AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF THE LIVED EXPERIENCES OF FAMILY MEMBERS CARING FOR DEMENTIA PATIENTS

by

LEANDA JANICE RYAN

submitted in accordance with the requirements for
the degree of

MASTER OF ARTS

in the subject

PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: SEAN HAGEN

(January 2023)

Declaration

Name: Leanda Janice Ryan

Student number: 45904618

Degree: MASTER OF ARTS PSYCHOLOGY – MA (Psychology)

An Interpretative Phenomenological Analysis of the Lived Experiences of Family Members Caring for Dementia Patients

I declare that the above dissertation is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the dissertation to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

Ryan

Signature

30 January 2023

Date

Abstract

Dementia affects an estimated 55 million people globally. The dearth of dementia care facilities and the costs associated with them mean more families are having to shoulder the responsibilities of caring for family members with dementia at home, thus adversely affecting carers' quality of life. Using a phenomenological approach, this study aimed to explore how family caregivers develop the coping skills necessary to foster the resilience required to care for a family member with dementia. Purposive sampling was employed to recruit eight participants with whom semi-structured interviews were conducted. The analysis revealed five themes that highlighted coping strategies employed by participants that foster resilience, namely (1) positive personality characteristics, (2) an experiential understanding of caregiving, (3) the impact of information, (4) accessing external resources as a key factor, and (5) coping with the impact of caregiving. This study contributes to a better understanding of the experiences of familial dementia caregivers.

Key terms: dementia, activities of daily living, resilience, coping strategies, cognitive deterioration, phenomenology, interpretative phenomenological analysis, family caregiver, family member with dementia, adversity, hardiness, thriving

Table of Contents

List of Figures

Dedication

In Memoriam

It is with deep gratitude and warm regard that I dedicate this work to my late husband, my soul mate, Lencaster Ryan.

“I know you can do it.” Your words inspired me throughout this journey. Dear Lenny, your positive attitude and gentle words helped me complete this journey. I will be forever grateful, having been blessed with such a precious soul.

Lenny, I will love you until the day after forever.

Acknowledgements

I would like to express my deepest gratitude to:

God, for blessing me with wisdom, insight, and perseverance throughout my studies.

My supervisor, Mr Sean Hagen. Thank you for your mentorship, encouragement, patience, support and motivation, throughout this course.

My children, Loréal Howard, Larique Ryan and Kirsten Howard, for always listening to my chatter about this experience and being my cheer leaders.

My mom, Jennifer Fonseca, and my extended family, for putting up with me.

My colleagues, Samukelisiwe Ndovela and Girlie Twaibane, for being my sound board and continuously encouraging and supporting me.

The Alzheimer’s S.A. Foundation and the participants, without whom this study would not be possible.

My copy-editor, Erika Bodenstein, for her assistance.

A heartfelt thanks to all.

Chapter 1

A phenomenological investigation was conducted to discover how individuals - tasked with the care of a family member with dementia cope with the demands of caregiving and how these strategies build resilience. A dearth of information exists with regard to individuals tasked with the care of a family member with dementia, although such data is crucial to the health profession, as mental illness is not prioritised in South Africa. Booysen, et al., (2021) and the World Health Organization [WHO] (2012) agreed that the mental healthcare system, concerned with mental illness in South Africa, is in a precarious state and must be prioritised. Family caregivers often face the care of a dementia sufferer in the absence of prior knowledge of or training related to care. These individuals generally experience extreme emotional, psychological, financial and physical stressors. For example, dementia caregivers reported higher levels of stress, depression and anxiety, than non-caregivers (Sörensen & Conwell, 2011). Chapter 1 discusses the study's overview, rationale, problem statement, research question and significance.

Rationale of the Study

Dementia is a chronic degenerative syndrome, classified by the Diagnostic and Statistical Manual of Mental Disorders, 5th ed. (American Psychiatric Association [APA], 2013), as a mild or major neurocognitive disorder. The symptoms manifest as multiple forms of cognitive, social and physical deterioration, therefore, warranting the classification of dementia as a syndrome. According to new research, Alzheimer’s disease is the most common form of dementia, accounting for 60-70% of dementia cases (WHO, 2022). The trajectory of dementia involves a gradual and irreversible deterioration of cognitive abilities, to the extent where it interferes with daily life (Bunn et al., 2012; Harding et al., 2007). Individuals suffering with dementia need assistance with activities of daily living. The cognitive decline brought about by the disease causes an increase in dependence on the caregiver of the dementia sufferer.

The WHO (2022) estimated that, globally, 55 million individuals have dementia, with 60% living in low and middle-income countries. This number is expected to increase to 78 million by 2030 (Nebehay, 2021). This increase in incidence warrants the need for dementia to be considered a global priority (Ashrafizadeh et al., 2021). De Jager et al., (2015) asserted that the number of people affected with dementia in South Africa is much higher than reported, owing to the lack of research on its prevalence, and as the incidence of dementia increases, the need for care will, concomitantly, also increase.

Furthermore, 80% of dementia patients are cared for by their family members, resulting in the healthcare system's dependence on the support of family caregivers for the care of dementia patients (White et al., 2018). In this context, family caregivers are the main providers of care to dementia patients. In addition, in a study conducted by Mahomed and Pretorius (2022), it was found that caregivers of dementia patients did not receive any additional support with the activities of daily living. On account of the shortage of frail care facilities, as well as professional training, family members manage the care of the patients with limited resources and knowledge (De Jager et al., 2015; Van Wyk et al., 2016).

Dementia adversely affects the quality of life of both the family members caring for the dementia patient and the patient themselves (Thomas et al., 2006). The stress and burden associated with caregiving compound the negative effects of caring for a dementia patient and are the main contributors to illness in family members living with a dementia patient (Schulz & Sherwood, 2008). Research found that visits to physicians were 45% more prevalent in family-caregivers of dementia patients, compared to caregivers of patients with other illnesses (Potocnik, 2013). Additionally, these family members consume 70% more prescription medications than the average person (Potocnik, 2013). The challenges of caring for a dementia sufferer are numerous, resulting in these family caregivers becoming the invisible secondary patients (Brodaty & Donkin, 2009). Nonetheless, a number of caregivers reported positive outcomes of caregiving, such as a sense of purpose, personal growth, satisfaction, acquisition of skills and improved quality of the care rendered.

The literature on the lived experiences of caregivers of dementia patients, while informative, does not address how caregivers cope with and develop resilience in caring for a family member with dementia. There is a critical need to close this information gap, both worldwide and in South Africa, and to establish a foundation for further study of the lived experiences of families caring for a dementia patient.

In South Africa, advocacy of dementia and mediation of support structures and training regarding coping strategies for dementia caregivers - usually family members - are lacking (Gurayah, 2015). Several researchers concur with Van der Poel and Pretorius (2009), that a lack of education exists concerning the identification of the disease and care for dementia patients. Dementia is severely underdiagnosed in South Africa since the symptoms of dementia are often mistaken for normal ageing. This is ascribed to a lack of education on the illness. This concern is magnified by the fact that people show reluctance in seeking diagnoses, especially when related to a mental illness (Steyn, 2010). Hence, it is essential for families caring for people with dementia, to be educated (Gurayah, 2015). South Africans caring for dementia patients need training in all aspects of dementia, to ensure the quality of caregiving practices and that of the life of the dementia patient (Gurayah, 2015).

A scarcity of information related to resource centres, information, and care options available to the public, may explain the deterioration in the health of familial patient caregivers (Rodrigo et al., 2013). By empowering family members of dementia patients, the health of these informal caregivers, in general, will be positively affected. Thus, this study aimed to understand the lived experiences related to the coping skills that build resilience in individuals tasked with the care of a family member with dementia.

Problem Statement

The WHO reported that life expectancy increased by more than 6 years, between 2000 and 2019 (WHO, 2022). Tom et al. (2015) posited that, as life expectancy increases, the number of people diagnosed with dementia also increases. Likewise, the number of family members tasked with the care of dementia patients will thus increase. Steyn (2010) posited that, whilst a plethora of studies based on the experiences of dementia patients at the onset of the disease exists, the lived experiences of individuals taking care of a dementia sufferer are not well understood. These individuals are ill prepared for such care duties. There is also a lack of knowledge, support, respite programmes and frail care centres.

Understanding the adversities faced by caregivers of dementia patients can contribute greatly to the knowledge regarding this illness can and also inform health authorities about the needs of these individuals. The general challenge is that no or limited formal training is conducted.

Furthermore, an in-depth understanding of the lived experiences of family members of dementia patients is a meaningful focal point for changing how dementia is viewed and treated by society (Laranjeira, 2015).

The purpose of this phenomenological study was to provide an understanding of how individuals tasked with the care of a family member with dementia cope with the caregiving task, and how they develop resilience. The study included individuals who were residing, or had resided in the past, in the same residence as the dementia patient, and who were regularly involved, or had been regularly involved in the past, with the day-to-day care of a family member with dementia. Interviewing these individuals provided insight into how they coped and developed resilience, whilst caring for a dementia patient.

Theoretical Framework

Axelrod (2018, para. 4) stated that “As long as there is life, there is hope. As long as there is hope, there is life.” Adversities are an inevitable part of human encounters in life. Individuals shape the course of their lives by the decisions they make (Lopez, 2008).

Resilience is the ability to rebound or bounce back from adversity, utilising various coping strategies (Miller et al., 2016). Resilience is a dynamic process. In order to develop resilience, the individual must face an adversity and adapt positively to the adversity (Fletcher & Sarkar, 2013, p. 13). Several resiliency theories are described in detail, in Chapter 2. Richardson's (2002) model of resilience posited that a disturbance in the comfort zone or biopsychospiritual homeostasis can ignite resilience. The model indicates that a disturbance can be any factor, such as a diagnosis of dementia, that causes the person to move out of their comfort zone into unfamiliar territory. The individual will employ coping strategies or protective factors to deal with the disturbance (Fletcher & Sarkar, 2013). However, the outcome differs from one person to another, depending on how the adversity is dealt with (Fletcher & Sarkar, 2013).

This study employed the Worsley resilience doughnut. This model is a framework that combines research on the interaction of internal and external resources required to develop resilience when faced with adversity. The resilience doughnut model is illustrated using a diagram of two circles. The outer circle symbolises seven external variables that may contribute to developing personal skills, while the inner circle reflects an individual's internal qualities. The inner circle within the outer circle visually represents the interactions between a person's internal and exterior worlds. The model considers different strategies to build resilience. A detailed discussion is presented in Chapter 2.

Methodology

The intent was to study the subjective experiences of family members tasked with the care of a family member with dementia. A qualitative research design was employed for this study. Furthermore, a phenomenological approach was employed to aid in understanding the lived experiences of individuals tasked with the care of family members with dementia. The phenomenological approach allowed the researcher to gain a comprehensive and holistic understanding of the core meaning participants attached to their experiences, and to discover the essence of this phenomenon. A fundamental advantage of employing a qualitative design is the depth of data obtained, resulting from the use of interviews that explore lived experiences (Creswell, 2009). A qualitative approach allowed the researcher to interact with participants in an attempt to fully understand their subjective experiences.

As described by Merriam (2009) and Van Rensburg et al. (2013), the purposive sampling technique best suited the recruitment of participants. The sample was drawn from eight home-based family-caregivers of dementia patients residing in South Africa, with the aid of Alzheimer’s S.A.

Data were collected by interviewing the participants, using open-ended, semi-structured interviews. Descriptions of participants’ daily experiences of caring for a family member with dementia were utilised to obtain information and gain sincere insight.

The study employed, using a descriptive data analysis methodology to uncover participants’ lived experiences. The data were transcribed verbatim, coded and, utilising inductive analysis, organised into emerging themes. The lifeworld terminologies (the language used to describe experiences) were transformed into psychological meanings to emphasise the lived experiences of the participants. Details concerning the specific design are provided in Chapter 3.

Research Question

The objective of a phenomenological approach is to understand the experiences, understanding and meaning individuals attribute to a phenomenon (DeCarlo, 2018). Such an approach enabled this study to explore the lived experiences of individuals tasked with the care of a family member with dementia. Hence, the research question addressed by the study was:

How do familial caregivers develop coping skills that foster the resilience required to successfully manage the challenges of caring for a dementia patient?

Descriptions of participants' daily experiences of caring for a family member with dementia were utilised to obtain information and gain sincere insight. In order to answer the research question, this study explored the psychological, social, financial and emotional effects of caring for family members diagnosed with dementia. The central questions posed to participants included:

- Tell me about your experience of caring for a dementia patient/family member?
- How does the role of caregiver affect your everyday life relating to work, interests and relationships?
- Are there any kinds of support that makes caring for a family member diagnosed with dementia better, such as support from family, friends, or others?
- Tell me about your relationship with significant others (family). How do they assist with the process of caring?
- Does your relationship with your partner help you cope with the challenges/emotions of caring? How?
- In your own words, which characteristics helped you adapt to caring for a family member who is diagnosed with dementia?
- How do you feel about caring for a family member diagnosed with dementia?

- How do you deal with the uncertainties and continuous changes of caring for a dementia patient?
- What, according to your opinion, would make the caregiving task easier and effective?
- Is there anything else you would like to add about your experience of being a primary caregiver?
- Is there anything positive that you gain from caring for a dementia patient? Please give me examples of these gains.
- Is there anything else you would like to add about your experience of being a primary caregiver?

These questions were utilised to gain insight into the experiences of caregivers, how they cope with the situation and what they have gained from this experience.

Significance of the Study

Home-based care for dementia sufferers is critical to the health system as a shortage of frail care facilities is reported. De Jager et al. (2015) posited that South Africa had less than ten geriatricians and only five specialists in old-age psychiatry available. As indicated by the WHO, dementia was the seventh leading cause of death, amongst other diseases (WHO, 2022). The disease causes mental disability and results in dependency on others. This research study can inform the major role players, such as the Department of Health, the Department of Education and the Department of Social Development, providing invaluable information regarding the daily challenges faced by caregivers.

Findings from this research contribute to the body of knowledge regarding the challenges family members confront as well as highlighting the lack of support that exists regarding caring for dementia patients. In addition, the findings indicate how education related to home-based caring for dementia patients and their family members can positively impact caregiving as well as the quality of life of the family-caregiver. Similarly, Prorok et al., (2013) stated that the experiences of individuals tasked with the care of a family member with a dementia can provide valuable information concerning their needs and preferences with regard to services and service delivery. These services can alleviate many of the challenges experienced by family members (Harding et al., 2007).

Summary

The objective of the study was to understand how individuals tasked with the care of a family member with dementia cope and develop resilience. Chapter 1 rendered a general overview of the study. Chapter 2 presents a comprehensive review of the literature on dementia and resilience. A description of the research method is provided in Chapter 3. Chapter 4 focuses on the data collected via the interviews. Chapter 5 provides interpretations and recommendations based on the findings.

Chapter 2

Literature Review

This study focused on the development of resilience in individuals tasked with the care of family members living with dementia. Specifically, the research aimed to explore the impact of caring for a family member with dementia on the physical, psychological, emotional, social and economic wellbeing of family members. This included exploring the challenges associated with caring for dementia patients and the coping mechanisms employed to manage these challenges, in an attempt to understand how family members develop the resilience required to care for a family member with dementia.

In order to understand how an individual develops resilience, whilst tasked with the care of a family member living with dementia, Chapter 2 explores the nature, prevalence, symptoms and needs of dementia patients. Following this, the impact of caregiving on carers and family members, as well as the respite services available to family members, are considered. Finally, the discussion turns to the theoretical framework employed by this study in order to conceptualise the experiences of family members, namely resilience theory.

Explication of Dementia

Dementia is a syndrome of disorders, classified by the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (APA, 2013), as a mild or major neurocognitive disorder. The classification of a mild or major neurocognitive disorder is determined by the severity of the impact on the patient’s capability to function autonomously in their normal routine activities (APA, 2013). Furthermore, it is not a singular disorder but manifests as multiple forms of cognitive, social and physical deterioration, therefore, warranting the classification of dementia as a syndrome.

Dementia is, thus, an umbrella term used for a collection of related, but heterogeneous conditions affecting the brain, and is marked by cognitive decline (Johnson, 2016). Dementia is ordinarily related to old age, however, it can also be brought about by HIV infection and hereditary factors. Dementia results from damage to the cerebral cortex of the brain (Greenblat, 2017). It is a degenerative, acquired or age-related disease that prohibits patients from functioning at a former level (APA, 2013).

The DSM-5 identified six cognitive areas affected by the neurocognitive disease. The six cognitive domains are complex attention, executive function, learning and memory, language, perceptual-motor, and social cognition activities (APA, 2013). The impaired functioning of some or all of the cognitive domains is used as criteria to diagnose dementia. The six domains are characteristically affected by the disease, resulting in reliance of the patient on family members to assist with their normal daily activities. The different types of dementia include Alzheimer’s dementia, vascular dementia, dementia with Lewy bodies, frontotemporal dementia, dementia from Parkinson's disease and similar disorders, and Creutzfeldt-Jakob disease (APA, 2013). De Jager et al. (2015) asserted that Alzheimer’s disease, the most common form of the syndrome, accounts for 60-70% of dementia in patients.

A rudimentary definition of dementia is the demise of cognitive functions, of sufficient severity that prohibits a person’s normal functioning on a daily basis (Harding et al., 2007). According to Bunn et al. (2012) dementia is a gradual, irreversible disintegration or decline of cognitive abilities, conscious reasoning, and physical and social functions, that results in confusion, and thereby prohibiting patients from continuing with their normal daily routine or life. Moreover, a gradual loss of memory and a confused state of thinking, is characteristic of the cognitive decline. Consequently, it affects a person’s spatial orientation, concentration, temperament, attention, problem solving skills, as well as language skills, and often imitates other old age-related problems (Greenblat, 2017). It has been reported that the consciousness of a person is, however, not affected in a dementia patient (Greenblat, 2017).

According to the Alzheimer's Association, the Reisberg scale or Global Deterioration Scale indicates that the progression of dementia is informed by the cognitive decline of the patient and can be divided into seven stages (Reisberg et al., 1982). Stages one to three are regarded as no-dementia stages, as the patient does not exhibit enough or obvious symptoms warranting a diagnosis of dementia. Subsequently, early dementia sets in at stage four, and progresses to mid-dementia in stages five and six. Late dementia eventually occurs in stage seven, as the patient's cognitive ability declines and the condition worsens.

Prevalence of Dementia

The prevalence and burden of dementia in South Africa cannot be ignored. Harding et al. (2007) maintained that the footprint of dementia on society demands deliberation amongst all generations of society. Dementia is a growing public health concern, worldwide. Research has shown a rise in the number of patients diagnosed with dementia. This rise is attributed to an increase in urbanisation and the expected life span of a great number of South Africans who face dementia related issues, daily (Van der Poel & Pretorius, 2009). Furthermore, Greenblat (2017) estimated that, globally, 50 million people have been diagnosed with dementia, and 10 million new cases are reported, annually. Their study, moreover, reported that for every 100 people aged 60 and older, five to eight people suffer from dementia.

Globally, new dementia cases are diagnosed every three seconds, as per statistics rendered by the WHO (Prince et al., 2013). Research conducted by Bunn et al. (2012) found that the statistics in respect of the diagnoses of dementia indicates that, worldwide, one in five people over the age of 80 are affected by dementia, and one in 20 over the age of 60. Consequently, predictions indicated that the number of people affected by dementia is set to increase and virtually double every 20 years, to more than 65,7 million in 2030, with an estimated rise of 7,7 million, annually (Mavrodaris et al., 2013; Prince et al., 2013). Additionally, Brodaty and

Donkin (2009) reported that more than 60% of people with dementia reside in third world countries.

The number of people diagnosed with dementia in Africa is approximated to be 818 106 annually, bringing the total number of people living with the disease in Africa to more than four million, in 2016 (Meyer et al., 2016). Moreover, the World Alzheimer Report claimed that the number of people living with dementia in South Africa is estimated to be 186 000 (Meyer et al., 2016). Additionally, a considerable number of dementia patients are cared for at home (Iavarone et al., 2014).

In South Africa, however, where there is a paucity of research investigating prevalence rates, the number of people suffering with dementia is believed to be much higher than the number reported (De Jager et al., 2015). De Jager et al. (2015) and Meyer et al. (2016) maintained that the occurrence of dementia in South Africa is severely under-reported, veiled and misunderstood. A local study undertaken by Steyn (2010), in respect of the metropolitan black population, suggested the prevalence to be nearly three times higher than initially projected. Furthermore, De Jager et al. (2015) argued that owing to the lack of epidemiological studies in Africa, there is inadequacy in terms of statistics of people living with dementia in low and middle-income countries.

Brooks et al., (2015) reported that 200 000 Australians are currently providing informal care to dementia patients. This number represents close to 91% of dementia patients who are cared for at home. However, similar statistics in respect of South Africa, regarding the home-based care of dementia patients, are not available (Potocnik, 2013). De Jager et al. (2015), therefore, proposed that additional research is needed regarding the statistics in respect of home-based care for South African dementia patients. De Jager et al. (2015) further proposed that additional research regarding the pervasiveness of dementia is needed, in order to evaluate the community health burden.

Symptoms and Stages of Dementia

The different types of dementia may manifest differently and, therefore, complicate early identification. Early symptoms of dementia can commonly be mistaken for other old age-related problems, as it tends to be vague and subtle (De Jager et al., 2015). In an Alzheimer's disease international global survey (Lynch, 2020), 62% of the healthcare providers perceived dementia as a normal part of aging. Accordingly, failure to identify symptoms often occurs (Harding et al., 2007) and the disease may remain undetected or undiagnosed for a considerable period of time (Greenblat, 2017). Dementia South Africa stipulated, as an added challenge, the fact that dementia symptoms also imitate symptoms similar to those of many other illnesses, such as stroke, depression, excessive long-term alcohol consumption, infections, hormonal disorders, nutritional deficiencies, and brain tumours (Dementia SA, 2020).

Symptoms of dementia vary according to the part of the brain that is damaged. Dementia is separated into two categories, namely cortical and subcortical dementia. Cortical dementia presents when the cerebral cortex of the brain is affected or damaged, whilst subcortical dementia affects the areas of the brain beneath the cortex. Cortical dementia will affect the patient's memory and linguistic ability, and subcortical dementia will affect the speed of thinking and the ability to start activities. Patients diagnosed with subcortical dementia may not experience problems with memory loss or forgetfulness. It must however be emphasised that some types of dementia can affect both parts of the brain (Huber et al., 1986).

Greenblat (2017) identified three stages of dementia, namely early, mid and late-stage dementia. During the early or mild stage of dementia, the symptoms are often disregarded or might only be apparent in retrospect (Greenblat, 2017; Meyer et al., 2016). Early symptoms of dementia include, inter alia, memory loss, confusion over the correct change when shopping, forgetfulness, getting lost in familiar places, struggling to follow a conversation or find the appropriate word, confusion concerning time and place, reduced concentration, personality or behavioural changes, apathy, withdrawal or depression, and difficulties with routine tasks (Greenblat, 2017). As the condition of the patient deteriorates, the moderate middle or mid-stage of dementia commences.

During the moderate middle stage, the challenges experienced by the dementia patient become more overwhelming, further limiting and incapacitating the patient. At this time, the manifestation of the disease becomes more apparent to the family members (Greenblat, 2017). This stage is marked by changes in behaviour, and difficulties with activities of daily living and cognition. Moreover, some of the signs that patients may exhibit include the inability to recall recent events and people's names, losing their way in the home, increased communication difficulty, inability to manage personal care, and changes in behaviour, such as repeated questioning or wandering.

In the more advanced stage, namely the late or severe stage, the symptoms of the dementia patient present as difficulties concerning appetite, weight and mobility, and bladder and bowel incontinence. The dementia patient becomes more dependent on others, experiences increased disability relating to physical tasks, and requires a great deal of aid, sometimes even becoming totally dependent on others. Dominant features of this stage include the inability to recognise family and friends, no cognition of time and place, a greater need for support and assistance, difficulty walking, and mood changes - which may include aggression.

According to the Reisberg Scale, the warning signs and symptoms related to the seven stages of dementia are summarised as follows (Reisberg et al., 1982):

Stage 1: No Dementia. During this stage, there is no cognitive decline or impairment. There is no evidence of memory loss or abnormal functioning, and the person displays a healthy mental state. Although symptoms may not be evident at this stage, medical tests may indicate a problem (Dementia Care Central, 2020).

Stage 2: No Dementia. Evidence of very mild cognitive decline is characteristic of this stage. The symptoms, such as forgetfulness, may be ascribed to the normal course of aging. The person may be unable to recall the names of certain people and where they have placed certain items. During this stage, dementia symptoms are concealed from both the family members and the physician. Minor changes in behaviour may be noticed. The patient is still able to function independently, and the changes may only be recognised retrospectively (Dementia Care Central, 2020).

Stage 3: No Dementia. The signs and symptoms described in Stage 2 become more apparent during Stage 3, as the disease progresses to mild cognitive decline. The patient displays increased forgetfulness and moderately challenged concentration. Spatial confusion, becoming disorientated in familiar places and the inability to verbalise the correct word, become more frequent (Greenblat, 2017). The patient may encounter challenges with the recollection of recent events, commit repetitive speaking, and need to plan in advance to compensate for changes in thinking and reasoning. Family members may start to notice a decline in cognition (Dementia Care Central, 2020).

Stage 4: Early Stage: This stage is marked by a moderate cognitive decline. Patients will experience challenges related to concentration, short term memory-recalling of recent events, managing finances, or challenges related to planning and traveling by themselves (Greenblat, 2017). Complex tasks will pose a challenge for the dementia patient. A change in personality may be marked, where patients exhibit withdrawal from others. The physician may be able to detect a decline in cognition in Stage 4, during a consultation with the patient (Harding et al., 2007).

Stage 5: Mid Stage. In stage 5 there is a moderate to severe cognitive decline. Memory is seriously affected, and patients experience great difficulty completing daily activities, thus, requiring assistance with a number of basic day-to-day functions, such as personal hygiene activities, deciding what to wear, and preparing meals. The memory loss is more noticeable and may include the inability to recall key aspects of current events. For example, patients may not be able to recall names of people or remember their home address or phone number. They may also be disorientated regarding the days of the week or the time (Dementia Care Central, 2020).

Stage 6: Mid Stage. Severe cognitive decline presents during this stage, rendering the patient unable to perform activities of daily living independently. In addition, memory loss progresses to an extent where the patient may have very little or no memory of recent events, and the names of close family members - including spouses and children - are forgotten. Memory is usually restricted to earlier life events. The patient is unable to concentrate for long periods of time and often does not finish the task that was started. Physical deterioration is also observed at this stage. Patients will be more dependent on others for assistance with basic, daily activities such as using the toilet, as bladder and bowel incontinence develops (Harding et al., 2007). The changes in personality and emotions are evident, as the patient becomes delusional, compulsive, agitated and/or anxious (Dementia Care Central, 2020).

Stage 7: Late Stage. The late stage of dementia occurs when the patient displays extremely severe cognitive decline. The ability to communicate via speech ultimately disintegrates (Greenblat, 2017). The patient cannot perform activities of daily living and is totally dependent on others for assistance (Zwaanswijk et al., 2013). Psychomotor skills are lost, including the ability to walk, and patients are bedridden most of the time. Loss of appetite resulting in weight loss also manifests in the late stage (Dementia Care Central, 2020).

The trajectory of the disease varies amongst patients. Dementia Central Care declared that the type of dementia plays a pivotal role in the signs and symptoms experienced by each person (Dementia Care Central, 2020). For instance, persons diagnosed with frontotemporal dementia do not exhibit symptoms of memory loss, whilst memory loss is a core characteristic of

Alzheimer’s dementia (Dementia Care Central, 2020). Azermai (2015) indicated that the symptoms are likely to occur in clusters, depending on the type and severity. Harding et al. (2007) emphasised the importance of educating society regarding the identification of symptoms of dementia, in order to seek treatment at an early stage and delay the progression of the disease.

Needs of Dementia Patients

Dementia, also known as “the disease of the family”, is an ailment that affects the entire family, as dementia patients are dependent on others to assist them with their normal, daily routines and activities (Deist, 2013, p. 1). Dementia is one of the leading causes of disablement in patients amongst the elderly, that results in dependence on others (Greenblat, 2017). The majority of these patients are cared for by family members. Statistics reported by Iavarone et al. (2014) indicated that 80% of patients diagnosed with dementia are cared for at home. The overwhelming responsibilities of administering care to dementia patients are not only physically exhausting but also psychologically distressing, to the caregiver (Farina et al., 2017). Being tasked with the care of family members living with dementia can be difficult, overpowering and taxing, for both the patient and their family members.

The needs of dementia patients are categorized as frail care needs, implying that dementia patients need help and care to perform routine activities, such as eating, personal hygiene activities, and even physical movement. Brooks et al. (2015) reported that, on average, caregiving rendered by family members comprised 24 hours per day. Dementia patients can sometimes refuse to cooperate and may display defiant behaviour, thus, rendering caregiving even more challenging, and increasing the burden on family members (Cheng, 2017). Patients require assistance with various daily activities, including preparation and eating of meals, taking care of their finances, taking medication, bathing, dressing, shopping, and exercising. They may also experience feelings of isolation and need some form of social interaction. As the neurodegenerative process advances, the aid needed by dementia patients increases and they become more dependent on family members to assist them with fundamental activities that involve intensive care, such as helping the patient out of bed, and feeding and toileting the patient (Brooks et al., 2015).

State frail care facilities are insufficient, resulting in the bulk of the care becoming the responsibility of the family members. Gurayah (2015) reported that 80% of informal caregivers reported a willingness to care for their loved ones at home for as long as possible, rather than admitting them to a care facility.

Formal Care Services and Respite Programmes

Family members of patients with dementia often do not have information regarding where to find support about how to care for the patient (Zwaanswijk et al., 2013). To exacerbate this challenge, Stroebel (2014) posited that South Africa holds no formal support structures for these family members. Furthermore, Gurayah (2015), concluded that health care professionals are needed to train and support individuals tasked with the care and management of family members living with dementia. Family members must acquire knowledge concerning where to find the necessary support, the evolution of the disease, as well as the coping skills that are required to care for a dementia patient (Sousa et al., 2017). Sousa et al. (2017) posited that family members need this support, since institutionalisation of the patient is often delayed when family members take on the role of caregivers, during the early and moderate stages of the disease. Research has indicated that the support available to family members lags far behind that which is available to the dementia sufferer (Reinhard et al., 2008).

Raising awareness about dementia, was a campaign undertaken by Dementia South Africa to raise the awareness of the general public concerning dementia (D. G. Murray Trust, 2014). The research conducted by this organisation showed that there is a shortage of state-subsidised care homes in South Africa. De Jager et al. (2015) emphasized this statement by stating that only 2% of patients requiring 24-hour frail nursing care in South Africa, are catered for. South Africa has less than ten geriatricians and less than five specialists of old-age psychiatry, to service a population of 3.8 million persons aged 60 years and older (De Jager et al., 2015). This further contributes to the daily stress, demands and frustrations experienced by the family members. Van der Poel and Pretorius (2009) contended that the shortage of frail care facilities could be attributed to government's prioritisation of primary health care, rather than secondary health care. An added challenge is the cost of frail care, that is estimated to range between R13 000 and R25 000 per month (Du Preez, 2018). Family members, at times, are presented with no alternative but to shoulder the responsibility of nursing their loved ones.

The experiences of individuals living with and tasked with the care of family members living with dementia, may provide valuable information regarding preferences relating to services and service delivery (Prorok et al., 2013). Dementia training could also assist in alleviating the financial burden of having to institutionalise the dementia patient in a frail care facility. Alzheimer's South Africa and Dementia South Africa have undertaken to collectively raise awareness by initiating development within communities, hosting informal workshops, developing support groups and rendering counselling services to the broader population (Dementia SA, 2020; Hugo & Van Wyk, 2007). A national telephone helpline has also been made available. However, since dementia advocacy is neglected in South Africa, many families are not aware of the disease and, thus, do not seek help or fail to benefit from these activities (De Jager et al., 2015). The campaign by the WHO (2012), maintained that the onus is on society to raise awareness and encourage the government to ensure dementia is declared a national health priority. This statement is substantiated by the fact that more than 50% of affected family members are at risk of clinical depression (Potocnik, 2013).

Impact of Caregiving

Grief and loss are inevitably connected to human existence. Every person will likely suffer some type of meaningful loss during their lifetime, and the experience thereof is stressful and exhausting (Psycom, 2022). Meuser and Marwit (2001) declared that when a loss is suffered, grief is initiated. Grief can be defined as a mental reaction to a noteworthy disruption via death or loss, and can be characterised as types of grief and losses, namely compounded serial losses, ambiguous losses and anticipatory grief (Blandin & Pepin, 2017). The grief associated with dementia is characterised as a type of anticipatory grief, owing to the experience of compounded serial losses suffered as the disorder progresses. Compounded serial loss is a build-up of irresolvable losses the family members experience, as the patient’s condition progressively deteriorates. As the patient’s abilities decline, losses of functionalities such as independence, physical health, and the ability to bath, groom or perform normal daily tasks, become the responsibility of the family members. These losses are recurring and plentiful, and are, thus, regarded as compound serial losses (Blandin & Pepin, 2017). These compounded serial losses are dominated by ambiguity and uncertainty (Blandin & Pepin, 2017). Family members experience losses themselves, as the disease progresses. The relationship between the family member and the dementia patient changes as separation takes place - familiarity and emotional connections formed prior to the onset of the disease, change. The family members also feel a loss of affection as well as a loss of a confidant (Schulz & Sherwood, 2008).

Ambiguous losses and grief are related to experiences where the dementia patient is physically present with the family members, but psychologically or emotionally absent. Ambiguous loss refers to a situation where the person has not physically died, but there is no hope that the patient will recover to become the person they were before the disease (Boss, 2006). The person may not be able to participate in conversations like they did before. As the patient’s cognitive, social and physical functioning deteriorates, anticipatory grief is experienced - the family members anticipate the imminent death of the patient. Hall (2011) delineated grief as a response to a loss in all of its totality, and this response impacts both the mind and body. The response to grief can be seen in physical, emotional, cognitive, behavioural and spiritual manifestations.

Dementia Care Central reported that dementia primarily affects the patient, but secondarily impacts the family and community (Dementia Care Central, 2020). The findings by Rodrigo et al. (2013) suggested that family members rarely choose to become informal caregivers. The choice is hardly a conscious one, as they are often compelled to become informal caregivers owing to the patient's abrupt illness or disability, or as a result of an accident. Family members may therefore experience a sense of obligation to take on the responsibility of attending to the health and care of a loved one.

Schulz and Sherwood (2008) stated that individuals tasked with the care of family members living with dementia suffer more negative health effects, compared to caregivers of patients with other types of diseases. They reported that taking care of a dementia patient often requires more time, than attending to patients with other diseases. Furthermore, these patients do not express appreciation or gratitude, and usually become depressed or violent (Rodrigo et al., 2013). Zwaanswijk et al. (2013) noted that a lack of support, knowledge, formal services and preparedness to look after a dementia patient, increase the physical, psychological and emotional challenges faced by the family members, more so than is the case with other diseases. Family members often have little or no knowledge of how adequate support should be rendered to distraught patients on a day-to-day basis (Van Wyk et al., 2016).

The deleterious physical, psychological and emotional challenges that family members face, include feelings of guilt, psychological morbidity, depression, anxiety, poor mental health, poor physical health, high levels of stress, emotional distress, burn out, lack of motivation, and hypertension (Brodaty & Donkin, 2009; Greenblat, 2017; Gurayah, 2015; Iavarone et al., 2014;

Kimura et al., 2015). Schulz and Sherwood (2008, p. 24) concluded that the stress of looking after a dementia patient may result in incapacitated wellbeing-conduct and mental stress, that encourage biological reaction leading to infirmity and death.

Family members attending to the care of a dementia patient often develop physical ailments, owing to the demanding stressors. These family members are at a greater risk of developing chronic diseases, such as cardiovascular disease and impaired kidney functioning, as well as other ailments, such as reduced immunity, slow wound healing, hypertension, and high levels of the stress hormone (Brooks et al., 2015). Sleep disturbances are also a common occurrence, when tending to the care of a dementia patient (Sarkar, 2015). These chronic conditions, in turn, increase the mortality rates of both the family members and the dementia patients, alike (Brooks et al., 2015).

The negative impact on individuals tasked with the care of family members living with dementia, may also include psychological illnesses (McCabe et al., 2016). Sarkar (2015) stated that caregiving for a dementia patient is taxing and time-consuming, and could result in high levels of depression, stress and anxiety. The support needed by a dementia patient often becomes overwhelming and burdensome, for both the patient and family members (Greenblat, 2017). Potocnik (2013) maintained that caregiving often results in intense psychological changes and effects, including substance abuse, and also results in increased rates of hospitalisation. Family members may experience feelings of frustration, fatigue, annoyance, resentment, sadness, guilt, being “robbed of a future” and, sometimes, destitution (Kimura et al., 2015, p. 215). This may lead to a form of chronic stress, thereby increasing the possibility of developing mental and physical pathologies (Manzini et al., 2016).

As a consequence of the increased levels of supervision required in respect of dementia patients, as the diseases progresses, family members are at risk of becoming socially isolated, confined or imprisoned in their role as caregiver, and must sacrifice leisure time, such as family vacations and interaction with friends (Brodaty & Donkin, 2009). Family members may inadvertently become dependent on others, owing to the high demands of looking after a dementia patient (Kimura et al., 2015). Emotional distress may also manifest, resulting from the loss of the family member's previous relationship with the dementia patient, as the patient declines cognitively (Brooks et al., 2015).

An added challenge of caring for dementia patients relates to the financial burden or strain suffered by the family members. The cost of care is monetary, i.e., family members are obliged to assume the financial responsibilities of the patient or they could face a complete loss of income when full time care is required, and also includes other sacrifices, such as time to provide aid and to travel to medical appointments. Rodrigo et al. (2013) postulated that the diagnosis of dementia may negatively impact the family when the caregiver or dementia patient is, or was, the sole breadwinner in the family. Findings from a study conducted by Faronbi et al., (2019) revealed that family members are likely to experience financial difficulties owing to the needs of the dementia patient. Gurayah (2015) explained that the increased cost of medication, food and transport of the dementia patient, contributes to the financial stress of the caregiver. Statistics reported by Dementia Australia reported that 54% of family members were of working age (Brooks et al., 2015) and that, moreover, 74% of the family members had to stop working since there were no other alternative care arrangements available, therefore, increasing the financial burden they experienced.

The challenges experienced by family members of dementia patients are classified into two categories, namely subjective and objective burden (Brodaty & Donkin, 2009). Objective burden refers to the level to which the dementia patient is dependent on the family members, regarding day-to-day activities. It relates to the physical impact the caregiving has on family members, such as not being able to work or socialise. The subjective burden, however, relates to how the objective burden is perceived by the family members and the influence it has on them. The emotional wellbeing of the family members and their attitude towards caring for a family member with dementia influence their perception of their subjective burden. Brodaty and Donkin (2009) classified the subjective burdens family members encounter as, inter alia, psychological morbidity, social isolation and financial strain.

Harding et al. (2007) asserted that a better understanding of dementia can alleviate many of the stressors faced by family members. Early psychosocial intervention may lessen or address the stressors experienced by the family members living with a dementia patient (Galvin, 2013).

Conversely, Brooks et al. (2015) reported that taking care of a dementia patient can also have a positive impact on the caregiver, as it can increase the familial bond and encourage personal growth through the development of resilience. Brodaty and Donkin (2009) added that tending to the needs of a dementia patient can encourage spiritual growth, as well as instilling a sense of accomplishment and mastery. Nevertheless, a World Alzheimer Report in 2019 (Lynch, 2020) reported that 50% of family members worldwide claimed that their wellbeing had deteriorated as a result of their caregiving duties, despite their positive perception of their role as caregiver.

Resilience

Conceptual Framework

The word ’resilience’ originates from the Latin word ‘resilere’ and ‘resiliens’ meaning to leap back or to be able to resist or rebound from a challenging situation, thus, resulting in a positive outcome (Ledesma, 2014). Adversities are a part of human encounters in life, and the majority of people will experience a “potentially traumatic event” at least once in their lifetime (Fletcher & Sarkar, 2013, p. 12). Such events are referred to as ‘potentially’ traumatic, as the individual’s characteristics and life experiences influence the way they respond or adapt to these adversities or challenges, and trauma may be a result (Southwick et al., 2014).

‘Psychological resilience’ is a developmental, psychosocial process where individuals positively adapt after being subjected to adversity (Graber et al., 2015; Jackson et al., 2007).

There are three tenets of resilience theory - firstly, it is a developmental process; secondly, it is a process that unfolds over time; and thirdly, it is influenced by the circumstances of the individual (Graber et al., 2015). Resilience is a developmental process, in the sense that individuals lay foundations for dealing with adversities, from childhood experiences (Graber et al., 2015). It is a personal ability and a dynamic process, that is influenced by external resources and the individual’s response to the adversity. It, therefore, refers to the individual process of personal growth that occurs whilst navigating and negotiating adversities (Liebenberg et al., 2017; Rutter, 2012; Worsley, 2015). Hence, resilience is not an outcome, rather, it is an innate, self-righting mechanism, and an incessant process of positive growth and meaning making (Graber et al., 2015; Windle, 2010).

Qualities such as a positive self- esteem, optimism, cognitive flexibility, coping skills, a moral compass, personal well-being, and how we partake in the world and a supportive environment, positively affect how we respond to challenges, and the way we employ our coping strategies and build resilience (American Psychological Association, 2012; Nugent et al., 2014; Van den Hoonaard & Van den Hoonaard, 2008). Moreover, Worsley (2015) declared that developing a resilient attitude and behaviour help maintain mental health and assist people to transition through several life stages. Joling et al. (2016) added that resilience directs attention to an individual’s strengths rather than their weaknesses.

Resilience theory posits that individuals are embedded in the world of personal relationships and society (Graber et al., 2015). According to Liersch-Sumskis (2013), resilience is an interactive concept, indicating that resilience develops through the interaction of the individual and their unique characteristics with the social environment. Resilience is considered interactive in that its existence must be independently derived from different end results amidst those who were exposed to considerable hardship or substantial mental strain (Rutter, 2012, p. 336). Luthar et al., (2000) identified two core conditions necessary for an individual to build resilience, namely exposure to a risk or threat, and the individual's successful adaptation to the threat. Shean (2015) agreed, positing that, despite the adverse experiences, resilience is concerned with the combination of severe risk experiences and a fairly positive psychological outcome. Resilience is, therefore, initiated when a person encounters a difficult situation and must employ a certain set of skills – i.e., thoughts, feelings and behaviours - to overcome the challenge (Jackson et al., 2007). Resilience and adversity are, therefore, interdependent. It captures how individuals, in the face of adversities, not only survive a range of challenges, but also thrive in the face of these challenges (Graber et al. 2015).

The majority of theories on resilience propose that the development of resilience is a dynamic process (Fletcher & Sarkar, 2013) and comprises ability, adjustment and compromise (Graber et al., 2015). This suggests an improved state, after an adversity has been overcome and coping mechanisms have successfully been employed. Researchers agree that resilience cannot be bound to only one psychosocial construct. Several factors, that are related to resilience, play a pivotal role in the development of resilience, namely thriving, hardiness and coping (Ledesma, 2014).

Thriving

Psychological thriving is related to resilience, and is defined as the increase of abilities, understanding and self-assurance, or the sensation of safety in relation to individual bonds (Ledesma, 2014, p. 3). Liersch-Sumskis (2013) indicated that the outcome of adversity is dependent on the level of disruption caused, as well as the availability and employment of protective and risk factors. According to Ledesma (2014) and Liersch-Sumskis (2013), individuals respond to adversity with resilience, and the outcome of that response is survival, recovery or thriving. Similarly, Worsley (2015) noted three outcomes, namely recovery, sustainability and personal growth. Following the experience of an adversity, the individual may function at a lower level, at a previous level, or at an improved level.

A survival response occurs when a person survives an adversity by responding well to the challenges encountered, but functions at an impaired state or lower level following the adversity (Ledesma, 2014). Carver (1998) expanded on four different outcomes to an adversity. The first probable outcome is one where the individual may respond by functioning at a lower, more dysfunctional level, than they did prior to the adversity. Richardson (2002) labelled this response as dysfunctional reintegration. This response involves resorting to detrimental and/or destructive behaviours, such as substance abuse, in an attempt to lessen the distress caused by the disruption (Fletcher & Sarkar, 2013; Liersch-Sumskis, 2013). The second outcome, identified by Carver (1998), is where the individual survives the adversity, but is weakened or impaired in some respect, with some loss of function. Richardson (2002) termed this outcome reintegration with loss. This outcome involves a lower level of functioning and/or a loss of protective factors, resulting in negative attitudes, such as pessimism, a decrease in motivation to address the problem, and a loss of hope for a better future (Liersch-Sumskis, 2013). Ledesma (2014) and Worsley's (2015) definition of a survival response comprises both the outcomes of dysfunctional reintegration and reintegration with loss. Recovery involves returning to the same level of functioning that was present prior to encountering the adversity, and corresponds with the third possible outcome identified by Carver (1998), namely a return to the pre-adversity level of functioning. The return can be rapid, or more gradual. Richardson (2002) termed this outcome homeostatic reintegration and defined it as a response to adversity that does not involve any change, but a return to the individual's initial biopsychospiritual state or comfort zone (Liersch-Sumskis, 2013). Worsley (2015) stated that individuals may recover in a short period of time when faced with an adversity, but that recovery time differs from one person to the next. Individuals with strong family and community bonds can draw on existing relationships to recover from the adversity. Whilst some individuals recover from an adversity, others may evolve beyond recovering from the adversity. These individuals may sustain their lifestyle and their high level of functionality in the midst of an adversity. The stress caused by the adversity does not affect their relationships with others. These individuals sustain clarity in respect of the import and objective of their actions, by maintaining their personal wellbeing and pursuing their goals (Worsley, 2015). Connections with significant others are reinforced, especially when a common goal is shared. Some individuals, however, surpass the sustainability response by experiencing personal growth or thriving as an outcome of the adversity. This corresponds to the fourth and final possible outcome identified by Carver (1998). This outcome involves one in which the individual functions at a higher level than the level before the adversity was encountered (Carver, 1998). Richardson (2002) termed this outcome resilient reintegration or improved function, whilst Ledesma (2014) termed it thriving and Worsley (2015) termed it personal growth. This outcome is marked by the development of improved or new protective factors, resulting in the attainment of a higher level of functioning or homeostasis.

Thriving, therefore, refers to the experience of personal growth, enhanced resourcefulness and flourishing by the individual, after facing an adversity (Liersch-Sumskis, 2013). Thriving manifests when an individual move beyond their original level of functioning prior to the experience of the adversity (Ledesma, 2014). Psychological growth and emotional growth are central to the concept of thriving (Fleming & Ledogar, 2008). This implies a positive transformation, a stronger sense of self, refocused priorities, and a cognitive shift relating to the adversity. Personal qualities that characterise resilience and thriving, as postulated by Ledesma (2014), include significant forbearance of instability, a favourable self-image, dedication, fortitude, resolve, robust internal resources, rationality, conviction, a diminished anticipation of unsuccessful outcomes, hopefulness, courageousness, dependable social resources, and adaptability. Thriving, thus, refers to positive growth and positive social outcomes as a result of facing adversities, risk or threats. Personal growth, wisdom, and positive personality changes, underpin the concept of thriving and are based on an individual's resilience capacity (Liersch-Sumskis, 2013). Growth occurs when the individual's positive emotions are enhanced or amplified through the experience of the adversity, thus, experiencing positive, personal growth. Liersch-Sumskis (2013) stated that resilience is the result of reintegration, accompanied by an improvement in functioning. According to Fleming and Ledogar (2008), resilient integration can be defined as the experience of growth or the development of deeper insight. Thriving is, therefore, reinforced hardiness resulting from having braved severe adversity (Ledesma, 2014).

Hardiness

Resilience is the potential to adapt to adverse situations, whilst hardiness refers to stable personality traits together with a person's ability to handle and respond to stressful situations (Fleming & Ledogar, 2008; Windle, 2010). In psychological terms, hardiness is a combination of personal attitudes that an individual utilises when faced with a stressful life event (Ledesma, 2014). It is a measure of the individual's ability to withstand stressful situations, whilst preserving an internal balance (Bartone, n.d.; Nikolaeva & Elnikova, 2015). It refers to the internal strength, inner resource and durability of an individual (Bartone, n.d.; Brown-Baatjies et al., 2008; Ledesma, 2014; Luthar et al., 2000; Mosley & Laborde, 2016; Walsh 1996; Worsley, 2015). These internal strengths, that include flexibility, control, confidence and commitment, form a path for resilience-building (Eroz & Onat, 2018; Ledesma, 2014). Moreover, hardiness is a function of life-approaches comprising self-conviction, faith in people and in cosmic interaction, that an individual utilises to learn from negative experiences (Nikolaeva & Elnikova, 2015, p. 219).

Hardiness is the ability to adjust to unanticipated changes, and is founded in a sense of purpose and control over the happenings in one’s life (Ledesma, 2014; Mosley & Laborde, 2016). It emerges as a positive attitude of development, towards a stressful event (Eroz & Onat, 2018). These dispositions or attitudes comprise a combination of three components, namely commitment, control, and challenge (Bartone, n.d.; Brown-Baatjies et al., 2008; Eroz & Onat, 2018; Jackson et al, 2007; Kardum et al., 2012; Ledesma, 2014; Nikolaeva & Elnikova, 2015). Theorists explicated the three dimensions as a) a belief that there is a meaningful purpose in life and a commitment to finding the purpose; b) a belief that external resources can be influenced and controlled by the individual; and c) a belief that personal growth will result from the challenges faced, by minimising their appraisal of the stressfulness of the situation, resulting in effective coping, learning and growth (Bartone, n.d.; Eroz & Onat, 2018; Jackson et al., 2007; Ledesma, 2014; Mosley & Laborde, 2016; Nikolaeva & Elnikova, 2015). Commitment refers to the attitude that, irrespective of the intensity of the stressful event, it is imperative to remain involved with people and events. It, therefore, provides a sense of internal balance where the individual displays a genuine interest and curiosity with regard to activities, events and others (Eroz & Onat, 2018; Kardum et al., 2012). Control is an attitude of perceiving the stressful event as an opportunity for growth, that results in increased adaptability. The individual believes that they must attempt to control and influence the outcomes of a stressful situation, that will lead to a more meaningful outcome (Eroz & Onat, 2018; Kardum et al., 2012). The challenge attitude is an acceptance of the stressors of life as growth and development opportunities (Eroz & Onat, 2018; Kardum et al., 2012). These characteristics of hardiness allow an individual to overcome physical and psychological stress, whilst remaining physically healthy (Bartone, n.d.; Kardum et al., 2012; Walsh, 1996). Hardiness is, thus associated with coping strategies and the employment thereof (Mosley & Laborde, 2016; Nikolaeva & Elnikova, 2015). It can lessen the effects of stressors and act as a protective factor against adversities by reducing the cognitive appraisal of a threat, resulting in an increased expectation of effective coping (Jackson et al., 2007; Kardum et al., 2012; Ledesma, 2014; Mosley & Laborde, 2016; Walsh, 1996).

Coping

Manzini et al. (2016) explicated the concept of 'coping' as a response a moment that provides a resolution to that specific situation. They declared that resilience, however, is the reaction to the circumstances, in its entirety. According to these scholars, the core characteristic of coping strategies is that they are conscious and intentional. The adversity is therefore consciously perceived and analysed. Manzini et al. (2016) noted that coping behaviour requires continuous cognitive and behavioural adaptations, in order to address the internal and external demands posed by the adversity. The conscious nature of coping implies that it is viewed as a tactic rather than a personality trait.

Iavarone et al. (2014) agreed and defined coping as a means of positively adjusting to disturbances or stressors. Cognitive and behavioural resources are used as a response to the adversity. In addition, coping strategies are primarily developed consciously and purposefully. The person intentionally evaluates the disturbance to their state of homeostasis (Manzini et al., 2016). Each person will, thus, develop their own coping mechanism in order to cope with the disturbance - these mechanisms are, therefore, personal and not universal to all (Nikos et al., 2009). However, as argued by Manzini et al. (2016), the employment of coping strategies does not necessarily warrant the achievement of resilience. A change in the individual's behaviour and cognition are required, to manage stressful events. These changes are regarded as coping strategies that positively contribute to building resilience. Iavarone et al. (2014) established the three types of coping mechanisms generally employed as strategies that are task-focused, emotion-focused and avoidance-focused. Firstly, task-focused coping mechanisms aim to decrease stress by seeking a solution. The activities of task-focused coping are performed in an attempt to eliminate the problem or render the problem less stressful (Iavarone et al., 2014). An emotion-focused strategy, on the other hand, is a mechanism used to control one's emotions, by means of reflection. It constitutes an attempt to control the stressful or disturbing emotions, such as imagining beautiful and relaxing sceneries, and is employed to lessen the effect of the stress. Studies in respect of 'coping' found that neither emotion-focused- nor task-focused coping strategies are superior to the other, with regard to dealing with stress (Worthington & Scherer, 2004). Avoidance-focused strategies, on the contrary, involve avoiding or evading the problem or adversity. Iavarone et al. (2014) regarded this strategy as dysfunctional, based on the premise that no attempt is made to understand or manage the problem.

Liebenberg et al. (2017) and Shean (2015) identified various cognitive and emotional factors that affect how an individual copes. These include effective self-control, self-reflection, self-efficacy, positive self-concept, self-esteem, a sense of agency, self-confidence, determination, the ability to plan, optimism, cognitive abilities, being inspired, maintaining attention, problem solving capacities, creative thinking, positive personality traits, executive functioning, an easy temperament, a positive outlook, positive affect, a sense of humour, adaptability, competence, faith, and spirituality. These cognitive and emotional factors play a vital role in the development of resilience.

In summation, theorists define resilience as the ability to overcome adversity using protective factors to address the risk. The individual employs their set of skills to navigate and negotiate the traumatic event, by positively adapting to the risk. The outcome of this adaptation is resilience and may result in personal growth, improved coping skills and thriving. This is marked by an improved or higher state of functioning, following an adversity that has been faced. The facilitating factors in developing resilience are based on the interaction of both internal factors (personality traits) and external factors (family and external resources).

Resilience is, therefore, a dynamic process, and is motivated by hardiness and the utilisation of coping strategies.

Risk and Protective Factors for the Development of Resilience

To successfully build resilience, the individual must draw on their individual assets and external resources in order to positively cope with the presented phenomenon. It is an ever-changing process of adaptation that draws on the inherent strength and hardiness of the person (Walsh, 1996). Resilience is the result of effectively adapting to disturbances through cognitive and social flexibility and modification, that can be refined or learnt (American Psychological Association, 2012; Van den Hoonaard & Van den Hoonaard, 2008). Joling et al. (2016) defined resilience as the successful and positive outcome following an individual’s experience of a risk, challenge or adversity. Risk factors are stressful life events that cause disruption to the life of an individual. Moreover, these stressful events are elements that threaten the homeostasis and mental health of the person (Shean, 2015). Zauszniewski et al. (2009) reported that stigma, isolation, employment restrictions, or appraising a situation as burdensome, are examples of risk factors. Theorists agree that cumulative risks, that are also defined as multiple risks, affect an individual to a greater extent than the occurrence of a single risk (Shean, 2015). Rutter, Garmezy and Masten (as cited in Shean, 2015) also indicated that cumulative risks increase the chance of the individual developing a psychiatric disorder. However, not all risks are necessarily negative, and the avoidance of risk is not the best resolution (Shean, 2015).

Low-level risks and controllable risks are likened to an inoculation against a disease, or to a steeling event or strengthening effect (Rutter, 2012). Rutter (2012, p. 341) defined “steeling events” as the occasional subjection to benign, succinct, stressful intervals that improves the ability to withstand subsequent strains. Exposure to various stressors may desensitise or lower the individual’s vulnerability to certain stressors, resulting in an increased resistance (Rutter, 2012). Walsh (1996, p. 3), moreover, stated that “inoculation”, in psychological terms, refers to deterrent social and psychological engagements, that positively affects hardiness and resistance to threats and adversities. Luthar et al. (2015) posited that uncontrollable risks - stressors that the individual is unable to control – often do not result in a positive outcome. These are defined as high-level risks. Shaboltas and Zhukov (2011, p. 327) defined an uncontrollable risk as a challenging impact that is unforeseeable, unyielding or inevitable. Additionally, Fleming and Ledogar (2008, p. 5) defined a "high-risk condition" as a circumstance that is vastly predisposed to mental ill-health. Uncontrollable stress is detrimental to the health of an individual and may negatively affect their personality, resulting in a general state of helplessness, that may lead to the development of depressive disorders (Shaboltas & Zhukov, 2011). Furthermore, cumulative risks are viewed as precursors to high-level risks (Trentacosta et al., 2008).

Rutter (as cited in Fletcher & Sarkar, 2013, p. 13) defined "protective factors" as determinants that alter, adjust or improve an individual's reaction to particular contextual risks, that would generally render a person susceptible to a dysfunctional result. Protective factors positively alter the effects of a risk or disturbance and assist the individual in achieving a positive outcome, irrespective of the risk (Jackson et al., 2007; Luthar et al., 2000). Positive thoughts and insights fundamentally foster protective factors that activate and facilitate resilience (Deist & Greeff, 2014).

According to Garmezy et al., (1984), protective factors refer to ecological (environmental) factors, familial factors and factors external to the family, that significantly contribute to resilience and reduce stress in the individual. Garmezy et al. (1984) further posited three aspects that influence protective factors, namely aspects relating to the individual, family, and community. Individual factors refer to personal attributes, including the way in which new challenges are characteristically faced. Walsh (1996, p. 3) identified "familial factors" as the degree of cohesion present in the family system, as well as a positive emotional climate that include unambiguous, fair boundaries and networks, as well as compassion, devotion and psychological reassurance. Community (support) factors are regarded as any support external to the family, such as relational and kinship infrastructures that provide fiscal care, community aid, functional help and a feeling of fundamental bondedness (Walsh, 1996). Similarly, Liebenberg et al. (2017) noted that the facilitating components of resilience are dependent on three factors, namely individual assets, availability of resources, and the individual's skill in utilising the available resources. Individual assets are related to individual protective factors and are regarded as internal resilience processes. Examples of individual assets are skill, wit and conviction (Liebenberg et al., 2017). Individual assets furthermore include "agency" and life-world approaches, operational management, analytical abilities and proficiency (Liebenberg et al., 2017, p. 5). In this context, agency is central to the development of resilience and refers to individual capability (Liebenberg et al., 2017), including the individual's framework of meaning-making, as well as the process of making meaning. The meaning-making framework starts developing from a young age and provides the individual with a set of methods to help make sense of, understand and interpret the adversity (Liebenberg et al., 2017). Liebenberg et al. (2017) defined the meaning-making process as the manner in which individuals make sense of their experiences by using personal agency and resources, that influence how adversities are managed. Interactions with others play a key role in shaping individual assets. As the assets develop and grow, the individual's ability to overcome adversities increases.

Theories of Resilience

Based on their research, theorists emphasise different factors that affect the development of resilience. Consequently, a plethora of definitions and explanations for the development of resilience have emerged. This section aims to provide an explication of resilience-indicators that promote individuals’ capacity to overcome adversities. A synopsis of the major contributors to resilience theories, follows.

Michael Rutter

Michael Rutter, regarded as one of the pioneers of the resilience theory, proposed an ecological view of resilience. An ecological view infers that individuals encounter various environments throughout their lives that influence their behaviour or response to adversity. The emphasis is, therefore, on the environment as a catalyst for resilience, rather than on the individual (Shean, 2015). According to Rutter (2013) the environment and familial structures determine whether an individual will show or lack resilience, when facing an adversity. This notion implies that resilience alters when circumstances change (Fletcher & Sarkar, 2013).

Rather than conceive resilience as a psychological trait, Rutter regarded resilience as a normal adaptation to a risk, given the availability of positive, supportive resources or environmental and genetic influences, or biological functioning (Liersch-Sumskis, 2013; Rutter, 2006). According to Rutter, resilience refers to a diminished susceptibility to adverse contextual exposure, that results in a relatively positive outcome (Rutter, 2012, p. 336).

Rutter (2006) noted seven features/factors associated with the development of resilience. The presence or display of resilience suggests one of seven features/factors: 1) the employment of psychological or physiological coping, rather than protective factors; 2) brief exposure to low level risks; 3) social competence or positive mental health; 4) turning point experiences; 5) biological and genetic factors; 6) social relationships; and 7) the fact that protective factors are of equal value.

Firstly, according to Rutter (2006), resistance to challenges may develop from physiological or psychological coping and not essentially from the utilisation of protective factors. Rutter (2013, p. 477) posited that resilience may emanate from negative aspects, separate from contextual hazards, that may result in a balanced or, more so, hazardous outcome. Resilience may originate from characteristics or situations that have little impact when there are no risks (Rutter, 2006).

Secondly, brief exposure to controllable or low-level risks and challenges plays a pivotal role in the normal development of an individual, as it may lead to improved coping strategies and increased resistance for future adversities (Rutter, 2006). Exposure to these repeated low-level risks, rather than avoidance thereof, can facilitate coping skills (Rutter, 2013). Rutter (1999, p. 125) termed these experiences of low-level risks as “steeling effects”. Steeling effects or low-level risks may strengthen resistance to later stress.

Thirdly, resilience concerns an individual's social competence or positive mental health, in relation to a serious risk (Rutter, 2013). According to Rutter (2006), individual differences determine how a person will respond to risk and protective factors. Since individual traits and mental features differ, risk and protective factors may have different consequences in different individuals (Shean, 2015). Rutter (2013) described the mental features necessary to overcome an adversity and build resilience as the ability of an individual to plan; exercise self-control; do self-reflection; possess a positive sense of self agency and confidence; and their determination. Furthermore, Rutter (2013) posited that individuals who possess these mental features can successfully control the changing events.

Fourthly, a turning point experience refers to a constructive change that takes place during adulthood. A turning point experience occurs when the individual removes detrimental past experiences and replaces them with new, constructive options - a delayed recovery may, thus, be derived (Rutter, 2006).

In the fifth instance, biological and genetic factors play a major role in how risk is addressed and how resilience develops (Liersch-Sumskis, 2013; Rutter, 2006; Shean, 2015). Environmental factors may, however, alter genes and biological functioning, i.e., the detrimental effects of stress on neural structures (Liersch-Sumskis, 2013; Shean, 2015).

Biological programming or the damaging impact of stress or adversity on neural structures can constrain resilience (Rutter, 2006).

Sixth, Rutter (2013) emphasised that social relationships, such as a positive family atmosphere, act as protective factors against behavioural and emotional disturbances. Rutter (2006) posited that the employment of protective factors is dependent on the social context of the individual. For instance, when individuals receive more family support, they are likely to experience increased family stability via the social experiences they have encountered (Shean, 2015). Positive and healthy social relationships foster resilience.

Finally, Rutter claimed that all protective factors are of equal value, with none taking precedence over the other, and that cumulative risks are linked to poorer outcomes (Rutter as cited in Shean, 2015).

Norman Garmezy

Garmezy (1991) focused on the identification of the characteristics of individuals who thrived and showed resilience, whilst living in difficult circumstances. The focus of their research was on the prevention of mental illness by employing protective factors such as cognitive skills, motivation, social change and personal voice. Garmezy (1987) referred to protective factors as stress-resistant factors and considered resilience (Garmezy, 1991) to be the effective functioning of an individual during a stressful period. For Garmezy, resilience does not necessarily signify being impervious to stress, but it rather reflects the ability to recover from an adversity and maintain competent, adapted behaviour.

Garmezy (1993) identified three protective factors that promote resilience, namely dispositional factors of the individual, family bonds and cohesion, and external support systems. “Dispositional factors” refer to the temperament of the individual and include (Garmezy, 1991, p. 464). Familial factors promoting resilience include warmth, family cohesion, a stable family structure, and a concerned parent or caring adult, such as a supportive grandparent (Garmezy, 1987). Garmezy (1991) posited that the societal factors refer to support external to the family, such as a concerned teacher or social worker, and community relationships. This triadic model of resilience highlights the fact that resilience is a process in which an individual can shape their environment and vice versa. Garmezy (1991), furthermore, posited that genetics, as well as the environment, play a pivotal role in the development of resilience.

Suniya Luthar

Luthar et al. (2000, p. 5) advocated that the term resilience be applied with reference to "competence despite adversity". Resilience is seen as multidimensional, where the individual may portray competence in some - but not necessarily all - areas of functioning. Luthar et al. (2000), furthermore, posited that resilience is not a personality trait, but an outcome of the interaction between the individual and the environment. Similar to the definitions of resilience presented earlier in this chapter, these scholars perceived resilience to infer two critical conditions, namely the experience of an adversity and a positive adjustment outcome (Luthar & Cicchetti, 2000; Luthar et al. 2000; Shean, 2015).

The adversity or risk is a negative experience that requires a positive adjustment or adaptation. The positive adaptation is defined in terms of the social competence demonstrated by the individual. However, Luthar and Cicchetti (2000) suggested that high social competence is not the only measurement of resilience, and that the absence of a behavioural or emotional maladjustment can also serve as an indication of the development of resilience. Moreover, the development of resilience is influenced by vulnerability and protective factors. Vulnerability and protective factors are regarded as negative and positive risk modifiers, respectively. Luthar et al. (2015) and Luthar and Cicchetti (2000) defined vulnerability factors as indices that worsen or aggravate the negative effects of stress in individuals. These factors were identified as poverty, parental mental illness, isolation from peers, family conflict, and modelling of ineffective coping mechanisms (Luthar et al. 2015). It was concluded that low intelligence and being male can also be viewed as vulnerability factors, as individuals with low intelligence do not adjust easily to adversities and boys are more reactive to the environment than girls (Luthar & Cicchetti, 2000). Luthar agreed with Rutter and Garmezy, in perceiving protective factors or forces as those that regulate the effects of an adversity and steer it in a positive direction (Luthar & Cicchetti, 2000; Luthar et al., 2015). These factors include a strong value system, supportive relationships, an internal locus of control, social competence, and enriched coping skills (Luthar & Cicchetti, 2000; Luthar et al., 2015). High intelligence, previously regarded as a protective factor, was identified as a vulnerability factor, founded on the belief that these individuals are more sensitive to environmental issues than people of moderate/average intelligence (Shean, 2015). Luthar (1993) argued in favour of the introduction of superlative distinct labels to mark salient processes, in order to minimise the ambiguity in connotations of core terms in resilience studies. Luthar categorised protective factors as those factors that are protective-stabilising, protective-enhancing, and protective but reactive (Luthar et al., 2000). Luthar and Cicchetti (2000) explained that individuals with protective-stabilising traits demonstrate positive adjustment, despite the increasing risk. They exposited that the protective-enhancing trait allows individuals to engage with a stressful event in a such a manner that their competence is strengthened with increasing risk (Luthar et al, 2000). The final trait proposed by Luthar is protective but reactive. This trait usually offers advantages, but less so when stress levels are high rather than low (Luthar et al, 2000). Vulnerability and protective factors are influenced on multiple levels involving the individual, the family, and the community (Luthar et al., 2015). Luthar and Cicchetti (2000) identified poor impulse control and low intelligence as individual attributes that can negatively affect the vulnerability of an individual. Protective factors include a positive sense of self-efficacy, malleability, an internal locus of control, and an easy-going disposition (Luthar et al., 2015). Vulnerability factors are exacerbated in families where factors, such as inconsistent discipline and maltreatment, are evident. Protective family forces include a sense of belonging, nurturance, and parental support in the form of clear discipline guidelines, warmth and appropriate control (Luthar et al., 2015). The protective processes within communities relate to early intervention, attachment-based interventions, and positive peer and social networks, whereas vulnerability factors at the community level include exposure to and the effects of violence.

Ann Masten

Citing the “ordinariness of resilience”, Masten (2001, p. 227) concluded that resilience is the ordinary result of a normal developmental process. They explained that the development of resilience forms part of normal human functions or competencies, and that adaptation in the face of a threat is not an extraordinary process (Masten, 2001). This perspective accommodates a more positive outlook on human development, shifting the focus from a deficit model to a positivist perspective.

According to Masten and Coatsworth (1998) resilience refers to manifested competence when an adversity is encountered. They posited that competence implies a healthy adaptation, where the individual is able to perform optimally in future (Masten & Coatsworth, 1998). This result stems from the interaction between the individual and the environment. Masten’s research highlighted the connections between individual and contextual resources in the development of resilience - demonstrating the non-linear characteristics of resilience (Liebenberg et al., 2017). This non-linearity implies that competence can develop in a favourable or unfavourable environment, depending on the capabilities of an individual and the context in which they live (Masten, 2001).

According to Masten (2001), a threat is any occurrence that compromises the protective factors by negatively affecting developmental and adaptive processes, such as cognitive development, self-regulation, motivation for learning, and interacting with the environment.

Masten and Coatsworth (1998) identified the protective system and factors in the individual's life as a prerequisite for the development of competence. These protective factors exist on three levels, namely the individual, family and community levels. At an individual level, protective factors refer to intelligence, a sociable and positive disposition, self-efficacy, self-regulation of emotion, behaviour and attention, self-confidence, high self-esteem, talents, and faith. At the family level, protective factors include authoritative parenting, competent adults, close relationships with caring parental figures, warmth, structure, high expectations, and supportive relationships with extended family. At the extra-familial level, protective factors include supportive relationships with prosocial adults or organisations outside the family, as well as attending an effective school (Masten, 2001; Masten & Coatsworth, 1998).

Michael Ungar

One of the most influential accounts on the social ecological perspective of resilience, emanated from Michael Ungar. The development of resilience is not bound solely to the individual's set of characteristics (Shean, 2015). Ungar (2008) posited that the interaction between the individual, the environment and culture, influences the development of resilience when there is exposure to a significant adversity. Ungar (2011, p. 1) proposed that the emphasis should be on the role of "social and physical ecologies" when considering resilience, and that both the person and their environment influence resilience.

Ungar (2008) theorised that resilience is the ability to navigate and negotiate the social environment and health resources, using individual, family, community and cultural assets. Navigation relates to the ability of the individual to employ personal agency to seek help, as well as the accessibility and availability of the required assistance. Navigation can only take place if the resources are accessible and available (Ungar, 2008). Negotiation occurs when resources are culturally meaningful to the individual, that is, when the resources provided can positively contribute to the needs of the individual. According to Ungar (2012), resilience is both a process of the individual’s ability to navigate towards, and the individual’s potential to negotiate for, health resources. Shean (2015) posited that individual traits such as motivation, personal agency, disposition, personality variables, and genetic predispositions, are facilitated by the environment. The environmental resources - or lack thereof - will positively or negatively influence the choices an individual will make (Shean, 2015).

Ungar (2008) identified seven tensions of resilience in cultures, namely access to material resources; positive relationships with significant others; a positive sense of identity; power and control to access health resources; the experience of social justice; adherence to cultural beliefs, practices and values; and cohesion relating to balancing personal, social and spiritual interests. According to Ungar (2008), a resolution of tensions is necessary for the development of resilience.

In summation, across these different theorists’ conceptions of resilience, several commonalities exist. Firstly**,** two core ideas are evident in each of the theoretic definitions of resilience, namely that the individual experiences an adversity, and shows a positive adaptation. Resilience is regarded as a normal adaptation to the experience of a risk or adversity. Luthar (1993) added that resilience is less about the absence of psychopathy but is rather more concerned with the positive adaptation and development of an individual.

Secondly, they all concurred that resilience is not an innate attribute possessed by some individuals, but rather an outcome of the positive interaction between the individual and the environment in which the individual is embedded. Contrary to this stance, Luthar (1993) indicated that resilience can occur in both a favourable and unfavourable environment.

Thirdly, considering resilience is not only an ever-present personality trait, each of the theories posited that it is a dynamic and ongoing process. Resilience is not static, but rather develops over time, in the context of individual-environment interactions. This process is influenced by risk and protective factors. Furthermore, Rutter (2013), Ungar (2011) and Luthar

(1993) agreed that risk and protective factors are not bipolar, that is, they are not at opposite ends of the spectrum. For example, Rutter (2013) stated that a risk in one situation may constitute a protective factor in another. Contrary to this perspective, Masten (2001) regarded risk and protective factors as bipolar.

In the fourth instance, theorists agreed that cumulative risks are worse than individual risks. However, not all risks are detrimental, as argued by Rutter (2013), Luthar (1993) and Ungar (2011). Some risks may act as steeling events and, as such, the avoidance of risks may not always be the best response.

In the fifth place, the resilience conceptualisation process acknowledges the effects of protective factors. The theorists agreed that protective factors are conceptualised and interact on three levels, namely that of the individual, the family, and the society or community. These positive individual traits, family bonds, and social relationships, are pivotal to the development of resilience. However, Ungar (2011) adds another level of protective factor interaction, namely culture.

Sixth, Rutter (2006) advocated the importance of turning points. This implies that past risk experiences can have a positive effect on later adaptation, where negative experiences from the past are replaced with new constructive options. Similarly, Ungar (2011) suggested that a healthy adaptation takes place in a positive environment. Masten (2001) agreed by stating that competence implies a healthy adaptation, where the individual is able to perform optimally in future.

Lastly, Rutter (2006) and Ungar (2011) agreed that resilience is influenced by genetic factors. Both theorists asserted that biological functioning plays a pivotal role in the development of resilience. Luthar stated that low intelligence can negatively influence the development of resilience.

Rutter noted, however, that coping processes are more important than external risk or protective factors, whereas Luthar (1993) considered vulnerability and protective factors to contribute more significantly to the development of resilience. Garmezy (1991) focused on the capacity of the individual to recover under stressful conditions, as well as the factors that influence the development of resilience. In order to develop competence, Masten (2001) stressed the importance of protective factors as a prerequisite for the development of resilience. Masten, furthermore, highlighted the ordinariness of resilience development (Masten & Powell, 2003). Ungar, however, advocated that greater emphasis should be placed on the physical and social ecology of the individual (Ungar, 2011).

The Resilience Doughnut Model

Numerous models of resilience have been developed to conceptualise the interaction between risk and protective factors (Worsley, 2015). The resilience doughnut model, developed by Worsley in 2006, is an ecological model, founded on Bronfenbrenner's ecological systems theory (Basch, 2019; Miller et al., 2016). Ecological systems theory focuses on the quality of the individual's relationship with society (Paquette & Ryan, 2001). Basch (2019) noted that the resilience doughnut model is a solution-focused and strengths- based approach. In a solution-focused approach, individuals focus on their goals and then identify their strengths. A strength-based approach focuses on both the individual and their environment.

Implicit, concerning this model, are three interacting tenets. Firstly, resilience is a process of continual development; secondly, individuals negotiate and navigate available resources; and thirdly, these processes occur when adversities are present. Furthermore, the resilience doughnut model focuses on both the personal characteristics that enable a person to recover from adversity, and the interaction between the individual's internal characteristics and the available external resources. These external factors can positively or negatively influence the response of the individual, when faced with an adversity. The ability of the individual (internal strengths) and availability of supportive environmental factors (external resources) are central to the model. The model highlights the dynamic interaction and combination of external and internal factors, as well as multiple pathways towards developing and strengthening resilience. Research indicated that individuals exhibit improved coping skills in adverse situations, when they combine their internal assets with external resources (Basch, 2019; Worsley, 2015). The resilience doughnut model explicates how resilience is developed and how an individual may ultimately thrive in the face of an adversity (Basch, 2019).

Worsley (2015) defined internal assets and strengths as protective and promotive factors, vital to the individual. These internal assets include ability, internal resources, analytical competencies, independence, application, character disposition, and expectation alignment (Basch, 2019). Internal strengths play a pivotal role in the interpretation of adversity and how people make sense of adversity or derive meaning from dealing with adversity. The resilience doughnut emphasises that positive changes within an individual are the result of the individual's strengths or are drawn from supportive, positive and intentional relationships. Worsley (2010) agreed with Masten's (2001) theory that the development of resilience is an everyday, ordinary process, and part of normative human resources found in the cognition of individuals, in their families, and in their social relationships. Resilient individuals sort, prioritise and order their resources, as a strategy to activate recovery from the adversity and sustain the growth experienced, thus, rendering their approach solution-focused and strengths-based.

A prerequisite to building resilience is that the internal assets of the individual operate in tandem with external resources, thus, implying that the external resources must feed into the internal strengths of the individual (Miller et al., 2016). The resilience doughnut model consists of two connecting circles (Basch, 2019). Figure 1 illustrates how the interaction of the internal and external factors is highlighted by the inner circle situated within the outer circle.

Figure 1
The Resilience Doughnut

(Worsley, 2015, p. 76)

The internal structure (inner circle) of the resilience model represents the personal agency or internal characteristics of the individual. Concepts such as self-efficacy, self-esteem, and an awareness of resources available to them, form the core of the structure. Worsley (2015) theorised that the individual’s internal strengths or characteristics related to how they view themselves in the world, are divided into three categories, namely I have, I am, and I can. Rutter (2012) identified similar categories for promoting resilience, namely coping mechanisms (I have), mental sets (I can) and personal agency (I am). Ledesma (2014), likewise, identified the internal variables in resilience as self-factors (I can), personality factors (I am), or individual resources (I have).

“I have” relates to the cognisance of sustainable and supportive social resources available to the individual (Miller et al., 2016). Resilient individuals hold the ability to navigate and negotiate their external resources, when required to do so (Worsley, 2015). “I have” is an awareness of resources that can be utilised to promote resilience in the face of adversity, such as “I have a trusting relationship” and “I have others who help me to become independent” (Miller et al., 2016, p. 3; Worsley, 2010).

“I am” is defined as the secure sense of self and personal strengths held by the individual. It refers to the self-concept or self-esteem of the individual, such as “I am lovable” and “I am willing to take responsibility for my actions” (Miller et al., 2016, p. 3) that develops via interaction with parents, peers, family and the community. Resilient adults can adapt their behaviours when faced with different challenges, owing to their secure sense of self (Worsley, 2015).

“I can” refers to the interpersonal and social skills that render the individual self-efficient. It relates to the self-efficacy of the individual, such as “I can communicate”, “I can solve problems”, and “I can exercise self-control” (Miller et al., 2016, p. 3; Worsley, 2010). A resilient adult will utilise their skills related to problem solving, sense of purpose, social competence, and autonomy, to alter their circumstances (Miller et al., 2016). Worsley (2015) reported that when a common purpose unites the internal characteristics of an individual, it appears to have a positive outcome in respect of sustainability, recovery and personal growth.

The internal factors interact with the external contexts, to build resilience. Basch (2019) posited that individuals cannot successfully develop resilience by drawing purely from their internal factors - external resources play an integral role in the process. The external layer of the resilience doughnut is representative of the external factors or relationships that contribute to building the individual’s internal strengths (Worsley, 2015). Rutter (2012) and Ledesma (2014) agreed that the external variables involve relationships and the social support in an individual’s life.

Worsley (2015) identified seven external resources or protective factors that may enhance the building of resilience. These are the partner factor, the skill factor, the family factor, the education factor, the friend factor, the community factor, and the work and money management factor.

The partner factor concerns a positive relationship with a significant other/others based on love, affection and thoughtfulness. Decisions are made in consultation with the partner, to enhance a feeling of security as well as predictability. A strong partner factor supports optimal functioning (Worsley, 2015).

To acquire a strong skill factor, the individual must possess hardiness, optimistic thinking patterns, problem solving skills, feelings of success and successful achievements, recognition of skill, the willingness to try new experiences, and self-confidence (Worsley, 2010; Worsley, 2015). Being recognised for one’s skills creates a sense of contentment and a sense of achievement with regard to one’s skills.

Worsley (2015) described the family factor as strong relationships with immediate or extended family members. A strong family factor is related to the intense feeling of belonging to a group, that is of significant importance to the individual when identity formation develops. A sense of connectedness, closeness, family traditions, mutual respect, family identity, family expectations, shared spiritual values, and responsibility, positively contributes to the development of resilience (Walsh, 1996; Worsley, 2010). Worsley (2015) explained that strong families have often faced adversities together. Walsh (1996) theorised that resilience is strengthened when a family has community resources available to them. However, conflict within a family structure can exacerbate chronic stress within the individual (Hepburn et al., 2018).

The education factor denotes that the enjoyment of and participation in learning and understanding play a pivotal role when faced with a risk (Worsley, 2015). Resilient individuals are involved in a life-long, continual learning process, in order to empower themselves by doing research and reading persistently. The education factor instils a sense of belonging, engagement and acceptance within the individual. DuMont et al. (1996) posited that the level of education influences the capacity of an individual to acquire information and resources relating to the adversity.

The friend or friendships factor relates to a sense of belonging, common interest, improvement in social skills, and acceptance and understanding of differences (between friends or in close relationships) and plays a dominant role in the moral development of the individual. A strong friend factor requires a supportive group of friends, sharing a common interest. Friendships are strengthened if friends have experienced difficulties together, and hold a sense of belonging, cooperation, sharing, closeness, group identity, cohesion, support, conformity, loyalty, self-regulation and social awareness (Worsley, 2010).

The community factor relates to being part of, and having ties with, a community structure, such as a society, support group, church or sporting team. It serves as a positive basis to enhance a sense of belonging and a shared purpose (Worsley, 2010). Being part of a local community or support group, or sharing a common purpose, contributes positively to building resilience (Worsley, 2015).

The work and money management factor refers to the presence of a strong work ethic, work values and accountability, as well as economic stability with regard to basic needs and security (Worsley, 2015). An individual with a strong work factor harbours a positive sense of responsibility and accountability for their work and feels valued for the work they perform.

Effective management of finances enhances the work factor. Resilient individuals hold a sense of control over earning and spending money, an understanding of the value of money, and exhibit self-discipline and self-efficacy in relation to money.

Worsley (2015) noted that not all the external factors in the model need to be present or strong, to allow resilience to develop. Only three of the seven external factors, interacting and connecting with the internal factors, need to be robustly present for an individual to build resilience when encountering adversities (Basch, 2019; Miller et al. 2016; Worsley, 2014). According to Worsley (2015), past experiences shape personality traits, social skills, and behaviour when seeking help. This may serve as a buffer when future adversities are faced, as individuals are able to identify available resources and patterns of how to interact with these resources and, thus, harbour a well-developed sense of self.

Research showed that strong and healthy relationships with significant others, shared meaning, the interaction of strong internal and external resources, use of available resources, past experiences, patterns of interactions, and positive emotional experiences, aid in the development of resilience (Worsley, 2015).

The resilience doughnut model provides a comprehensive framework to explore how individuals, tasked with the care of family members living with dementia, activate resilience, employ coping skills and, ultimately, may thrive. It accounts for the external resources available to an individual, as well as how family members combine their internal assets and strengths with the external resources available to them. The model, thus, proposes change in the manner that individuals deal with adversity, given the presence or absence of various contextual factors (Worsley, 2010). The model accounts for multiple pathways towards developing resilience.

Conclusion

Dementia is an acquired, comprehensive impairment of a person's cognitive ability, that is sufficiently severe to interfere with their normal daily activities. It is one of the more serious age-related illnesses owing to its social, economic, physical and psychological impact on both the patient and the caregiver. Recent statistics indicated an upsurge in the diagnosis of dementia and researchers have forecast an even greater increase in the next 20 years, owing to the increase in expected lifespan. The WHO (2012) reported that a new dementia case is diagnosed every three seconds, globally. Statistics concerning the total number of dementia patients in South Africa, however, are difficult to establish, in view of the lack of such research.

The increase in the number of patients diagnosed with dementia, directly impacts the number of family members and health care facilities required to render aid to the patients. Considering that dementia is not classified as a primary healthcare need in South Africa, scarcity of dementia health care facilities is apparent. Family members are, therefore, often tasked with taking care of the dementia patient. Research indicated that the key challenges experienced by the family members are related to a lack of education, social support, and information concerning available resources to assist family members (Van der Poel & Pretorius, 2009). This results in family members experiencing higher levels of stress, depression and social isolation, compared to family members of patients with other disorders (Gurayah, 2015).

This chapter outlined the nature and prevalence of dementia, as well as the impact of dementia on the family members. There is a paucity of research as to how these family members cope with the challenges of managing the care needs of the dementia patient and how they may build resilience, or even thrive, in the midst of the adversity.

The conceptual and theoretical framework outlined in the chapter, revealed different theorists' conception of resilience, founded on the interaction of internal and external factors that an individual employs towards the development of resilience.

Understanding the lived experiences of individuals tasked with the care of a family member living with dementia, can potentially render insight into how they develop resilience in the process. The aim of the study is, therefore, to explore and understand how resilience is developed by individuals tasked with the care of a family member living with dementia, in the South African context.

In order to address the aims of this study, the resilience doughnut model serves as a theoretical framework to understand how family members develop resilience whilst tending to the requirements of a dementia patient and is therefore best suited to the study.

Chapter 3

Methodology

Research Problem

Numerous studies have indicated an increase in life expectancy in the general population (Cheng, 2017; De Jager et al., 2015; Greenwood et al., 2017; Gurayah, 2015; Iavarone et al., 2014; Prorok et al., 2013). Furthermore, statistics confirm that, in recent years, the number of people living with dementia has escalated significantly, resulting in scores of families tasked with the care of family members living with dementia. The care of a family member afflicted with dementia is demanding, negatively impacting the caregiver and resulting in a decline in psychological, emotional, and physical health, as well as financial concerns (Iavarone et al., 2014) and social isolation (Greenwood et al., 2017). Caregivers may be prevented from attending to family matters, experience frustration with themselves or the patient, become depressed or inadvertently lose their jobs (Rodrigo et al., 2013). The lack of any formal training or knowledge on how and where to access respite programs, furthermore, adversely affects the quality of life of the family member tasked with the care of a patient with dementia (Thomas, 2010).

The body of literature concerning the lived experiences of caregivers of patients with dementia, although informative, does not address the question of how caregivers develop resilience and manage caring for a patient with dementia. There is an urgent need to address this gap in the knowledge base both internationally and in South Africa, thus providing a rationale for exploring the lived experiences of family members living with patients with dementia. Providing support for patients with dementia is particularly traumatic, resulting in the increased incidence of psychological illness, physical ailments, social isolation, and hospitalisation (Brooks et al., 2015). It is therefore imperative to understand the challenges associated with dementia caregiving and how caregivers develop the resilience necessary for managing and dealing with the caregiving process.

Research Purpose

The purpose of this study was to explore the subjective experiences of family members tasked with the care of a dementia patient, in order to understand how they develop and employ resilience to manage the demands of caregiving. The specific objectives of this research include exploring the impact that caring for a family member with dementia has on the carers' physical, psychological, emotional, social, and economic well-being. This included exploring the challenges associated with caring for a family member with dementia and the coping strategies employed to manage these challenges. The research findings will emphasise how family members develop the resilience necessary to effectively deal with the challenges of dementia patient care. Furthermore, this study may potentially contribute to the body of knowledge regarding the challenges familial caregivers face when caring for a family member living with dementia. The study findings may be useful to policymakers and healthcare authorities in formulating strategies to educate and render assistance to home-based caregivers, in order to mitigate the demands of caregiving, and to develop and employ the coping skills necessary to develop resilience.

Research Questions

In order to address the research objective, the core research question posed by this study is related to the lived experiences of family members tasked with the care of dementia patients i.e., how do familial caregivers develop coping skills that foster the resilience required to successfully manage the challenges of caring for a dementia patient?

Research Design

A research design is a blueprint, logical or master plan detailing how the study will unfold. It provides particular information concerning the process and procedures of the research employed to address the phenomena under investigation (Creswell, 2009). The research design for this study served as a guide for the collection and analysis of the data as well as the interpretation of the findings and the write-up of the results.

The researcher employed a qualitative design towards the collection, analysis and interpretation of the data. The underlying philosophical assumptions of Interpretative Phenomenological Analysis (IPA) informed the analysis of the data and the write-up of the findings. IPA was deemed a suitable approach to explore the essence of participants' lived experiences related to the care of a patient with dementia, and the resilience required to manage with the caregiving process.

Qualitative Research

The study employed a qualitative research design to facilitate insight into and an understanding of how the participants make sense of their perceptions and create meaning (Biggerstaff, 2012; Merriam, 2009). A key strength of a qualitative research design pertains to the extent of the perspectives offered by the participants, emanating from the application of specific data collection methods that explore their subjective experiences (Creswell, 2009). This approach utilises interviews, observations, fieldwork, questionnaires, documents, and texts, to analyse and explore crucial attributes of the phenomenon (Merriam, 2009).

Creswell (2009) and Merriam (2009) posited that the foundations of qualitative research involve several key elements, namely that 1) the research is conducted in a natural setting (*in situ*); 2) the researcher is the primary instrument for data collection and analysis; 3) the process is emergent, flexible and inductive; and 4) it seeks to elicit rich, elaborate descriptions of the participant’s experience of and meaning related to the phenomenon, in order to render a holistic view of the phenomenon.

In this study, the researcher gathered data by conducting virtual, semi-structured interviews via the MS Teams online platform, observing Coronavirus Disease 2019 (COVID-19) protocols, guidelines, and regulations. The researcher, therefore, devoted a considerable amount of time during the virtual interaction to affording participants the opportunity to make sense of their experiences (Featherston, 2008; Merriam, 2009).

Another key element of qualitative research is that the researcher is the principal instrument in the collection and analysis of data. The purpose of this study was to understand the human experience in caring for a dementia patient. The researcher developed an empathic relationship with the participants that encouraged them to speak honestly and openly. Polkinghorne (2010) asserted that an individual’s inner psychological state cannot be directly observed and that the goal of a qualitative researcher is, thus, to uncover this submerged inner state. The qualitative researcher is, therefore, considered to be the ideal data collection instrument (Featherston, 2008).

The third key element of a qualitative approach is the flexible and emergent nature of such a design (Merriam, 2009). The study adopted the concept of flexibility by employing semi-structured interview questions that afforded participants the freedom to table and discuss various issues relating to the research focus, without necessarily restricting the conversation to the interview schedule. The participants responded freely, utilising their own conceptions to describe their experiences. In addition, the flexibility of the semi-structured interviews allowed the researcher to probe the participants’ initial responses for further clarification. Furthermore, Mack et al., (2005) advocated that the qualitative approach allows for greater freedom (flexibility) and adaptation (emergent design) during the interaction between the participant and researcher. Featherston (2008), moreover, claimed that the design of the study may change as the researcher commences collecting data, in response to changing conditions (emergent design).

Participants conveyed their real-life experiences in as much detail as they preferred, with no time restrictions to the interviews. In addition, verbal and non-verbal communication by the participants rendered deeper insights into their experiences of the phenomenon under study, providing an elaborate description of their experiences - the fourth key element of qualitative research identified by Merriam (2009).

The study focused on meaning and understanding attributed to the phenomenon, yet another characteristic of a qualitative approach. The significance of the meaning that participants attributed to their experiences, was of interest to the researcher. The aim was therefore to achieve an understanding of how participants interpret and construct meaning in and through their experiences (Merriam, 2009). Humans are “conversational creatures” and language is employed to explain their experiences, which is the purpose of this approach (Brinkmann, 2013, p. 2). Ultimately, this study aimed to elicit and extract information regarding the family members’ experiences in employing coping strategies to promote resilience (Maree, 2007). The analysis aimed to establish meaningful themes and examine the relationships amongst the themes emanating from the text. The inductive nature of this process implies that the researcher utilises the findings from the data to construct patterns, identify categories, and derive themes concerning the phenomenon under investigation (Creswell, 2009). This process entails revisiting themes in order to create a comprehensive set of themes.

Creswell (2013) emphasised five qualitative approaches, namely, narrative enquiry, grounded theory, ethnography, case studies, and phenomenological research (Creswell, 2013). This study employed phenomenological research, as it was best suited to the type of exploration desired. Phenomenology focuses on the study of the perception of an individual within the world (Creswell, 2013). Hermeneutics is a methodology of phenomenological interpretation.

The study was orientated towards the lived experiences of individuals (phenomenology) and the interpretation of these experience (hermeneutics).

Phenomenological Approach

The study applied a phenomenological approach, allowing for a comprehensive, interpretive and naturalistic investigation relating to the understanding of the phenomenon. This approach enabled the researcher to render a pure, accurate, and truthful account (Polkinghorne, 2010) of the lived experiences of family members living with and tasked with the care of a dementia patient, specifically concerning the coping strategies employed whilst developing resilience to the contextual challenges, in the process. Polkinghorne (2010) defined the study of phenomena as phenomenology. Phenomenology is a detailed examination of the lived experiences of individuals, and how they assign meaning to phenomena and make sense of their experiences (Smith, 2018).

Edmund Husserl (1859–1938), recognised as the founder of phenomenological research, essentially developed the approach to improve upon the study of the lived experiences or '*erlebnis'* of individuals. The phenomenological approach, employed by this study, enabled the researcher to focus on the world or reality as uniquely experienced and interpreted by the participants - a world that is not separated from the person (Eatough & Smith, 2010; Laverty, 2003). The strategy of enquiry intended to discover accurate meanings of the lived experiences of family members involved with the care of a dementia patient, by probing deeper into the participants' reality, thus exploring the individual's lifeworld or '*lebenswelt'* (Laverty, 2003; Smith, 2018). Phenomenology "thematizes [*sic*] consciousness and its functions" (Giorgi et al., 2017, p. 177) and addresses the '*noema'* of a person, i.e., what is perceived, thought, remembered, imagined, and felt by the individual regarding an object or event (Moustakas, 2010). To fully understand the '*noema'* of a person, the focus of phenomenology is on intentionality, eidetic reduction and constitution of meaning (Adams & Van Manen, 2008).

Intentionality, the central focus of this approach, is a function of the person who perceives the phenomena via their consciousness (Laverty, 2003). Intentionality assumes that consciousness, that is non-sensorial, is a medium via which we become consciously aware of the phenomenon (Giorgi, 2014). The concept of intentionality, furthermore, signifies that conscious activities are directed toward an object and it refers to how meaning is attached to an object (Sages, 2014). It is the process that knowingly and intentionally transpires in relation to the focal object, reality, or event (Creswell, 2009; Laverty, 2003). Intentionality is, thus, “the experience of perception, thought, memory, imagination, and emotion” of an individual concerning a phenomenon (Reiners, 2012, p. 1).

In phenomenological research, the researcher must employ eidetic reduction to fully explore and understand the reality of the participant. Adams and Van Manen (2008) declared that eidetic reduction is a technical term employed to describe the phenomenological mechanism of bracketing, applied by the researcher. Bracketing is a strategy that allows the researcher to revoke all biases, preconceived ideas, prejudice, and subjectivity, in order to explore the lifeworld of participants. Bracketing aims to fully explore and understand the experiences as perceived by the participants, that is, to see the phenomenon as it exists, to “make the invisible visible”, and to allow the phenomenon to speak for itself (Laverty, 2003, p. 28). This is referred to as ‘*epoché’*, a Greek term, meaning to refrain or stay away from judgement and prejudice (Groenewald, 2004, p. 47). This eidetic method involves exploring the experience and interpretation of a phenomenon from the participant’s perspective (Pietkiewicz & Smith, 2014). Ortlipp (2008) explained that the researcher employs a reflexive journal to facilitate self-reflexivity and bracketing, as a strategy for examining their assumptions, beliefs, and subjectivity.

Eidetic reduction was accomplished by bracketing all biases related to the phenomenon of interest, employing a reflexive journal during the various phases of the study. The researcher chronicled all biases and preconceived ideas in the reflexive journal. The preconceptions held by the researcher prior to the inception of the study included the assumption that the care of a family member with dementia is experienced as stressful, exhausting and frustrating, and that the familial caregivers’ situation is akin to imprisonment as they are prevented from social participation in any activities other than those involving the patient. Eidetic reduction enabled the researcher to understand the constitution of the meaning attributed to the phenomenon by the participants.

As recommended by Van Rensburg et al. (2013), the multiple realities of the participants’ experiences were considered, and a commitment to the understanding of the phenomenon from the participants’ viewpoint was the focal point of the study. The researcher sought to recreate the meanings participants ascribed to their experiences - fully comprehending what the participants experienced by remaining committed to each case. Furthermore, the multiple realities of the participants’ life worlds informed the meanings attributed to the caregiving activities, coping, and the development of resilience. Vosloo (2014) reported that individuals consciously direct constitution of meaning and their understanding of the social world towards an object. The mind constructs meaning by interpreting experiences and events - reality is, therefore, the interpreted connotations people attribute to their experiences that can only be uncovered by understanding the individual’s reality (Vosloo, 2014). In phenomenological research, each experience is regarded as unique (idiographic) owing to the complexity of human nature.

Hermeneutics

The object of the study was to discover and interpret the latent or hidden meanings in the descriptions of the participants’ experiences (Adams & Van Manen, 2008). Pringle et al., (2011) affirmed that phenomenology uncovers meanings attributed to a phenomenon whilst hermeneutics interprets the meaning. The central tenet of the study related to the personal experiences of the lifeworld of the participants (Laverty, 2003; Pringle et al., 2011). The researcher applied the perspective that each participant experienced living with and caring for a dementia patient uniquely, as was also the case with the development of resilience. The participants' experiences informed the interpretation of the phenomenon, as the researcher attempted to gain an insider's perspective. The researcher employed the data corpus obtained from the participants to understand, interpret and give meaning to their experiences and the development of resilience in caring for a dementia patient.

Martin Heidegger and Hans-Georg Gadamer expanded on Husserl's phenomenological approach. Whereas Husserl focused on perception, awareness and consciousness, Heidegger primarily focused on the ontological question of 'being' - the individual's existence itself (Laverty, 2003). Heidegger's work is referred to as interpretative phenomenology. The central question posed by Heidegger related to "how the being of beings shows itself as a revealing of being [*sic*] itself" (Adams & Van Manen, 2008, p. 2). The essential principle of hermeneutics concerns our contextual relation to the phenomena. Heidegger perceived the individual as submerged in the world and concluded that the world consists of contextual relationships, social structures, and objects. He termed being-in-the-world as '*dasein'* (Groenewald, 2004; Laverty, 2003). Heidegger posited that human understanding is founded on descriptions that are essentially the researcher's interpretation of the phenomenon.

The participants relayed their experiences via the medium of language during the interviews. The researcher and the object of study were, thus, merged through language. Hermeneutics is founded upon the premise that people experience their world by employing language (Eatough & Smith, 2010). Gadamer agreed with Heidegger's perspective that language and understanding cannot be separated from the individual's being-in-the-world (Laverty, 2003). His philosophy is termed hermeneutic phenomenology. Groenewald (2004) and Laverty (2003) explicated that hermeneutic phenomenology stipulates that language is the medium employed by the researcher to examine how people understand, interpret and attribute meaning to their experience in the world.

The ultimate purpose of hermeneutics is to clarify the phenomenon in its entirety, regardless of the individual experiences (Shinebourne, 2011). All the sections of meaning must be seen as part of a whole and the researcher must, therefore, rotate between considering the interdependent meanings constructed by the participants and the concept as a whole. This circular relationship aids in the understanding of the participants in their contexts.

Interpretative Phenomenological Analysis (IPA)

The premise of IPA is how the entire experience of the phenomenon is important and meaningful in the context of the individual's life (Eatough & Smith, 2010). This study was positioned in the interpretative phenomenological paradigm, deemed best suited to the investigation. The research explored, in detail, the perceptions of the participants, in order to understand how they make sense of their personal and social worlds (Smith & Osborn, 2008). The objective of IPA is to assist truthful understanding of the participants' experiences and to "uncover" the essence of the phenomena, and how participants make meaning of their life experiences (Merriam, 2009, p. 5). The notion that humans are interpretive beings is fundamental to this approach.

Creswell (2009) defined a paradigm as a set of beliefs from which a worldview is derived. The term 'paradigm' in research refers to the representation of a conceptual framework utilised to conduct data analysis. It is a lens through which we view the world (ontology) and defines the research relationship between the knower and what can be known (epistemology). It furthermore employs certain strategies of enquiry and analysis (methodology). The ontological perspective of interpretivist phenomenology is that of multiple realities. The researcher explored these realities by conducting interviews to discover how participants interpret and make sense of their lifeworld in their natural setting. The manner in which participants constructed their experiences of living with a dementia patient and how they displayed resilience, informed the study’s findings. Ontology, as defined by Creswell (2009), is the study of the theory of knowledge. The ontological assumption of IPA is that reality resides in the meaning we attach to it, via our experiences and language. It focuses on how people mentally construct events, ideas or objects, in the external world, and assumes that the world is already in existence and that the individual experiences it uniquely. The lifeworld is the concrete and immediate experience of an individual in the here and now (Laverty, 2003).

In IPA, the epistemological standpoint is that data is contained within the idiosyncratic perspective of an individual (Reid et al., 2005). Epistemology refers to the stance or orientation of the researcher with regard to the question of the inquiry and what can be known (ontology). Epistemology relates to how phenomena can be discovered, disclosed and known, and which assumption can be made about that which can be known. The researcher can only know what can be known by immersing themselves in the world of the participants. This implies that the phenomena of interest in this study were interpreted and understood via conscious mental processes in interaction with the social context. This allowed the researcher to gain a comprehensive and holistic understanding (a phenomenon in totality) of the core meaning that participants attributed to their experiences.

The themes and patterns in the data were derived from the knowledge that emerged from the participants’ context. Emergent themes were uncovered cyclically and assisted the researcher’s comprehension of the participants’ experiences. The researcher continually reviewed and analysed portions of the text, as well as the text as a whole, during the interpretive process (Laverty, 2003; Reiners, 2012). Pietkiewicz and Smith (2014) claimed that IPA promotes an inductive approach to data analysis. Smith and Osborn (2008) asserted that IPA employs double hermeneutics during the analytic process. Double hermeneutics, also referred to as a dual interpretation process, is applied when the researcher “attempts to interpret how participants make sense of their experience" (Pringle et al., 2011, p. 20). The participants first have to make sense and meaning of their experiences, followed by the researcher's decoding of that meaning to make sense of the participant's meaning-making process. The researcher, therefore, has to understand the phenomenon from the participant's perspective to interpret the essence of their experience. This approach's theoretical orientation depends on idiography, meaning that the researcher focuses on the particular rather than the universal (Smith, 2018).

Population and Sampling

The study employed purposive sampling - a non-probability sampling technique. As posited by Groenewald (2004) and Merriam (2009), purposive sampling techniques are employed to ensure that the research participants will be able to provide information relevant to the research phenomenon under investigation. Merriam (2009) stipulated that the population parameters need to specify the units of analyses, the unique characteristics of interest of the population to be studied, the geographical area where the sample can be accessed, as well as timeline considerations.

The population sample was drawn from eight home-based familial caregivers of dementia patients, residing in the greater Johannesburg area of the Gauteng province, in South Africa. The success of the study depends on the employment of an appropriate sampling technique. Purposive or purposeful sampling is a technique where the researcher intentionally selects a sample of participants with the desired characteristics, to ensure that the study gathers appropriate, detailed information (Merriam, 2009).

The unit of analysis was family members who are caregivers, currently living with and caring for - or who have lived with and cared for a family member afflicted with dementia. This sample was ideally suited to the study, considering their lived experiences with a dementia patient. The participants were sourced from Dementia South Africa.

Pietkiewicz and Smith (2014) posited that the purpose of an IPA study is precisely to provide an in-depth account of each case. They elaborated that a large sample size will be inappropriate for IPA, as the objective is to obtain a full understanding of the experiences communicated by the participants. As recommended by Van Rensburg et al. (2013), additional factors considered upon selection of an appropriate sampling technique were the size of the population, the type and nature of the research, the method of data analysis, and the method of data collection.

The primary criterion for purposive sampling is eligibility (Merriam, 2009). Participants were selected according to their exposure status. To ensure sample homogeneity, participants were considered eligible for inclusion in the research if they met the following criteria:

- Family members presently residing, or having resided in the past, in the same residence as the dementia patient.
- Family members presently regularly involved, or having been regularly involved in the past, with the day-to-day care of the dementia patient (for example, bathing, dressing, feeding and toileting).
- Such family members had to be at least 18 years of age.

The study excluded those potential participants failing to meet the inclusion criteria, and/or whose English language skills were inadequate to enable meaningful participation in interviews.

Data Collection

Data Collection and Research Instrument

This study employed virtual one-on-one interviews as the data gathering technique and instrument (Eatough & Smith, 2010). As advocated by Merriam (2009), the researcher posed semi-structured questions to participants, informed by the objective of the study. This data collection method brought to the fore an understanding of experiences of family members living with a dementia patient and how resilience was fostered.

According to Eatough and Smith (2010) and Featherston (2008), the role of the researcher in a qualitative interview is to conduct the interview, observe, and document field notes. Furthermore, the researcher's role during interviews entails attentive, empathic, and active listening, posing of questions and prompts, dealing with silences, noting voice intonations, and taking note of the non-verbal communication, whilst being self-reflexive. In this study, the researcher generated a warm, positive and caring relationship with the participant, as such was imperative to the exploration (Laverty, 2003). The role of the researcher, as a concerned listener, enabled exploration of the phenomenon. A good researcher is neutral, reflexive, and critically aware (Biggerstaff, 2012). Furthermore, Eatough and Smith (2010) identified the qualities of a good researcher as those of being open, sensitive, empathic, and an active listener. The researcher is an integral part of the process and becomes a "coproducer" of the data (Biggerstaff, 2012, p. 179). The researcher, therefore, focused on establishing a warm, empathic relationship with the participant at the inception of the interview, maintained throughout to ensure a successful interviewing process. Laverty (2003) posited that the relationship between the researcher and the participants should be grounded in safety and mutual trust. The researcher acted as non-directive as possible during the interviews.

The researcher consciously set aside all presuppositions prior to commencing with the interviews, and adhered to all ethical principles (Laverty, 2003). The researcher applied a phenomenological reduction or '*epoché'*, as a strategy to enhance the validity of the study and ensure that the study aptly reflected participants' experiences. The researcher was mindful and aware of their thoughts, emotions, beliefs and expectations, whilst conducting the interviews as well as during the process of data analysis, as advised by Fusch and Ness (2015). This strategy was employed by utilising a reflective diary. The use of field notes as a data collection method entails transcription of all occurrences during the interview. The researcher documented details of their opinions concerning the care of a patient with dementia, as well as their thoughts on the development of resilience during the process. The researcher, furthermore, applied phenomenological reduction and bracketing, in order to remain true to the realities and descriptions of the participants' experiences. Bevan (2014, p. 139) stated that "critical self-questioning is a reflective process that remains self-conscious". Eatough and Smith (2010) reiterated that a researcher must be aware of their knowledge, deliberate naiveté and bias. The researcher employed the aforementioned in order to remain faithful to the participants' descriptions.

Face-to-face interviews were videotaped via the MS Teams Online platform. At the time of the interviews, South Africa was under lockdown due to the Covid 19 pandemic. Data collections procedures had to be amended to comply with the restrictions and it was thus decided to conduct the interviews via the MS Teams electronic platform. The duration of the interviews ranged from 45 minutes to 1 hour 30 minutes, depending on the particular participant. The open-ended nature of the questions allowed for follow-up questions, in order to ensure that the interview process explored participants' experiences as closely as possible (Merriam, 2009). The interview schedule and questions were initially developed based on the theoretical inquiry into the development of resilience outlined in the literature review (Chapter 2) that aimed to elicit information about participants' experiences of caring for a family member living with dementia. In specific, the questions focused on the elements of resilience as identified in Worsley's donut model. Although this served as the guiding framework for the development of the interview schedule, the semi-structured nature of the interview allowed participants to voice their own ideas and opinions and to introduce any additional information and experiences related to how they developed resilience in the process of caregiving. This iterative process meant that the interview schedule served as an agenda to guide the interviews whilst at the same time allowing the interview to probe any additional information offered by participants using prompts to interrogate new information not included in the original schedule. As advised by Laverty (2003), the researcher documented non-verbal cues, such as silence and uncertainty, as field notes in the reflexive journal, throughout the interview. The questions and prompts underpinned the information required by the theoretical orientation of the study. As such, the interviews were focused conversations (Merriam, 2009). Specifically, the questions garnered information from participants concerning their partner, skills, family, education, friends, community, and financial factors. Participants expressed their perceptions, thoughts, emotions, desires, images, sensations, and memories – i.e., their stream of consciousness (Waters, 2017). To eliminate misinterpretation during the interview, the researcher immediately clarified information, in order to interpret it in a manner that is true, appropriate and factual - an advantage of face-to-face interviews (Merriam, 2009).

The researcher noted incidences and similarities following data redundancy, when a clear understanding of the participant’s experience had been obtained. An adequate degree of data saturation and understanding of the participant’s perspectives were achieved following completion of eight interviews, thus, no additional interviews were conducted (Saunders et al., 2018).

A vital requirement of successful research is that interviews must proceed until saturation is attained. Saturation is defined as a criterion for discontinuing data collection. Saunders et al. (2018) postulated that data saturation is obtained when the same data is repeated and no new analytical information is arising. This indicates that the data elicited is levelling off, with no new perspectives or explanations concerning the research questions emerging from the data. The study reached saturation or redundancy when it became evident that additional interviews would not add new information. Additional data would only serve to confirm a developing understanding of the phenomenon.

Data Management

All interviews were video recorded. The researcher documented field notes as “back-up insurance”, in the event of unforeseen challenges such as a failure to record owing to faulty instruments (Biggerstaff, 2012, p. 196). The researcher assigned a pseudonym to each participant, in order to ensure their anonymity and the confidentiality of the study. The copies of the signed informed-consent forms, field notes, data analysis notes, the reflexive diary, transcriptions and any additional information, were properly filed. This file is preserved in a password-protected folder and will be available for perusal for two years following publication of the research paper, as per the Health Professions Council of South Africa's [HPCSA] requirements (HPCSA, 2016). The recordings of interviews and other electronic copies of the study are stored in a password-protected account.

Procedure

The Alzheimer’s society for South Africa, i.e., Alzheimer's SA, was the first point of contact for the recruitment of the sample. The researcher informed the organisation about the nature and purposes of the study. A request was made that the organisation identify and inform potential participants of the study (refer to Annexure A). The study's sample criteria were explained to the social worker, who proceeded to recruit potential volunteers.

Prospective participants who consented to participation in the interview were contacted telephonically and provided with an explanation of the study's rationale and process. An information session, presented to the interested family members, outlined the nature, aims, risks, benefits and voluntary nature of the research. Participants were advised that they were at liberty to pose questions concerning the research.

Data Analysis

Within the framework of the qualitative design, the data analysis process occurred in accordance with the methodology associated with an interpretative data analysis. Data analysis and data collection occurred concurrently (Vosloo, 2014). In order to render a holistic account of the lived experiences of familial caregivers involved with the care of a dementia patient, the data analysis focused on an analysis of the subjective experiences of the participants and the meanings they attributed to their experiences. The interpretative data analysis strategy informed the techniques employed to facilitate the analysis of data.

The central characteristic of interpretative data analysis is to utilise a nascent or emerging strategy (Waters, 2017). The study employed an emergent strategy, where the researcher allowed the data and themes to emerge from an understanding of the essence of the experiences conveyed by participants. The researcher employed inductive analysis, by attempting to make sense of the data, allowing for the emergence of themes and categories (Suter, 2012). The advantage of inductive analysis is that it offers a comprehensive and in-depth knowledge of the phenomenon, that is compatible with the objectives of a qualitative approach (Waters, 2017). The disadvantage, however, is that it is time consuming.

The principles of interpretative data analysis imply that a phenomenon is context-bound, as the phenomenon can only be understood within its own context (Groenewald, 2004). The researcher interchanged between analysis of the information and the social context, in an attempt to reconcile the data and as a strategy to employ dual interpretation. As posited by Merriam (2009), dual interpretation or a double hermeneutic process occur during the analytical process of IPA. The IPA approach dictates two stages in the interpretation process. Vosloo (2014) clarified that the first hermeneutic (stage) refers to the meaning created by participants in their accounts. The second hermeneutic (stage) involved the researcher's interpretation of the participants' explanations of their accounts, resulting in the researcher uncovering the meaning of participants' accounts. The study applied these stages throughout the process of analysis. As encouraged by Creswell (2009), the researcher sought to provide an accurate account of the information and its interpretation.

The data analysis process was continuous and iterative, as the researcher continuously gathered data and reflected on the data obtained (Laverty, 2003; Maree, 2007). The iterative technique applied to the analysis of the data was employed as a guide to and basis of subsequent interviews (Van den Hoonaard & Van den Hoonaard, 2008) thus directing the subsequent collection and analysis of data, whilst utilising an idiographic approach (Achari, 2014; Smith & Osborn, 2008). Each stage built on the preceding stage of the analytic process, in the manner discussed by Suter (2012). Vosloo (2014) explained that with reference to IPA, an iterative process requires interchanging focus between emic and etic perspectives. An emic or insider's perspective refers to understanding the phenomenon from the participant's point of view, whilst an etic perspective is defined as the researcher's or outsider's point of view (Merriam, 2009, p. 14). The cyclical nature of IPA required the researcher to continuously transfer focus between the emic and etic perspectives, in order to fully comprehend what had been communicated and to interpret it accordingly. The researcher explored the emic perspective of participants by considering the thoughts, wishes and emotions of the participant (Eatough & Smith, 2010).

The researcher recorded all their thoughts and feelings (throughout the process) in the reflexive diary, as a technique to enforce bracketing (Van den Hoonaard & Van den Hoonaard, 2008). Speculation concerning developments, questions raised by the data, and theoretical links, were also transcribed in the diary. An audit trail was employed to document the process and to trace the researcher's 'thinking trai'l (Suter, 2012). An analysis of how the researcher made sense of the data was also performed. The researcher had to be fully aware of their biases prior to attempting to make sense of and attribute themes to the data. Biases concerning the phenomena were curbed by the employment of bracketing, reflexivity and reduction. Bracketing occurred via a process of reflection, where the researcher's personal experiences and thoughts relating to dementia were scrutinised in respect of any assumptions, presuppositions, prejudice, or biases the researcher might hold, regarding dementia and the experiences of family members involved with the care of a dementia patient. As claimed by Merriam (2009), to ensure the validity of the findings, the researcher first was required to recognise their positionality or stance regarding the phenomenon of family members looking after a dementia patient. Laverty (2003) emphasised that the researcher's insights play a pivotal role in the understanding, analysis and synthesis of the data corpus.

Data were analysed until saturation was reached (Fusch & Ness, 2015). To gauge data saturation, the study employed an iterative approach throughout the process of data analysis. The study employed data, inductive and thematic saturation. Saunders et al. (2018) defined data saturation as the identification of redundancy with reference to the data. Data saturation occurs at the point where the data reveals no new information, owing to recurring codes and patterns. Ando, Cousins, and Young, (2014) and Saunders et al. (2018) defined theoretical saturation as a stage where no additional themes relating to the study were found, and the researcher could render no further analyses of the study phenomenon. Similarly, inductive thematic saturation focused on the identification of new codes or themes and was not bound to the level of analysis (Saunders et al., 2018).

The first step in the process was to transcribe the data verbatim from the video recordings (Vosloo, 2014) using the MS Teams online platform. The next step was to implement Braun and Clarke's six-phase guide. This guide served as a practical framework for conducting thematic analysis (Maguire & Delahunt, 2017, p. 3354). The phases were applied as follows:

Phase 1

The first phase of Braun and Clarke's data analysis framework requires the researcher to become familiar with the data corpus. The researcher executed the cyclical process of repeatedly listening to the first interview, whilst referring to the field notes. The study applied this strategy to obtain an overall, comprehensive sense of the participant's account and then to reflect on the meaning attributed to the experience by the participant (Creswell, 2009; Maguire & Delahunt, 2017). Pietkiewicz and Smith (2014) recommended that researchers immerse themselves in the data by endeavouring to step into the participants' shoes, as far as possible.

After reading the transcription several times, the researcher noted their comments in respect of similarities, differences, reverberations, emphases and inconsistencies, of each participant's narrative, in the right-hand margin of the transcription. The researcher utilised the left-hand margin to write a comprehensive line-by-line description of each participant's experience, in order to fully understand that which has been conveyed (Larkin et al., 2006). Horizontalization was also implemented, where the data were deemed to be of "equal weight" (Merriam, 2009, p. 26). These strategies ensured that valuable information was not lost in the process. The researcher was fully immersed in the information collected, prior to commencement of the coding process. The process continued in respect of the entire first transcription. Upon becoming familiar with the content, the researcher embarked on the next phase of the process, namely, identifying overt patterns via coding.

Phase 2

Codes were generated during the second phase of the process. The cyclical coding process commenced by attaching labels to the transcribed text, in order to formulate groups based on similarities. Saldaña (2013) proposed that the researcher start with coding as soon as the collected data is available, that is, whilst writing field notes and transcribing recorded data. Saldaña (2013), moreover, differentiated between manifest coding, where the content is clear, and latent coding, where the content is hidden. In phase 2 of the process, the researcher assigned labels to the initial codes. The notes recorded in the reflexive diary served as a reference and also to identify emerging codes from the initial impressions. The researcher was mindful of both manifest and latent codes. The objective of this was to ensure that the information gleaned was completely understood and absorbed. The textual content informed the analysis. Codes were identified and captured. The researcher “systematically combed” through the textual content to render the large amount of content more “manageable and analyzable [*sic*]” (Roller & Lavrakas, 2015, p. 236). Recurrent words, phrases and comments were emphasised. The coding scheme employed was named or labelled and allocated a descriptive definition, with verbatim examples of each. Subsequently, the data and concepts were systemically arranged, in a codebook. Benaquisto (2008) defined a codebook as a written document comprised of concepts. The information contained in the book consisted of the name of the code and a detailed description thereof, as well as the criteria for including and excluding text under a particular code. A codebook was employed throughout the data analysis process.

Phase 3

The next phase in the framework involved the searching for themes. Saldaña (2013) described a theme as an abstract entity, an outcome, trend, concept or pattern of coding. The researcher searched for patterns in the data and generated codes by applying various coding strategies to develop an all-inclusive, expansive set of themes that emerged across the interviews. All connections and patterns were highlighted during phase 3, in order to identify significant, over-arching- and central themes. The researcher noted down emerging themes in another margin. The identification of themes continued up to the non-emergence of new codes or themes, that is, until inductive saturation was evident (Saunders et al., 2018).

A table of analysis was generated to orient the analysis of the subsequent texts. The literal content, similarity, difference, frequency and correspondence, informed the characteristics of the identified pattern or theme (Giorgi et al., 2017; Saldaña, 2013). The final process, of constructing “superordinate” themes, was implemented upon completion of the analysis of each participant’s text (Smith & Osborn, 2008, p. 70).

Phase 4

The fourth phase in the analytic process involved reviewing and evaluating the relevance of each identified theme. The generated themes were verified against the codes, to ensure that the identification of themes was linked to the codes. Connections and interrelations across all categories of themes were derived and noted. The themes were listed according to the categories related to the theoretical framework of the study, and interpretations and implications were drawn and verified from the data (Roller & Lavrakas, 2015). Data relating to each theme was colour-coded as advised by Maguire and Delahunt (2017). Quotations exemplifying each theme were also captured and explained. The process of reviewing themes facilitated an understanding of the themes and the way in which they could be tied to each other.

Phase 5

Phase 5 entails defining the themes. The themes emerging from the categories were transformed into the qualitative narrative as a method of reconstructing the "inner world" of participants (Groenewald, 2004, p. 51). The researcher transformed participants' everyday expressions into psychological meanings, to emphasise the lived experiences of the participants. This was employed to derive and express the psychological structures of the experiences in developing resilience. These structures were informed by the interconnecting and interrelated, interpreted themes and descriptions. The notes were transformed into succinct psychological phrases to capture the vital qualities of the text and create links with theoretical connections. This transformation process continued throughout the entire transcript.

Phase 6

Phase 6 concluded the process, with the writing-up of the research. The researcher maintained rigour by staying true to the text derived from the interviews, field notes and reflexive diary. During this stage, the researcher captured the essence of the data. The focus of this stage related to the question of what had been learnt. Van den Hoonaard and Van den Hoonaard (2008) advocated that engaging in the writing up of data as soon as possible, may produce a more profound analysis.

Ethical Considerations

The UNISA College of Human Sciences Research Ethics Review Committee granted ethical clearance to conduct the research (refer to Annexure B). Ethical considerations and COVID-19 protocol, guidelines and restrictions, were strictly observed and adhered to. Creswell (2009) declared that the rights, needs, values, and desires of participants must be respected.

Merriam (2009) proposed that an ethical researcher must observe and consider the principles of explaining the purpose and method of the study; promises and reciprocity; risk assessment; confidentiality; informed consent; data access and ownership; researcher mental health; advice; data collection boundaries; and ethical conduct versus legal conduct. To illustrate that the research was executed ethically, a discussion of the adherence to these principles follows.

The researcher clarified the purpose, method, data collection strategies and boundaries of the study during the initial contact session with all participants. Polkinghorne (2010) stated that the research must not be intrusive or threaten the belief system of the participants and, therefore, the researcher was careful to avoid psychological harm to participants by allowing them to refuse to answer questions that may cause distress. The principles of harm, risk, promises and reciprocity were considered since this was, potentially, a high-risk population. The researcher managed the risk of emotional distress via the referral to appropriate counselling services provided by Alzheimer’s SA. None of the participants were harmed as a result of the study. Furthermore, the principle of beneficence was upheld by arranging a feedback session with participants who wished to be informed of the results of the study. A copy of the dissertation was made available to participants if they so wished, and a copy was also provided to Dementia SA.

In keeping with the requirements of an ethical study, each participant's integrity, privacy, confidentiality, anonymity, and rights, were upheld (Republic of South Africa [RSA], 2013). Privacy concerns the participants, whilst confidentiality refers to the data (Merriam, 2009). The study ensured the privacy of participants by applying the research method of interacting with the participant on an individual, face-to-face basis. This method allowed the participant to speak freely, without the fear of judgement by others. Another ethical consideration was the confidentiality of information, in order to protect the interests of the research participants.

A research agreement was provided by the researcher, to not divulge or publicise any data where participants may be identified. The participants' responses were not publicly linked to them, as personal identifying characteristics were removed. The ethical issues observed were explained to the participants prior to obtaining their agreement to participate in the study. The researcher assigned pseudonyms to each participant in compliance with the Protection of Personal Information Act (POPIA) 4 of 2013 (RSA, 2013), to ensure anonymity. These pseudonyms were utilised in the coding process to analyse the data.

The researcher emailed and explained the consent forms to the participants, prior to the interviews (refer to Annexure C). The content of the consent form was elucidated. Participants were well informed about the nature of the research, and they indicated their awareness that participation was voluntary and not binding. The researcher obtained written, informed consent via email prior to commencement of the interviews. No person was coerced or induced to participate in the research and the decision to participate was autonomous. The researcher requested permission to record the interview prior to conducting the interviews. Furthermore, the participants were alerted as to when the actual recording commenced. Participants were requested not to divulge any personal information or mention any names that could lead to possible identification.

The principles of data collection and boundaries were clearly stated. Participants were informed about the process and assured that they had the right to withdraw from the research at any given time, without any consequences. Participants were also informed with regard to the potential contribution of the research and that they would not be exploited in any way. The sole purpose of the study was to obtain research information and the study adhered to the principle of non-maleficence. The collected and analysed data obtained from participants' narratives were anonymously reported. This strategy was applied as a means of safeguarding the anonymity of participants, in order to eliminate possible identification of the participants. Reporting was executed utilising the pseudonym allocated to each participant.

The study upheld the principles of data access, ownership and ethical conduct. Participants were informed that the UNISA Policy on Research Ethics was available on request and were afforded access to the research findings, if so requested.

Validity and Reliability

Brink (1993) identified various strategies to increase validity in research. The researcher adhered to the following strategies in order to increase the validity of the study, namely, ensuring participants were well informed concerning the nature of the study; building a relationship of mutual trust; interviewing participants more than once, when deemed necessary; and comparing the data to the field notes. In addition, accurate and detailed field notes were recorded. Bevan (2014), Merriam (2009) and Yüksel and Yildirim (2015), moreover, identified the clarification of the researcher's bias and bracketing as strategies to enhance the internal validity of a study.

The results of the study must correlate with the data, to ensure reliability (Merriam, 2009). The researcher utilised an "audit trail", i.e., a documented account cross referenced to evidence of how findings were arrived at, to ensure that the aforementioned was attained (Merriam, 2009, p 223). In addition to the abovementioned strategies, Merriam (2009) claimed that the conduct of an investigation in an ethical manner ensures validity and reliability. The study adhered to all the ethical requirements.

Research Evaluation: Trustworthiness of the Study

Trustworthiness is the standard for ensuring the external validity of a study (Merriam, 2009). This poses a challenge to qualitative research, as human behaviour is dynamic and ever-changing. Nevertheless, it is not the goal of qualitative research to establish universal laws or causality. Merriam (2009, p. 77) postulated that the sample size in qualitative research is usually small, as "generalization [*sic*] in a statistical sense" is not the main objective of qualitative studies. The aim is rather to render detailed descriptions and explanations of the participants' experiences.

As asserted by Polkinghorne (2010), the trustworthiness of a study refers to the quality of the research, in other words, the truth value it holds, and is determined by how trustworthy and believable the data and findings are. The quality criteria for trustworthiness in qualitative research are determined by how credible, transferable, confirmable and dependable the findings are. The design must be cognisant of how the information is obtained, analysed and presented, to ensure that the results are credible, reliable, dependable and confirmable (Merriam, 2009). Rigorous research must be conducted ethically to ensure credibility, reliability, transferability and dependability (Laverty, 2003).

Credibility

Credibility is determined by the extent to which the research findings correlate with reality and the truth (Polkinghorne, 2010), in other words, how credible the findings are (Featherston, 2008). Credibility relates to how believable the presented findings are and whether the findings represent plausible information based on the original data. Credibility, additionally, refers to the correct interpretation of the participant's perspective. Strategies employed to increase the credibility of this study were those of prolonged engagement and persistent observation.

Relating to prolonged engagement, specific questions were posed to participants based on the interview guide. Participants were requested to support their answers with examples and follow-up questions assisted to ensure that the phenomenon under study was appropriately addressed. No time-limit was set for the interviews, instead, the researcher engaged with the participants for as long as was needed to capture the essence of their experiences related to the care of a family member afflicted with dementia. The data were thoroughly studied until the researcher could identify the emerging themes based on the data. Adequate engagement was exercised relating to the collection of data, that is, until the data became saturated (Merriam, 2009). Elaborate, in-depth and authentic descriptions of participants' experiences contributed to the study's credibility and served as an indication that the inquiry was conducted in a truthful manner (Laverty, 2003). The researcher executed continuous analysis reading, re-reading and analysing the transcribed interviews to identify the codes, categories and themes. The data were studied until the intended depth of insight could be achieved (Korstjens & Moser, 2018).

Transferability

Merriam (2009) defined transferability as the extent to which the research findings apply to other situations and is, thus, tantamount to external validity. Korstjens and Moser (2018), furthermore, described transferability as the question of whether the research findings can be transferred or generalised within another, similar context or setting, with different participants. This is referred to as the "transferability judgement" (Korstjens & Moser, 2018, p. 122). By detailing the methods employed during the research process, transferability was facilitated. A thorough and detailed account of the sample size, sampling method, demographics, inclusion and exclusion criteria, interview procedure and questions, were discussed by the researcher, in order to contextualise the study (Featherstone, 2008). The researcher also provided elaborate descriptions of the lived experiences of family members living with a dementia patient and how resilience was developed, as a strategy to facilitate dependability (Merriam, 2009).

Confirmability

Polkinghorne (2010) indicated that confirmability is analogous to objectivity and neutrality - it is the extent to which the research can be corroborated or validated by others. The findings must be solely based on data obtained from the participants. By use of an audit trail, a methodological self-critical account of the researcher's biases was documented, in order to provide a rationale for the research decisions (Korstjens & Moser, 2018). A reflexive journal and audit trail was employed to document the process, in order to warrant confirmability. The researcher first employed bracketing and phenomenological reduction, prior to commencement of the interviewing process and data analysis. The reflexive diary was employed as a reflective journal during and following the data collecting process, to assist with reduction and bracketing (Van den Hoonaard & Van den Hoonaard, 2008). Critical self-reflection concerning the researcher's relationship to the phenomenon, the research question, codes, categories and theme choices, emergent themes concerning the proposed theory, and challenges and dilemmas, were recorded. A reflexive diary was utilised to identify possible themes, although no inferences were drawn. In the reflexive diary, a left-hand margin was utilised for the written recording of notes and thoughts. The researcher's experiences, biases and presuppositions were also noted and reviewed in the diary, as the reflexive and analytical process unfolded.

Dependability

According to Korstjens and Moser (2018, p. 121), dependability is the "stability of findings over time" or the consistency in findings. Merriam (2009) stated that dependability relates to how accurately the research and its findings can be replicated should the research be repeated under similar conditions. The concept of dependability, therefore, poses the question of whether the same research can be repeated and whether the same results will be obtained.

Should the outcomes be consistent with the data obtained, the dependability of the findings is strengthened (Merriam, 2009). The results must correlate to the data, to ensure dependability. The researcher utilised an audit trail or a documented trail of research, detailing how findings were arrived at, to ensure the aforementioned was attained (Merriam, 2009).

Triangulation

Triangulation in qualitative analysis increases the validity of the study (Carter et al., 2014). The researcher employed triangulation in this study to account for the validity of the research. When applying a qualitative, analytical approach, Suter (2012) asserted that utilising other sources can supplement and corroborate triangulation. Carter et al. (2014) explained that employment of other sources, such as interviews, observations and field notes - related to a specific phenomenon - is regarded as a type of triangulation known as multiple methods of data collection, when applying a qualitative approach to analysis. The researcher achieved data triangulation by utilising different data sets to identify themes, categories and codes. The researcher employed three methodological observations when analysing data, namely, the comparison of data via an iterative process; combining the data, in order to obtain a clear understanding of the phenomenon studied; and the “convergence” of data, to strengthen trustworthiness (Carter et al., 2014, p. 546). Triangulation was utilised to ensure the “completeness” of the data obtained (Bekhet & Zauszniewski, 2012, p. 6).

Summary of Chapter

Chapter 3 chartered the methodology of the research. It addressed the ontology, epistemology, research paradigm, research method, design and strategies, employed in the study. The chapter outlined the procedures followed with respect to sampling and data collection. The techniques employed in the analysis of the data were discussed, and the issues of ethics, and internal and external validity of the study, were substantiated.

Chapter 4

Results

This study focused on the development of resilience in individuals tasked with the care of a family member with dementia. This chapter provides a phenomenological interpretation of the emergent themes following the analysis of the participants' transcripts. The discussion of the analytic results details themes and subthemes elicited from the participants' texts, rendering an interpretative account of the experiences of the individuals tasked with the care of a dementia sufferer. The objective was to capture the challenges experienced and how these were overcome, resulting in the development of resilience.

Theme 1 highlights the positive, intrinsic, or acquired personality characteristics employed by the participants to cope with the confusing and unpredictable experience of the caregiving process. Theme 2 focuses on the experiential understanding of caregiving the participants gained from the caregiving process itself as well as how this understanding was employed to improve the care provided. With regards to theme 3, the impact of the information obtained about the disease was emphasized when providing care. In addition, there was a call to advocate for awareness of the signs, symptoms, and care of dementia patients. In some cases, a lack of knowledge about the disease led to a lack of support. The fourth theme outlines how individuals navigated and negotiated external support systems that were available to them to render better care. The last theme, theme five, pertains to how individuals caring for a family member with dementia coped with the impact caregiving. A discussion of coping strategies employed to assist in dealing with their experiences, is the core of the theme.

Sociodemographic Variables

All the caregivers were related to the family member with dementia. All participants were females with ages ranging from 49 to 81 years old. Six of the eight participants were of working age and were employed or self-employed and two participants were retired. All participants provided care for a family member with dementia for at least one year. Figure 2 below illustrates the sociodemographic characteristics of the participants in the study.

Figure 2
Sociodemographic Details of the Study Participants

	Age of caregiver	**Gender**	**Care provided for:**	**Employment Status**
Participant 1	51	Female	Grandmother	Employed – Full-time
Participant 2	50	Female	Uncle	Employed – Full-time
Participant 3	57	Female	Father	Employed – Full-time
Participant 4	67	Female	Spouse	Retired
Participant 5	56	Female	Sibling, and spouse	Employed – Part-time
Participant 6	40	Female	Mother	Employed – Full-time
Participant 7	81	Female	Spouse	Retired
Participant 8	49	Female	Mother	Self-employed

(Source: Own)

Explication of Data

The study aimed to answer the following question: How do familial caregivers develop coping skills that foster the resilience required to successfully manage the challenges of caring for a dementia patient?

Employing the Braun and Clarke coding guide (Maguire & Delahunt, 2017) five themes emerged from the data corpus. Themes often overlapped, as complete separation of a specific theme was not always possible and necessitated cross referencing, owing to the complexities of participant experiences.

Explication of Themes and Subthemes

The analysis generated five themes emerging from 20 subthemes. The following themes emerged from the analysis of caregivers’ experiences: (1) positive personality characteristics; (2) an experiential understanding of caregiving; (3) the impact of information; (4) accessing external resources as a key factor; and (5) coping with the effects of caregiving.

The themes and subthemes emerged from the codes utilised during the data analysis. Figure 3 illustrates the themes and sub-themes that emerged from the analysis of data.

Figure 3

Themes and Subthemes

THEME	SUBTHEMES
Theme 1: Positive personality characteristics	Patience Calm and tranquillity Tolerance Perspective
Theme 2: An experiential understanding of caregiving	Insights through observations Adaptation and acceptance Personal gains and growth
Theme 3: The impact of information	The importance of continuously gathering information Educating oneself Educating others
Theme 4: Accessing external resources as a key factor	Partner support Community support Friends/colleagues support Familial support Medical practitioners Support groups
Theme 5: Coping with the impact of caregiving	Coping with activities of daily living Coping with the absence of personal time Impact on employment Impact on finances

(Source: Own)

Theme 1: Positive Personality Characteristics

A person's individual cognitive process, as well as their feelings, moods, attitudes, perspectives and behaviours, represent personality characteristics. These characteristics encompass both innate and acquired behavioural qualities, that distinguish one person from another, and can be observed in people's interactions with their environment and their social groupings (Diener et al., 2019). All participants revealed how their innate or acquired personality characteristics assisted them to manage the challenges of caregiving. Participants' characteristics, emotions, thoughts and behaviours, will be highlighted in the discussion related to positive personality characteristics, being attributes utilised and/or acquired by them to cope with the difficulties associated with caregiving. Participants emphasised patience, calm and tranquillity, tolerance, and perspective, as positive personality characteristics that facilitated and enhanced the task of caregiving.

Patience. Patience refers to the ability to accept the challenges of rendering care to a family member with dementia, without becoming annoyed. Six of the eight participants reported the necessity of exercising patience, when tasked with the care of family members living with dementia. As indicated by the extracts below, the participants demonstrated patience, by displaying calm and forbearance when dealing with the uncertainties of the situation, that assisted them when confronting the strains of caregiving.

According to Participant 4, dementia is one of the most detrimental conditions that can affect a person with respect to cognitive decline, and the care of its sufferers requires a considerable amount of patience: “You, you must have patience… it's the worst that can happen to anybody…so, if you're dealing with that, with Alzheimer's and dementia, good luck to you. That's all I can say, [because] you need patience.”

The acquisition of patience, as a personality characteristic, was essential for Participant 2, as a result of caring for their uncle with dementia: “It’s uhm, like I said, it, it certainly makes you patient...”

Participant 1, likewise, identified patience as an invaluable quality to possess during the process of cognitive decline of a person with dementia. As indicated, possessing patience assisted them to overcome the difficulties of caring for their grandmother living with dementia:

> Well, uhm, my experience with her is that, is that you have to be patient… they become like small children, like a grade R child, like any five-year- or six-year-old… That's still, that's the main thing that I practice with her, patience… Have the patience with the family member and don't get frustrated.

Participant 5 stated that admitting their husband and sister with dementia to a care centre was not an option, as the caregivers in these facilities were dispossessed of patience, owing to the large number of patients under their care. Patience was declared a prerequisite characteristic required to care for a person with dementia: "And in, in the [*sic*], in the kind of home [care facility] that they [the family] are talking about, those people are not going to have that time and the patience for them [the dementia sufferer]."

Perseverance and patience, amongst other qualities, were highlighted by Participant 8 as important qualities, required to provide appropriate care for their mother: "Yoh. Yeah, yeah, yeah. There is, uhm, perseverance, patience, love. That's the only thing [*sic*], perseverance, patience, love, and you need to ask God to give you strength each and every day…"

Calm and Tranquillity. A calm and tranquil demeanour denotes that the caregiver is not disturbed or upset by the behaviour of the family member with dementia - even when there is cause to be. Six participants reported that remaining calm assisted in avoiding feelings of frustration, in improving care, and in ameliorating the caregiving task. A sense of calm and tranquillity were brought about by remaining positive, accepting the inevitable, acquiring information concerning the condition, and understanding the situation of family members with dementia.

Participant 1 elected to ignore the outbursts and sudden mood swings of their grandmother, by remaining calm during these episodes. When requested to explain how they maintain calm and composure amid the trials and tribulations, they replied: “Just to ignore her, especially when she start [*sic*] using vulgar vocabulary words. And, uhm, I would rather try to give her something to keep her busy… You must know how to treat them and create calmness within yourself.”

When requested to indicate which personal attributes aided them in adapting to the care of their father with dementia, Participant 3 stated that maintaining calm in the situation assisted them:, as seen below: “I think my calmness. I was like, very calm… So I think my calmness… I think that's, that's, that's what helped me.”

Participant 2 commented that they remained positive and avoided focusing on the frustration. It inevitably helped them stay calm:

> I would say that if [you’re] going to focus on the frustration part, uhm, the emotional part, then you are just gonna [*sic*] dwell on that, uhm, and that would then make everybody equally frustrated, equally emotional, and nobody would actually be, uhm, bringing a sense of calm into [*sic*] the situation; and then you would also deal with the person from a place of contempt like, uhm, you, you, you, you, you are going to start treating the person as if that person is now a nuisance to your comfort and to your time and to your life.

Furthermore, Participant 4 stated that their tranquillity, compassion and understanding of the circumstances of the dementia patient, rendered the care of them easier and less stressful. It was regarded as crucial to understand the situation in its entirety and remain calm: “And if a person needs help and you understand what that person is going through, try and be calm, compassionate and understanding. Then you won't have any problems. Make your life easier by being understanding, by just being calm.”

Participant 7 emphasised the need to understand the behaviour of their spouse and what aggravated the spouse, and the importance of remaining calm as a caregiver, especially when their spouse was uncooperative:

> And then from then on, for most of the time, be calm most of the time, do not shout at the person with dementia. Because that is aggravating their angry mood when you, you shout at them. So, you've got to try and be calm.

Tolerance. Tolerance refers to the ability and disposition of the participant to deal with the disagreeable behaviour of the family member with dementia, despite the challenging circumstances. Dementia alters the behaviour and personality of the individual who has been diagnosed with the illness. The unwanted behaviour, sudden outbursts, sleep disturbances, pacing and unpredictability, were accepted by participants as symptoms of the condition. Tolerance was a personality characteristic practised by all participants. Participants displayed tolerance by remaining even-tempered during these episodes, as they focused on the person, rather than their conduct. The participants acknowledged that, while it is possible to lose one’s temper, it would be an ineffective method to bring calm to or manage the situation.

Upon realising that their uncle was not intentionally aggressive, but that their conduct was a result of the condition, tolerance was exercised, as is evident by Participant 2’s account of their experience:

> He is not just outright being aggressive, it's part of the bigger problem, so we deal with that manners, so you can calmly respond. You can calmly deal with whatever, uhm, surfaces on any other day, and I think it's just the shift in thinking, that, look, this is what we have to deal with, this is how you handle it and… if you are patient and then that makes it easy.

Dementia causes strange and unfamiliar behaviour. According to Participant 1, their grandmother was temperamental at times and the grandmother frequently uttered curse words. The participant described how they developed tolerance by treating their grandmother as if caring for a child, when their grandmother exhibited uncalled-for verbal outbursts. This undesirable conduct by their grandmother did not anger or frustrate them:

> She is not a TV person, but, uhm, when she is in that bad [mood], you know, [firstly], people with dementia, you can't swear at them and you can't get angry with them. And you can't get frustrated with them. Most important, you can’t get frustrated.

Cognitive decline manifests differently in people with dementia. Participants’ family members with dementia occasionally engaged in socially undesirable behaviour. The emotional and psychological distress associated with the care of a family member with dementia were frequently cited as unavoidable aspects of the caregiving process. Participant 3 demonstrated tolerance by explaining how the stress-inducing behaviour was managed, whilst tasked with the care of their father:

> Yoh, [name] you know, caring for someone who has a dementia is very, very stressful, because in the beginning, remember, you, you are not even aware that the person is sick, and you become impatient. And the minute you, you realise that, uh, the person is not doing all these things deliberately, then, [it] is then that you realise that, uh, you are in, you are in a big trouble… He [father] could not take himself to the toilet and then he would just urinate anywhere around the house. And you can imagine the smell of urine of an adult? Then you have to wash the curtains, you'll have to wash the blankets. Actually, we used the wash the blankets every day.

Participant 4 developed tolerance by avoiding disagreements with their spouse and dealing compassionately with their husband’s memory loss:

> So what I've learned, what I've experienced, is that you, you do not argue with a person like that… Anybody with Alzheimer's, carers should not, uh, uh, say, but you are wrong, or you did eat, or let's go and bath. And if they argue that they, they did have a bath, and you, you just, you know, you sort of, what, [*sic*] what you become, you, you become, uhm, compassionate.

Perspective. Perspective refers to the participant's point of view regarding the way in which the situation of caregiving was perceived. Caregiving requires moving away from an egocentric perspective, towards an altruistic frame of mind. It is a shift from a perspective where the carer's needs and ego are put first, to a state where the best interest of the dementia patient takes precedence. Furthermore, their perspective refers to the beliefs a caregiver holds concerning the disease and the realisation that they must make a necessary and conscious decision to hold a positive view of the situation. Participants expanded on the belief that the dementia sufferer is not responsible for their disease and/or their behaviour. The participants accepted the inevitability of the disease and its course. Five participants noted the shift in their perspectives related to prioritising the care of the dementia sufferer, in order to better meet the needs of the patient.

Participant 2 communicated the change from their egocentric perspective to one where the care of their uncle became a priority. Their narrative revealed that their journey or process resulted in an instinctive shift in perspective and instilled an appreciation for their own quality of life, given the diminishing quality of life of the patient:

> You realise now that it's [*sic*], you move from, from having an egocentric point of view. This person needs this now more than you need, whatever you want to do. So, and also if you, if you observe them and you see how the quality of life diminishes, because it takes place, that also makes you value your quality of life.

The caregiving task was ameliorated when the focus was directed to the relative suffering from dementia and a conscious decision was made in favour of their care. Participant 2's perspective shifted to one where the focus was on the patient, by making a conscious decision to care their uncle:

> Well, it, it, uhm, actually impacts on it [employment]. Uhm, I wouldn't say, uhm, negatively so much, because if you make that decision to, to, to full time be, uhm, caring for the person, then you sort of work everything around the person.

For Participant 6, being tasked with the care of their mother presented a challenge with regard to balancing their interests with caregiving activities. They balanced their interests with the demands of caregiving by altering their mindset, from one where they prioritised their own needs and interest, to one where the needs and care of their mother were prioritised:

> So, it's, it's been interesting, uhm, it does affect your life, uhm, and I can't say positively (laughs) because your mindset changes as well, [you're] trying to juggle, uhm, between, uhm, you know, not losing yourself, uhm, in it, uh with regards to your interests and stuff… Uhm, I want to be able to take care of her and still have a life of my own.

Theme 2: An Experiential Understanding of Caregiving

An experiential understanding of caregiving refers to the insights gained into the unique demands and trajectory of the disease, through the knowledge acquired via observation, from the adaptations that were made, from the acceptance of the situation, and from the skills acquired from the act of caregiving. Dementia causes people to act and behave in unexpected ways, that can be unpleasant or upsetting. According to the participants, a solid understanding of the course and symptoms of dementia rendered the challenges of caregiving bearable. All eight participants expressed a sense of accomplishment and fulfilment as they came to understand the disease and acquired knowledge of the needs of the family member with dementia. Their understanding and awareness of the needs of the dementia patient, as the disease progressed, were not based solely on communications from medical practitioners or support groups, or on information acquired from online resources. Participants also gained insight into the unique demands and trajectory of the disease through observation of the dementia patient, resulting in an experiential understanding of what to expect and of the patient's requirements. The subthemes reflect the different coping strategies employed by participants in order to self-regulate and to manage the stress and demands of caring for a family member with dementia. Insights through observation, acceptance and adaptation, positive gains and rewards, are all subthemes of an experiential understanding of caregiving.

Insights Through Observation. Insights through observation refers to observations of the behaviour of the dementia patient and how this conduct were interpreted or understood by the participants. These experiences provided participants with insights and assisted them to make sense of their experiences of the caregiving task, as they derived meaning from the situation. Individuals suffering from dementia are often unable to express their needs and feelings verbally, owing to cognitive decline. All the participants used observation of the family member with dementia as a valuable instrument to acquire information concerning the disease and its progression and gain insight into the needs of the dementia sufferer. These observations and insights assisted participants in identifying the cognitive deterioration of the family member with dementia and informed them when to seek help and/or advice. Furthermore, it allowed participants to attempt to understand the family member's experience of dementia from the perspective of the dementia sufferer. Participants relayed the irrational thought processes and behaviour observed, as well as the measures implemented to address the unwanted conduct. This further prompted the participants to make decisions on behalf of the family member with dementia, relating to their needs and feelings. Participants expressed the necessity to think for and take decisions on behalf of the family member with dementia, as they observed that the dementia sufferer was unable to communicate their needs. A sense of accomplishment was instilled by the participants’ daily engagement with their family members, resulting in improved care.

By way of meticulous observation, Participant 4 gained insight into the needs of their spouse, as they could predict when their spouse was hungry or needed to use the restroom. The participant assessed the situation on behalf of their spouse and directed their observation toward taking decisions on the spouse’s behalf:

> With the process, you, you, you go on, you, you get used to it, and you know, we know what to expect. A person with Alzheimer's, you can read them. You can see that, uh, you know they feel hungry, but they don't know what is going on, you know, or they got to go to the toilet, or they want to drink water, or you gotta [*sic*] be there to, to, to, to, to sort of, because they, they don't know what is happening. So, you've gotta [*sic*] be hands on to, to think maybe this person is hungry.

Participant 1’s grandmother was closely observed to determine whether the medication was effective. The observed behaviour of their grandmother afforded them the insight to adjust the times at which medication was administered, owing to the benefits thereof:

> Now, what I've [noticed] is that the tablet works during the day, she will have this different characteristic to [*sic*] these different moods. So, I've changed her medication and let her rather have the tablet during the day, because it's calming her. She doesn't need it at night because she's sleeping. And she's not moody when she sleeps, it works better during the day, when she's awake, yes.

Participants gained insight into the course of the disease, over time. As the condition deteriorated, the family member with dementia experienced a higher degree of memory loss.

This observation afforded participants insight into what stage of dementia the family member was in or was about to enter. The information gleaned from the observation provided the participants with a better understanding of the disease and assisted them in overcoming obstacles.

The observation of the symptoms their uncle presented also assisted Participant 2, indicating the need to seek medical advice. The participant recognised the need for professional advice and support by others. They collaborated with health care specialists regarding the decline of their uncle's cognitive abilities. The uncle was closely observed to determine whether the medication was effective, as its efficacy appeared to fluctuate. The information gained was crucial, as it aided the management of emotions related to helplessness and distress:

> The uncertainties , uhm, look if, if you sense a certain mood and the medication doesn't help, or what you, what worked in the past didn't work, then obviously you would then say no, uhm, uhm, a professional person to come in and advise, because now I've done all I knew how to do, but it's not changing.

Moreover, the family member with dementia is dispossessed of their independence, as their condition deteriorates. Participants concluded that a single person would not be able to manage the care of a family member with dementia, owing to the need for 24-hour care and an increased need for assistance and constant monitoring, as the disease progresses. All the participants expressed a need for additional assistance, based on their observations and the insight that dementia sufferers are rendered unable to care for themselves. Participant 8 made the following statement:

> So, if I'm alone, when the kids are not here, it, it, it's very stressful, because I need to put my whole attention towards her… She's, she's supposed to be hospitalised. Because as it [*sic*] right now is to me, maybe it's the help that I'm needing.

Adaptation and Acceptance. Constant adaptation and flexibility on the part of the participants, were necessitated by the continuous changes in the trajectory of the disease and the cognitive deterioration experienced by the family member with dementia. Furthermore, the participants accepted the reality of the situation and made the necessary adjustments. Acceptance of change is not affected easily or swiftly, as dementia impacts every area of the patient’s life. The participants adapted their schedules, planning and lifestyles, by improvising when required. Participants accepted the trajectory of the disease, the fact that the disease cannot be cured, the role reversal, the need for additional assistance, and the responsibility of taking care of a family member with dementia. All participants acknowledged that, no matter how onerous the challenges of being tasked with the care of a family member with dementia, the situation could not be reversed.

Participant 1 accepted that they were prevailed upon to expend long hours at the hospital when they accompanied their grandmother to appointments and they adapted to the situation by utilising it as a respite: “I have to stay with her at the hospital for the entire day and then return late and then I treat that day as a day off.”

Dementia patients typically display unexpected behaviour, prompting improvisation by the caregiver. For Participant 1, understanding the condition simplified management of the unpredictable situation. They relayed how plans were adapted to the daily encounters with their grandmother:

> …but that day when I, when I [arranged] for a meeting to go and see this, it's a doctor, there in Soweto, then my granny was in a [totally] different mood. She didn't want to get out of the house that day. Then she started with her moods. It's like she was a [totally] different person, so I had to cancel the appointment...

The care of a family member with dementia impacted participants’ relationships with others. The cognitive decline displayed by Participant 2’s uncle, resulted in them becoming more dependent on the participant for assistance with the activities of daily living. In order to mitigate these challenges, Participant 2 explained that the situation was controlled, by adapting the way planning was executed and by prioritising their uncle’s needs:

> It's like that person is the centre of everything. Whether you, uhm, go out to people, whether you meet people at home, it's like everything must fit into this person's way of living and in the broader context his, his way of life. The mood on the day, eating habits etcetera, etcetera. So, you, you actually adjust, uhm, any other relationship to this person.

Participant 6 stated that they were adaptable and flexible, since the family structure or household conditions may alter, at any given time. When requested to describe how they coped with the uncertainties and daily changes involved in the caregiving process, Participant 6 responded that: “Uh, wow, I think, I don’t know, I think the biggest thing that I have is that I am very adaptive, uhm, shall I call it, uhm, I’m a project manager, so I’m gonna [*sic*] call it agility.”

Role reversal and the modification of priorities are common when the condition of the family member with dementia deteriorates. The majority of participants reported that adult relationships with the dementia-affected family member morphed into parent-child relationships, with the caregiver assuming the role of parent-provider - a distressing task and an arduous adjustment. Seven of the eight participants indicated that the cognitive decline of the family member diagnosed with dementia, resulted in a role reversal. Additionally, participants reported that the person who had been their caretaker their entire life suddenly lacked independence and needed assistance with activities, such as bathing, toileting, personal hygiene and managing finances. Participant 6 stated that they had always attempted to determine why the person with dementia engaged in specific behaviour. The knowledge gained by the participant enabled them to provide improved care and overcome the daily challenges, resulting in a feeling of mastery that assisted them in coping with the daily changes encountered:

> Uhm, through it [*sic*], uhm, you know, even when she couldn’t go to the [*sic*], she started not being able to go the toilet by herself, you know, you don’t understand that because this person’s been your caregiver all their lives and then now, all of a sudden, they’re losing all these, you know, all this independence. It’s for me, Google has been (laughs) like so helpful because, uhm, every time I see something new, I will go and educate myself so that I can understand it better and be able to deal with it better.

Caring for a family member with dementia restricted individuals from participating in their usual activities. Participant 5 accepted that they were unable to participate in activities that they previously enjoyed. They accepted the situation and abandoned these activities:

> I've always been a person that was able to [*sic*], I would go and run every day, and [exercised], literally six days a week. And when I started taking care of my mom, that was the one thing that went out the window. I could no longer do that. And that was the hard part for me. I ended up giving up that which was keeping me strong. And it's something I'd like to get back to, but I can't. Not yet.

Personal Gains and Growth. Personal growth and gains refers to the development of new skills or attitudes that positively impacted the lives of the participants. It involves mental, physical and emotional development, resulting in the acquisition of an ability or quality. All eight participants recounted their personal growth and gains, as a result of rendering care to a family member with dementia. A sense of purpose and reward were communicated by all participants. This sense of purpose and reward motivated the participants to strive to improve the care they provided. They experienced the feeling of being needed and assumed responsibility for the well-being of the family member with dementia. They commented on their competencies, beliefs and constructive feelings of self-efficacy. Six participants expressed a sense of contentment and satisfaction. This stemmed from their realisation that the challenges of the caregiving task were not avoided or delegated to an organisation or care centre. Participants were motivated by a strong sense of responsibility and obligation toward their family members living with dementia.

The fact that Participant 2 was tasked with the care of their uncle, prompted a sense of appreciation for their own life and acted as a motivator to render the most effective care possible:

> …you didn't just walk away and made it someone else's problem, uh, because you could put a price tag to it or something. I think the fact that you were present in it, uhm, will, will maybe, not now, have, have a consequence, but later on. You know it will, it will add, add value to who you are as a person…You do it out of your free will, and your body would [*sic*] follow the brain when you say ‘I want to do this’. You just get up and do it, effortlessly. But that’s, that’s the deterioration of, of, of, uhm, the quality of your [his] life, that diminishing factor, makes you more appreciative of, of your quality of life.

Personal development involves personal growth and enrichment of all the facets of a person and their emotions, as well as self-efficacy, resulting in proficiency with regard to the care provided. All the participants reported gains during the care of a family member with dementia. Gains in ability, skills, experience and confidence were noted, as a result of these experiences. Participant 2 identified the situation of caregiving as an opportunity for self-discovery and selflessness:

> To realise that you, you, you can actually stretch yourself as a human being. Uhm, and then you would also, uhm, it becomes selfless. And, and you won't feel like [you’re], uhm, being short-changed and it's like [you’re] losing yourself in the process. I don't think it's about that. I think it adds value because then you can at least do something for

> someone, and the person being, uhm, in my case, related, makes it, for me, meaningful. And you would then be, uhm, it will become easier if you just shift the way you think about it.

Furthermore, Participant 4's caregiving standards were high, and they were unwilling to compromise their standards as it enhanced the level of caregiving. The participant also expressed their satisfaction with their accomplishment, perceived as a personal gain:

> Well, I think the gains for me is on a personal level, is that you, that you know you're actually helping somebody and insisting to add value to their life. And, and knowing that you are actually taking care of a person in, in, in a way that is of a standard. Uh, yeah, I know. I know when I spoke to a social worker one time at the hospital, and that was in the time when I was still taking care of my mom, and I was having struggles then. And she literally just said to me: 'Lower your standards.'.

This sentiment regarding personal gains was emphasised by Participant 6, who realised the importance of nurturing one's mental health when tasked with the care of a family member diagnosed with dementia:

> Uhm, the biggest thing that I have gained is that, and I think we as, me, and even my daughter will tell you, is [*sic*] that it's so important to take care of your mental health and I know that's been thrown around. Uhm, and, and, and [*sic*] but I think, uhm, I've learnt what that means.

Theme 3: The Impact of Information: Knowledge is Power

This theme refers to the process of learning about dementia, as caregivers continuously sought to acquire knowledge concerning the condition and its effects on daily life. This included knowledge concerned with what to expect as the disease progresses, i.e., the aetiology, symptoms and progression of the illness, and an understanding of the ways to manage the changes that occur as a result of the cognitive decline. Information positively impacted all eight participants' ability to improve the quality of the care provided, as well as their understanding of the trajectory of the disease. Additionally, the theme relates to how acquired knowledge impacted the participants favourably, or how the lack of information impacted participants adversely. Participants discussed the importance of gathering information from diverse resources, and the importance of educating oneself and others.

The Importance of Continuously Gathering Information From Various Sources. All participants stressed the necessity of gathering knowledge from a range of sources, including books, pamphlets, health professionals, support groups, videos and the Internet. This quest for knowledge was initiated by their observations of the dementia sufferer. The participants cited the inexplicable and changing behaviour of a family member with dementia as one of the core reasons for their search for information. The emergence of uncharacteristic aggression was one of the challenges revealed by all participants. The search for information was undertaken to identify and address the uncalled-for behaviour and also to understand the genesis behind it, and in order to render improved care. It was evident that, when a family member with dementia exhibited new or unexpected behaviour, it was critical to acquire assistance and knowledge from various sources, such as social workers, the Alzheimer's Institute or the Internet. Assistance by health professionals was also regarded as crucial. Participant 1 utilised several knowledge platforms to educate themselves in respect of the condition:

> You must get knowledgeable. You must read about dementia. You don't have to study about it... I rather asked for advice that day, over the phone, and they gave me advice, yes, and I also, I also read books and pamphlets on dementia. How to deal with people with dementia… Yes, uhm. I've got brochures and, uh, I’ve got brochures and contact numbers.

Furthermore, reading literature concerning the disease provided the necessary knowledge and assisted Participant 3 in coping with the caregiving task: “I used to buy books pertaining to, to the disease. Ja [yes], to read. So that I should understand the disease more. So, I think that also helped me cope.”

The increasingly aggressive behaviour resulting from the progression of the disease, was initially misunderstood by several participants. Participants reported occasions when the individual with dementia displayed aggressive conduct. This behaviour was confounding to Participant 6, until a health professional communicated the disease's trajectory and symptoms:

> Uhm, and, and it’s been a real challenge, uhm, because throughout, I guess, in the beginning with the dementia, she was very aggressive. Uhm, we had to learn to understand that (laughs), that, that was part of the process… I even [asked] Lorraine [social worker], for instance, like, I’ll pop her a message and be like, you know, ‘she’s doing this, I don’t understand’… So, it’s, it’s been a journey of learning, uhm, and it continues to be a journey of learning. Ja [Yes].

The information acquired enabled Participant 2 to deal with their uncle’s increased aggression:

> But then we discovered that dementia is an add-on, and that was the result of, uhm, the aggressive behaviour. So, now we understand how to deal with the aggression from an informed place, because before we couldn't understand why the aggression seems to be worse or even escalating.

Participant 4 shared their experience related to the care of their spouse with members of a dementia support group and that was one of their sources of knowledge concerning the condition:

> Once you understand the disease and you know what, what it's all about, it makes it easier to cope and it makes it easier to look after a person with Alzheimer's. And if you don't know, you ask, I used to go like every second day just for an hour, uh, uh, uh, support [*sic*], to a support group... You know, so that we knew. So, understanding all that, well I didn't understand it, but what I did, I, I downloaded a whole lot of things. And I also, uh, joined, in the hospital where he was, uh, admitted back then, a group, you know, a, an Alzheimer's dementia group, and we learned so much about, uh, dementia, Alzheimer's, that it actually helped me a great deal.

As reported, the Internet played a pivotal role as a tool to acquire knowledge. Notwithstanding Participant 5’s medical background – working in a health care centre - they relayed that the Internet was continuously utilised to research the condition:

> Well, I did do a lot of research on my own as well, so besides the fact when I worked at a health care centre, that uh, also specialise in dementia. Uh, I did also do, I just continuously, even now, I still do a lot of research and, and do a lot of courses thereon, on YouTube, to, to gain information as to what to do. So, I'm always looking for how do we deal with that situation? What do you do in that kind of situation? How can we apply things differently? Uh, how can we use a different method of giving a bath.

Additionally, Participant 2 stated that the online information acquired and the advice received, were reviewed during discourse with health professionals, to ensure that the information obtained was appropriate:

> Yes, uhm, well you know not everything you read can really warrant as, uhm, things that you can use. But most of the time, with the Internet, uhm, there's a lot of information, yes. And like I said, if you run it by a professional person, they would tell you yes, they know, and they would also tell you the reasons why it will work or it won't work.

Educating Oneself. This subtheme denotes the process of educating oneself, via reading, consultation with experts and informal study. The information acquired by participants played a pivotal role in the management of the family member’s condition. All the participants stated that it was crucial to understand the disease's progression, as well as the role of a caregiver. It was regarded critical to monitor the progression of the disease, in order to devise measures that resulted in improved caregiving. Evidently, knowledge regarding the condition altered the way the participants dealt with the family member with dementia.

As the memory of a person living with dementia deteriorates, they become increasingly unable to identify everyday items or to comprehend how it is utilised. Continuous and increased supervision is required, and the patient should never be left to their own devices, as advised by Participant 4:

> So, you, as a person, must understand that the, this, uh, patient with Alzheimer's is not, he needs help, they need help, because there's no ways they can look after themselves, because if everything goes away, you know, they don't know that this is a cup or that is a saucer, this is a bed, I must sit on the chair, and they forget everything and everybody. So, you gotta [*sic*] understand. Once you understand the disease then it's easier to look after a person like that.

Participant 3 was confounded by events unfolding at the onset of the disease and was initially angered by their father’s conduct, until expanding their knowledge concerning the condition. They only understood the situation when they started to gather information, resulting in their acceptance of the unexplained behaviour: “…remember, at the beginning, you become angry because you don't understand what is happening to this person. But, as, as time goes on, now you learn to be calm, you learn to accept.”

Participant 5 commented that everyone will not be possessed of the ability to execute the care of a family member with dementia, and they expressed the necessity of acquiring information relating to the scope of the caregiving task: “I understand that every family member cannot take care of a person that has dementia, it is a disease, and it is something that you need, you need to have knowledge on.”

It is essential to monitor and evaluate unfamiliar behaviour of a family member with dementia. Participants noted that, when the patient exhibits new, unexpected, or unexplained behaviour, the guidance and understanding of, for example, a social worker, the Alzheimer's Institute and/or medical personnel, and access to the Internet, are exceedingly valuable. The participants recognised that interacting with a medical practitioner remained essential, even though the information available via the Internet was beneficial. Support by medical practitioners aided Participant 4’s understanding of the various phases of dementia:

> And also, there was help because he (neurologist) used to hold, every second day, a sort of group meeting, you know, about different stages… So as a carer, you should understand that, this is why it's important to go for, for, for lessons too. It's important for any carer to go and, and learn about the disease.

Being knowledgeable regarding the condition assisted Participant 2 in maintaining a calm demeanour, as they were equipped to understand the reasons for their uncle’s conduct:

> Well, I would say that you should be, uhm, firstly, you need to be well informed. You need to educate yourself on the condition and you need to educate yourself on behavioural issues. Why is the person behaving a certain way? Because if you do know why, then you can deal with it… It's like they, they told us that aggression forms part of it at a later stage or somewhere in-between the stages...

Educating Others. Educating others refers to the participants sharing information concerning dementia with the extended family and community. The behaviour of individuals diagnosed with dementia might appear strange, when the cognitive deterioration is not recognised, or when the individuals tasked with the caregiving have not been educated regarding the decline in cognition. Participants’ family members were informed of the dementia patient's behaviour and how to adapt to it, enhancing the care rendered. As a result, the unwanted behaviour of the family member with dementia was tolerated and not frowned upon.

Six of the eight participants indicated that information concerning the disease was shared with others who may have contact with a family member with dementia. In this regard, Participant 7 declared:

> In fact, teach them [the community] what dementia is… So, they've got to try and be calm, and they must take them for treatments, and you must try and make the neighbours aware also that the family member is now having dementia, so that they must not be surprised when they see a person searching for somebody, calling the neighbours and people in the street. Because some even walks [*sic*] half-naked. So, they must try and understand what dementia is.

Educating others was deemed imperative and the need for advocacy was emphasised, to ensure that people are aware of the condition. Although Participant 3 informed the neighbours that their father was diagnosed with dementia, the neighbours still assumed that their father was insane. This participant concluded that the general public misunderstood the condition:

> Yeah, yeah I, I did tell people that my father has Alzheimer [*sic*], but there were those who were saying: ‘Hey, you know, have you seen [name’s] dad is now mad?’ They will say he's mad, uh, so, yeah, they don't understand.

Participant 2 opined that dementia is a widely misunderstood condition. The community displayed a sense of unease related to people with the condition, as it is associated with mental illness - highlighting the need for advocacy. According to Participant 2, the misconceptions regarding dementia resulted in the responsibility of caregiving resting solely on the patient’s family:

> … I think it is very misunderstood. And, uhm, and if you, you know, it's, it's like with mainstream mental illness, people don't really want to talk about it… So there is still that in communities that this is not something that you discuss, like or, or it's, it’s misunderstood and it's like, it's only the family or the immediate family that needs to deal with it. That is the perception that we still get.

Similarly, Participant 5 stated that dementia was frequently misunderstood, and family members erroneously assumed that the patient would not remember them, despite the reality that a number of dementia sufferers do retain certain memories. Participant 5 noted that, irrespective of the effort expended in attempting to educate other family members, they never completely understand dementia:

> But because the family feels, they’ve got dementia, so, hey, they don't remember anything. And this is the one thing you try to make them understand. Just because you have dementia [it doesn’t] mean you don't remember. They just don't remember what happened in the moment. But you certainly don't forget everything in your life or in your world.

It is challenging to manage a dementia sufferer in the absence of knowledge concerning the disease. Participant 6 reported that the African community associates mental disease with witchcraft, therefore, it is crucial to educate society with regard to dementia and mental illness, in general:

> Ja [yes], it’s a lot, it’s a lot and it’s [*sic*], and for me I guess, the biggest gap that I also think needs to be bridged, is the education gap. I wish there were more road trips, maybe by government and staff to educate people, uhm, to inform them that this, you know, this is there, and it has nothing to do with witchcraft. Uhm, you know, people are

> sick and mental illness is just like a big thing now… I just wish, ja [yes], education, education, education. Empowering people, ja [yes].

Theme 4: Accessing External Resources as a Key Factor

The theme of external support refers to the various types of assistance participants received to aid their adaptation and management of caregiving. In this study, the importance of access to external resources was highlighted, by all participants. The sources of support were identified as meaningful relationships with partners, friends, colleagues, family and the community, as well as medical professionals and formal support groups. Participants reported the positive impact of the emotional and physical support received from external resources. Participants also relayed the lack of external support and how they coped with its dearth.

Support played a pivotal role, influencing the way participants managed the challenges of the care of a family member with dementia. Emotional support, instrumental support (assistance with daily activities) and informational support, can all be described as forms of support. The type of support received, varied from one participant to the next, although overarching support systems were identified. These support platforms allowed participants to discuss their frustrations and, indirectly, relieved the stress they experienced. This also afforded them the opportunity to attend to activities, other than the activity of caregiving to the family member with dementia. Their friends, colleagues and/or community played a significant role in participants' emotional and psychological well-being.

Partner Support.

Three of the eight participants reported the positive contributions made by their partners. Two participants rendered care to their partners with dementia, and three did not hold relationships with significant others. Additionally, Participant 5 described how their spouse supported their mother with dementia, prior to the spouse’s own diagnosis with dementia. Participants 6 and 8 acknowledged that caregiving responsibilities were time-consuming. They had, therefore, decided not to become involved in a partner-relationship, whilst providing care to a family member with dementia.

Participant 1 disclosed that their partner maintained a positive attitude by employing humour, in order to escape the reality of the situation. Although their partner had initially been unsupportive, as time progressed, they became sympathetic, as they came to understand the illness. Their partner utilised humour to address the behavioural issues displayed by their grandmother and regularly enquired about their grandmother's health. This emotional support was well received by the participant:

> And when she [grandmother] is frustrated, she will swear, and everything and anything works on her nerves, even the children when they are playing outside. Then he [partner] will always ask me when he calls: 'Uh, did your grandmother swear, again?' Then, then he will laugh about it, not in a bad way. Just because he likes the way she's, she is using certain words. But, uhm, he's supportive, yes.

Participant 3 found that having a competent partner who understands the disease's progression, was beneficial and minimised the impact of the difficulties faced. The informational support and advice the spouse – a former nurse – provided, aided the participant in improving the quality of care rendered to their father: "Yeah, it did help because you know my, my partner he, he once was a nursing sister. So, he understood all this dynamic. So, sometimes he would give some advice. So, it was not like a big challenge."

Participant 5 relayed the critical importance of support by their spouse when their mother was diagnosed with dementia. The participant's spouse provided instrumental support when they were at their place of work:

> Okay, uhm, in, in that respect, uh, he made it easier from the point of view that, uhm, there was, uh, one stage when I was really struggling and I had to find financial means

> in, in [*sic*], to support us. So, I actually left my mom in his [her husband's] care, [and] went to go and work.

Community Support. Individuals tasked with the care of a family member with dementia, require as much assistance as possible. According to a number of the participants, when the community understands the condition, it becomes supportive and even monitors the patient's well-being. In such an environment, a caregiver does not experience a sense of exclusion from society. Only three participants received community support. Participant 6 received support from the community, who recognised their mother's illness, rather than assuming their mother was 'crazy'. This caused the participant to experience a sensibility of being an integrated part of the community:

> Uhm, and I think, because of how we were, uh, the community, or the people around us, were really supportive. Uhm, they [*sic*], I noticed that they were very open to the fact that she was sick and that we were taking care of her… People would ask about her, how she's doing… So, having people who ask and care and stuff, that, that really helps. So, ja [yes], I, I [*sic*], it's, community support is important.

Similarly, the church clergy and members supported Participant 7. The church minister administered holy communion when they attended at the residence: "But the Minister comes and gives us holy communion at home with some church members, at least since we're [*sic*] we started [COVID-19] level three, they came. I think three times, ja [yes]."

Moreover, Participant 5 asserted that it was essential to maintain amiable relationships with one's neighbours. The neighbours were encouraging and understanding of the challenges experienced by the participant, occasionally donating necessities and rendering instrumental and emotional support:

> Well, uhm, some people in terms of like, neighbours, might be like, next door, and if I need physical assistance, they're there. Uhm, they stress over my health at, at best of

> times. But, uhm, they do also understand that sometimes things really gets tricky and, uh, they can give us like, give assistance in, in terms of like I said, maybe just a: 'Hello, how are you?' or: 'Hey, I, I made something. Here's something over the fence for you.'. And, uh, we do likewise also. So that kind of relationship is still very much there.

Friends / Colleagues Support. Five participants emphasised the importance of friendships, as friends provided advice and allowed participants to vent their frustrations. Additionally, participants reported the instrumental assistance received. Participants reported that the support rendered by friends, in the form of discussions and informal conversations, aided them in dealing with the challenges of caregiving.

Participant 1 recalled various occasions when their morale was low. They expressed how the conversations with their colleagues and friends assisted them to manage the frustrations experienced. Additionally, friends encouraged the participant to be more tolerant of their grandmother, and as such, rendering emotional support:

> Yes, even my colleagues. Uh, my best friend that I lost, that is the person, that was my go-to person. I would tell her every day about, you know, this is happening. I'm encountering this with my grandmother because she has dementia and, uh, she will always give me advice because she is a teacher with a background of psychology… Okay, uhm, like, I will talk to my friends and, yes, I will talk to my friends and, uhm, they will advise me.

Participant 2 discussed their friendships and how comfortable they were with revealing the challenges they experience to their friends. Close friendships were undoubtedly significant sources of emotional support to the participant:

> You can discuss it with them [friends] openly. You don't need to withhold certain information. They are quite comfortable, they know. I mean the relationships needs are

> of such a nature that you, you can be open with the good, with the bad. It boils down to the type of friendship you have and how close are you with the people.

Similarly, Participant 8 mentioned the instrumental support they received from a close friend. When the friend visited the participant, they supported the participant by aiding them with various caregiving activities:

> This other one, that's my closest friend, she will feed her (mother), she will, you know, it’s, it’s that. We’ll kinda like, dress her up, change her nappy, put on her nighties, put her on the bed… So, they have taken to a point whereby they understand that, you know what, there are places where [name] can’t be with us, and it has been like that. And it’s like that.

Participant 3 described how their father’s childhood friend assisted the family by temporarily caring for their father, even though their father was unable to communicate with the friend. As a result, the participant, as caregiver, was able to take full advantage of the opportunity for much-needed rest provided by this instrumental support:

> And then my father had a friend, a childhood friend… So, on, on some days he would come and take him, even though he [father] was no longer speaking. But he will take him and then talk to him, and then they would chat, and then my father would just laugh even though he’s not responding. So, I think that also helped, because it gave us a break as a family.

Participant 5 described how their friends and ex-colleagues assisted them financially, by providing food and other necessities:

> Uh, other things is, like I say, I’ve, I’ve really got, uhm, people that I was friends with, and people that I’ve worked with, that assist me in different ways. In terms of, uh, sometimes with, with food and with the funding for incontinence pads, and things like that. It’s really been a tremendous help.

Familial Support. Family support was essential to manage the challenges associated with the care of a family member with dementia. Seven participants reported that the support they received from their families helped to ameliorate the challenges experienced. Participants' family members provided support, both emotionally and instrumentally. The assistance by family members decreased the participants' physical occupation with the dementia patient, affording them the opportunity to expend time on activities that were unrelated to the care of the patient. Participant 1 conveyed how the task of caregiving was divided amongst the family members:

> …My mother is also there, who takes, uhm, she will do her duties taking care of my grandmother while I'm at school. And then I take care of her when I come from school. We both make sure that she takes her medication on a daily basis, that she has food for the day, and water, tea.

The importance of strong, loving family relationships to keep one grounded in the face of the challenges of caregiving, cannot be overstated. Participant 6 described their family as large and close-knit. The family members were eager to provide a sympathetic ear and offer emotional support, that assisted the participant in coping:

> I also come, from my dad's side of the family, I come from a very, very strong, uhm, family, Uhm, you know, a close-knit family, we're a big family, but we're close-knit. Like, the next person knows what's happening in the next person's life. And I will always have someone, uhm, to talk to, uhm, and more than one person, you know. Uhm, to keep me grounded, uhm, and to share, uh, whatever it is that I'm going through… I think, uhm, for me, support from family has been awesome, uhm, I think, having people around you, it is definitely something that, uhm, is important.

When dealing with the care of a family member who has dementia, new friendships are occasionally formed with people who are experiencing similar difficulties. According to

Participant 5, the people who assisted them and with whom they interacted frequently, became their family:

> While there's, uh, quite an entire new family, if I can put it that way and, uh, most of that family structure that I now have is not, uh, blood relatives or any, uh, kind of link in that respect. So, it's for me, it's more the kind of people that you now interact with, is the people that is it for you, for help. Some of them are neighbours, friends and so on.

The instrumental assistance Participant 4 received from their family, was beneficial. The participant stressed the importance of being surrounded by individuals who can assist one in the caregiving process. Participant 4's children and family members assisted them in feeding and caring for the patient:

> I helped [name] with her children, because she, you know she went back to study, and they helped me with my husband, with their father. So, there was help, there was help, all, from all, both sides. So that's what made it so easy. Because her husband was very helpful. And my youngest, [name] who used to come, and they used to sit with him, feed him, see to him. So, that's why I'm saying it's important to, for family or friends or carers to get support, to be assisted. You need assistance.

Medical Practitioners. Education concerning the disease and its trajectory enlightened the family with regard to the responsibilities of a caregiver. Awareness of the requirements of caregiving-duties attained via information-sharing sessions and counselling sessions, was extremely important to the individuals tasked with the care of a family member with dementia. Health care professionals offered informational and emotional support - this was effected by the participants' close relationships and partnerships with such health care practitioners. This support was provided by institutions and people other than family members. Seven participants reported the positive relationship maintained with the medical practitioners and/or social workers. The support rendered by health care professionals and social workers were crucial to ensuring that participants were prepared for the demands of caregiving and educated concerning the disease's progression. Participant 4 elaborated in respect of the pre-care preparation offered by the neurologist, nurses and counsellor, following their spouse's diagnosis with dementia:

> He (the neurologist) first sort of, he even, he got [*sic*] a counsellor to counsel me, you know. And then he explained everything about care, being, uh, everything about Alzheimer's and dementia… that prepares you, it helps you, you know, and you, and you know exactly what to do… They told me, he told us, not just me, us, what to do, what to expect, and if it wasn't for his words that told us that, well first of all before he diagnosed, before he seen to my husband, he's, he's seen to me. He told me, him, and the nurses, they explained to us, gave us diagrams and videos.

Participant 3 underscored the importance and influence of the information communicated by health professionals: "We just took each day as it comes. Remember, we were already at the doctor who called us, and then she, it was a lady doctor, so she told us what to expect."

When tasked with the care of a family member with dementia, one must consult all available resources, including friends in the medical field. Participant 5 sought guidance from a friend, an occupational therapist, in respect of their spouse's physiotherapy:

> I think in, in, in our situation here, now, uh, I've actually contacted a friend of mine who works at the Netcare centre, uhm, close by. Uh, she's an OT [occupational therapist], and, uhm, that is something that we do need knowledge on and hopefully we might be getting some of that soon. But we do need people to, to come and do, uhm, assistance in that respect. So, the physio and things like that, that needs to be done.

Participant 2 noted how the knowledge acquired from the health professionals aided in managing their uncle's evident cognitive impairment:

> …Meaning, uhm, (assistance) from the health care facility, you know. About characteristics, what should you look for. What should you do if this happens or that happens, and they take the time to explain to you that this is what normally would transpire if you do X, Y and Z.

Additionally, the assistance of and guidance by social workers were perceived as crucial by Participant 6, as this participant-caregiver suffered a mental breakdown and was counselled and supported by the social workers, who facilitated their understanding of their mother's conduct:

> Uhm, and, and they helped me, so Lorraine and her partner (social workers), helped me understand that… Uhm, and they were really, really supportive so, it's, it's, I think that the, the journey has been [*sic*], I think without that kind of support it, it would be really, really hard for me.

Support Groups. One participant accessed a support group as an external resource that contributed to their psychological well-being. Support from individuals in similar situations assisted Participant 4 with managing their experiences. Participant 4 reported that the support group provided emotional support, as they shared their experiences and gave each other advice:

> What helped me a lot was, was, uhm, attending (support) groups, you know, like, like, uh, uh, talking about it and understanding the disease… So that is why I said, also it is, is it [*sic*], it's very important to, to, to, to attend support groups, you know. So, we, we used to help each other… You know for that, support and in, in, in it for me, I would say that was my counselling… But the minute you, you, you, you, you, you, you sort of interact with other people and you talk about it, and you explain, and you know, uh, it makes the task easy.

Theme 5: Coping with the Impact of Caregiving

The theme, coping with the impact of caregiving, encompasses the changes in participants' lives, that resulted from the task of the care of a family member with dementia. Participants reported the impact of caregiving on their employment, finances and relationships. It was evident, from the interview-discourse, how family relationships changed. Owing to the challenges experienced with activities of daily living and the consequent magnitude of the caregiving task, participants expressed the need for relaxation. Furthermore, the demands of rendering care to a family member with dementia restricted employment options and affected participants’ income, as there were obvious financial expenses involved with the provision of such care. The hidden cost of transport, medical supplies and care products, impacted the experiences of five participants.

Coping With Activities of Daily Living. Activities of daily living refers to activities, such as bathing, feeding, toileting, grooming and dressing, that becomes progressively difficult, as the independence of the family member with dementia diminishes. Activities of daily living became compromised, as the dementia advanced and patients’ abilities deteriorated. As the demands of caregiving increased, so did the caregivers’ duties. Seven participants elaborated on the stresses of performing or assisting with activities of daily living, and the ways that they managed to cope.

Participant 2 believed that people were preoccupied with their own lives, since there was no assistance from others, outside of the family. The family accepted this as the norm and devised strategies to cope, by making a family decision to deal with what needs to be done within the family. The participant coped by accepting the arrangement that the caregiving activities had to be managed within the family:

> So, so what we have decided was that,uhm, as a household we will try and, uh, deal with it, because if there's no outside [*sic*], if people don't offer outside assistance, uhm, you not going to demand it from them and you not gonna keep on asking. So, within

> the household, we have accepted arrangements, that we work around it… So we, within the household, that's how we manage. And I think making that decision helped a lot, because now you know that this is what you have to deal with and, uhm, and that I think makes you cope better.

The doctor suggested that Participant 7's spouse be committed to a care facility, owing to the participant's health condition and age. The participant coped by finding a suitable placement for their husband:

> He's [doctor] also very supportive, because he even suggested, as I am not too well and old, we must find some placement for him [husband]... A home, yes. And we had it easy with the process, probably. We have even paid the deposit.

Participant 4 relayed that the care of their spouse was an arduous task and they were obliged to obtain assistance, in order to manage the task. They found it to be impossible to cope without outside help. The participant coped with the activities of daily living by acquiring external assistance, in the form of a male nurse. Participant 4 explained that the male nurse, crucially, assisted with bathing, showering, shaving, and toileting, and supervising their spouse on walks, as they could not have managed in any other way:

> Be it a male or a female nurse, it's important to get that person, uh, uh, when you cannot be available because, uh, uh, for instance, it's also a relief for the carer. I used to get somebody to come in every second day for me, to just have a sort of a, a morning break, or an afternoon break. And it is very, very, very important. And also, when it's, a man too, uh, I preferred the male because my, my, it was for my husband. So, you get a male, uh, uh, person, a carer to assist with, with showering and bathing and shaving and taking him for walks and, and sort of, you know, lifting him up from the, the toilet use, and you know, the ablution facilities or vice versa, but you do need support. Definitely, there's no ways.

Likewise, Participant 3 employed a caregiver to assist with the caregiving task and ameliorate its burden:

> After that we looked for someone, a relative of course, who helped with washing him. It was a man. And then from that old age home where we took him to, there was this one lady, I think who, uh, she got interested in, in him. And she just approached us to say, on the days when she is off, she will come over to know to do all the other duties, like washing the blankets. With bathing him and stuff like that.

Participant 5 explained that it was necessary to receive the assistance of a competent person, someone who understood the demands of caregiving, since they were tasked with the care of two family members with dementia:

> Well, so for what, uh, what has helped me tremendously, is that I've also got now a person that assist me, uh, in, in the caregiving, uh, because I've got two people that, uh, that we are, I'm taking care of. So, that person being here, has been a tremendous help, because, first of all, I'm dealing with somebody who understands what it is.

Coping With the Absence of Personal Time. The absence of personal time refers to the absence of time needed by the participants to take care of themselves - physically, psychologically and emotionally. Owing to the demands of caregiving, five participants expressed their unmet need for personal time, and how they coped with it.

Participant 6 indicated that self-care was vital, by underscoring the need for personal care in dealing with the stressors of caregiving. They were fearful of resenting their mother for becoming ill, should they neglect to manage their own issues whilst providing care for their mother. A decision was taken to ensure that the participant took care of themselves:

> And I, and I always say to people that, uhm, I’m at a point now, where I want to take care of myself, I want to do the things that I need to do, I want to push myself, because I never want to resent her for getting sick and, and taking over my life.

Likewise, Participant 2 indicated that they needed to relieve the strain, as the caregiving experience was stressful. The participant would have better coped with the absence of personal time by engaging someone to assist temporarily, to allow them a respite from the caregiving duties:

> I would say, uhm, for me, it would be time-out. You know, maybe just have, uhm, like, ‘can we take the person?’. ‘Can we look after the person for one weekend out of a month?’ Just to to relieve the strain from it, that, that would be, that would make the world of difference.

Participant 4 stressed the importance of taking time off from caregiving:

> ... A carer must take time off. For instance, if you have to look after your husband or your wife and, and it’s only you, you need to get support. Support for a, for a carer, it, it has to be two, or family member, or you've got to get time off, or maybe do it the morning shift and evening shift, or a day shift or night shift. It's very, very important.

In retrospect, Participant 3 realised that the family member with dementia should be admitted to a care facility or that the services of a full-time caregiver should be employed:

> My advice would be to seek for professional help. I realised that, uh, we did take him to a home, but, uh, we took him back. But then, actually, we shouldn't have done that. Because, uhm, I realised that it was strainful, strainful, for my mom, because as soon as my dad passed on, my mom was very sick, and I was also very sick. I would advise that is [*sic*] either they get a full-time caregiver, or they take him to a place where they will take care of the person.

Impact on Employment. Participants reported that the impact of rendering care on their employment, included arriving late at work, being partially or completely absent from work, reduced working hours, or even the termination of employment in order to cope with the demands of caregiving. Of the eight participants to the study, six were of working age and executing the care of a family member with dementia. Disruptions in employment exacerbated the emotional stress experienced by family caregivers. The process of caregiving indirectly influenced the employability of two participants, resulting in diminished financial resources. Participants discussed the challenges encountered at the workplace and how it was managed. The care of a family member with dementia necessitated compromises. Two of the eight participants reported becoming unemployed or having to work reduced hours, owing to the demands of the caregiving rendered to a family member with dementia. The assistance of family members - and even the gardener and domestic helper – contributed greatly to Participant 4's ability to cope with the caregiving demands. Participant 4 retired early and relocated to Cape Town, in order to provide care for their spouse:

> Well, I had to take early retirement, because, uhm, I had to move to Cape Town and also, I was living with my children… Well, in the beginning, because my daughters were amazing and also, uh, uhm, we had a, uhm, we, we used to, we still have a family that's working for us, like the gardener, and they lived on the property. You know the domestic helper, they were all helping, you know. They would come and change the bedding and do things. So, if you, if you have support, then you don't mind, me, I mean anybody, any human being cannot do, uh, what, that kind of job alone. I mean [you're] stressed.

Furthermore, Participant 1 discussed the detrimental impact of the care of their grandmother, on their employment. They stated that the caregiving task was stressful and time-consuming, resulting in their late arrival to work, or their absence from work on the days of hospital attendance. They cited patience as a quality that assisted them with coping:

> It is also stressful when I take her to the clinic or the hospital, because I transport her to the clinic and the hospital. Then I have to ask for few hours off or rather come late at

> work, even if it's an hour late, because everything takes time… then I treat that day as a day off. But the main thing is, you got [*sic*] to have patience.

The unpredictability of the behaviour by a family member with dementia, could also negatively impact one's employment environment. Participant 3 encountered difficulties with their colleagues, as they frequently arrived late for work. They resolved negative comments regarding their tardiness, by explaining the situation to the manager:

> You know what, it affected my work. My mom was working as a [nursing] sister. And then she would leave very early in the morning. And then I was the one who was supposed to prepare him [father] to stay behind. So, I used to be late at work. Yeah, because, uh, on some days he would respond positively and then I'll be on time. On some days he will respond negatively, doesn't want to dress and then I would struggle. So, it really affected my work and, uh, you know, people at work will start commenting to say he's [*sic*], 'she's always late' and stuff like that. But, fortunately for me, I spoke to my manager then, and then he understood...

Participant 2 overcame the employment challenges by their candid admission concerning the need for assistance. They shared their experiences and requested assistance, and this enabled them to cope with the demands of caregiving combined with employment:

> It's actually, uhm, sometimes it is difficult. But, uhm, how can I say? You, you try and juggle everything. Like, you would make people aware that this is what you deal with, and if [you're] open about it, it makes you cope better and your schedules, you can then, uhm, adjust it accordingly. And I think it's a question of, if you need assistance, then you just need to be open about it and ask people for help.

Impact on Finances. Finances to access medical resources and information is essential when rendering quality care to a family member with dementia. Participant 4 stated that the assistance of a nurse is imperative, however, should the family be unable to acquire the assistance of a nurse, the extended family must assist:

> If you cannot afford a nurse, day nurses or a night nurse or a special carer for Alzheimer's, it is very difficult, extremely difficult to support a person with Alzheimer's, it's terrible… I don't know if the people that cannot afford carers, it's very tough, but it's very, very difficult. So that's where the, the family comes in. Support wise, you know, if you have a family to assist you.

Caring for a dementia sufferer necessitates financial resources. The food and medical supplies for Participant 5’s husband and sister, were expensive. The participant was supported by their ex-colleagues and friends, who regularly donated these necessities:

> Uh, other things is, like I say, I've, I've really got, uhm, people that I was friends and people that I've worked with, that assist me as [*sic*] in different ways, in terms of, uh, sometimes with, with food and with the funding for incontinence pads and things like that. It's really been a tremendous help.

Similarly, Participant 8 reported that they hired someone to run errands for them as they were unable to leave their mother at home. They remarked that it was an expensive exercise, however, there was no other recourse:

> …I have to kinda [*sic*], like, always, uhm, hire people to go there and there for me, to get things for me. And that on its own, it's kinda [*sic*] like, uh, too much, because of, it's also consuming and a lot of money. [Because] I need to pay these people, they [*sic*] and, uhm, I don't have, I don't have [a] life anymore. I can't move, I'm forever at home. … I sent people around to do things for me, even my personal things, I will have to trust a certain person to kinda [*sic*], like, do things for me too, and that on its own, also it's, it's, it's, it's a problem, because now there are things out there that need me in person.

Summary

In chapter 4, participants' interview transcripts were analysed, in order to determine the results of the study, using a phenomenological approach. Emergent themes and subthemes were analysed and presented. Five themes emerged from the analysis, underscoring the importance of personality characteristics, the impact of information, experiential understanding, access to external resources, and coping with the impact of caregiving. A significant part of the discussion focused on the coping strategies utilised by participants during their caregiving experiences. Based on the results of the data analysis in chapter 4, chapter 5 will summarise the findings, limitations and recommendations, derived from the study.

Chapter 5

Findings, Discussion and Conclusion

Chapter 5 presents the findings of the data analysis in respect of the lived experiences of individuals tasked with the care of a family member with dementia. The Worsley resilience doughnut model and research questions informed and guided the discussion. Following the analysis of data discussed in Chapter 4, an overview of the research findings and recommendations are presented.

Overview of the Study

A qualitative design was utilised to gain a deeper understanding of how participants interpret and construct meaning regarding their lived experiences when tasked with the care of a dementia sufferer. Specifically, this study examined how participants employed coping strategies, resulting in the development of resilience. This study adopted a phenomenological approach in order to achieve its objective. Semi-structured interviews were conducted with eight individuals who were purposively selected and met the inclusion criteria. All interviews were video recorded, transcribed and analysed, employing the guidelines for an interpretative phenomenological analysis. The interviews addressed the research question:

How do familial caregivers develop coping skills that foster the resilience required to successfully manage the challenges of caring for a family member with dementia?

Five themes and 20 subthemes emerged from the narratives. The findings derived from the five themes, namely (1) positive personality characteristics, (2) an experiential understanding of caregiving, (3) the impact of information, (4) accessing external resources as a key factor, and (5) coping with the impact of caregiving, will be discussed next.

The Themes and its Implications

Resilience is the ability to rebound from adversity, resulting in a positive outcome (Ledesma, 2014). Resilient individuals positively and successfully adapt to the disturbance of their homeostasis, by employing coping skills to address adversity (Joling et al., 2016). The resilience doughnut model comprises three interacting tenets. Firstly, resilience is a process of continual development; secondly, individuals negotiate and navigate available resources; and lastly, these processes occur when adversities are present (Graber et al., 2015). As per the data analysis reported in Chapter 4, all three tenets of the resilience doughnut theory were present. Participants showed resilience whilst being tasked with the care of a dementia sufferer by continuously developing their informational repertoire and improving their skills relating to providing care and coping with adversities. Furthermore, participants also negotiated and navigated the different available resources, including their partners, communities, families, colleagues, friends, medical practitioners, and other resources, such as websites containing information on dementia. All of the participants encountered the adversity of having to care for a family member with dementia whilst having no formal training or prior experience relating to the care duties. Participants thrived and showed hardiness, by educating other friends and family members concerning the disease. The resilience doughnut model considers both the personal characteristics that enable one to overcome adversity, and the person's interaction with the available external resources.

Theme 1: Positive Personality Characteristics

Participants coped with the impact of caregiving by employing and/or developing positive personality characteristics, such as patience, calm, tolerance and perspective. This study found that these personality characteristics played a major role in the development of resilience in participants. Similarly, Worsley (2015) found that positive personality characteristics play a pivotal role in the development of resilience. Accordingly, these characteristics proved invaluable in coping with the uncertainties and unwanted behaviours that accompany dementia. Furthermore, these characteristics served as promotive and protective factors for participants. Masten and Coatsworth (1998) also identified positive personality traits as individual protective factors.

This study showed that caregivers managed adversity by remaining calm and employing patience. The participants were not disturbed or upset by the behaviours of the dementia sufferer. They practised patience and calm during the erratic episodes associated with the disease and coped, for example, by opting to leave the room until the person had calmed down or by simply ignoring the behaviour exhibited by the dementia sufferer. Resilience was therefore fostered by taking decisive actions to ignore such outbursts.

Ledesma (2014) identified a high sense of tolerance of uncertainty as a personal quality for developing resilience. Innate or acquired positive personality characteristics of patience and calmness enabled caregivers to exercise tolerance and changed the participants' perspectives concerning caregiving duties. The socially unacceptable behaviours of the dementia sufferer were perceived as part of the trajectory of the condition, not as deliberate acts. By obtaining information regarding the disease, caregivers acted from a position of understanding, that enabled them to tolerate the undesirable behaviour. Participants, thus, reacted compassionately to the dementia sufferer's plight.

Ledesma (2014) defined thriving as strengthened resilience. Additionally, Fleming and Ledogar (2008) identified psychological and emotional growth as central concepts of thriving, positing that, in order to develop resilience, individuals must experience a positive transformation, a stronger sense of self, refocus their priorities, and undergo a cognitive shift concerning adversity. This study found that a positive transformation occurred when the caregiver's perspective of providing care for a family member with dementia changed. The change in perspective and priorities assisted participants to better accommodate the needs of the dementia sufferer and resulted in caregivers coping with the situation. This transformed the perspective from egocentrism to altruism, where the needs of the family member with dementia were afforded precedence over the carer’s own needs. A cognitive shift in the participants' approach to the caregiving task also resulted from the understanding that the dementia sufferer's erratic behaviour was a symptom of the disease. The change of perspective, where the dementia sufferer's behaviour was attributed to cognitive decline, was a conscious and intentional coping strategy that promoted resilience. Manzini et al. (2016) emphasised that a characteristic of coping strategies is that it is intentional and conscious. Cognitive and behavioural changes must be employed to successfully overcome adversity (Manzini et al., 2016). The focus was on the family member with dementia and not the condition. Rather than viewing the experiences as negative, perspectives were altered, and the focus shifted to positive aspects of caregiving. Participants continuously improved the quality of care provided so that their loved ones with dementia could live better lives. Participants relinquished previously enjoyed activities and hobbies to provide care to the dementia sufferer, refocusing their priorities.

In order to cope with the adversities associated with caregiving, caregivers developed a stronger sense of self and derived meaning from the experience. Participants expressed a sense of value for the life of the family member with dementia and treated them in a humane and dignified manner. The individuals expressed a sense of purpose and commitment to the task of caregiving, as well as a sense of mastery and satisfaction, that aided in the development of resilience. In a recent study, Basch (2019) also identified assets associated with resilience as a sense of purpose, competence and autonomy.

Moreover, the resilience doughnut model defines I am as the positive sense of self and the strengths of the individual (Worsley, 2015). Findings from this study highlighted the secure sense of self and internal strengths (positive personality characteristics) or assets individuals developed after obtaining information concerning the disease. These individuals accepted responsibility for their actions by adjusting their caregiving activities according to the needs of the family member with dementia. The care rendered by the participants increased their feelings of self-confidence, leading to an appreciation of the quality of their own lives. The employment of positive personality characteristics, self-efficacy and the utilisation of available resources, were imperative in coping with the adversity of caring for a dementia sufferer. The participants employed these assets, resulting in the development of resilience.

Theme 2: An Experiential Understanding of Caregiving

Participants coped by gaining an experiential understanding of the disease via the insights acquired from their observations, the adaptations made, the acceptance of the situation, and the personal growth that resulted from the caregiving process. The participants explained how, based on their observations and daily experiences, they could predict and anticipate the behaviour of the family member with dementia. As a result of observing and caring for the patient, the participants acquired knowledge and insights that assisted them in dealing with stressful situations. Their understanding and awareness of dementia and the progression of the disease were not solely based on information communicated by medical practitioners or such that was acquired online. Observations were a crucial instrument to gain insight into the unique needs and demands of the patient and the trajectory of the disease. These insights led to an in-depth understanding of the family members' needs, daily caregiving challenges and/or the suffering associated with the disease. Participants developed skills in observing and understanding the needs of the dementia sufferer in response to the decrease in communication on the part of the patient, as a result of the disease’s trajectory. The insights also facilitated an understanding of the efficacy of the medication. One participant noticed that the medication calmed the dementia sufferer when it was taken during the daytime and therefore changed the time when the medication was administered. The participant used this coping strategy to assist with reducing erratic behaviour episodes. Furthermore, the insights acquired from observations aided the participants in deciding how to manage the ever-changing behaviour of the family member with dementia. These insights instilled a sense of accomplishment and fulfilment, as they acquired new skills to deal and cope with uncertainties. Participants could identify when external assistance was required, based on the insights garnered. This also prepared them to cope with future adversities. The insights gained nurture protective factors and enhance resilience (Deist & Greeff, 2014). Participants reported their experiences of personal growth resulting from insights gained via self-exploration and observation of the family member with dementia. Participants were informed regarding the symptoms of the disease and were able to cope with the changes in the behaviour of the dementia sufferer, based on the insights garnered from their observations.

Luthar et al. (2000) suggested the necessity of two conditions to build resilience, namely exposure to a risk or threat, and adaptation to the risk. The participants were exposed to the risk of caregiving without prior knowledge of the demands that it entailed. Additionally, adaptation to the process of caregiving occurred by improving their skills to deliver enhanced care for a dementia sufferer. The participants effectively adapted their lifestyles to better support the family member with dementia, by being flexible. Van den Hoonaard and Van den Hoonaard (2008) found that resilience is a result of adapting to adversities. The participants also portrayed hardiness in dealing with the undesirable behaviour of the patient. Hardiness can be seen in how the participants coped with the unanticipated changes required in the process of caregiving. Ledesma (2014) and Mosley and Laborde (2016) explicated that psychological hardiness is the ability of an individual to successfully master change. All the participants adapted to the caregiving demands and utilised different approaches and skills, according to the needs of the dementia sufferer, in order to successfully cope with the ever-changing demands of caregiving.

The APA (2022) noted that, in order to build resilience a person must, amongst other factors, acknowledge that change is a part of life, and they must move toward realistic and attainable goals. This study found that participants acknowledged and accepted the fact that the dementia patient was not the same person they used to be. This is attributed to the cognitive impairment that is characteristic of the disease. The family members also accepted that change was a part of life and altered their perspective. They understood that the disease is fatal and that it cannot be reversed. As a result of the participants' acceptance of the diagnosis of dementia, they were able to adapt positively, which contributed to their resilience.

Miller et al. (2016) reported that a resilient adult will employ problem-solving skills, display a sense of purpose and social competence, as well as demonstrate the ability to adapt. The sense of purpose in providing the most effective care to the dementia sufferer, combined with participants' internal characteristics, resulted in the positive outcomes of sustainability, recovery and personal growth. Similarly, Worsley (2015) found that sustainability, recovery and personal growth are the result of a combination of internal characteristics.

According to Eroz and Onat (2018), the attitude of a resilient individual comprises a combination of control, commitment and challenge. The participants employed their social competence skills and accessed external resources successfully, when required. The participants communicated a sense of purpose, with one participant stating that they were born to care for dementia sufferers. Participants showed commitment by not relegating the task to someone else, despite the challenging nature of caregiving. Through these challenges, personal growth occurred, as they adapted and improved their caregiving skills, whilst negotiating and navigating resources outside the family. Eroz and Onat (2018) explained that resilience emerges as an attitude that transforms potential threats into opportunities for growth.

Family members with dementia require 24-hour assistance and continuous monitoring, and the associated care is classified as frail care. One of the participants opted to admit the family member with dementia to an institution, as a coping strategy, as a consequence of her poor health and inability to provide adequate care. However, seven participants expressed a reluctance to admit the dementia sufferer to a care facility, as they would not receive the same quality of care that would be provided at home. Having their skills recognised by others created a feeling of contentment and a sense of efficacy. Likewise, Worsley (2015) postulated that a strong skill factor is an indication that a person mastered a skill and has a reputation for possessing a skill, that leads to a sense of satisfaction. The participants, thus, employed effective coping strategies to lessen the effect of the adversity, resulting in the development of resilience. Similarly, Jackson et al. (2007), Kardum et al. (2012), Ledesma (2014), Mosley and Laborde (2016), and Walsh (1996) explained that effective coping strategies reduce the negative impact of adversity and ultimately aid the development of resilience. This study found that an understanding of the dementia sufferers' needs and demands, and the employment of coping strategies, resulted in an improved state of functioning - subsequent to overcoming the adversities associated with caring for a dementia patient. Furthermore, psychological thriving reflects gains in skills (Carver, 1998; Ledesma, 2014). Participants acquired new skills whilst providing care and personal growth occurred, as they acquired novel caregiving skills, resulting in psychological thriving. Additionally, Carver (1998) and Liersch-Sumskis (2013) advocated that a person who experiences thriving exhibited functioning at a higher level than prior to the encounter with the adversity. As new protective factors were developed and personal growth occurred, participants experienced improved functioning pertaining to providing care for a dementia sufferer. This experience of personal growth underpins the concept of thriving (Liersch-Sumskis, 2013).

Liebenberg et al. (2017) stated that individuals required self-awareness in order to effectively engage their own meaning-making processes. This self-awareness is the ability to discover who they are and what they are capable of. To adapt to and cope with their situation, participants developed self-awareness, by employing a variety of coping strategies, such as sharing their experiences with others and journaling. Dias et al. (2015) reported that when coping strategies are employed, a higher level of resilience associated with strengthened psychological well-being is achieved and the stress is lessened. This reduction in stress and the perception of being in control, fostered resilience. Furthermore, resilience was strengthened by the use of positive cognitions, such as optimism and a healthy sense of self-worth. The study has confirmed the findings of Windle and Bennett (2012), that a caregiver’s optimism positively contributed to the development of resilience.

Additionally, Worsley (2015) indicated that the factors promoting the development of resilience are a combination of internal and external factors. Internal factors are categorised as I have, I am, and I can. Worsley and Hjemdal (2016) defined I am as self-awareness and positive self-esteem and I can as experiences of self-efficacy. All participants shared how their experiences brought about a sense of self-awareness, as well as how they needed to find the inner strength to manage and cope with the demands of administering care to a dementia sufferer. External support and resources contribute to the development of personal skills required in developing resilience (Worsley & Hjemdal, 2016).

Family members have learned and mastered the skill of providing for the dementia sufferers. Whilst caring for the family member with dementia, the participants invoked hidden strengths and courage that enabled them to thrive in the face of adversity. This was accomplished through acceptance, coping, negotiation, and adaptation to the stress created by caring for a dementia sufferer. Participants utilised their inner strengths to navigate and negotiate available external resources, as a way to develop and foster resilience. Coping skills improved when caring for a family member with dementia. These vital assets functioned as protective and promotive factors during adverse situations.

Worsley (2015) stated that a strong skill factor requires, *inter alia*, hardiness, recognition of skill, a willingness to try novel experiences, and a sense of success and achievement. This study found that all the participants improved their caregiving skills by exploring creative ways to attend to the needs of the dementia sufferer. Participants gained an experiential understanding of the skills associated with caring for a dementia sufferer, which assisted them in coping with the cognitive decline associated with the disease.

Theme 3: The Impact of Information

Worsley (2015) defined a strong education factor as an enjoyment of learning as well as an understanding of how to conduct research. By consistently engaging with information concerning the disease and its symptoms, the participants empowered themselves through continuous learning - a characteristic of resilient adults. Education is considered a protective factor in promoting resilience.

All the participants emphasised the importance of obtaining information and knowledge related to the condition. There was a general lack of knowledge regarding the disease itself and caregiving requirements specifically, during the early stages of the disease, as caregivers were initially ignorant of what to expect as the illness progressed. Individuals only acquired knowledge in respect of dementia subsequent to its diagnosis. It was vital to consider this pertinent issue since it impeded the identification of the onset of the disease and hindered the initial provision of appropriate care for the family member with dementia. Moreover, the lack of knowledge extended to the general public, where there was a paucity of awareness of dementia. As a consequence of this lack of general awareness, the undesirable and unexplained behaviour of the family member with dementia was, at times, attributed to witchcraft. Additionally, society was also apprehensive when dealing with a disease caused by mental illness, as some community members were not informed of the symptoms of dementia. This study found that the knowledge gap was reduced when caregivers consulted various research platforms. Conducting research on the condition and frequent consultations with health care professionals served as information sources regarding the disease and the trajectory of its symptoms. The participants were, thus, able to identify the various stages of the disease and understand the newly acquired behaviours of the dementia sufferer. All participants engaged in continual development with regard to obtaining knowledge pertaining to the disease.

The irrational and unpredictable behaviour of the family member with dementia, was found to be one of the major stressors experienced. Participants were often prone to abuse or embarrassing situations, as a result of this behaviour. In addition, this behaviour was initially misunderstood by the community and frequently scorned. Participants experienced increased emotional and psychological stress, as a result of the dementia sufferer's refusal to cooperate.

Over time, participants acquired a deeper understanding of the trajectory and symptoms of the disease, from a variety of sources. Knowledge and insight gained from the caregiving experience resulted in the reduction of emotional and psychological strain. Acquiring knowledge concerning dementia assisted individuals tasked with the care of a family member with dementia, to cope with the challenges faced. Participants experienced a better understanding of the condition, upon obtaining information from numerous sources. Advocacy of the symptoms and trajectory of the disease was undoubtedly critical and lacking, however, this was overcome by sharing the newly acquired information with relatives, friends and neighbours.

Theme 4: Accessing External Resources as a Key Factor

Miller et al. (2016) and Worsley (2015) found that the development of resilience involved positive changes within an individual and is the result of the interaction of the individual's internal strengths with healthy external resources and relationships. These external factors that promote the development of resilience are the partner factor, the skill factor, the family factor, the education factor, the friend factor, the community factor, and the work and money management factor (Worsley, 2015). In addition, Garmezy et al. (1984) found that the familial factors (family cohesion, positive emotional climate), and factors external to the family (community assistance, physical help, feelings of bondedness, financial assistance) contributed significantly to the development of resilience. These factors are referred to as protective factors. Findings in this study indicated that access to and support from various external sources played a crucial role in managing and coping with the stressors of administering care to a family member with dementia. The caregivers emphasised the need for emotional, instrumental and informational support, from a variety of sources. Access to positive emotional, psychological, instrumental and informational support from sources outside of the family, positively contributed to the participants' ability to manage and cope with the adversities associated with caregiving.

Participants conducted meaningful relationships with spouses, friends, supportive family members, community members, support groups and medical practitioners. Additionally, these meaningful relationships provided a number of participants with a form of respite, as they were able to address some of their personal needs and allowed them take time off from caregiving in order to relax. Healthy relationships with available external sources were significant sources of support and are necessary for the development of resilience. Similarly, Liebenberg et al. (2017) identified supportive and trusting relationships as a main factor in the development of resilience. A secure and trusted environment, where open communication and effective support occurred, fostered resilience. Caregivers coped by strengthening existing relationships and/or forming new friendships. These emotional support structures allowed participants to seek advice, vent their frustrations, and assisted them to cope with the demands of caregiving. In addition, these support structures allowed individuals to talk about their challenges. These discussions assisted participants to relieve stress and also engage in an activity other than caring for the dementia sufferer.

Three of the participants’ spouses provided support and assisted with caregiving duties. This reduced the emotional and physical stress experienced by the relevant participants. Worsley (2015) emphasised the importance of healthy and strong relationships with significant others, as a tool for building resilience. Participants reported the positive psychological effects that having a supportive partner had on building resilience and increasing their sense of security. Carver (1998) and Ledesma (2014) posited that a sense of security positively contributed to psychological thriving.

One of the three levels of protective factors, identified by Masten and Coatsworth (1998), is the family level. This level includes close and supportive relationships with extended family, to build resilience. Positive family characteristics, such as love, affection, optimism, clear and open communication and family closeness, enabled the participants to exercise emotional and self-regulation. This allowed family members to cope with the condition, to exercise control over their emotional states and manage their frustrations. These included actions, such as rethinking the situation to alleviate frustration or anxiety, suppressing outward signs of stress or fear, or focusing on reasons to feel positive or relaxed.

Participants also shared their feelings with other family members. They reported strong and healthy relationships with their families, based on a sense of belonging and connectedness, as they shared the same concern and affection for the family member with dementia (Garmezy, 1987). These feelings contributed positively to coping with adversity. Similarly, Walsh (1996) found that a sense of connectedness and closeness within the family positively contributed to the development of resilience. In addition, Rutter (2013) and Shean (2015) stated that positive familial and environmental structures facilitated resilience, when faced with an adversity. The positive family environment acted as a protective factor against the behavioural and emotional disruption of caregiving and fostered the development of resilience.

Community support was one of the levels of support available to both caregivers and dementia sufferers, alike. This support came from individuals and institutions, other than family members. Participants commented on the role that the community played in contributing to their resilience and the healthy relationships they formed with community members. Masten (2001) posited that resilience is not a result of special and rare qualities held by individuals, rather, it is a result of, *inter alia*, relationships formed with community members. Community support included support from church members, neighbours and other community members. The community often supported the participants instrumentally, such as through physical assistance and financial aid, as well as emotionally, by regularly checking on the well-being of both the carer and the patient. This created a sense of belonging and a shared interest in the well-being of the family member with dementia, that positively contributed to building resilience amongst participants. This study found that community support factors included financial assistance, instrumental assistance, social support, and a common interest in the well-being of both the caregiver and dementia sufferer. These support structures acted as a platform for participants to obtain advice and vent their frustrations, and assisted them to cope with the demands of caregiving.

Support from those in similar situations also served as a coping mechanism, in the development of resilience. One participant reported the positive influence of support groups, serving both as a form of motivation as well as offering some respite time.

In addition, this study found that healthy relationships with medical practitioners was imperative. Medical professionals provided informational and emotional support, to assist participants in accepting the changes in the behaviour of the dementia sufferer, and to self-regulate when frustrated.

According to Miller et al. (2016), I have”in the resilience doughnut model is an awareness of sustainable and supportive social resources available to an individual, that promote resilience. Participants used their internal strengths to successfully navigate and negotiate the available resources. Likewise, Ungar (2012) posited that the processes associated with the development of resilience involved the positive negotiation and navigation of the available resources. Participants were possessed of a sound understanding and awareness of the resources available to them and fostered resilience in the face of adversity by establishing trusting relationships with family, friends and the community. The influence of social support networks played an influential role in addressing adversities faced by caregivers. The social support networks positively contributed to the psychological well-being of the caregivers, by alleviating stress. Aside from the instrumental support offered by external sources, family and friends also served as emotional support structures, by providing participants with a platform to express their frustrations. Similarly, communicating their experiences of caregiving was found to be a critical factor in building resilience. It is important to note that not all seven factors identified by the donut model need to be present or prevalent, for resilience to develop (Basch, 2019; Miller et al. 2016; Worsley, 2014). Miller et al. (2016) concluded that only three of the seven factors need to be present and strong, to enable the development of resilience. Findings in this study indicated that at least three strong external resources were available to all participants.

Theme 5: Coping with the Impact of Caregiving

Previous findings regarding the challenges associated with the care of dementia sufferers revealed a great number of similarities. Although Zauszniewski et al., (2009) identified stigma, isolation, employment restrictions, or appraising a situation as burdensome as examples of risk factors, participants discussed the coping strategies they employed to cope with such challenges.

In this study, each participant assisted the family member with dementia with activities of daily living. The participants performed these activities more frequently as the neurodegenerative process progressed. Participants experienced stress ascribed to these physical demands of caregiving. However, external resources were acquired to alleviate the stress associated with the demands of care. The care for a family member with dementia is nearly impossible without the assistance of competent individuals. Participants requested their friends and family members to assist them with the caregiving duties. Furthermore, the services of formal caregivers, such as nurses, were enlisted when the caregiving task became too arduous.

Exposure to the gradual deterioration of the dementia sufferers' cognitive abilities, was one of the low-level risks confronting the participants. Daily exposure to these low-level risks - acting as steeling events, facilitated coping skills, as the dementia sufferer's disease progressed. Similarly, Rutter (1999) found that repeated exposure to low-level risks facilitated resilience. This assisted the participants to process and cope with the loss of communication experienced by the dementia sufferer, in the later stages of the disease.

People with dementia often experience cognitive decline and revert to a childlike state as the disease progresses. This regression required a new role for caregivers, as a consequence of the dementia patient's cognitive decline. The person with dementia was no longer able to assume the role of father or mother, resulting in the caregiver adopting a maternal role. The caregivers became responsible for all tasks and decisions previously performed by the person with dementia. Over time, the roles of the person with dementia and the caregiver changed from a mother-child or husband-wife role to a maternal-dependent role. This transformation often resulted in emotional and psychological stress that was not only attributed to the loss of the relationship, but also ascribed to the additional responsibilities that accompanied the new roles. In addition, the person who had previously been the participant's support system now required care and support themselves. The information gleaned by the participants from their research on the disease, explained the changes to be expected in the relationship with the patient and enabled participants to find novel ways of managing the situation, thus adapting positively to the adversity. Similarly, Iavarone et al. (2014) and Nikos et al. (2009) defined coping as a positive adaptation to an adversity. Rather than succumbing to depression or avoiding adversity with unhealthy coping strategies, participants faced the challenges, thus, resulting in resilience and - in certain cases - even thriving.

Zauszniewski et al. (2009) reported restriction of employability as a risk factor. Being tasked with the care of a family member diagnosed with dementia, negatively impacts employability. Reduction of working hours and - in one case - early retirement, were certain consequences of the caregiving responsibilities. The participants frequently arrived late for work or were compelled to take leave from work for a day, as a consequence of providing for the family member with dementia. One participant coped by performing odd jobs when they had time available, as they were unable to work a full day. Additionally, some participants made alternative arrangements to cope with work demands or they worked fewer hours on the days on which hospital visits were required and/or treated these days as work-leave days. Another participant coped with their challenges by communicating with their employer and co-workers to explain their late arrivals and absence.

The findings in this study indicated that some participants reported little or no impact on their finances, while others experienced major challenges with regard to the financial burden associated with caring for a dementia patient. Irrespective of whether they were facing financial difficulties or not, it was found that being tasked with the care of a family member with dementia resulted in significant financial implications. Furthermore, as the disease progressed, additional expenses related to adult diapers, hospital visits and medication, were incurred. Although some participants experienced challenges with the effective management of finances, plans were developed to address the lack of finances. Cognitive and behavioural adaptations were made by the participants. Positive psychological adaptation to financial burden assisted caregivers in coping with the challenges they faced (Manzini et al., 2016). The ability to plan and determination are two of the cognitive factors that positively affected the way that participants coped with these adversities and played a vital role in the development of resilience. Rutter (2013) identified the ability to plan and a sense of determination as contributing factors that enable individuals to exercise control over changing events that, in turn, build resilience. The participants coped by executing a conscious effort to access external resources, i.e., requesting friends and family to contribute to the medical supplies and other needs of the dementia sufferer. Similarly, Manzini et al. (2016) found that financial support alleviates the caregiver's emotional and physical burden. Financial support from external sources relieved and ameliorated the negative financial impact of caregiving on participants. Nonetheless, the majority of participants reported a state of financial stability. The assumption of additional financial responsibilities instilled a sense of requiring financial management skills, related to the gains in skills that fosters the development of resilience. The resilience doughnut model explicates that the work and money factor relate to the presence of a strong work ethic, work values, accountability and economic stability, all of which were portrayed by the participants (Worsley, 2015).

Participants were availed of limited or no time to engage in social activities or to attend to personal matters, as a result of the caregiving activities. Participants were no longer able to participate in previously enjoyed activities, as caregiving took precedence over social activities. Participants overcame these challenges by employing different coping strategies. One participant employed a friend to run errands on their behalf, whilst another participant managed to balance their interests with the caregiving activities by hosting social gatherings at their own home.

Conclusion

In summation, participants overcame the adversity of caring for a family member with dementia by employing protective factors, navigating and negotiating external resources, and acquiring skills. This study found that participants experienced growth (personal growth), optimism/positive attitudes (positive personality characteristics), successful adaptation to a threat (acceptance and adaptation), gains in knowledge and skills (experiential understanding/continuously gathering knowledge), and connections with others (accessing external resources), that assisted them to develop resilience and, ultimately, thrive.

The findings provide insights into the lived experiences of individuals tasked with the care of a family member with dementia, revealing the coping strategies employed to deal with the adversity. Furthermore, the study underscored the development of resilience within these individuals. There are several commonalities across different theorists' conceptions of resilience. Firstly, theorists postulated that resilience requires both experiencing a disruption in the individual's homeostasis and executing positive adaptations in order to face adversity. All participants endured the adversity of caring for a family member with dementia and implemented positive adjustments to meet the needs of the dementia sufferer. Secondly, theorists agreed that resilience is an outcome of the successful interaction between the individual and the environment. As observed, participants used their internal strengths to successfully access external resources. Thirdly, resilience is a dynamic and ongoing process. Participants in the study evolved by changing their perspectives and experiencing personal growth through the caregiving task. Fourthly, theorists agreed that cumulative risks are more detrimental than individual risks. The study illustrated that the cumulative and individual risks faced acted as steeling events for the participants. Fifthly, the effects of protective factors operate at three levels, i.e., the individual, the family, and the environment. Participants employed their positive personality characteristics, family cohesion and relationships with others, to develop resilience. Sixth, turning points are essential in the fostering of resilience. Participants utilised their past experiences to adapt to the novel experiences of providing care positively and constructively, by utilising the insight gained.

Worsley (2015) asserted that resilience developed when internal and external factors work in tandem to successfully face adversity. The findings in this study illustrate this interaction between various internal and external factors. This study has shown that participants drew from their positive personality characteristics and their experiential understanding, to interact with the various external resources in order to cope with the adversities they faced whilst caring for a dementia patient.

Furthermore, resilience is a dynamic process and is motivated by hardiness and the utilisation of coping strategies. The results of the study confirmed that individuals tasked with caring for a family member with dementia developed resilience by employing coping strategies and developing hardiness, whilst providing care. These individuals employed a variety of coping strategies to manage the emotional, physical and psychological stressors they experienced. Positive adaptation to risk was achieved by navigating and negotiating the resources available to them. As a result, each caregiver developed a method for managing, accepting and adapting to the stressors associated with caregiving, that resulted in personal growth, improved coping skills and resilience, enabling them to thrive.

In addition, activities of daily living, coupled with a lack of information, were shown to play a significant role in participants' distress. The participants effectively addressed the lack of knowledge by educating themselves and seeking external assistance. Participants conveyed the need for advocacy, support, respite services and frail care centres. The results of this investigation show that participants employed a variety of coping strategies in the face of adversity, resulting in the development of resilience.

This phenomenological study provided insights into the lived experiences of family members tasked with the care of a dementia sufferer. The study revealed that the participants endured stressful experiences related to caregiving. However, through the caregiving journey, these caregivers thrived, by employing positive personality characteristics to cope with the demands of caregiving. Moreover, participants were able to manage the adversity and develop resilience, by gaining an experiential understanding of care responsibilities, gathering information, and accessing external resources. The present study provides additional information to contribute to the growing body of literature on the lived experiences of individuals tasked with the care of a family member with dementia.

Recommendations

The recommendations are focused on addressing the challenges confronting individuals tasked with the care of a family member with dementia. This study produced three recommendations for the care of a family member with dementia. The first is for advocacy and education of the general public concerning dementia and its symptoms, to enable individuals to recognise the disease at an early stage and to improve their understanding of what the care of a dementia sufferer entails. The need for advocacy, support services, counselling sessions and ongoing skills training, must be met by the health department. Dissemination of information is an essential part of the function of health departments. Caregivers will benefit from the information as they would be better prepared, psychologically and emotionally. The provision of educational events should be an objective of the health department. Caregivers should be encouraged to join support groups for their psychological well-being. These forums will allow caregivers to communicate with others, who face similar situations and experiences. Secondly, a state subsidy or grant for medical supplies, is recommended for people with dementia. This will reduce the financial stress experienced by caregivers in providing appropriate care for a person with dementia. The final recommendation is that the state should provide counselling services for both the person with dementia and the caregiver. One finding in this study was that few participants had access to counselling services that offered them an opportunity to deal with the emotional and psychological stress they were experiencing.

Previous studies reported on the lived experiences of individuals diagnosed with dementia, and how these individuals develop resilience. However, the development of resilience in the caregivers is less explored. There is a need for additional studies concerning the development of resilience in family-caregivers of dementia sufferers. Moreover, there is a need for research to explore the employment of protective factors and interventions in individuals tasked with the care of a dementia sufferer. The health department should seek to identify and address the challenges faced by caregivers, by conducting such vital research.

Limitations

This study was conducted with a limited number of participants. IPA research employs a small number of participants to elicit lavish, detailed descriptions. The sample in this study was small, with eight participants, as in-depth interviews were conducted with all participants. IPA is judged according to the information it renders regarding its applicability in the broader context. Furthermore, Thomas (2010) substantiated that the outcomes of IPA cannot be extensively generalised and only present the contextual discoveries to advance our general understanding of the phenomenon. A second limitation of the study is that it does not represent all races. Participants were sourced from the Alzheimer's institute in South Africa based in Soweto, Gauteng. The study included four coloured participants and four African participants. There were no Indian or White participants serviced by the specific unit. A third limitation identified, was that the interviews were not conducted in participants' first language. Interviews in the participants’ first language could possibly have yielded richer descriptions. A fourth limitation of the study pertained to the fact that the interviews were conducted online rather than face-to-face. Although the interviewer aimed to create rapport with the participants, they may have been more comfortable expressing themselves in a face-to-face setting, rather than virtually. Interviewers can potentially build a stronger rapport with participants when conducting face-to-face interviews, that can produce richer information related to the participants’ experiences.

References

Achari, P. D. (2014). *Research methodology*. Horizon Books. ISBN 9384044075

Adams, C., & Van Manen, M. (2008). Phenomenology. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 615-619). SAGE Publications. http://dx.doi.org/10.4135/9781412963909.n317

American Psychological Association. (2012, January 1). *Building your resilience*. https://www.apa.org/topics/resilience/building-your-resilience

Ando, H., Cousins, R., & Young, C. (2014). Achieving saturation in thematic analysis: Development and refinement of a codebook. *Comprehensive Psychology*, *3*, 03.CP.3.4. https://doi.org/10.2466/03.cp.3.4

APA, see American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5-TR*. American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890425596

APA, see American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders, fifth edition, text revision (DSM-5-TR)*. American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890425787

Ashrafizadeh, H., Gheibizadeh, M., Rassouli, M., Hajibabaee, F., & Rostami, S. (2021). Explain the experience of family caregivers regarding care of Alzheimer’s patients: A qualitative study. *Frontiers in Psychology*, *12*. https://doi.org/10.3389/fpsyg.2021.699959

Axelrod, J. (2018, October 8). *The 5 Stages of Grief & Loss*. Psych Central. https://psychcentral.com/lib/the-5-stages-of-loss-and-grief/

Azermai, M. (2015). Dealing with behavioral and psychological symptoms of dementia: A general overview. *Psychology Research and Behavior Management*, 181. https://doi.org/10.2147/prbm.s44775

Basch J. (2019, November 12). An exploration of internal assets and external resources as a pathway for building resilience. In L. S. Lattke, A. De Lorenzo, M. Settanni, E. Rabaglietti (Eds.), *Socio-relational well-being and dropout in vocational schools: A study on school engagement and satisfaction* [Conference Session]. 2nd International Conference on Well-being in Education Systems, Svizzera, Italy. https://www2.supsi.ch/cms/wellbeing/wp-content/uploads/sites/28/2019/10/2ndEdition_ScientificProgram.pdf

Bartone, P. T. (nd). *Hardiness concept*. https://www.hardiness-resilience.com/hardy-text1/

Bekhet, A. K., & Zauszniewski, J. A. (2012). Methodological triangulation: An approach to understanding data. *Nurse Researcher*, *20*(2), 40-43. https://doi.org/10.7748/nr2012.11.20.2.40.c9442

Benaquisto, L. (2008). Coding frame. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (p. 89). SAGE Publications. http://dx.doi.org/10.4135/9781412963909.n49

Bevan, M. T. (2014). A method of phenomenological interviewing. *Qualitative Health Research*, *24*(1), 136-144. https://doi.org/10.1177/1049732313519710

Biggerstaff, D. (2012). Qualitative research methods in psychology. In G. Rossi (Ed.), *Psychology selected papers*. IntechOpen Ltd. http://doi.org/10.5772/38931

Blandin, K., & Pepin, R. (2017). Dementia grief: A theoretical model of a unique grief experience. *Dementia*, *16*(1), 67-78. https://doi.org/10.1177/1471301215581081

Booysen, D., Mahe-Poyo, P., & Grant, R. (2021). The experiences and perceptions of mental health service provision at a primary health centre in the Eastern Cape. *South African Journal of Psychiatry*, *27*, a1641. https://doi.org/10.4102/sajpsychiatry.v27i0.1641

Boss, P. (2006). *Loss, trauma, and resilience : Therapeutic work with ambiguous loss*. W. W. Norton and Company.

Brink, H. I. L. (1993). Validity and reliability in qualitative research. *Curationis*, *16*(2).

https://doi.org/10.4102/curationis.v16i2.1396

Brinkmann, S. (2013). *Qualitative interviews: Understanding qualitative interviews*. Oxford University Press. ISBN 978 0 19 986139 2

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*, 217-228. http://doi.org/10.1201/b13196-17

Brooks, D., Ross, C. & Beattie, E. (2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers*. Dementia Australia Ltd. https://www.dementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-42.pdf

Brown-Baatjies, O., Fouche, P., & Greeff, A. (2008). The development and relevance of the resiliency model of family stress, adjustment and adaptation. *Acta Academica*, *40*(1), 78-126. https://scholar.sun.ac.za/handle/10019.1/103114

Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E., & Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *PLoS Medicine*, *9*(10), e1001331. https://doi.org/10.1371/journal.pmed.1001331

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, *41*(5), 545-547. https://doi.org/10.1188/14.ONF.545-547

Carver, C. S. (1998). Resilience and thriving: Issues, models, and linkages. *Journal of Social Issues*, *54*(2), 245-266. https://doi.org/10.1111/j.1540-4560.1998.tb01217.x

Cheng, S. T. (2017). Dementia caregiver burden: A research update and critical analysis. *Current Psychiatry Reports*, *19*(64). https://doi.org/10.1007/s11920-017-0818-2

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Sage Publications.

Creswell, John. (2013). *Qualitative inquiry & research design: Choosing among five approaches*. Sage Publications.

DeCarlo, M. (2018, August 7). *8.4 Qualitative research questions – Scientific inquiry in social work*. Pressbooks. https://scientificinquiryinsocialwork.pressbooks.com/chapter/8-4-qualitative-research-questions/

De Jager, C. A., Joska, J. A., Hoffman, M., Borochowitz, K. E., & Combrinck, M. I. (2015). Dementia in rural South Africa: A pressing need for epidemiological studies. *South African Medical Journal*, *105*(3), 189. https://doi.org/10.7196/samj.8904

Deist, M. (2013). Resilience factors in families caring for a family member diagnosed with dementia [Master's thesis, Stellenbosch University]. SUNScholar Research Repository. https://scholar.sun.ac.za/handle/10019.1/80360

Deist, M., & Greeff, A. P. (2014). Resilience in families caring for a family member diagnosed with dementia. *Educational Gerontology*, *41*(2), 93-105. https://doi.org/10.1080/03601277.2014.942146

Dementia Care Central. (2020, April 24). *Stages of Alzheimer’s & dementia: Durations & scales used to measure progression (GDS, FAST & CDR)*. DementiaCareCentral.com. https://www.dementiacarecentral.com/aboutdementia/facts/stages/#care

Dementia SA. (2020). *Managing Alzheimer's and dementia care in South Africa*. https://www.dementiasa.org/

D. G. Murray Trust. (2014). *Raising awareness about dementia, South Africa*. DGMT. http://www.dgmt-community.co.za/organisations/dementia-sa/learning-briefs/raising-awareness-about-dementia-south-africa

Dias, R., Santos, R. L., De Sousa, M. F. B., Nogueira, M. M. L., Torres, B., Belfort, T., & Dourado, M. C. N. (2015). Resilience of caregivers of people with dementia: A systematic review of biological and psychosocial determinants. *Trends in Psychiatry and Psychotherapy*, *37*(1), 12-19. https://doi.org/10.1590/2237-6089-2014-0032

Diener, E., Lucas, R., & Cummings, J. (2019, June 28). *16.1 Personality traits – Introduction to psychology*. Pressbooks. https://openpress.usask.ca/introductiontopsychology/chapter/personality-traits/

Du Preez, L. (2018). *Frail care: What you should know*. Geratecza.com. https://geratecza.com/2018/07/30/frail-care-what-you-should-know-laura-du-preez/

DuMont, K., Ehrhard-Dietzel, S., & Kirkland, K. (1996). Averting child maltreatment: Individual, economic, social, and community resources that promote resilient parenting. In M. Ungar (Ed.), *The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct* (pp. 199 – 218). Springer. https://doi.org/10.1007/978-1-4614-0586-3_17

Eatough, V., & Smith, J. (2010). Interpretive phenomenological analysis. In C. Willig & W. Staiton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 179-194). Sage Publications. http://doi.org/10.4135/9781848607927.n11

Eroz, S. S., & Onat, E. (2018). Psychological hardiness: A survey in hospitality management. *Pressacademia*, *5*(1), 81-89. https://doi.org/10.17261/pressacademia.2018.820

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, *13*(5), 572-581. https://doi.org/10.1016/j.jalz.2016.12.010

Faronbi, J. O., Faronbi, G. O., Ayamolowo, S. J., & Olaogun, A. A. (2019). Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. *Archives of Gerontology and Geriatrics*, *82*, 8-14. https://doi.org/10.1016/j.archger.2019.01.013

Featherston, J. (2008). *21st century psychology: A reference handbook*. Sage Publications.

https://sk.sagepub.com/reference/psychology/n11.xml

Fleming, J., & Ledogar, R. J. (2008). Resilience, an evolving concept: A review of literature relevant to Aboriginal research. *Pimatisiwin*, *6*(2), 7-23. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2956753/

Fletcher, D., & Sarkar, M. (2013). Psychological resilience. *European Psychologist*, *18*(1), 12-23. https://doi.org/10.1027/1016-9040/a000124

Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, *20*(9), 1408-1416. https://doi.org/10.46743/2160-3715/2015.2281

Galvin, J. (2013). The importance of family and caregiver in the care and management of people with Alzheimer's disease. *Alzheimer's & Dementia*, *9*(4), P1-P2. https://doi.org/10.1016/j.jalz.2013.04.012

Garmezy, N. (1987). Stress, competence, and development: Continuities in the study of schizophrenic adults, children vulnerable to psychopathology, and the search for stress-resistant children. *American Journal of Orthopsychiatry*, *57*(2), 159-174. https://doi.org/10.1111/j.1939-0025.1987.tb03526.x

Garmezy, N. (1991). Resilience in children's adaptation to negative life events and stressed environments. *Pediatric Annals*, *20*(9), 459-466. https://doi.org/10.3928/0090-4481-19910901-05

Garmezy, N. (1993). Vulnerability and resilience. In D. C. Funder, R. D. Parke, C. Tomlinson-Keasey, & K. Widaman (Eds.), *Studying lives through time: Personality and development* (pp. 377–398). American Psychological Association. https://doi.org/10.1037/10127-032

Garmezy, N., Masten, A. S., & Tellegen, A. (1984). The study of stress and competence in children: A building block for developmental psychopathology. *Child Development*, *55*(1), 97. https://doi.org/10.2307/1129837

Giorgi, A. (2014). Phenomenological philosophy as the basis for a human scientific psychology. *The Humanistic Psychologist*, *42*(3), 233-248. https://doi.org/10.1080/08873267.2014.933052

Giorgi, A., Giorgi, B., & Morley, J. (2017). The descriptive phenomenological psychological method. In C. Willig, & W. Stainton-Rogers, (Eds.), *The Sage handbook of qualitative research in psychology* (2nd ed, pp. 176-192). https://doi.org/10.4135/9781526405555.n11

Graber, R., Pichon, F., & Carabine, E. (2015). *Psychological resilience: State of knowledge and future research agendas*. ODI. https://cdn.odi.org/media/documents/9872.pdf

Greenblat, C. (2017). *Dementia*. World Health Organization. https://www.who.int/news-room/fact-sheets/detail/dementia

Greenwood, N., Smith, R., Akhtar, F., & Richardson, A. (2017). A qualitative study of carers' experiences of dementia cafés: A place to feel supported and be yourself. *BMC Geriatrics*, *17*(1). https://doi.org/10.1186/s12877-017-0559-4

Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, *3*(1), 42-55. https://doi.org/10.1177/160940690400300104

Gurayah, T. (2015). Caregiving for people with dementia in a rural context in South Africa. *South African Family Practice*, *57*(3), 194-197. https://doi.org/10.1080/20786190.2014.976946

Hall, C. (2011). *Beyond Kübler-Ross: Recent developments in our understanding of grief and bereavement*. Australian Psychological Society. https://psychology.org.au/for-members/publications/inpsych/2011/dec/Beyond-Kubler-Ross-Recent-developments-in-our-und

Harding, E., Wait, S., Siba, N., Pointon, B., & Georges, J. (2007). *Dementia in my family: Taking an intergenerational approach to dementia*. International

Longevity Centre. http://www.worldcat.org/oclc/176106729

Hepburn, K., Kovaleva, M., & Clevenger, C. (2018). Education programs for informal dementia caregivers. In G. E. Smith & S. T. Farias (Eds.), *APA handbook of dementia* (pp. 579-597). https://doi.org/10.1037/0000076-031

HPCSA, see Health Professions Council of South Africa. (2016). *Guidelines for good practice in the health care professions. Confidentiality: Protecting and providing information*. https://www.hpcsa.co.za/Uploads/Professional_Practice/Conduct%20%26%20Ethics/Booklet%205%20Confidentiality%20Protecting%20and%20Providing%20Information%20September%202016.pdf

Huber, S. J., Shuttleworth, E. C., Paulson, G. W., Bellchambers, M. J. G., & Clapp, L. E. (1986). Cortical vs subcortical dementia: Neuropsychological differences. *Archives of Neurology*, *43*(4), 392-394. doi:10.1001/archneur.1986.00520040072023

Hugo, F., & Van Wyk, L. (2007, November 6). *The role of support groups*. Health24. https://www.health24.com/Medical/Dementia/Support-groups/The-role-of-support-groups-20120721

Iavarone, A., Ziello, A. R., Pastore, F., Fasanaro, A. M., & Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer’s disease. *Neuropsychiatric Disease and Treatment*, *10*, 1407-1413. http://doi.org/10.2147/NDT.S58063

Jackson, D., Firtko, A., & Edenborough, M. (2007). Personal resilience as a strategy for surviving and thriving in the face of workplace adversity: A literature review. *Journal of Advanced Nursing*, *60*(1), 1-9. https://doi.org/10.1111/j.1365-2648.2007.04412.x

Johnson, H. (2016). Exploring the lived experience of people with dementia through interpretative phenomenological analysis. *The Qualitative Report*, *2,* 695-711.

https://doi.org/10.46743/2160-3715/2016.2261

Joling, K. J., Windle, G., Dröes, R., Meiland, F., Van Hout, H. P. J., MacNeil-Vroomen, J., Van de Ven, P. M., Moniz-Cook, E., & Woods, B. (2016). Factors of resilience in informal caregivers of people with dementia from integrative international data analysis. *Dementia and Geriatric Cognitive Disorders*, *42*(3-4), 198-214. https://doi.org/10.1159/000449131

Kardum, I., Hudek-Knežević, J., & Krapić, N. (2012). The structure of hardiness, its measurement invariance across gender and relationships with personality traits and mental health outcomes. *Psychological Topics, 21*(3), 487-507. https://psycnet.apa.org/record/2013-03108-006

Kimura, N. R. S., Maffioletti, V. L. R., Santos, R. L., Baptista, M. A. T., & Dourado, M. C. N. (2015). Psychosocial impact of early onset dementia among caregivers. *Trends in Psychiatry and Psychotherapy*, *37*(4), 213-219. https://doi.org/10.1590/2237-6089-2015-0038

Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. *European Journal of General Practice*, *24*(1), 120-124. https://doi.org/10.1080/13814788.2017.1375092

Laranjeira, C. (2015). Capturing the experiences of people living with dementia. *European Psychiatry*, *30*(30), 1001. https://doi.org/10.1016/s0924-9338(15)30784-7

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102-120. https://doi.org/10.1191/1478088706qp062oa

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, *2*(3), 21-35. https://doi.org/10.1177/160940690300200303

Ledesma, J. (2014). Conceptual frameworks and research models on resilience in leadership. *SAGE Open*, *4*(3), 215824401454546. https://doi.org/10.1177/2158244014545464

Liebenberg, L., Joubert, N., & Foucault, M. (2017). *Understanding core resilience elements and indicators a comprehensive review of the literature*. http://lindaliebenberg.com/wp-content/uploads/2017/11/PHAC-Resilience-Report-Final-Version-November-2017.pdf

Liersch-Sumskis, S. (2013). *A phenomenological examination of the meaning of resilience as described by people who experience schizophrenia* [Doctoral thesis, University of Wollongong]. Thesis Collection 1954-2016. http://ro.uow.edu.au/theses/3840

Lopez, S. J. (Ed.). (2008). Positive psychology: Exploring the best in people, Vol. 1. Discovering human strengths. Praeger Publishers/Greenwood Publishing Group. https://psycnet.apa.org/record/2008-13953-000

Luthar, S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, *71*(3), 543-562. https://doi.org/10.1111/1467-8624.00164

Luthar, S. S. (1993). Methodological and conceptual issues in research on childhood resilience. *Journal of Child Psychology and Psychiatry*, *34*(4), 441-453. https://doi.org/10.1111/j.1469-7610.1993.tb01030.x

Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: Implications for interventions and social policies. *Development and Psychopathology*, *12*(4), 857-885. https://doi.org/10.1017/s0954579400004156

Luthar, S. S., Crossman, E. J., & Small, P. J. (2015). Resilience and adversity. *Handbook of Child Psychology and Developmental Science*, 1-40. https://doi.org/10.1002/9781118963418.childpsy307

Lynch, C. (2020). World Alzheimer report 2019: Attitudes to dementia, a global survey. *Alzheimer's & Dementia*, *16*(S10). https://doi.org/10.1002/alz.038255

Mack, N., Woodsong, C., Macqueen, K., Guest, G., & Namey, E. (2005). *Qualitative research methods: A data collector's field guide. Module 1.* Family Health International. http://www.fhi.org

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *The All Ireland Journal of Teaching and Learning in Higher Education*, *9*(3). https://ojs.aishe.org/index.php/aishe-j/article/view/335

Mahomed, A., & Pretorius, C. (2022). Understanding the lived experiences of family caregivers of individuals with dementia in Soweto, a South African Township. *Dementia*, *21*(7), 2264-2287. https://doi.org/10.1177/14713012221118441

Manzini, C. S. S., Brigola, A. G., Pavarini, S. C. I., & Vale, F. A. C. (2016). Factors associated with the resilience of family caregivers of persons with dementia: A systematic review. *Revista Brasileira de Geriatria E Gerontologia*, *19*(4), 703-714. https://doi.org/10.1590/1809-98232016019.150117

Maree, K. (2007). *First steps in research.* Van Schaik Publishers. ISBN: 9780627037085

Masten, A. S. (2001). Ordinary magic: Resilience processes in development. *American Psychologist*, *56*(3), 227-238. https://doi.org/10.1037/0003-066x.56.3.227

Masten, A. S., & Coatsworth, J. D. (1998). The development of competence in favorable and unfavorable environments: Lessons from research on successful children. *American Psychologist*, *53*(2), 205-220. https://doi.org/10.1037/0003-066x.53.2.205

Masten, A. S., & Powell, J. L. (2003). A resilience framework for research, policy, and practice. In S. S. Luthar (Ed.), *Resilience and vulnerability: Adaptation in the context of childhood adversities* (pp. 1-25). Cambridge University Press. https://doi.org/10.1017/CBO9780511615788.003

Mavrodaris, A., Powell, J., & Thorogood, M. (2013). Prevalences of dementia and cognitive impairment among older people in sub-Saharan Africa: A systematic review. *Bulletin of the World Health Organization*, *91*(10), 773-783. https://doi.org/10.2471/blt.13.118422

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *The Gerontologist*, *56*(5), e70-e88. https://doi.org/10.1093/geront/gnw078

Meyer, J., Harirari, P., & Schellack, N. (2016). Overview of Alzheimer's disease and its management. *South African Pharmaceutical Journal; 83*(9), 48-56. http://www.sapj.co.za/index.php/SAPJ/article/view/2348

Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. *Revised and expanded from qualitative research and case study applications in education*. John Wiley & Sons.

Meuser, T. M., & Marwit, S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, *41*(5), 658-670. https://doi.org/10.1093/geront/41.5.658

Miller, K., Worsley, L., Hanstock, T., & Valentine, M. (2016). Evaluating the effectiveness of a resilience program for children and young people in a private Australian psychology clinic. *Journal of Solution Focused Practices, 2*(2). https://digitalscholarship.unlv.edu/journalsfp/vol2/iss2/5/

Mosley, E., & Laborde, S. (2016). Performing under pressure. *Performance Psychology*, 291-314. https://doi.org/10.1016/b978-0-12-803377-7.00018-1

Moustakas, C. (2010). *Phenomenological research methods*. Sage Publications. ISBN: 978-0803957992

Nebehay, S. (2021). *Number of people with dementia set to jump 40% to 78 mln by 2030*. Reuters.

https://www.reuters.com/business/healthcare-pharmaceutical/number-people-with-dementia-set-to-jump-40-78-mln-by-2030-who-2021=09-02/ 2030

Nikolaeva, E. I., & Elnikova, O. E. (2015). A comparative analysis of the parameters of “hardiness” and “resilience”. *Mediterranean Journal of Social Sciences*, *6*(5), 219-224. https://doi.org/10.5901/mjss.2015.v6n5s4p219

Nikos, N., Edmunds, J., & Duda, J. L. (2009). Understanding the coping process from a selfdetermination theory perspective. *British Journal of Health Psychology*, *14*, 249-260. http://doi.org/10.1348/135910708X349352

Nugent, N. R., Sumner, J. A., & Amstadter, A. B. (2014). Resilience after trauma: From surviving to thriving. *European journal of psychotraumatology*, *5*, 10.3402/ejpt.v5.25339. https://doi.org/10.3402/ejpt.v5.25339Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, *13*(4), 695-705. https://doi.org/10.46743/2160-3715/2008.1579

Paquette, D., & Ryan, J. (2011). *Bronfenbrenner’s ecological systems theory*. ResearchGate. https://www.researchgate.net/publication/265485344_Bronfenbrenner

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Czasopismo Psychologiczne Psychological Journal*, *20*(1), 7-14. https://doi.org/10.14691/cppj.20.1.7

Polkinghorne, D. E. (2010). Qualitative research. In J. C. Thomas & M. Hersen (Eds.), *Handbook of clinical psychology competencies* (pp. 425-456). Springer. https://doi.org/10.1007/978-0-387-09757-2_16

Potocnik, F. C. V. (2013). Dementia. *South African Journal of Psychiatry*, *19*(3), 12. https://doi.org/10.4102/sajpsychiatry.v19i3.944

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and metaanalysis. *Alzheimer’s & Dementia*, *9*(1), 63-75.e2. https://doi.org/10.1016/j.jalz.2012.11.007

Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: A discussion and critique. *Nurse Researcher*, *18*(3), 20-24. https://doi.org/10.7748/nr2011.04.18.3.20.c8459

Prorok, J. C., Horgan, S., & Seitz, D. P. (2013). Health care experiences of people with dementia and their caregivers: A meta-ethnographic analysis of qualitative studies. *Canadian Medical Association Journal*, *185*(14), E669-E680. https://doi.org/10.1503/cmaj.121795

Psycom. (2022). *The five stages of grief: An examination of the Kübler-Ross model*. Remedy Health Media. https://www.psycom.net/depression.central.grief.html

Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*(1), 20-23. https://psycnet.apa.org/record/2005-02203-005

Reiners, G. M. (2012). Understanding the differences between Husserl's (descriptive) and Heidegger's (interpretive) phenomenological research. *Journal of Nursing and Care*, *1*(119), 1-5. http://dx.doi.org/10.4172/2167-1168.1000119

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. In R. G. Hughes (Ed.), *Patient safety and quality: An evidence-based handbook for nurses* (chapter 14). Agency for Healthcare Research and Quality (US). https://www.ncbi.nlm.nih.gov/books/NBK2665

Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, *139*(9), 1136-1139. https://doi.org/10.1176/ajp.139.9.1136

Richardson, G. E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology*, *58*(3), 307-321. https://doi.org/10.1002/jclp.10020

Rodrigo, C., Fernando, T., Rajapakse, S., De Silva, V., & Hanwella, R. (2013). Caregiver strain and symptoms of depression among principal caregivers of patients with schizophrenia and bipolar affective disorder in Sri Lanka. *International Journal of Mental Health Systems*, *7*(1), 2. https://doi.org/10.1186/1752-4458-7-2

Roller, M., & Lavrakas, P. (2015). Applied qualitative research design: A tool quality framework approach. The Guilford Press. ISBN 9781462515752

RSA, see Republic of South Africa. (2013). *Protection of Personal Information Act, 4 of 2013.* Government Printing Works. https://popia.co.za/

Rutter, M. (1999). Resilience concepts and findings: Implications for family therapy. *Journal of Family Therapy*, *21*(2), 119-144. https://doi.org/10.1111/1467-6427.00108

Rutter, M. (2006). Implications of resilience concepts for scientific understanding. *Annals of the New York Academy of Sciences*, *1094*(1), 1-12. https://doi.org/10.1196/annals.1376.002

Rutter, M. (2012). Resilience as a dynamic concept. *Development and Psychopathology*, *24*(02), 335-344. https://doi.org/10.1017/s0954579412000028

Rutter, M. (2013). Annual research review: Resilience - Clinical implications. *Journal of Child Psychology and Psychiatry*, *54*(4), 474487. https://doi.org/10.1111/j.1469-7610.2012.02615.x

Sages, R. B. (2014) Meaning constitution analysis - A transcendental phenomenological approach to empirical research. In I. Cermak & S. Kreitler (Eds.), *Conceptions of meaning* (pp. 113-147). Nova Publishers. https://www.researchgate.net/publication/281448770_Sages_RB_2014_Meaning_Constitution_Analysis-_A_transcendental_phenomenological_approach_to_empirical_research_In_Conceptions_of_Meaning_edsCermak_I_Kreitler_S_Nova_Publishers_New_York

Saldaña, J. (2013). *The coding manual for qualitative researchers*. Sage Publications.

Sarkar, S. (2015). *Impact of caregiving role in the quality of life of family caregivers for persons with Alzheimer's disease* [Master's thesis, Minnesota State University]. All Graduate Theses, Dissertations, and Other Capstone Projects. https://cornerstone.lib.mnsu.edu/etds/395/

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893-1907. https://doi.org/10.1007/s11135-017-0574-8

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, *108*(Supplement), 23-27. https://doi.org/10.1097/01.naj.0000336406.45248.4c

Shaboltas, A. V., & Zhukov, D. A. (2011). Risk behavior as a reaction on uncontrollable stress. *Psychology in Russia*, *4*, 324-334. http://doi.org/10.11621/pir.2011.0021

Shean, M. (2015). *Current theories relating to resilience and young people*. *A literature review.* Victorian Health Promotion Foundation. https://www.vichealth.vic.gov.au/-/media/ResourceCentre/PublicationsandResources/Mental-health/Current-theories-relating-to-resilience-and-young-people.pdf?la=en&hash=3DFACAE0B3CC3554DA74B98C04DF42FD 845F108F

Shinebourne, P. (2011). The theoretical underpinnings of interpretative phenomenological analysis (IPA). *Existential Analysis*, *22*(1), 16-31. https://psycnet.apa.org/record/2011-05339-003

Smith, D. W. (2018). Phenomenology. In E. N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Summer 2018 Edition). Stanford University. https://plato.stanford.edu/archives/sum2018/entries/phenomenology/

Smith, J.A. & Osborn, M. (2008) Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 53-80). Sage. http://dx.doi.org/10.1002/9780470776278.ch10

Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: Effects on mental and physical health, intervention strategies, and research needs. *The American Journal of Geriatric Psychiatry*, *19*(6), 491-496. http://doi.org/10.1097/JGP.0b013e31821c0e6e

Sousa, L., Sequeira, C., Ferré-Grau, C., Neves, P., Lleixá-Fortuño, M., Monteiro, A., Meireles, J., Pinto, M., & Gomes, T. (2017). "Living together with dementia": Training programme for family caregivers – A study protocol. *Porto Biomedical Journal*, *2*(6), 282-286. https://doi.org/10.1016/j.pbj.2017.04.003

Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: Interdisciplinary perspectives. *European Journal of Psychotraumatology*, *5*(1), 25338. https://doi.org/10.3402/ejpt.v5.25338

Steyn, L. (2010, October 8). *Dementia: SA's hidden disease*. The Mail & Guardian. https://mg.co.za/article/2010-10-08-dementia-sas-hidden-disease

Stroebel, R. (2014, November 18). *Caring for a family member with dementia is fraught with burden and stress: A discussion of this statement.* Slideshare from Scribd. https://www.slideshare.net/GERATEC/caring-for-a-family-member-with-dementia-is-fraught-with-burden-and-stress-a-discussion-of-this-statement

Suter, N. (2012). Qualitative data, analysis, and design. In W. N. Suter (Ed.), *Introduction to educational research: A critical thinking approach* (pp. 342-386). Sage Publications. http://doi.org/10.4135/9781483384443

Thomas, P. Y. (2010). Towards developing a web-based blended learning environment at the University of Botswana [Doctoral thesis, University of South Africa]. Institutional Repository. http://uir.unisa.ac.za/handle/10500/4245?show=full.2

Thomas, P., Lalloué, F., Preux, P., Hazif-Thomas, C., Pariel, S., Inscale, R., Belmin, J., & Clément, J. (2006). Dementia patients caregivers quality of life: The PIXEL study. *International Journal of Geriatric Psychiatry*, *21*(1), 50-56. https://doi.org/10.1002/gps.1422

Tom, S. E., Hubbard, R. A., Crane, P. K., Haneuse, S. J., Bowen, J., McCormick, W. C., McCurry, S., & Larson, E. B. (2015). Characterization of dementia and Alzheimer’s disease in an older population: Updated incidence and life expectancy with and without dementia. *American Journal of Public Health*, *105*(2), 408-413. https://doi.org/10.2105/ajph.2014.301935

Trentacosta, C. J., Hyde, L. W., Shaw, D. S., Dishion, T. J., Gardner, F., & Wilson, M. (2008). The relations among cumulative risk, parenting, and behavior problems during early childhood. *Journal of Child Psychology and Psychiatry*, *49*(11), 1211-1219. https://doi.org/10.1111/j.1469-7610.2008.01941.x

Ungar, M. (2008). Resilience across cultures. *British Journal of Social Work*, *38*(2), 218-235. https://doi.org/10.1093/bjsw/bcl343

Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *The American Journal of Orthopsychiatry*, *81*(1), 1-17. https://doi.org/10.1111/j.1939-0025.2010.01067.x

Ungar, M. (2012). *The social ecology of resilience: A handbook of theory and practice*. Springer. https://doi.org/10.1007/978-1-4614-0586-3

Van den Hoonaard, D., & Van den Hoonaard, E. (2008). Data analysis. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 187-188). Sage Publications. https://doi.org/10.4135/9781412963909.n94

Van der Poel, R., & Pretorius, C. (2009). Dementia in low and middle income countries: The need for research and advocacy. *Dementia*, *8*(4), 451-454.

http://doi.org/10.1177/1471301209350290

Van Rensburg, G. H., Alpaslan, A. H., Du Plooy, G. M., Gelderblom, D., Van Eeden, R., & Wigston, D. J. (2013). *Research in the social sciences.* University of South Africa.

Van Wyk, A., Manthrope, J., & Clarke, C. (2016). The behaviours that dementia care home staff in South Africa find challenging: An exploratory study. *Dementia*, *16*(7), 865-877. http://doi.org/10.1177/1471301215622092

Vosloo, J. (2014). Chapter 5: *Research design and methodology*. Cape Peninsula University of Technology. https://dspace.nwu.ac.za/bitstream/handle/10394/12269/Vosloo_JJ_Chapter_5.pdf?sequence=6

Walsh, F. (1996). The concept of family resilience: Crisis and challenge. *Family Process, 35*, 261-81. https://doi.org/10.1111/j.1545-5300.1996.00261.x

Waters, J. 2017. *Phenomenological research guidelines*. Scribd Inc. https://www.scribd.com/document/364346010/Phenomenological-Research-Guidelines#

White, C. L., Overbaugh, K. J., Pickering, C. E. Z., Piernik-Yoder, B., James, D., Patel, D. I., Puga, F., Ford, L., & Cleveland, J. (2018). Advancing care for family caregivers of persons with dementia through caregiver and community partnerships. *Research Involvement and Engagement*, *4*(1). https://doi.org/10.1186/s40900-018-0084-4

Windle, G. (2010). What is resilience? A review and concept analysis. *Reviews in Clinical Gerontology*, *21*(2), 152-169. https://doi.org/10.1017/s0959259810000420

Windle, G., & Bennet, K. M. (2012). Caring relationships: How to promote resilience in challenging times. In M. Ungar (Ed), *The social ecology of resilience.* Springer. https://doi.org/10.1007/978-1-4641-0586-3_8

WHO, see World Health Organization. (2012). *Dementia: A public health priority*. https://apps.who.int/iris/handle/10665/75263

WHO, see World Health Organization. (2022). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Worsley, L. (2010). *The resilience doughnut framework: The contextual factors which combine to build resilience in young people*. The Resilience Centre. https://www.theresiliencedoughnut.com.au/wp-content/uploads/2019/08/Resilience-The-Resilience-Doughnut-Framework.pdf

Worsley, L. (2014). Building resilience in three Australian high schools, using the resilience doughnut framework. In S. Prince-Embury & D. Saklofske (Eds.), *Resilience interventions for youth in diverse populations* (pp. 217-257). http://doi.org/10.1007/978-1-4939-0542-3_11

Worsley, L. (2015). The resilience doughnut: Combining strengths to survive. In M. Patron & S. S. Holden (Eds.), *Victim victorious: From fire to Phoenix* (pp. 67-87). Nova Science Publishers. https://psycnet.apa.org/record/2015-33203-005

Worsley, L., & Hjemdal, O. (2016). Scale development and psychometric qualities of the resilience doughnut tool. A valid, solution focused and ecological measure of resilience with Australian adolescents. *Journal of Solution Focused Practices*, *2*(2). https://digitalscholarship.unlv.edu/journalsfp/vol2/iss2/4

Worthington, E. L., & Scherer, M. (2004). Forgiveness is an emotion-focused coping strategy that can reduce health risks and promote health resilience: Theory, review, and hypotheses. *Psychology & Health*, *19*(3), 385-405. https://doi.org/10.1080/0887044042000196674

Yüksel, P., & Yildirim, S. (2015). Theoretical frameworks, methods, and procedures for conducting phenomenological studies. *Turkish Online Journal of Qualitative Inquiry*, *6*(1), 1-20. https://doi.org/10.17569/tojqi.59813

Zauszniewski, J., Bekhet, A., & Suresky, M. (2009). Effects on Resilience of Women Family Caregivers of Adults With Serious Mental Illness: The Role of Positive Cognitions. *Archives of Psychiatric Nursing*, *23*(6), 412–422. https://doi.org/10.1016/j.apnu.2008.12.004

Zwaanswijk, M., Peeters, J. M., van Beek, A. P. A., Meerveld, J. H. C. M., & Francke, A. L. (2013). Informal caregivers of people with dementia: Problems, needs and support in the initial stage and in subsequent stages of dementia. A questionnaire survey. *The Open Nursing Journal*, *7*, 6-13. https://doi.org/10.2174/1874434601307010006

Annexure A

Permission Letter

PERMISSION LETTER

Request for permission to conduct research at Dementia, South Africa.

A phenomenological investigation into the lived experiences of family members living with a dementia patient.

October 2018

To Whom It May Concern,

I, Leanda Ryan, am doing research with Sean Hagen, a lecturer in the Department of Social Sciences towards a Master of Arts in Psychology degree at the University of South Africa. We are inviting you to participate in a study entitled: A phenomenological investigation into the lived experiences of family members living with a dementia patient.

The aim of the study is to describe and explore lived experiences of family members of dementia patients are; and find out what support systems are in place for these vulnerable family members.

Your company has been selected because it has an association with the family members of dementia patients. We hereby kindly request that the organization informs the family members about the proposed study and request their voluntary participation on our behalf. The organization will also be requested to provide details to the researcher of prospective participants who indicated their willingness to participate. It will afterwards be requested to arrange a suitable date, venue and time for the research to be presented to the prospective family members of the dementia patients.
A meeting will be conducted with the family members where an explanation outlining the aim of the research will be rendered. The contact details of the researcher will be given to all the attendees. This will give the potential participants time to decide whether they are willing to participate. The family members, who volunteer to participate in the study will be informed about the process and given consent forms to complete prior to the start of the research. The volunteers will be contacted telephonically to determine a venue, date and time for the interview to take place.

I hereby ask permission to access 8 of your patient’s family members who are willing to participate in my study and who are or were primary caregivers of those with Dementia. All volunteering participants in the study will remain anonymous in that, while their test results will be made known, their identities will remain confidential. I will not disclose the name of your institution unless you give me permission to.

The study will entail an audio taped, semi-structured person-to-person interview with the family members of dementia patients. The interview process will take approximately one hour at a venue the participants feel comfortable in.

The benefits of this study are placing emphasis on the challenges family members face as well as a possible lack of support from health authorities. It will highlight how education on dementia can positively impact the family member as well as the dementia patient's quality of life through of education. The onus is on society to raise awareness and encourage the government to ensure dementia be declared a national health priority. The research study can strengthen this stance given the major role-players such as the Department of Health, Department of Education and the Department of Social Development are enlightened about the daily challenges faced by the family members.

Potential risks are minor inconvenience, stress or discomfort when relaying personal feelings, thoughts and experiences or a feeling that it is an invasion of privacy. As the researcher, I will exercise sensitivity towards the partcipants by observing both the verbal, nonverbal, and non-behavioural communication and will do all I can to make them feel comfortable. Continual observations will be done to ensure that the questions posed do not cause emotional distress.

Feedback procedure will entail contacting Leanda Ryan on 081 504 1319 or e-mail Leanda.j.r@gmail.com and/or Sean Hagen on 012 429 8236 or Hagensn@unisa.ac.za.

I would greatly appreciate your favourable response and I am happy to discuss my project with you if you so wish.

Yours sincerely

____

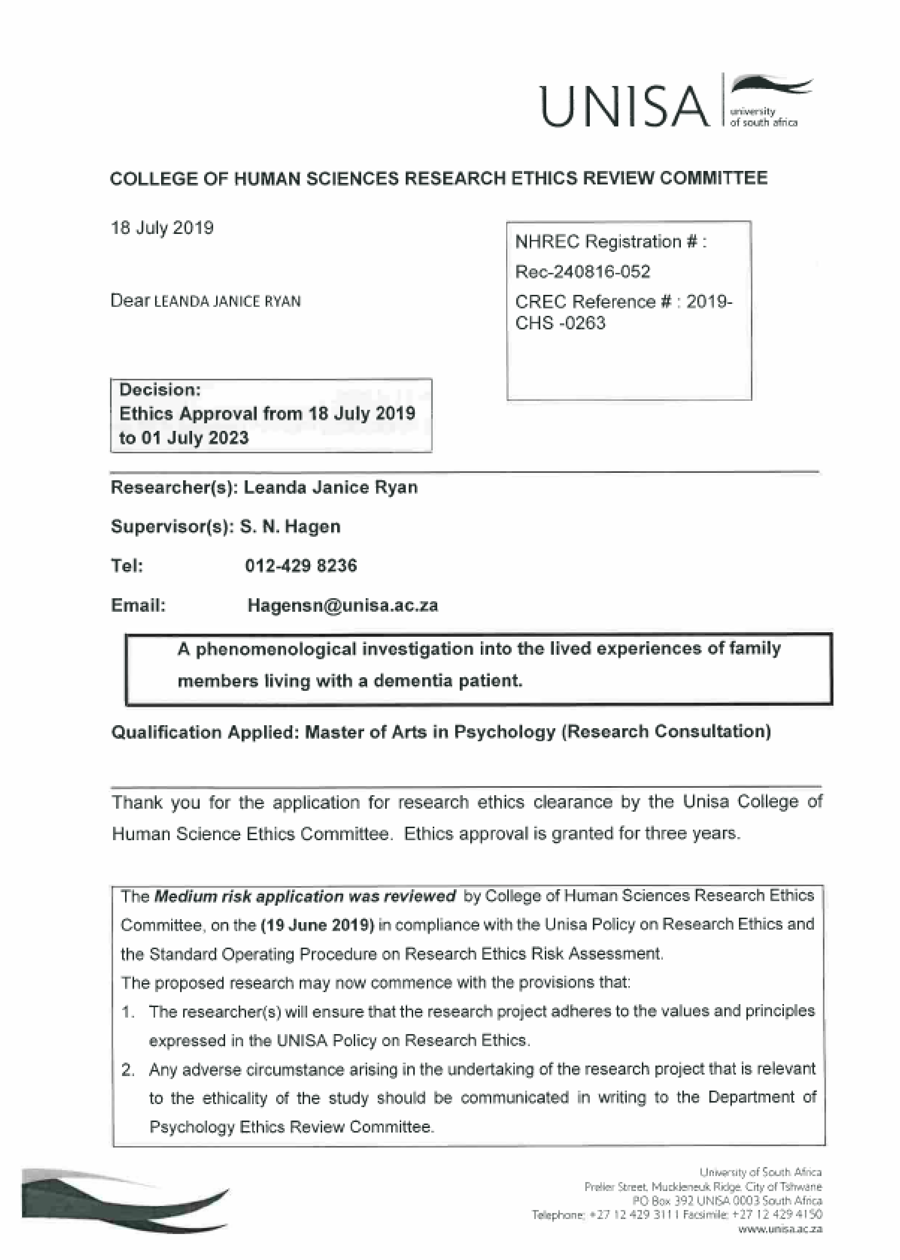
Leanda Janice Ryan
Researcher

____

Sean Hagen
Supervisor

Annexure B

Ethical Clearance Certificate



COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

18 July 2019

NHREC Registration # :
Rec-240816-052
CREC Reference # : 2019-CHS -0263

Dear LEANDA JANICE RYAN

Decision:
Ethics Approval from 18 July 2019 to 01 July 2023

Researcher(s): Leanda Janice Ryan

Supervisor(s): S. N. Hagen

Tel: **012-429 8236**

Email: **Hagensn@unisa.ac.za**

A phenomenological investigation into the lived experiences of family members living with a dementia patient.

Qualification Applied: Master of Arts in Psychology (Research Consultation)

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for three years.

The ***Medium risk application was reviewed*** by College of Human Sciences Research Ethics Committee, on the **(19 June 2019)** in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the Department of Psychology Ethics Review Committee.

3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.
5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date **(01 July 2023).** Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

The reference number **2019-CHS-CREC-0254** *should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signature :	Signature :
Dr Suryakanthie Chetty	Professor A Phillips
Deputy Chair : CREC	Executive Dean : CHS
E-mail: chetts@unisa.ac.za	E-mail: Phillap@unisa.ac.za
Tel: (012) 429-6267	Tel: (012) 429-6825

Annexure C

Consent Form

PARTICIPANT INFORMATION SHEET

Ethics clearance reference number: CREC Reference # : 2019 CHS -0263

Research permission reference number (if applicable): NHREC Registration # Rec-240816-052

Date: **October 2021**

Title: A phenomenological investigation into the lived experiences of family members living with a dementia patient

Dear Prospective Participant

My name is Leanda Janice Ryan and I am doing research with Sean Hagen, a lecturer in the School of Social Sciences towards a Master of Arts in Psychology degree at the University of South Africa. We are inviting you to participate in a study entitled: A phenomenological investigation into the lived experiences of family members living with a dementia patient.

WHAT IS THE PURPOSE OF THE STUDY?

I am conducting this research to find out what the lived experiences of family members of dementia patients are; and what support systems are in place for these vulnerable family members.

WHY AM I BEING INVITED TO PARTICIPATE?

Dementia South Africa was contacted and requested to supply names of participants who can give insights into the challenges they face as well as the lack of support in caring for dementia patients. These experiences will also indicate how education about home-based caring for a dementia patient and you can have a positive impact on caregiving as well as your quality of life. Family members from this organization were selected to participate in the research since they can supply firsthand information on what life is like living with a dementia patient. The population size for this study will be 8 participants. Participants who are willing to partake in the research will remain anonymous; their identities will remain confidential.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

The interview will be audio-recorded. The recordings are intended to allow the researcher to transcribe what was conveyed during the interview. Information which may lead to the identification of the participant will be changed in the final transcription. This will apply to names and any identifying statements made. The audio-recordings will be deleted as per requirements. The interview process will take approximately one hour at a venue you feel comfortable in. Questions to be asked will entail:

- Tell me about your experience of caring for a dementia patient/family member?
- How does the role of caregiver affect your everyday life relating to work, interests and relationships?
- Are there any kinds of support that makes caring for a family member diagnosed with dementia better, such as support from family, friends, or others?
- Tell me about your relationship with significant others (family). How do they assist with the process of caring?
- Does your relationship with your partner help you cope with the challenges/emotions of caring? How?
- In your own words, which characteristics helped you adapt to caring for a family member who is diagnosed with dementia?
- How do you feel about caring for a family member diagnosed with dementia?
- How do you deal with the uncertainties and continuous changes of caring for a dementia patient?

- What according to your opinion would make the caregiving task easier and effective?
- Is there anything else you would like to add about, your experience of being a primary caregiver?
- Is there anything positive that you 'gain' from caring for a dementia patient? Please give me examples of these "gains".
- Is there anything else you would like to add about, your experience of being a primary caregiver?

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

The purpose of this study is to describe and explore your lived experiences. This is a opportunity for you to relay experiences of your daily encounters whilst living with a dementia patient. Your experiences may help others, who find themselves in a similar position, to better understand their experiences. Findings from this research will highlight the challenges you face as well as a possible lack of support from health authorities. It will emphasize how education on dementia can positively impact your quality of life through of education. The onus is on society to raise awareness and encourage the government to ensure dementia be declared a national health priority. The research study can strengthen this stance given the major role-players such as the Department of Health, Department of Education and the Department of Social Development are enlightened about the daily challenges faced by you, the caregiver. You are therefore requested to share your journey of your life with a dementia patient.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

You are expected to convey the daily experiences you encounter whilst looking after a dementia patient. You may feel a minor inconvenience, stress or discomfort when relaying personal feelings, thoughts and experiences or feel that it is an invasion of privacy. As the researcher, I will exercise sensitivity towards you by observing both the verbal, nonverbal, and non-behavioural communication and will do all I can to make you feel comfortable. Continual observations will be done to ensure that the questions posed do not cause emotional distress to you. Counselling and/or debriefing contact details will be made available to you should you deem it necessary.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

You have the right to insist that your name will not be recorded anywhere and that no one, apart from the researcher and identified members of the research team, will know about your involvement in this research. Your answers will be given a code number or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, supervisor, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard/filing cabinet at 938 Vlei Avenue, Eldorado Park for future research or academic purposes; electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. Hard copies will be shredded and/or electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme.

HAS THE STUDY RECEIVED ETHICS APPROVAL

This study has received written approval from the Research Ethics Review Committee of the Department of Psychology, UNISA. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Leanda Ryan on 081 504 1319 or e-mail Leanda.j.r@gmail.com. The findings are accessible for 5 years.

Should you require any further information, clarification or translation, or want to contact the researcher about any aspect of this study, please contact Leanda Ryan on 081 504 1319 or e-mail Leanda.j.r@gmail.com.

Should you have concerns about the way in which the research has been conducted, you may contact Sean Hagen on 012 429 8236 or Hagensn@unisa.ac.za.

Contact the research ethics chairperson of the Ethics Review Committee, Prof. Piet Kruger on 012 429 6235 or krugep@unisa.ac.za if you have any ethical concerns.

Thank you for taking time to read this information sheet and for participating in this study.

____

Leanda Janice Ryan

CONSENT TO PARTICIPATE IN THIS STUDY

I, __________________ (participant name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty (if applicable).

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I agree to the recording of the interview.

I have received a signed copy of the informed consent agreement.

Participant Name & Surname………………………………………… (please print)

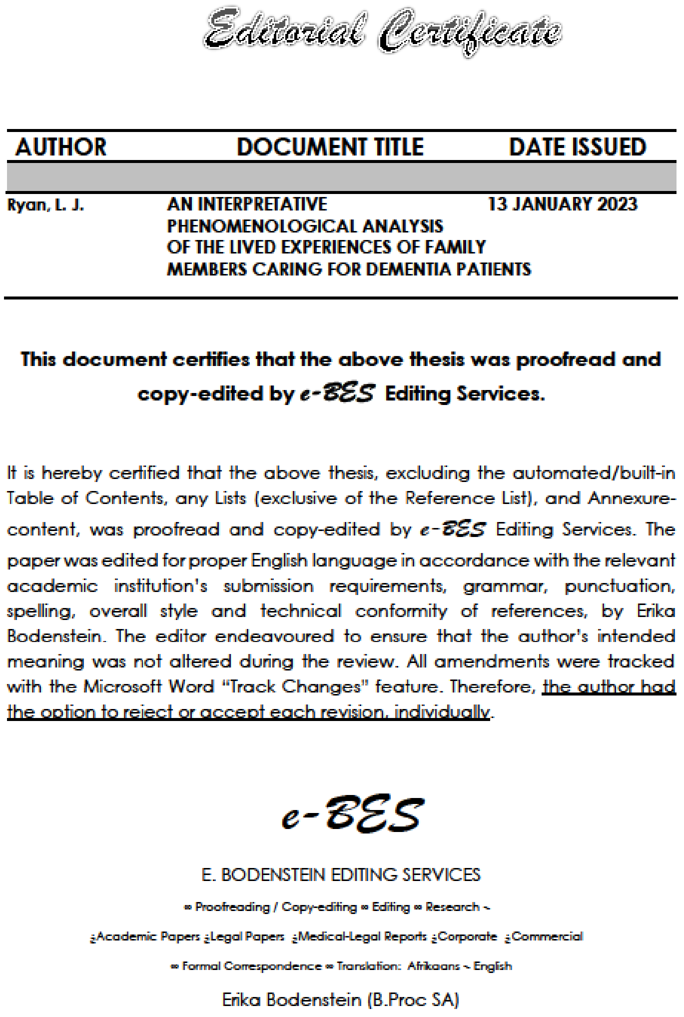
Participant Signature…………………………………………..Date…………………

Researcher's Name & Surname: Leanda Janice Ryan (please print)

Researcher's signature…………………………………………..Date…………………

Annexure D

Editorial Certificate



Editorial Certificate

AUTHOR	DOCUMENT TITLE	DATE ISSUED
Ryan, L. J.	AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF THE LIVED EXPERIENCES OF FAMILY MEMBERS CARING FOR DEMENTIA PATIENTS	13 JANUARY 2023

This document certifies that the above thesis was proofread and copy-edited by *e-BES* Editing Services.

It is hereby certified that the above thesis, excluding the automated/built-in Table of Contents, any Lists (exclusive of the Reference List), and Annexure-content, was proofread and copy-edited by *e-BES* Editing Services. The paper was edited for proper English language in accordance with the relevant academic institution's submission requirements, grammar, punctuation, spelling, overall style and technical conformity of references, by Erika Bodenstein. The editor endeavoured to ensure that the author's intended meaning was not altered during the review. All amendments were tracked with the Microsoft Word "Track Changes" feature. Therefore, the author had the option to reject or accept each revision, individually.

e-BES

E. BODENSTEIN EDITING SERVICES

∞ Proofreading / Copy-editing ∞ Editing ∞ Research ~

¿Academic Papers ¿Legal Papers ¿Medical-Legal Reports ¿Corporate ¿Commercial

∞ Formal Correspondence ∞ Translation: Afrikaans ~ English

Erika Bodenstein (B.Proc SA)