this when compiling the findings. The extracts were very similar in terms of their feelings. This was an eye-opener for me.*