Pietermaritzburg Charismatic Christian Pastors' Conceptualizations of Major Neurocognitive Disorder (Dementia)

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Declaration Page

I, Nompilo Khanyile, declare that:

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II. This dissertation has not been submitted for any examination at any other university.

III. This dissertation does not contain other person's data, pictures, graphs, or other information unless specifically acknowledged as being sourced from other persons.

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Mrs Xoli Mfene

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If it had not been for the merciful God, I would not be where I am today. Therefore, I will never stop saying, ‘to God be the Glory.’

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To my mother and siblings, I do not know where I can start to show how much I appreciate you for the support you have offered me. You believed in me where I doubted myself. Now harvest time is at hand. Let us rejoice in the Lord.

To my friends, thank you for being there and celebrating every minor achievement I have accomplished.

ABSTRACT

Background: Religion and spirituality are essential affiliations people with Major Neurocognitive Disorder (dementia) depend on for better health outcomes and better adjustments with this diagnosis. Pastors are key role players in providing spiritual care. While they engage in this process, interacting and delivering care for these individuals, they develop conceptions about this illness. As a result, their pastoral role may be shaped by these conceptions, and they employ a set of religious practices to manage this illness.

Aim: To explore Charismatic Christian pastors' conceptions about dementia. To explore the influence of conceptions of dementia on how pastors might provide care to people with dementia and their caregivers. To explore the role played by religious practices in managing dementia.

Methods: An exploratory research design and a qualitative approach were adopted. Six Charismatic Christian pastors from Pietermaritzburg were sampled through non-probability sampling, and a snowballing technique was employed. The research adopted the explanatory models of illness as a theoretical framework, and the data were analysed using thematic analysis.

Results: Dementia is conceptualized as an illness associated with cognitive deterioration caused by emotional distress. Pastors' role, amongst others, is to share the knowledge they have about dementia with misinformed communities. Religious practices appear to be effective measures put in place to manage the severity of this disease.

Conclusion: This study shows that reliance on religious and spiritual avenues for people with dementia resulted in positive outcomes. Two recommendations are made: 1) a collaborative treatment approach and 2) further research on the emotional distress-dementia relationship and underlying socio-cultural aspects.

Keywords: Charismatic Christianity, Constructivism, Dementia, Explanatory Models, Spirituality.

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ABBREVIATIONS

AD:	Alzheimer's disease
ADI:	Alzheimer's Disease International
DETP:	Dementia Education & Training Program
n.d:	No date
SSA:	sub-Saharan African
UKZN:	University of KwaZulu-Natal
VD:	Vascular Major Neurocognitive Disorder

CHAPTER 1: INTRODUCTION

1.1 Problem Statement

Major Neurocognitive Disorder is a degenerative condition that is associated with aging. It is characterized by loss of meaning (Hudson, 2015), impaired communication, difficulties in organizing daily tasks, and memory loss (Heerema, 2018). This disease also affects and elicits hopelessness among caregivers, as it is an incurable condition. Hudson (2015) states that religious healing systems in many sub-Saharan African (SSA) countries help people who are facing psychiatric problems. This avenue serves as a source of spiritual and religious support for those affected (the diagnosed and caregivers) by Major Neurocognitive Disorder.

Religion and spirituality play a crucial role in helping people with Major Neurocognitive Disorder better adjust and cope with this illness. Reliance on religious and spiritual avenues has been an essential source for coping with both physical and mental illnesses (Parker et al., 2003; Powell et al., 2003). Available studies present a positive association between religiosity/spirituality and coping with Major Neurocognitive Disorder (Agli et al., 2013; Beuscher & Beck, 2008; Stuckey & Gwyther, 2003; Vitorino et al., 2018). However, little is known about how religious leaders conceptualize this disease, or about how they offer care and support to the diagnosed and caregivers, and the role of religious practices in managing the disease.

The prevalence of Major Neurocognitive Disorder is gradually increasing among elderly persons. According to Alzheimer's Disease International (ADI) (2017), 2.13 million people in SSA were estimated to have this disorder in 2015, and this figure is expected to rise to 3.48 million by 2030. Major Neurocognitive Disorder is a burdening disease that does not only

affect the diagnosed, but affects their caregivers as well. When caring for their family members who have dementia, caregivers' financial resources become exhausted, and their emotional well-being, spirituality, and religiosity are compromised, leading to a lowered quality of life (Dementia Education & Training Program (DETP), n.d.). Those affected by this disease often rely on spiritual and religious avenues to find meaning and better cope with the life adversities they encounter (Agli et al., 2013).

This qualitative study, which was based within the Pietermaritzburg area, explored Charismatic Christian pastors' conceptions of dementia, how these conceptions influence pastoral care provided to those affected by this disease, and how they manage it through the use of religious practices. The data gathered from this study can potentially endorse spirituality and religion-based awareness among Western healthcare practitioners, traditional healers, caregivers, pastors, other faith-based organizations, and it will provide more literature about the topic at hand. This awareness may inform pathways used among these healthcare systems to assist spiritual and religious people with dementia.

1.2 Purpose of the Study

Conceptions about illness have a causal effect on how a particular illness is managed. With this in mind, the explanatory models of illness approach informed this study, and its purpose was to explore pastors' appraisal of Major Neurocognitive Disorder (which is used interchangeably with dementia in this dissertation).

Spirituality and religion are essential aspects that influence people's health before and after diagnosis. In their research, Vitorino et al. (2018) reported that participants with strong religion and spirituality have better health outcomes. A positive association between

spirituality/religiosity and better adjustment to sickness are apparent in the available literature (Beuscher & Beck, 2008; Stuckey & Gwyther, 2003). This study assumes that pastoral care, involving spiritual and religious healing, is essential for better adjustment and coping mechanisms against dementia. Furthermore, as people with this disease may maintain a good connection with their respective spiritual and religious avenues, they develop a sense of belonging due to social support from their pastors and fellow brethren. Also, the study assumes that people affected by this disease engage in certain religious practices, leading to better adjustment and enhanced coping mechanisms.

1.3 Objectives of Research

The main objectives of this study were as follows:

- To explore the conceptions of Major Neurocognitive Disorder among Charismatic Christian pastors;
- To explore the influence of these conceptions on the care and support that Charismatic Christian pastors might provide to congregants with Major Neurocognitive Disorder and their families;
- To establish the contributory role of Charismatic Christian religious practices in managing Major Neurocognitive Disorder.

1.4 Research Questions

The questions that this study aimed to answer are as stated below:

- What are Charismatic Christian pastors' knowledge and understanding of Major Neurocognitive Disorder?
- What is the influence of Charismatic Christian pastors' conceptions in providing support and care to those with Major Neurocognitive Disorder and their families?

- What contributions can Charismatic Christian religious practices make to the support and care of those affected by Major Neurocognitive Disorder?

1.5 Research Methodology Outline

This study adopted an exploratory qualitative research design. Six Charismatic Christian pastors from Pietermaritzburg were recruited through purposive sampling and the snowballing technique. The data collection tool was a semi-structured interview schedule, and the data were analyzed using thematic analysis. The themes were generated using NVivo. Throughout this research, autonomy, informed consent, and beneficence were ethical rules that were adhered to. Dependability, confirmability, and transferability were applied in this research, to ensure the robustness of the study. The social constructivist paradigm was adopted to give insight into the context that informs the participants' ideologies.

1.6 Definition of Key Terms

Concepts	**Operational definition**
Charismatic Christianity	A faith-based organization that believes in the Holy Spirit, exorcism, prophecy, miracles, and praying in tongues (Kpobi & Swartz, 2018).
Conceptualization	A process of forming an idea, a concept, or an understanding of something (Rao & Asi, 2013).
Religion	Formal and organized doctrines established in a tradition in the form of joint worship (Schlehofer et al., 2008).
Religiosity	A personal preferences, emotions, beliefs, and actions towards an already stablished or self-made religion (Stolz, 2009).

Spirituality	A search for meaning and the sacred, and a quest for existentialism (Schlehofer et al., 2008).

1.7 Thesis Outline

Chapter 1 – Introduction: This chapter provides the introduction and the background of the topic at hand.

Chapter 2 – Literature Review: This chapter is composed of the collection of findings from other sources, which discussed a similar topic to the one discussed in this research.

Chapter 3 – Methodology: In this chapter, the researcher presents the research objectives, research questions, data collection methods, data analysis, ethical issues, and scientific rigor. Also, sampling, the research design, and the research paradigm are highlighted.

Chapter 4 – Findings: The themes are presented supported by transcript, aiding the analysis of the research findings.

Chapter 5 – Discussion: A detailed discussion of findings concerning the research questions is done. The findings are contextualized within the social constructivism paradigm.

Chapter 6 – Conclusion: The research findings are summarized, and recommendations are presented.

1.8 Conclusion

This chapter provided the background information about dementia, including the scientific and spiritual definitions of dementia, statistical data about this disease, and the context of the study. The purpose of the study was specified, and the research objectives and research questions were also highlighted.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter comprises integrated data from different studies providing definitions of Major Neurocognitive Disorder from scientific and societal perspectives. Like many other serious diseases, Major Neurocognitive Disorder is a burdening disease, and its effects will be discussed. This research seeks to understand this disease in light of Charismatic Christianity. Therefore, the role played by religiosity, spirituality, and religious practices in mental health is explored. Lastly, this chapter is informed by the explanatory models of illness approach.

2.2 Defining Major Neurocognitive Disorder (Dementia)

As defined by Heerema (2018), Major Neurocognitive Disorder is a chronic progressive deterioration of nerve cells resulting in a variety of cognitive, emotional, and behavioral symptoms, such as memory loss, communication impairment, and difficulties with planning daily activities. Major Neurocognitive Disorder has different subtypes, with the two most common subtypes being Alzheimer's disease (AD) and vascular major neurocognitive disorder (VD). Both these subtypes of dementia are associated with old age. Other risk factors for vascular dementia are associated with medical conditions such as hypertension and acute stroke or ischemic attack caused by interrupted blood flow to the brain (Heerema, 2018).

How society defines dementia may differ from psychiatric ways of defining it. DETP (n.d.) states that spiritual communities tend to define this disease as a disorder of the soul. According to these communities' perspectives, symptoms may be perceived as intentional (DETP, n.d.). Consequently, people with dementia may be perceived either as: a) a senior church member who no longer recognizes other fellow brethren; b) a person who used to be polite who now starts to insult and throw false accusations at others; c) a person who no longer wants to take

care of his or her hygiene; and d) a person who refrains from attending church services (DETP, n.d.). DETP (n.d.) defines dementia as a disorder of the brain that alters behavior. Expanding on this definition, DETP (n.d.) gives its descriptionby using a brain-mind-soul continuum. This continuum aims to describe the nature of dementia and distinguish the function of each element found in this continuum. DETP (n.d.) used singing as an example to illustrate how this continuum works and which element is being affected by this disease:

- The brain remembers the words.
- The mind gives meaning to the words of the song.
- The soul is uplifted as a result of the brain and mental functioning.

From this continuum, it is concluded that dementia is a brain disorder resulting in the inability to remember things (DETP, n.d.), and it is caused by the degeneration of nerve cells (Corfield, 2012; Hereema, 2018).

2.3 Prevalence of Major Neurocognitive Disorder

There has been a gradual increase in the prevalence of dementia in Africa. ADI (2017) estimated dementia prevalence of 6.38% in the sub-Saharan African (SSA) population. According to ADI (2017), 2.13 million people in SSA were estimated to have Major Neurocognitive Disorder in 2015, and this figure is expected to rise to 3.48 million by 2030. A study conducted by Ramlall et al. (2013) estimated the prevalence of dementia to be 7.9% in a sample of 104 participants within the Durban metropolitan area. This estimation reiterates the growing number of people with dementia. As this number continues to grow, there is still no cure for the disease (McFadden et al., 2001), and there is limited support or care available and accessible for people with dementia and their families.

2.4 Effects of Dementia on the Diagnosed and Caregivers

As cognitive decline progresses, those with dementia and their caregivers experience a decreased quality of life. This experience is usually due to a lack of pharmaceutical support to assist at this stage, as there is no cure for the illness (McFadden et al., 2001). The lack of clinical interventions leaves the burden with the caregivers to provide the daily support and care. This perceived lack often leads to further deterioration in the caregivers' mental health and pushes them to seek support from other avenues, such as religion and spirituality.

Dementia not only causes distress for those diagnosed with it but it also affects caregivers, and they frequently resort to spirituality and religion to draw strength. Nightingale (2003, as cited in Stuckey & Gwyther, 2003) emphasizes the value of spirituality on the dementia care provision experience by stating that caregivers' commitment to spiritual and religious avenues yields positive caregiving attitudes, as they also encounter spiritual and emotional difficulties. People with dementia need intensive care daily, thus leading their caregivers to not attend church services, which exacerbates their feelings of social isolation (DETP, n.d.). Furthermore, caregivers experience a lowered quality of life because, when caring for persons with dementia, they often use up their financial resources, and the process of caregiving is emotionally, physically, and spiritually draining (Corfield, 2012; DETP, n.d.).

Providing care to persons who have deteriorated cognitions is a daunting task for those who offer this care. In their study, Farran et al.'s (2003, as cited in Stuckey & Gwyther, 2003) caregivers reported that they depended on their relationship with God to find the strength to provide optimum care to family members with dementia. DETP (n.d.) describes dementia as human development in reverse. As cognition degenerates, the individual depends on others to carry out basic activities such as being clothed, fed, and bathed. They become more like

children (Corfield, 2012). According to Farran et al. (2003, as cited in Stuckey & Gwyther, 2003) and Corfield (2012), having to bear the pain of observing a loved one's brain failing to send messages to the body to perform the most necessary tasks makes the caregivers seek God and connect with Him in order to draw strength and courage.

2.5 Societal Perceptions of Dementia

The relational and cognitive decline that people with dementia manifest leads to their personhood being scrutinized. How people with dementia are related to and perceived influences how they are as persons, and these perceptions shape their personhood and actions, and how they interact with others (Sabat, 1998, as cited in Dewing, 2008). Memory loss is associated with the onset of dementia. Parfit (1984, as cited in Smebye & Kirkevold, 2003) states that memory loss is conceptualized as a loss of self and identity, resulting in the personhood of people with dementia being perceived as being 'stripped off'. Memory acts as an archive that helps individuals to store their life history, such as the goals they have achieved and who they are. Failure to narrate one's accomplishments and an inability to retrieve one's past due to memory loss are seen as a loss of self and self-identity (Corfield, 2012).

As the symptoms of dementia become severe, abnormal behavior increases, often resulting in unfavorable social reactions. According to Kitwood (1997, as cited in Dewing, 2008), this reaction leads to the dementia sufferer's human attributes being devalued, which leads to a regressive shift in social position among people with dementia. Corfield (2012) reports that, as memory loss, impaired communication, and behavioral difficulties persist, people with dementia are viewed as 'socially dead' or faced with 'an endless funeral'. The concept of social death, as constructed by society, is due to the incurability of this disease and because people with dementia gradually disconnect from society (Corfield, 2012).

Though people with dementia manifest symptoms that make observers question their personhood, Frankl (2000, as cited in McFadden et al., 2001), in his study, reveals that people with dementia can retain their personhood, as they can continue to seek meaning amid stressful life events they encounter. They can also interact with the environment around them and keep social relationships alive, even though their communication proves to be below normal. Humanity exists beyond physical bodies and mental capabilities (Kitwood, 1997, as cited in McFadden at al., 2001), and it is beyond blood and flesh (Corfield, 2012). Therefore, these tangible elements do not serve as the main constituents of personhood. Though these people have difficulties with communication and cognitive processes, people with dementia can still portray elements that constitute personhood, including actions, emotions, and values.

In their research on personhood and dementia, McFadden and colleagues observed people with dementia residing in a nursing home. They discovered that residents needed a stimulating environment in order for them to engage actively with their surroundings. In other words, the surrounding environment must give residents access to resources to aid their involvement in practical activities, such as chores, and it must offer help in daily activities (McFadden et al., 2001). These findings emphasize that people with dementia can actively participate in activities if their surrounding environment is responsive, stimulating, and provides the necessary resources to elicit actions, which humans generally need (McFadden et al., 2001).

The human-environment interaction influences how the person responds to their experienced events. People with dementia express their feelings of sadness, joy, humor, and envy, and they can express these emotions through facial expressions and verbal cues (McFadden et al., 2001). In their research, Smebye and Kirkoveld (2013) reported relational emotions between people

with dementia and their family or professional caregivers, developing due to established trust and interdependency between these parties.

Despite the adverse life events they come across, people with dementia find courage in holding on to their values. Post-diagnosis, people who suffer from this disease seek to find meaning and purpose amidst their suffering, and this is what Robert Emotions (a psychologist who specializes in religiosity and spirituality) calls spiritual intelligence (McFadden et al., 2001). The act of seeking meaning makes people with Major Neurocognitive Disorder create a robust coping mechanism against this disease (Agli et al., 2015). People with dementia, though affected by a demeaning mental condition, continue preserving their religious beliefs and values (Stuckey & Gwyther, 2003), and holding on to the faith they have had in God's love prior to their dementia.

As mentioned initially, dementia results in degeneration of the brain, which is associated with emotional, behavioral, and cognitive impairments (Corfield, 2012; Hereema, 2018). Persons with this disease are often viewed, by society, as individuals who are insignificant. However, despite the societal views which label people with dementia as socially dead, insignificant, and having diminished personhood, in God's eyes, they remain of great worth; their soul is preserved, and their connection with God remains existent and intact (Corfield, 2012). Even though persons with this disease are being devalued and often socially isolated, their individual spirituality and religiosity help them retain positive attitudes amid the mental challenges they face.

2.6 Religion, Spirituality, and Mental Health

Spirituality and religion are concepts that have overlapping definitions, and they can exist exclusively of each other. According to MacKinlay and Trevitt (2010), spirituality comprises four elements, the first of which is relationship. This element is where the individual strives to maintain intimacy with God and other people. The second element is the environment, which consists of natural resources, such as the sea and mountains. The third element is religion, whereby individuals engage in religious activities such as prayer, worship, and meditation. The last element is arts, and it is made up of music, poetry, and dance. Humans connect with the transcendent or the sacred to find meaning in, adjust to, and cope with life situations, and they make use of these spiritual elements.

Religion is an institution that also involves human behavior in seeking the sacred or a Higher Power. Schlehofer et al. (2008) clarify that religion is distinct from spirituality because religious people adhere to organized activities created by tradition, and these activities are usually conducted in one central place, for example, in a temple. Furthermore, religion focuses on emotions, beliefs, reading of the Word, having faith in God or Christ, baptism (Schlehofer et al., 2008), and religious practices such as prayer and worship (Agli et al., 2015).

Spirituality and religion have always played a significant role in providing care and relief to those with health difficulties. An increasing body of research has focused on how religion and spirituality can also assist in dementia care. Researchers have concluded that spirituality's emotional aspects can significantly increase in those seeking to maintain connections with family members diagnosed with dementia (Gwyther, 1995; Stuckey & Gwyther, 2003). Stuckey and Gwyther (2003) stress that spirituality and religion are significant resources for coping with a diagnosis of dementia and caring for those with this condition. Bell and Troxel

(2001), McFadden et al. (2001) and Stuckey and Gwyther (2003) all emphasize a holistic approach to dementia care, that considers the religious and spiritual elements alongside the cognitive, physical, and emotional well-being of those affected. According to Stuckey and Gwyther (2003), ignoring the religious and spiritual well-being of people with dementia results in the loss of many moments of meaningful experience. As cognitive functioning declines, the person's spiritual aspect may become the only way to experience meaningful exchanges. Without the opportunity to experience these moments, those affected and impacted by dementia are likely to fall further into isolation or despair.

Spirituality and religion have been the focal point for previous research focusing on physical and mental health (Koenig et al., 2004; Parker et al., 2003; Powell et al., 2003). Most of these studies indicate that religious and spiritual avenues offer spiritual care that could reduce levels of psychological illnesses such as depression, anxiety, and stress (Parker et al., 2003), alleviate physical ailments (Powell et al., 2003), reduce ill-health and death (Hummer et al., 2004), improve cognitive functioning (Kaufman et al., 2007), and improve health (Ellison & Fan, 2008). Also, religion is known to help with adjustment and acceptance of illnesses, particularly in later life and in people with dementia (Beuscher & Beck, 2008; Stuckey & Gwyther, 2003).

Over the past decades, gerontologists have been interested in further researching the contributory role played by spirituality and religion towards health issues coupled with aging. This interest is mainly because older people believe in committing their lives into the hands of God, which increases their chances of having faith and hope for recovery (Stuckey & Gwyther, 2003). This hope is usually correlated with lessened helplessness (Holland et al., 1999), enhanced quality of life, security, confidence, and better adjustment (Stuckey & Gwyther, 2003).

In their study, Vitorino et al. (2018) state that spirituality and religion are associated with better outcomes in an individual's health; subscribing to formal religious doctrines has proven to enhance social support, healthy behavior, improved lifestyles, and happiness. Furthermore, spirituality and religion enhance coping mechanisms against anger, stress, apprehension, and sadness (Koenig et al., 2012, as cited in Vitorino et al., 2018). Research done by Pargament et al. (2011) revealed that the level of the individual's spirituality and religious commitment influences their likelihood of developing effective coping strategies against extreme life adversities. In a systematic review by Weber et al. (2017, as cited in Vitorino et al., 2018), it is argued that spirituality and religion are essential elements that sustain people's psychological health, while low involvement with these elements is closely associated with low coping strategies.

In his research, Snyder (2003) recounted that, for a woman who had stronger faith after being diagnosed with Alzheimer's disease, her faith helped her accept living with it. Coin et al. (2010) discovered that Alzheimer's disease patients who were significantly involved and regularly engaged in religious practices exhibited fewer cognitive challenges than a group of people who distanced themselves from practicing religious activities. The same seems to apply in people diagnosed during the early stages of dementia, compared to those already diagnosed with severe cognitive decline and less awareness of religion and spirituality.

Other studies (Macquarrie, 2005; Phinney et al., 2002) have revealed that, during the initial stages of Alzheimer's disease and post-diagnosis, people make an effort to exercise their coping strategies against declining memory and feelings of worthlessness, and they attempt to retain their lives as healthily as they lived prior to diagnosis. It is beneficial for these individuals

to have a stable supporting environment, seek a sense of meaning in life, and focus their thoughts on positive things in life. Moreover, denied close relationship or involvement with religious organizations is a determinant of, and may lead to, deteriorated mental health (Vitorino et al., 2018). Individuals who rely on religion may show more efficient coping against geriatric health difficulties, such as heightened stress levels, apprehension, and depression. A study by Helm et al. (2000, as cited in Agli et al., 2013) reported the positive relationship between engaging in individual or private prayer and enhanced well-being, which reduces mortality rates among the senior population.

There has been ongoing research focusing on the perspectives of people diagnosed with dementia, caregivers and clinicians, and the role of religion in dementia care (Stuckey & Gwyther, 2003; Bell & Troxel, 2001; Dungee-Anderson & Beckett, 1992;;;). However, there is a paucity of research focusing on the conceptualization of dementia among Charismatic Christian religious or spiritual leaders (pastors, specifically) and how these conceptions can be influential in care provision for people with dementia and their caregivers, and whether they (pastors) believe they can play a role in caring for this population. It is crucial to understand how religious and spiritual leaders understand dementia and how they care for people with dementia and their caregivers. This understanding contributes to alternative care and management for those with and affected by dementia. A few studies have focused on how religious and spiritual leaders understand diseases and their role in supporting and healing the sick, especially within the Charismatic Christian community, but with minimal focus on dementia (Kpobi & Swartz, 2018; Osafo et al., 2015).

If religion and spirituality play a role in caring for those diagnosed with dementia and their caregivers, it is vital to understand how pastors conceptualize this disorder and how they can

provide care. Although religion has been advocated for providing care and support in dealing with many other physical challenges, when it comes to mental illness, Charismatic Christian religion has also used many unorthodox traditions (such as cults, false prophets, holy water, anointing oil and fabricated miracles) claiming to assist those affected. Charismatic pastors have been criticized for making their sickened congregants depend on and obey them during therapeutic periods, thus compromising the latter's ability to make their independent decisions (Kpobi & Swartz, 2018).

2.7 Charismatic Christian Pastoral Care

A large number of South Africans affiliate with the Christian religion. According to BusinessTech (2016), an estimated seventy-eight percent of KwaZulu-Natal population is affilitated with Christianity , while eighty-six percent of the South African population is affilitated with this religion. There are several denominations within Christianity, but this study focused on and sampled Charismatic Christian pastors. This movement is well known by its reliance on the gifts from the Holy Spirit, such as prophecies, praying in tongues, salvation, performing miracles and revelations (Kpobi & Swartz, 2018; Osafo et al., 2015).

In their study, Osafo et al. (2015) report that, for Charismatic Christians, mental health problems have spiritual explanations attributed to them; participants (pastors and prophets) expressed their views and reported that they view mental illnesses as emanating from spiritual aspects and they are a problem of the soul. This perception emanates from the belief that those affected may suspect that they are being punished for the sins they have committed in the past (Osafo et al., 2015). This perspective is likely to elicit stigma against people affected by mental health and make them fall further into despair and guilt. However, DETP (n.d.) argues that

dementia is not a disorder of the soul; rather, it is a brain disorder, and therefore pastors should strive for competency to distinguish between soul and brain disorders.

Studies report that dementia affects the brain, while the soul is believed to remain intact (Corfield, 2012; DETP, n.d.). Thus, as pastors offer support and care for persons with dementia, they should not overlook spirituality because that is where the soul operates. The brain may be destroyed, and the person's physical body may be affected too, but the soul remains intact and continually yearns for a secured connection with the Higher Power. Corfield (2012) stresses that "dementia affects the mind and the body, but it cannot destroy the soul" (p. 70).

As dementia progresses within the individuals' brain, they disconnect from those around them, including family (Corfield, 2012). However, efficient pastoral care acts as a force that binds people with God, and, from Him, they find comfort and harmony amid hardships (Corfield, 2012). Family caregivers should not be deprived of pastoral care, because their well-being becomes subject to becoming demoralized due to caring for their loved ones who have become dependent on them. Caregivers experience spiritual wounds such as anger, grief, frustration, spiritual isolation, and guilt resulting from providing care to persons who suffer from this incurable disease (DETP, n.d.). They, therefore, need pastoral care to build resilience and hope, as this will aid them to continue courageously providing care.

Corfield (2012) states that pastoral care provision, where home visits are paid to the sick who are prayed for, is necessary because it serves as a source of comfort and healing to these vulnerable persons. However, the challenge lies in the communication difficulties when ministering to persons who have lost their cognitive abilities (Corfield, 2012; Hudson, 2015). Many spiritual caregivers have not committed themselves to learning and building their

understanding of how to counter predicaments that may arise when ministering to persons with degenerative disorders (Keck, 1996, as cited in Corfield, 2012). However, pastors who devoted their work to mental health, relied on theological perspectives to find pathways into providing optimum care to those who need it (Corfield, 2012).

Christian pastoral care is bible-based thus propelling pastors to observe certain scriptures when carrying out their duties as spiritual caregivers. Corfield (2012) refers to scriptures that could serve as a foundation and direction for pastoral care provision, as the scriptures can bring those cared for into the remembrance of how much God cares for them. In the book of Matthew 4:4, Jesus stated that people should not survive on bread alone, but God's words are a source of life as well (Corfield, 2012). 1Corinthians 6:19 declares that the human body is the temple where the Holy Spirit dwells (Corfield, 2012). Isaiah 48:14-19 reveals that, even though humans may be unable to remember the Lord, but He surely remembers them (Corfield, 2012). In the book of Jeremiah 29:11, the Lord said, He knows the plans He has for His people, and this scripture enhances hope for the better future (Corfield, 2012). Luke 10:20 states that those who believe in the Son of God, Jesus, are promised to be crowned with eternal life (Corfield, 2012). In Deuteronomy 31:8, humans are reminded that the Lord will never leave or forsake them; thus, they should fear nothing (Corfield, 2012). According to Corfield (2012), these scriptures help remind pastors not to disregard those facing dementia, because God's love is also extended to their souls, despite their psychological difficulties. DETP (n.d.) emphasizes that these souls remain members of the spiritual communities, and they need to be taken care of spiritually and religiously.

The primary duty that pastors perform is to provide the human soul with spiritual food, which is the Word of God. Corfield (2012) presents God's Word as a mightier sword upon any

stronghold, sin, or sickness. Sharing the Word of God with people who suffer from a range of degenerative disorders is seen as a gesture of love proclaimed by Jesus in one of His teachings. Regardless of the inconsistent behaviors that people with dementia may portray, they deserve to be loved and cared for. Corfield (2012) and DETP (n.d.) compare demented persons and children by stating that, although children may behave inconsistently, their parents continue pouring out their love to them. Such is the love that Christian pastors and the spiritual communities should share with their congregants who have dementia.

As DETP (n.d.) mentioned earlier, Major Neurocognitive Disorder attacks the brain and does not attack the human soul. The soul remains intact, enabling these individuals to strive to continually maintain their spiritual connectedness with God. Clergy have to embark on this journey with sick persons to direct their souls and spiritually hasten to God. Corfield (2012) states that pastors cannot cure this disease, but their role is to help connect the human soul to the Lord, which is the essence of pastoral care. Through pastoral care, those affected by this disease may experience relief, enhanced hope, and love. Thus, it cannot be taken at face value that religion is helpful and religious leaders always know what they are dealing with and how to assist.

In their research on Charismatic Christian ministry, Osafo et al. (2015) report on the two approaches used to provide pastoral care, and these approaches are aligned with psychotherapy. The first approach is hope induction, whereby the clergy attempts to inspire hope in the hopeless (Osafo et al., 2015). Studies report that dementia patients who affiliate with religious and spiritual avenues portray a hope for recovery and in the afterlife (Agli et al., 2015; Corfield, 2012; Dalby et al., 2011; Ramshaw, 1987, as cited in Wentroble, 1998). The second approach, used by Charismatic Christian movements, is prophetic deliverance. Gifford (2004, as cited in

Osafo et al., 2015) describes this approach as entailing how the prophet diagnoses the illness and prophetically discovers where the illness emanates. The prophets or pastors will then pray for the sick individual or use spiritual remedies such as Holy water, anointing oil, and reading the scriptures (Osafo et al., 2015).

2.8 Religious Practices

Hudson (2015) questions the relevance and meaningfulness of religious practices for persons who have lost meaning in most basic things. He refers to worship and enquires about a range of factors which include:

a) the value of worship for persons who can no longer attribute meaning to the words;

b) the meaning of the Eucharistic meal to persons who have forgotten how to eat or drink;

c) the meaning of being involved in a worship session for persons who have become relatively antisocial;

d) the most suitable worship style that can be used to accommodate those who do not know who God is;

e) who decides to take people with dementia to a place of worship, since they can no longer make their own informed decisions?

However, other studies present the effectiveness to elicit spiritual responses of religious practices implemented to reach the cognitions of persons who have lost their memory (Kpobi & Swartz, 2018; Agli et al., 2015; Osafo et al., 2014Corfield 2012; ;; Wentroble, 1998).

Religious practices can act as important reminiscent activities that trigger religious responses, even in individuals who have impaired memory. Bowlby (1993, as cited in Wentroble, 1998) describes the functions of religious practices. He mentions that these practices are an essential source of the following aspects:

- support and hope for people who suffer from the stress of coping with Major Neurocognitive Disorder such as Alzheimer's disease;
- they enable the patients to spiritually and emotionally express themselves;
- they are crucial for a holistic treatment approach;
- they enforce a unique way of communication when normal communication fails as the brain disorder progresses;
- they aid a process of reminiscence.

Spiritual and religious practices help people with dementia to experience enhanced hope for recovery, to find meaning and purpose in life, to build reliable and effective coping mechanisms, and to have something to hold on to amid stormy stages of their lives (Agli et al., 2015; Corfield, 2012; Stuckey & Gwyther, 2003). Dementia patients find spiritual healing and hope for recovery when practicing religious activities such as prayers, reading the Bible, meditating on the Word, and listening to sermons (Hill & Pargament, 2003, as cited in Agli et al., 2015; Bresnahan, 2003, as cited in Corfield, 2012; Kpobi & Swartz, 2018). Ramshaw (1987, as cited in Wentroble, 1998) reported on the effectiveness of liturgical remembrance, which is a process used to trigger memories that help Alzheimer's disease patients to remember the biblical promises made in the past about their life; this process brings into remembrance that God wonderfully and fearfully created them.

Demented persons may forget about God and their relationship with Him. Their memory loss may fade or erase such life narration. However, God never forgets His people in His everlasting mercy and unconditional love (Hudson, 2012). When Wentroble served The Nathaniel Witherell's residents with the Eucharistic meal, he discovered that tactile objects were likely to trigger memories about God and how the residents should handle themselves in humble

adoration of Him. When Christians render the Eucharistic meal, they help people with dementia remember who they are to God and God's love toward them, thus gaining hope. This remembrance, as aided by the meal, "signifies profound hope for those who are de-mented; who now in Christ become re-mented, re-minded, re-membered" (Hudson, 2012, p. 12).

Bruchett (2002, as cited in Corfield, 2012) states that "it is difficult but not impossible to reach a cognitively impaired person spiritually" (p. 22). When exploring Christian-based pastoral care for Alzheimer's disease residents in The Nathaniel Witherell, Wentroble (1998) discovered that reminiscent religious activities serve as a pathway to access the residents' spirituality. In their two-weekly sessions, residents were to sing religious songs; after singing, Wentroble asked them what the songs meant. They responded meaningfully and accurately, showing that they could apply their minds to the song and the meaning behind it. They could remember and interpret the words to construct the song's whole meaning. For example, residents sang very familiar songs such as: 'He's got the whole world in His hands'. When Wentroble asked who is the 'He' that the song refers to, residents replied saying, 'The Lord'. In addition, when reading familiar scriptures from the Bible, residents could fill in the relevant words when Wentroble strategically paused in the middle or at the end of the verses.

The illustration of elements that constitute spirituality informs people's religious practices to overcome their mental challenges (MacKinlay & Trevitt, 2010). People with dementia are subject to emotional distress due to their suffering, but some find peace from the natural environment where there is a range of natural objects that humans depend on for living today (Bowlby, 1993, as cited in Corfield, 2012). Thus, for people with dementia, though their memory is being shattered, when they behold nature and meditate on the natural resources that

God created, they can remember that there is a Mighty hand that is behind this creation in its beauty (Corfield, 2012).

2.9 Theoretical Framework: Explanatory models of illness

This study was informed by the explanatory models of Illness as a basis for understanding pastors' perceptions of Major Neurocognitive Disorder. This theoretical framework was pioneered by Arthur Kleinman, and it is well known for its efficacy in addressing five aspects concerning illness, and these include etiology, pathology, symptomatology, course of illness, and treatment (Kleinman, 1978; Weiss & Somma, 2007). Furthermore, Kleinman (1978) explored health care relationships using this framework and identified health care relationships such as patient-family and patient-practitioner relationships. This framework also responds to cultural perspectives to ensure appropriate health care provision, patient satisfaction, and adherence to treatment (Kleinman, 1978).

This framework assumes that how the illness and its symptomatology are appraised determines people's pathways to seeking treatment and whether they will comply with that treatment (Mathews, 2008). According to Weiss and Somma (2007), the explanatory models form part of the formulation process whereby the illness is appraised, using cognitive explanations, symptoms, social experiences, emotional experiences, and personal background.

According to Bhui and Bhugra (2002), Kleinman acknowledged that the patient's and the healer's cultural background significantly influence their perspectives when illnesses are conceptualized. This model puts emphasis on making explorative qualitative inquiries on the patients' illnesses. These inquiries are deemed to harvest an in-depth understanding of the patient's narratives and cultural context concerning their presenting complaint. According to

Weiss and Somma (2007), this model emphasizes the emic approach when conceptualizing illness, as it helps the practitioners gather localized narratives and perspectives pertaining to the illnesses. The patient's explanatory model helps the healthcare practitioners to understand the patient's worldview, which involves the meaning they hold towards the illness and their expectation of recovery. In other words, this model incorporates a traditional conceptualization of the illness, rather than that of Western biomedicine (Bhui & Bhugra, 2002).

Mathews (2008) stated that biblical scriptures shape the Christian population's frame of reference, shaping their explanatory models of psychological distress. These explanatory models are reported to seemingly mirror a cognitive-behavioral perspective, in which it is argued that the nature of the individual's thoughts and behavior are essential aspects that determine their psychological well-being (Mathews, 2008). However, in light of the cognitive-behavioral perspective, lay perceptions of dementia make society perceive people with dementia as regressing cognitively and behaving more like children (Corfield, 2012; DETP, n.d.; Levkoff et al., 1999).

As mentioned above, this framework explores a variety of aspects concerning illnesses, and these were of interest in this study. Furthermore, additional aspects were explored, and they include the following: pastors' conceptions of dementia, belief systems, and experiences from providing care to people with dementia and their caregivers.

Some studies reveal that the explanatory models of illness has proven to be a practical framework to conceptualize various illnesses, and following are a few of such studies: a study exploring personal perceptions of being hospitalized as a psychiatric patient (Sayre, 2000); a study to understand the causal factors of cardiac illnesses and depression (Lynch & Medin,

2006); a study exploring traditional healers' explanatory models and their treatment methods for mental disorders in South Africa, Mpumalanga Province (Sorsdahl et al., 2010); a study assessing how explanatory models can influence treatment methods for mental disorders and outcomes thereof, and issues that may arise when discrepancies between explanatory models by clinicians and patients are evident; (Dinos et al., 2017).

However, a restricted range of literature explores Charismatic Christian pastors' explanatory models concerning dementia, though they serve as an essential part of providing religious and spiritual care. Therefore the research questions and the interview schedule were designed to invite a detailed account of the topic at hand. The research sought to uncover the explanatory models that shape: a) pastors' appraisal of Major Neurocognitive Disorder; b) how these models may influence their pastoral care towards people with dementia and their families; and c) the role of religious practices in managing the illness.

2.10 Conclusion

This chapter is a synthesis of literature from different sources that provided research findings that are applicable to this study. The manner in which society understands dementia is highlighted. The literature review also illuminated how caregivers and people with dementia are affected by this disease. Furthermore, this chapter gave extensive arguments on how society perceives dementia. It is apparent that society uses spiritual and religious lenses to make meaning of this disease. Therefore, it was deemed essential to distinguish between religion and spirituality, and how these avenues impact mental well-being. Thereafter, literature that looks explicitly at Charismatic Christianity was provided to give context on how pastors provide care to those affected by this disease and what forms the basis of their care. The literature revealed

that pastoral care is done in conjunction with religious practices. Therefore, this chapter also paid attention to these practices and how they can benefit people affected by dementia.

In addition, the literature was centered around conceptions of dementia and how pastors provide care. Therefore, the theoretical framework deemed suitable to give perspective on this topic is the explanatory models of illness approach, which specifies that how people appraise disease influences how and where they might seek help.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter highlights the research process undertaken in conducting this study. The research design and paradigm used, the sampling procedure implemented, the methods used for data collection, the ethical considerations applied, and the data analysis procedure will be discussed in detail.

3.2 Research Paradigm: Social Constructivism

The social constructivist paradigm claims that meaning is constructed through a collective human interaction in order to understand the world and oneself (Cojocaru & Bragaru, 2012; Galbin, 2014). Cojocaru and Bragaru (2012) state that, in the socio-cultural frame, language, discussions, and symbolic practices aid the construction of meaning. Furthermore, the construction of knowledge and meaning is a process that is subjective and intersubjective. This means that, during the construction of meaning, there should be joint and active participation and conversations between the subjects involved (Charreire-Petit & Huault, 2008); this allows for the interpersonal and intergroup relations to bring about the formation of concepts and the understanding of each other's actions (Cojocaru & Bragaru 2012; Galbin, 2014). Galbin (2014) further states that the culture, history, and society to which the subject is exposed play a crucial role in understanding the world and constructing meaning.

The construction of meaning and knowledge stems from the interplay of three factors. This paradigm acknowledges the interaction of subject-object-knowledge development methods (Charreire-Petit & Huault, 2008). This illustration depicts that observers or researchers study the phenomena of interest, and in so doing, in order for them to find acceptable truth, they

make use of language, discourse, and symbols (Charreire-Petit, & Huault, 2008). Constructivists seek to understand how people experience the phenomena under study, the meaning they make of it, and to investigate how society talks about it (Terre Blanche et al., 2006).

In this research, Charismatic Christian pastors were requested to share the spiritual and religious conceptions they attribute to Major Neurocognitive Disorder. Pastoral duties are mainly religious, spiritual, social, and cultural. These duties are highly interactive, and this creates the platform for the pastors to construct meaning through linguistic exchanges between them and their congregants. Therefore, the constructivist paradigm was used in this research, as it assumes that reality is socially and culturally constructed; this approach is most suitable for research that aims to reveal an understanding of situations and phenomena (Charreire-Petit & Huault, 2008). This paradigm allows the researcher to explore the participants' subjective knowledge (Charreire-Petit & Huault, 2008). Therefore, in a nutshell, this paradigm also allows researchers to explore the use of socially constructed knowledge and how people construct reality (Terre Blanche et al., 2006). The questions that were asked in this research were subjective. The mandate was to explore what meaning the participants attach to the topic at hand and how it is constructed.

3.3 Research Design

This study adopted an exploratory qualitative research design. Exploratory research aims at exploring the research questions. This design's primary purpose is to give insight about topics that have not received much attention from the existing research (Sim & Wright, 2000). The distinctive attribute of a qualitative research design is that it is descriptive, meaning it allows the researcher to enquire about the participants' everyday lives (Cropley, 2019; Mohajan,

2018). Cropley (2019) states that qualitative research can be done without having a theory, and it does not require any objective measurements. Mohajan (2019) argues that, in a qualitative research design, the theory is derived from the data rather than using empirical methods to test a well-defined theory.

The use of this research design is advantageous in many ways. Firstly, it allows the integration and interpretation of unexpected data (Cropley, 2019; Conger, 1998, as cited in Mohajan, 2018). Secondly, in a qualitative study, questions are not designed to require fixed responses. Instead, this approach comprises open-ended questions that allow the participants to express their ideas, thoughts, and feelings using their own words (Cropley, 2019). Thirdly, in some instances, the researcher may feel that there is more information behind what is disclosed by the participant; thus, qualitative research is advantageous as it permits probing, allowing the participant to further elaborate on their initial responses (Cropley, 2019).

Some disadvantages come with using a qualitative research design, however. The sample size is relatively small, hindering the generalizability of the findings to broader populations (Mohajan, 2018; Harry & Lipsky, 2014, as cited in Rahman, 2016). Also, qualitative studies are well known for their potentially large pool of data, resulting in prolonged data interpretation and analysis (Mohajan, 2018). Qualitative designs are also vulnerable to researcher bias, whereby the data may be influenced by the researcher's expectations (Mohajan, 2018). Rahman (2016) argues that qualitative studies focus on subjective meanings and experiences; consequently, the researcher may partially consider the context in which these meanings and experiences arise.

Despite the shortcomings identified by other researchers, the qualitative design resonated well with this study. This study sought to uncover the participants' understanding and knowledge of the topic at hand. This research design enabled the participants to share their interpretation and their constructed meanings concerning Major Neurocognitive Disorder. The questions that this study aimed to answer did not require statistical reports and inferences. They, instead, needed a more in-depth insight into the Charismatic Christian context. Therefore, the researcher immersed herself within the topic, based on the context that informs it, Charismatic Christianity. Though other researchers state that interpretation of qualitative data may be costly in terms of time due to its large quantities, the researcher believed that the larger pool of data signifies in-depth, descriptive, rich, and insightful results.

There is limited research on Charismatic Christian pastors' conceptions of Major Neurocognitive Disorder; thus, this research aimed to discover potential salient factors and their significance to the research questions. Hence, an exploratory research design was adopted.

3.4 Location of Study

The study was conducted in KwaZulu-Natal, within the Pietermaritzburg area. Five pastors lived in the townships, while one lived in a surbuban area. According to the Department of Economic Development, Tourism and Environmental Affairs (2016), unemployment rates were estimated at twenty-four percent in Pietermaritzburg, suggesting that the socio-economic standing of the population in this area is poor.

3.5 Population and Sampling Techniques

The study used non-probability sampling. The participants were recruited using both purposive and snowball sampling methods. Purposive sampling was used in this study because it aimed

to research the knowledge and understanding of dementia by a defined sample, which is six ordained Charismatic Christian pastors. Snowball sampling was introduced as the initial recruitment failed to yield an appropriate sample size. According to Devers and Frankel (2001), purposive sampling selects participants who can provide information about the research questions. Then, as per the snowballing technique, these participants are requested to refer the researcher to other potential participants (Dever & Frankel, 2001).

The sampling frame for this study included ordained pastors in a Charismatic Christian church. Amongst these pastors, one is affiliated with inter-denominational Christianity in which he fellowships with traditional and Charismatic Christain religious movements simultaneously.Other pastors have never held pastoral positions in any other denominations except for Charismatic Christian churches. Pastors needed a minimum of five years' experience in their position to ensure they could provide sufficient knowledge and information. Lastly, pastors were not required to know or have a congregant with dementia, as the study was not about the experience of working with a person with dementia. Instead, the study was interested in the pastors' understanding of dementia.

3.5.1 Recruitment

Ethical clearance for the study was obtained from the UKZN Humanities and Social Sciences Research Ethics Committee (Appendix D). The researcher first visited websites of Charismatic churches within the Pietermaritzburg area. Secondly, pastors of these churches were contacted, using telephone numbers from these websites. The pastors were informed about the study, and for those interested in participating, an interview was scheduled with them. There were six participants; two pastors were recruited purposively, and four participants were recruited through snowballing. All the participants were male, because pastors referred the researcher to

other male potential participants when the snowballing technique was adopted. Another reason for the sample to be constituted of male pastors only is that female pastors are not yet much involved in this ministry compared to male pastors, who remarkably dominate the ministry in terms of numbers.

3.6 Data Collection

3.6.1 Instrument: Interview Schedule

Individual interviews were conducted using an interview schedule with open-ended questions (Appendix C); this was developed using literature in the area of dementia. This interview schedule is composed of the research questions mentioned above. However, these questions were broken down to cover content that would give much broader information for each research question. For example, for the first research question, that explores the participants' knowledge of dementia, the researcher formulated questions about the definition, symptoms, and perceived causes of this illness. The second research question was to find out more about how participants' knowledge of dementia impacts how they provide care to people with dementia and their families. Therefore, participants were asked to share their knowledge on the reasons that drive people to seek care from spiritual and religious avenues. Also, participants were asked to share their knowledge about the role played by these avenues in helping people with dementia. The last research question inquired about the role of religious practices; hence, it was accompanied by questions requiring participants to list those practices explicitly. The role of religious practices, and how they are made conceivable to people with cognitive difficulties, were also discussed.

The information sheet, consent form and interview schedule were available in isiZulu and English (Appendices A, B and C). The researcher did back-translation for the isiZulu

documents. To ensure accuracy and reduce obscurity after back-translation, a bilingual psychologist who works within the area of dementia was consulted. This consultation involved discussions about the use and meaning of words identified as problematic. However, to minimize confusion in terms of what this illness may be, the researcher used 'dementia', which is a commonly used term that can be easily understood. The interviews ranged from 30-60 minutes, and they were recorded in the interview schedule and with an audio-recorder.

After the interviews, the researcher listened to each recording on different occasions. After that, the process of transcribing began, where the researcher used a verbatim transcription method. The researcher spent two to three hours transcribing each recordings, depending on the length of the interview transcribed. Though this process may be time-consuming, it helps the researcher permanently store the data, and this is advantageous as the researcher can always refer back to the data when necessary (Lapadat & Lindsay, 1999, as cited in Lapadat, 2000). During transcribing, the researcher engaged in an intense process of converting the spoken words into written words, making the data easier to manage and interpret (Lapadat, 2000).

The process of transcribing is informed by the paradigm which the researcher is using for their study. The constructivist paradigm was used for analysis purposes. As part of the transcription process, the researcher converted the verbal discussions to written text and immersed herself in the data, while being interpretive at the same time. The audio-recorded data was transcribed verbatim, meaning precisely as the participants expressed their views (Poland, 1995, as cited in Halcomb & Davidson, 2006). This form of transcription helped the researcher preserve the participants' original meaning and avoided compromising the originality of the data, as the transcripts were produced using the participants' exact words, ensuring the inclusion of idiosyncratic cues (Oliver et al., 2005). Mishler (1991, as cited in Lapadat, 2000) states that

transcription should be seen as a continuous re-interpretation, as contextualized, and as a constructivist process.

After the data were collected and transcribed, the transcripts and the audio-recordings were kept in a secure password-protected computer accessible only by the researcher. All data will be stored in a secure filing cabinet by the supervisor for five years, as per UKZN research rules on data management.

3.6.2 Procedure

On the day of the interview, pastors were visited at their church site for interviews. Before commencing data collection, participants were informed about the study and given an information sheet (Appendix A). The information sheet included information on the study's objectives, the data collection process, voluntary participation, and confidentiality. After participants were satisfied with the information provided, they were asked to sign the consent form (Appendix B), indicating their agreement to participate. The consent form also included consent for audio-recording (Appendix B). In addition, Covid-19 did not affect any aspect of this study as the data collection process took place before this pandemic.

3.7 Data Analysis

In qualitative research, the data analysis process includes preparing and organizing the data and reducing the raw data into themes necessary for interpreting the study results; this process is called thematic analysis (Braun & Clarke, 2006). Thematic analysis is used in qualitative research to identify, analyze, and report themes within the dataset (Braun & Clarke, 2006). The researcher examines those themes to compile detailed discussions across the dataset. This study adopted the Explanatory models of illness approach, and thematic analysis was carried out

within the constructivist paradigm. Therefore, the researcher was enabled to tap into the participants' world or contexts, and it also allowed her to unpack the underlying themes and their meaning, based on the Charismatic Christian religious context. Below are the steps that the researcher followed in conducting thematic analysis as recommended by Braun and Clarke (2006):

3.7.1 Familiarizing Oneself with the Data

The data were collected in an interactive approach with the participants. Thus, verbatim transcribing was essential. The researcher then familiarized herself with the transcribed data. This process entailed the researcher's ability to engage with the data by actively and critically reading the transcripts and noting the items of interest. As a result, the meaning, richness, and complexity of the discussions were thus evaluated. This phase of thematic analysis informed the next phase, which involved identifying the 'bits' of meaning in the dataset.

3.7.2 Coding

This phase aided the researcher in identifying codes. According to Braun and Clarke (2006), codes can take the form of semanticity and latency, in which obvious meanings and fundamental ideas are captured, respectively. This process involved the identification of intriguing and precise ideas from the data. The researcher used Nvivo to identify the codes that were repetitively noted across all transcripts.

3.7.3 Generating Themes

In this phase, the researcher studied the codes from each transcribed interview, and this helped discover central themes that represented shared ideas across the dataset. The researcher evaluated the significance of these themes and further evaluated whether they related to the

research questions at hand. The evaluation of themes also involved looking at the extent to which participants' discussions were patterned and revealing the underlying meaning these patterns hold, allowing the researcher to uncover the overall narrative, as these themes were carefully explored.

3.7.4 Reviewing of Themes

The researcher sought to find congruence between the generated themes and the research questions, and looked at their richness level. The meaning behind those themes was re-evaluated, consequently leading the researcher to ask the following questions: i) Do they answer the research questions?; ii) Do they shed light on what the participants' ideologies are?; and iii) Can these themes enlighten the readers of the context that gives rise to the participants' perspective of the topic under study? This task required the researcher to immerse herself in the transcribed interviews, and consequently, this led to the dismissal of some of the themes, as they portrayed minimal significance across the dataset.

3.7.5 Naming and Defining Themes

In this phase of thematic analysis, the researcher went through a process whereby themes were named and defined to further evaluate their congruence with the entire data. The themes that portrayed minimal congruence were dismissed as they were seen to potentially obscure the data.

3.7.6 Compiling a Report

After thoroughly evaluating the identified themes, and after the congruence of these themes with the research questions was proven to be evident, a final report was produced.

3.8 Ethical Considerations

Ethical considerations in research refer to acts of accountability whereby the researcher ensures that the research participants are protected from any distress, harm, or vulnerability, emanating from participating in the research (Cacciattolo, 2015). Kaewkungwai and Adams (2019) state that, in order for the research to be considered ethically acceptable, the researcher must predict the possible outcomes of the research and evaluate how these may positively or negatively impact the research participants and society. Furthermore, ethical consideration protects participants' rights, health, and safety (Steering Committee of Bioethics, 2012, as cited in Kaewkungwai & Adams, 2019). The following ethical issues were considered in this study:

3.8.1 Autonomy

This principle endorses respect for persons, whereby the rights of the participants are observed. These rights include being informed about the study (done to obtain informed consent from the participants), free will to decide whether or not to participate in the study and a right to withdraw from participating at any time during the research without any adverse outcomes (Allan, 2016). When the researcher heeds this ethical principle, they acknowledge that participants have self-determination and decision-making capacity (Jahn, 2011).

Three provisos should be taken into consideration to ensure autonomy. Firstly, Jahn (2011) states that participants should have the intention of partaking in the research. Secondly, they should be given information about the research to help them understand its content. Lastly, participants' actions should be naturalistic, meaning any variables should not influence them to act in a certain way, as this may result in research bias (Sim & Wright, 2000). Participation was voluntary, and the participants were given full information on the nature and intentions of the study, therefore allowing participant autonomy.

3.8.2 Informed Consent

To ensure informed consent, researchers should provide the necessary information to the potential participants and explain the study's risks and benefits (Allan, 2015; Nijhawan et al., 2013). When this explanation is provided, the researcher must use language that is understandable to the potential participants to ensure that they fully understand the purpose of the research and can decide whether or not to participate in the study (Nijhawan et al., 2013). When obtaining consent from participants, it is vital to ensure that participants do not feel coerced to participate in the study.

It may be impossible to obtain informed consent from legally incapable people (American Psychological Association, 2017), such as minors and mentally ill people. However, this was not a predicament in this study, because the participants were within the majority age group and did not have mental illnesses affecting their legal capacity. Furthermore, the content may be subject to alterations as the research progresses; therefore, the researcher's duty is to provide enough information to ensure that consent is maintained throughout the data collection process (Allan, 2015;). Written consent was obtained from the participants, and it was indicated to them that they had the right to withdraw their participation at any time without unfavorable outcomes.

3.8.3 Beneficence

Beneficence was also observed in this study. This principle warns researchers to avoid harming the participants by breaching confidentiality; thus, participants' identities should be protected (Allan, 2016). Therefore, the participants' personal information was not disclosed publicly; instead, pseudonyms were used. In some qualitative studies, there is a possibility that

beneficence gets breached inadvertently. If research is conducted in small communities, participants' confidentiality is less likely to be ensured. However, in this study, participants were sampled from different churches (each participant serves in their respective church, except for two pastors who serve in one church but at different branches) in the Pietermaritzburg area. Also, it is the participants' right to know how the results will be published. Using quotations increases the chances of participants' identities being revealed, which has negative implications if data were collected from vulnerable individuals. Thus, as part of this awareness, participants should consent that their responses can be quoted. However, this study posed minimal threat to participants, because it did not recruit vulnerable individuals.

Spirituality and religiosity are aspects to which people, who observe them, attach their hearts. These aspects are constituted of different belief systems, in which different societies observe different beliefs. Consequently, spirituality and religion are contested aspects. The role of these aspects was the focal point in this study. Therefore, it was essential to be cautious and be linguistically sensitive when interviewing and probing spiritual and religious individuals, to ensure that respect for their beliefs was kept at the highest level.

3.9 Scientific Rigor

3.9.1 Dependability

Dependability is a measure that proclaims the adaptability of the study to changes as new inputs may be obtained during the study. The measure emphasizes the flexibility of a study (Gelling, 2015). A set of new ideas and codes surfaced from the interviews with Charismatic Christian pastors, and they proved to yield significant and logical data, and therefore they were incorporated in this study.

3.9.2 Confirmability

For research to be confirmable, its results must be reasonable, understandable, and fair, as per other researchers' judgments, and this measure can be met by the researcher's ability to reflect on and critically review the research tools used (Gelling, 2015). To ensure that the results from this research are confirmable, thematic analysis was done to discover the emerging themes and the extent to which they were significant for the research focus.

3.9.3 Transferability

The transferability measure in research is used to evaluate the relevance of the findings to other related settings; thus, findings must be conceivable and be understandable to other people from other fields (Gelling, 2015). To ensure that the data collected was sound, this study's objectives required a sample made up of Charismatic Christian religious leaders, who had considerable experience in pastoral positions. It is worth noting that participants did not necessarily need to have worked with people with dementia, as this research sought to explore the participants' conceptions of this disease. Therefore, the generated codes were evaluated from their responses to determine whether they yielded good or relevant data to other fields such as biomedical and traditional treatment fields.

3.10 Conclusion

This chapter discussed the methodology used in the study. It comprises sections that elucidate the paradigm adopted, and its suitability for this study. The research design, sampling techniques (including inclusion criteria), and the study population were highlighted. Data analysis was discussed, and due to the chosen research design, thematic analysis was found practical for this study. Ethical considerations and how they were adhered to in this study are

highlighted. Finally, a brief discussion is done regarding aspects of scientific rigor, including dependability, confirmability, and transferability.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter presents the research findings. Data were analysed using thematic analysis, and the themes answered the study's research questions which were:

- What are the Charismatic Christian pastors' knowledge and understanding of Major Neurocognitive Disorder?
- What is the impact of Charismatic Christian pastors' conceptions in providing support and care provision for those with Major Neurocognitive Disorder and their families?
- What contributions can Charismatic Christian religious practices make to the support and care of those affected by Major Neurocognitive Disorder?

The themes presented below were uncovered through thematic analysis, and they were interpreted using the explanatory models of illness approach as the theoretical framework. Extracts are presented to support the participants' main arguments about the research questions. Pseudonyms were used to keep the participants' identities anonymous; for example, P01 (P = Participant, 01 = the sequence or number of the interview).

Table 4.1 *Participant Characteristics*

Variables	**N (%)**	**Variables**	**N (%)**
Ethnicity		**Age**	
African	5 (83.3)	30-45	1 (16.6)
Indian	1 (16.6)	46-61	2 (50)
		62-77	2 (33.3)
Gender			
Female: 0	0 (0)		
Male: 100	6 (100)		
Years as pastor			
5-10	2 (33.3)		
11-20	2 (33.3)		
21-30	2 (33.3)		

Note. The participants' demographic data

4.2 Results

The results of the thematic analysis are presented as laid out in Table 4.2.

Table 4.2 *Research questions and themes*

Research Questions	**Headings**	**Themes**
What are Charismatic Christian pastors' knowledge and understanding of Major Neurocognitive Disorder?	4.2.1.1 Conceptualization of Major Neurocognitive Disorder	*Dementia as aging* *Dementia as forgetfulness* *Dementia as loss of mind* *Dementia as witchcraft*
	4.2.1.2 The perceived causes of dementia	*Emotional distress* *Dementia as a result of neglect* *Aging* *Spiritual forces*
What is the influence of Charismatic Christian pastors' conceptions in providing support and care provision for those with Major Neurocognitive Disorder and their families?	4.2.2 Pastoral care as influenced by conceptions of dementia	*Family support* *Social support* *Psychoeducation*

What contributions can Charismatic Christian religious practices make to the support and care of those affected by Major Neurocognitive Disorder?	4.2.3 Contribution of religious practices	*Healing* *Spiritual connectedness and revival*
*Emergent theme	4.2.4 Perceptions about dementia patients	*Seniors as world's treasure and guides*

Note. The presentation of research questions and themes

4.2.1 Charismatic Christian Pastors' Conceptualization of Major Neurocognitive Disorder

The first research question that this study sought to answer was how pastors conceptualized Major Neurocognitive Disorder. This question was answered by exploring the pastors' knowledge and understanding of Major Neurocognitive Disorder and their perceptions about the causes of Major Neurocognitive Disorder.

4.2.1.1 The Pastors' Understanding and Knowledge of Major Neurocognitive Disorder.

Participants had multiple beliefs and understanding of dementia. Four themes emerged from this topic, and these were dementia as aging, forgetfulness, loss of mind and witchcraft.

Dementia as aging

A fifth of the participants believed that people develop several illnesses as they progress in age, and dementia was also understood as an illness of old age. This implied that it occurred as a normal process of aging. The extracts below give a synopsis of the concept of dementia as a normal part of aging.

Extract 1

P03: Lesisifo ngathi sihambisana nokukhula komuntu.

(This disease, it is like it goes with aging of the person.)

Extract 2

P05: Iwu-iwukugula okuhlasela abantu abadala isikhathi esiningi.

(It is a disease that attacks older people most of the time.)

Extract 3

P06: Ayi izifo ezihambisana nokukhula nje. Ngike ngithi mina, mhlawumbe kusuke kuyi exhaustion, ukukhathala kwengqondo ukuthi manje ingqondo isikade yayisebenza.

(No, it is just diseases that come with aging. I usually say, maybe it is exhaustion, fatigue of the brain, that now the brain had been working for a long time.)

These participants expressed that they had been serving and providing pastoral care to older people presenting with dementia symptoms, and they estimated that the age of the congregants presenting with these symptoms usually ranges from the 60s to 90s. Their observations from these encounters included that a person's cognitive abilities decline gradually as the person progresses in age.

Dementia as Forgetfulness

The participants also appraised dementia as an illness that interferes with the individuals' cognitive abilities, and eighty-three percent attributed this disease to forgetfulness.

Extract 4

P02: I think it will be loss of memory.

Extract 5

P04: Mhlawumbe ikhona lokhu kokukhohlwa.

(Maybe it is this thing of forgetfulness.)

From their observations, the pastors realized that one of the prominent symptoms of this illness is memory loss. They referred to a couple of examples that indicate that memory has been affected:

a) Senior congregants need to be reminded of the days for church gatherings:

Extract 6

> P05: Labo bantu abadala, abanye babo, baze bakhohlwe nawusuku lokukhuleka. Bafuna ukuyokhunjuzwa, ukuthi "Namuhlanje uLwesibili." Uma ungazange mhlawumbe wabakhumbuza, lokho ngeke babekhona.
>
> (Those eldery people, some of them, they even forget the day of prayer. They need to be reminded, that "Today it is Tuesday". If you did not perhaps remind them that, they will not be present.)

b) They misplace objects.

Extract 7

> P01: Okunye, abeke into, la ayibeke khona ayikhohlwe avele athi uyithethe.
>
> (Another thing, she puts something, she forgets where she put it and says you took it.)

c) They forget what they wanted to say.

Extract 8

> P03: Ake ngithi mhlawumbe siyaxoxa kanje naye, siyakhuluma naye, bese ethi, "awu yazi khona into ebengikade ngifuna ukukutshela yona, ukuthi sengikhohliwe ukuthi yini."
>
> (Let me say perhaps we are having a conversation like this with them, we are speaking, and they say, "Oh you know there is something that I wanted to tell you about, but I forgot what it is.")

d) They confuse their children's names.

Extract 9

P01: Kuyenzeka mhlawumbe akubize ngegama lomfowenu.

(It happens perhaps that they call you by your brother's name.)

e) They are quick to forget the things that were shared with them in conversations.

Extract 10

P04: …*Yes,* ikhona lokhu kokukhohlwa; uthole ukuthi ukhulume into ethize naye ugogo, usethi "awu sengikhohliwe mntanami..."

(Yes, it is this thing of forgetfulness; you find that you spoke about something with the old woman, and she says "Oh, I forgot my child")

Dementia as Loss of Mind

In assessing the conceptualization of dementia, 'loss of mind' was identified as an indicator of this disease. The extracts below give an elaboration and justification on how dementia is seen as such:

Extract 11

P06: Uthole ukuthi umnt'omdala mhlawumbe, uze azithole mhlawumbe esephumile, ehamba phandle, a-akazi ukuthi mhlawumbe kwenzekani Ingqondo ngathi ifuna ukulahleka.

(You find that the older adult, maybe theyfind themselves having gone out, walking outside, they do not know maybe of what is going on. It is like the mind wants to get lost.)

P06 attributed dementia to ‘loss of mind’ among older people. The extract below highlights behavioural changes that are associated with loss of mind:

Extract 12

> P02: It will be also members, the patients, having the sense of, not understanding the whereabouts, not understanding that some of the things, that they have to have clothes on.

Fifty percent of the participants identified ‘loss of mind’ and disorientation as characteristic and indicators of dementia. People with dementia are described as people who appear to have lost their sense of time and place; they are prone to wandering around aimlessly, even at night. Disorientation could be one reason people with dementia are suspected of witchcraft, as demonstrated in Extract 14.

Dementia as Witchcraft

Though the pastors were probed about their own understanding about dementia, they also made reference to what they believe communities understood about this disease. They indicated that Major Neurocognitive Disorder is an illness that the general community can misunderstand, and the following are the extracts that present these societal misconceptions:

Extract 13

> P06: Uyabona leyonto, utholakala, bese bethi abantu uyathakatha ngoba kwaziwa ukuthi phela umuntu ohamba ebusuku umthakathi kanti cha, ingqondo ephazamisekile. (You see that, you find, and people say they are performing witchcraft because it is known that a person who goes during the night is a witch, but no, the mind is disturbed.)

Another pastor commented as follows:

Extract 14

> P04: Mhlawumbe nje usukeleke (umphakathi) nje uthi hhayi kuyathakathwa lapha kabani noma uyathakatha ugog' ubani.
>
> (Maybe just unreasonably they [the community] just say no they perform witchcraft in that house, or grandmother so-and-so is performing witchcraft.)

Though the question uncovered how the pastors conceptualized dementia, they further described the conceptions portrayed by lay communities where dementia is concerned. An estimated thirty-three percent of the participants demonstrated their awareness that the community is likely to misunderstand dementia and associate it with witchcraft. This is primarily due to the disorientation that sometimes affects older adults, where they can be found wandering at night; this causes a false alarm to the observers. Understanding dementia as witchcraft predisposes people with dementia and their families to violence and stigma.

4.2.1.2 Perceived Causes of Major Neurocognitive Disorder.

An inquiry on how pastors understood dementia was made; however, it was essential to uncover the perceived causes attributed to this disease. This inquiry was believed to directly link to or be congruent with the management of the disease through religious practices. Therefore, this section aims at providing the perceived causes.

Emotional Distress

Sixty-six percent of the participants understood dementia as emanating from emotional distress. However, just two extracts below were selected, and they shared similar sentiments with other pastors.

Extract 15

> P03: Mhlawumbe, umuntu washiywa izingane zakhe, kasenay' umuntu omnakekela kahle, mhlawumbe wahanjelwa umuntu owayeyithemba kakhulu lakhe. Nesimo ke sempilo. Ngingathi mhlawumbe mangithi isimo sempilo sani sokuthi akazitholi izinto ezanele kahle ezikwazi ukuthi, zimsize empilweni, uyabona? Manje lokhu kugcina sekucinene sekukuningi la engqondweni yakhe. Engazi ukuthi uzothathani ahlanganise nani, enze njani.
>
> (Maybe, the person lost their children, they no longer have someone to take care of them, maybe they lost someone who was their hope. And then life situation. I would say maybe, what life situation? It is that they cannot get enough resources that, can be of an aid to their life, you see? So this ends up crowding them here in their mind. Not knowing how to make means, what to do.)

This participant based his argument on what some cultures value: when children grow up, they have to give back to their parents and take care of them, as they fail to execute activities because of age. Thus, children are a hope figure for their parents. However, there is the possibility of unfortunate circumstances where their children pass away. This eventuality brings a remarkable change in the older adult's life; there will be no one who can ensure that their basic life necessities are taken care of. Furthermore, the loss of children is often accompanied by prolonged grief. When parents face life challenges in their children's absence, they are constantly reminded of what they have lost and continuously grieve. This pastor argues that the pressure exerted from this mourning can be a risk factor for dementia.

Agreeing with the argument above, another pastor expressed an opinion that is aligned with opinions as raised by other pastors and said:

Extract 16

> P06: Engingakugcizelela nje ukuthi *in the core, ecentre*, yakho konke kusuke kukhona isimo sokuhlukumezeka, ziningi izindlela zokuhlukumezeka; kungabe i*family violence*, ngabe i*emotional distress*, kungabauyabona amalokhuzana, ama *depression* izinto ezinjalo ama *depression*, mhlawumbe nezingane, mhlawumbe omakhelwane, mhlawumbe bayakuxakazisa, mhlawumbe isemsebenzini uthol' izinto ezikuxakazisayo. Uyabo nje ziningi izinto ezingama *contributing factors* ezenza ukuthi uzithole isimo sengqondo yakho sesila lasihlukumezeka khona; *icentre* yakho konke ukuhlukumezeka.
>
> (What I can just emphasize is that in the core, in the centre of it all, there would be misery, there are many ways of being in misery; it could be family, violence, it could be emotional distress, it could be, you see things like, depression things like that depression, maybe also children, maybe neighbours, they are conflicting with you, maybe at work you find things that distress you. You see there are a lot of things that serve as contributing factors that make you, your mind reaches a stage where it is in misery; the centre of it all is misery.)

Life adversities were predominantly identified as playing a remarkable role in the experience of emotional distress, which the pastors believed further put people at high risk of developing dementia later in life. Scientifically, dementia is described as a neurocognitive condition that is associated with aging. Pastors, in their arguments, mainly ascribed dementia to aging and negative emotional experiences.

Dementia as a Result of Neglect

Another pastor argued that dementia is caused by depression. In his argument, he revealed that neglect is the underlying factor that elicits depression in older adults. He elaborated on his argument as follows:

Extract 17

> P01: Ezinye zezinto, ukuba *stubborn* kwabantwana; ukuba *neglect(a)* kakhulu. Besekekuba naleyo *depression*.
>
> (Amongst other things, it is stubbornness of the children; they neglect them [older people] very much. And then they have that depression)

Pastors portrayed having a wide range of understandings, where dementia is concerned. They did not view it as solely a biological process; they acknowledged that other factors, including familial pressures, predispose people to dementia.

Aging as the Precipitator for Major Neurocognitive Disorder

Another factor that was seen as a contributing factor in the onset of dementia in the elderly population is aging. The pastors argued as follows:

Extract 18

> P02: I think it will just be a case of old age.

Extract 19

> P04: Mhlawumbe ngingathi nje ulwazi enginalo elokuthi ukukhula, kuyiyona imbangela.
>
> (,Maybe I would just say with the knowledge I have is that aging, it is the cause.)

The participants acknowledged that, as individuals progress into late adulthood, they change both physically and psychologically. Aging was, therefore, seen as related to deteriorated memory and mental abilities. Consequently, aging was appraised by thirty-three percent of the participants as playing an essential role in causing this disease.

Spiritual Forces

Spiritual explanations for the onset of dementia were shared, and the following extract demonstrates how spiritual forces are perceived as a cause of this disease:

Extract 20

> P06: Abantu abebengakujwayele nje ukuthandaza, ngoba lezi zinto zisuke ziyimimoya kahle kahle ehlasel' umuntu ngoba imfice esebuthaka engesenamandla. Kahle kahle zisuka zikudonsa lezizinto zifuna ukuyokubulala lemimoya le ikubulalele endle.
>
> (People who were not used to praying, because these things are spirits actually that attack the person because they found him weak and powerless. Actually these things pull you and aim to kill you and kill you in the wilderness.)

P06 presented a unique argument when the causes of this disease were explored. This pastor appraised it as emanating from spiritual forces. He viewed spirituality as an essential factor that deters mental health issues from affecting the individual. According to his argument, when individuals do not nurture their spiritual life with prayer, they become susceptible to adverse health conditions. If the person does not engage in this practice, they might be at risk of developing dementia. His argument shows that he perceived dementia as emanating from evil spirits that can overpower a person, if they do not pray.

4.2.2 The Influence of the Pastors' Conceptions in Caring for Those with Major Neurocognitive Disorder and Their Families

The section will focus on the second research question, which investigated how the pastors' conceptions of dementia influenced their pastoral care. The main objective of this research question was to establish the association between the pastors' conceptions of dementia and how these influence their care of the congregants with this disease and their family members.

Pastors Provide Family support

Pastors believed that family members who stay with people with dementia need support from the church. They argued that dementia puts pressure on and burdens the entire family, and thus they need support to provide effective care to their family members with this disease. Therefore, they reported that, as pastors, they needed to work closely with the family, and their role as religious leaders was expressed as follows:

Extract 21

> P04: Ikuwunika nje i*support* umndeni. Ukuthi "njengoba isimo sikagogo sikanje, uyakhohlwa manje , aninodwa". Nathi njengebandla sikhona to *support*.
>
> (It is just to give the family support. That, "as grandmother's situation is like this, she is forgetful now , you are not alone." We as the church, we are here to support.)

Another pastor reported that:

Extract 22

> P06: Bayakudinga [umndeni] ukwalulekwa kwayibona. *Then* bese *besupport(wa)* ngemikhuleko, *basupport(we)* nangendumiso, uyabona? So, izeluleko ezihambisana nezwi, nomkhuleko *then* kube indumiso. Lezo zinto zontathu, ziyabasiza abagadi balo muntu, naye uqobo.

(They [the family] also need counselling. Then they are to be supported through prayers, they should be supported through worship, you see? So, counselling that is accompanied with the word, prayers and then worship. Those three things, they help caregivers of that person, and themselves [person with dementia].)

In Extract 27, participant P06 reported that families end up using up their emotional capacity when caring for people with dementia, leading them to develop negative attitudes and feelings. In his response, he argues that family caregivers need extra support, including emotional and spiritual support.

Pastors Provide Social Support

Churches are mostly believed to be providing spiritual support. However, pastors reveal that they look beyond spirituality and also focus on social issues and provide support. Following are the extracts that give further elaboration on this argument:

Extract 23

P03: Simhambel' ekhaya; kuyenzeka kwesinye isikhathi akanakho ngisho ukudla. Akasebenzi, sihlanganise singabazalwane ukuthi, 'Hhayi. ake sihambise lokhu okuncane' njengoba kade kungama *festive* nje. Simhambisele ukuthi athole naye ajabule njengabanye abantu.

(We do home visit; it happens sometimes that they do not even have food. They are not working, we put something together as brethren that, 'No, let us take this small thing', as it was festive season. We take these to them so that they will get something as well and be happy just like other people.)

Extract 24

> P01: Kuba nezinsuku la uthole lakhona benikezwa izinsuku zabo banikezwa ama phasela nani.
>
> (There are days where you find, there are days dedicated to them, where they are given parcels and so on.)

From these arguments, pastors reveal that it is not enough to preach to people living with illness such as dementia. The church's responsibility is to provide support in all life aspects. P01 also argued that older people are left with the burden of caring for their grandchildren. This leaves older adults responsible for taking care of these children with the limited financial resources they receive from their pension pay-out. This income source may not be sufficient to cover the household costs, and he agreed with the idea of doing outreach programs to distribute food parcels. Therefore, according to these pastors, the church should intervene and give a helping hand.

Psychoeducation for Families of People with Major Neurocognitive Disorder

As part of the second research question, the role of religion towards caregivers and people with dementia was explored. The data that were harvested depicted the shared view that participants are advocating for psychoeducation. One of the participants argued:

Extract 25

> P06: Uyalibona lezikhali ezintathu engike ngakhuluma ngazo? Nala kungena zona ngoba uthol' ukuthi, , bashaywa izinto ezimbili labobantu. Kukhona ingcindezi ebabangela ubuhlungu nokuhlukumezeka kukhona ingcindezi ebabangela, ukucikeka, bafise ukuthi, 'Kodwa yini indaba avele afe lomuntu?' So, izeluleko ezihambisana

nezwi, nomkhuleko *then* kube indumiso, lezo zinto zontathu ziyabasiza abagadi balo muntu, naye uqobo.

(You see the three weapons I mentioned earlier [prayer, the word, worship]? Even here they are included, because you find that, , those people are affected by two things. There is pressure that causes them pain and misery, there is pressure that causes, irritability, and they wish that, 'But why does this person not die?' So, counselling that is accompanied by the word, prayers and then worship, those three things help caregivers of this person [person with dementia] and themselves.)

This participant argued that psychological changes witnessed in dementia affect those with dementia, and their families also experience the emotional burden. Therefore, they need counselling and emotional support. This support is believed to uphold the caregivers and give them the courage to care for their senior family members. Other pastors argued as follow:

Extract 26

P01: Ya, kufuna ukuthi unga *deal(i)* ngogogo kuphela, *deal(a)* nalaba abakhona, abashiya abantwana kubona ukuze ugogo aphile impilo yakhe yokuguga a *relax(e)*, angabi ne *depression*. Bangam' *overburden(i)* ngezinye izinto.

(Yes, you should not only deal with the grandmother, you should also deal with those [family] who are with her, who leave their children with her, so that the grandmother can relax and live her adult life. She must not have depression, they should not overburden her with other things.)

Another argument relating to psychoeducation was expressed as follows:

Extract 27

P04: Ukuwuchazela umndeni ukuthi ugogo hhayi ukuthi ungenwe ukuhlanya noma ungenwe ukusangana ingqondo yakhe isiyasangana usewuhlanya *or something.* Kodwa ukuwubek' esithombeni ukuthi umunt' omdala uma esuke esekwi *stage* esikanje ziyenzeka izinto ezikanje. Siwufundise ukuthi uku *understand(a) istage* asuke esekusona.

(It is to explain to the family that it is not that their grandmother has become insane or she has become insane that her mind has become crazy or something. But it is to paint the picture to the family that, when the elderly person reaches a stage such as this one, things like these happen. We teach them so that they understand the stage that she has reached)

The participants acknowledged that families may be confused by the onset and unfolding of dementia, and the subsequent abnormal changes. As pastors, the onus is on themresponsibility to enlighten the families about this illness and reach out to people with dementia. Their arguments revealed the importance of normalizing the onset of dementia, in order to help families be emotionally prepared to witness the cognitive changes.

Furthermore, P04 stressed that families should be taught that people with dementia are not experiencing insanity, but they have just reached a certain stage of their lives. One of the pastors' mandates is to preserve dignity for all human beings. Therefore, they normalize circumstances that people with dementia experience, and they teach the communities about the importance of accepting those experiencing cognitive difficulties. Psychoeducation was emphasized by sixty-six percent of the participants which signifies that this is a prominent role that pastors can play through the religious medium or avenues to reach out to families of and people with dementia.

4.2.3 Contribution of Religious Practices to Dementia Care

This section was based on the research question that sought to investigate the contributory role religious practices play in helping people with dementia. The themes harvested from the transcripts, and illustrated in the following extracts, provided an understanding of the role of religious practices and how they reach the older adults' mind meaningfully. It is noteworthy that participants listed four primary religious practices they use in helping people with dementia and their families. These practices were prayer, worship, the reading of scriptures, and counselling.

Healing

The pastors were asked to comment on the influence religious practices have in managing dementia and its symptoms. It was apparent that these practices are perceived to be helpful in various aspects of people' lives. The pastors' arguments elucidated that, although they are spiritual, religious practices also help regulate all aspects of their lives. Religious practices were argued to be effective in facilitating the individuals' healing of dementia, and below is the extract that elaborates on this argument:

Extract 28

> P01: Zibasiza ngento eyodwa. *The more* becabanga, *the more* behlaselwa izifo. *Physically,* bayabuya esimweni ngoba izifo eziningi. Ngingathi *idepression*, idala *high blood pressure*. *So* izifo lezi ezibabambayo ogogo, kubanconywana.
>
> (They help them with one thing. The more they think [worrying thoughts], the more they are attacked by sicknesses. Physically, they recover, because most diseases. I would say depression, causes high blood pressure. So these diseases that affect grandmothers, become better.)

Another pastor argued as follows:

Extract 29

> P06: Okokuqala, nje *icounseling*. *Icounseling* ibaluleke kakhulu ngoba uyelulekwa lapho ngokomqondo, ululekwe ngokomoya, ululekwe nangokwenyama nje, uthole ukuthi lezo zinto ozolulekwa ngazo zizokusiza ukuthi uma uzenza uzilandela kahle ugcina uzwa kwehla umthwalo; wehla lo mthwalo.
>
> (Firstly, it is just counselling. Counselling is very important because you get psychological counselling, spiritual counselling, and physical counselling, you find that the counsel you have been given, if you comply with it, you end up feeling the alleviation of the burden; this burden becomes alleviated.)

Fifty percent of the participants shared similar ideas about human beings that they are made up of various elements. P02 stated that humans are made of three aspects which include the spirit, body, and soul. In comparison, P06 emphasized the importance of ensuring holistic healing when providing care to people with dementia. Furthermore, P01 revealed his understanding of the interconnectedness of the life elements by arguing that psychological illnesses can predispose individuals to biomedical illnesses. Other literature focusing on Afrocentric understandings of mental health agrees with this notion and further states that, when one of the elements mentioned above goes through some distractions, other elements are most likely to be negatively affected. The pastors' arguments show that these religious practices play a crucial role in maintaining harmony among these elements and maintaining a better quality of life.

Spiritual Connectedness and Revival

Previous studies have argued that people with dementia often find it difficult to understand what is happening around them due to their cognitive challenges as they decline and progress

in age. This research sought to investigate how pastors access these old people's deteriorated cognitions using the religious practices, helping them understand these practices, even though they may have lost meaning in basic things and have become detached from the world around them. Pastors explained as follows:

Extract 30

> P01: Ya, *most of the time,* basuke bevele bekholwa. *So, just, sirevive(a)* lokho okusuke kukhona, okusuke kutshaliwe ngoba kuyavuswa. Bese kutholakala ukuthi uma esesekhaya, sekuhlasela lezinto (izifo), uma sewum-*revive(a)* kuma *teachings* esuke ewafundile vele *ubalance(a)* kuwona bese kuba lula ukuthi noma *idepression* uma ifika, uyathandaza.
>
> (Yes, most of the time, they are believers already. So just, we revive what is already there, what is already sown because it gets revived. Then you find that, when they are at home, when these things (diseases) attack them, when you revive them through the teachings they have already learned, they balance in them and it becomes easy that even when depression comes, they pray.)

Another pastor said:

Extract 31

> P02: Okay, sometimes, , we have to, we have to understand that we are tri-part beings, we are spirit, we are soul, we are body. So, because our spirit is connected to the Holy Spirit, we will always be God-conscious. Nobody can take that away from us. So, even though we may lose our faculties, , we may,we may lose our sense of sight, we may lose our, ability to walk, all these situations are gonna affect our bodies, but our mind and our spirit is in tune with God...

The above extracts show that, no matter the situation and illnesses that attack one's well-being, religiosity and spirituality continue to thrive within the individual. This is what helps individuals to find hope and overcome life-threatening illnesses. Participants' arguments show their belief that the progression of age and the onset of dementia do not wipe out God-related awareness in the person's mind. What needs to be done is to unlock what is already there and encourage older people to use or act on that awareness, elicited through spiritual means, to better their lives. P02 claims that spiritual connectedness can never be taken away from people; it is deeply embedded and engraved in one's soul. This claim relates to what P04 said when he commented about the elderly people's awareness about God and their ability to advise young pastors:

Extract 32

> P04: Yinto eyimpande leyo engasuki kalula kumunt'omdala noma esenaso isifo lesi sokukhohlwa.
>
> (It is a root that does not go away easily from the older person even though they have this disease)

From these extracts, pastors claim that the Godly spirit cannot be perplexed by the events that occur on a physical or psychological life domain. The spirit upholds the individuals' entire well-being and helps them be resilient though any of life's trials that may come. From the literature, it is argued that dementia has the power to destroy one's brain, but the soul remains intact. Therefore, the clergy is encouraged to get involved in the lives people who suffer from dementia, because the one entity that continually yearns for the Sacred is still not, and will never be, destroyed.

4.2.4 Perceptions about Dementia Patients

When engaging with the study participants, another aspect emerged where at least thirty-three percent of the pastors did not only base their arguments on how they conceptualized dementia. They also expressed how they perceived the seniors who lived with this condition and showed that they thought highly of them. Therefore, this section's primary goal is to briefly report on the comments and arguments brought forth by the participants in this regard.

Seniors as the World's Treasure and Guiders

Though they may be stigmatized and seem to have detached from their surroundings, older adults continue to possess wisdom that can serve as the 'bread of life' to the younger generations. Therefore, the pastors acknowledged that the senior congregants remain the world's treasure, and they argued as follows:

Extract 33

> P01: Ya, *and*, labantu bangama gugu esizwe; basuke bephethe izinto ezi *special* okufanele bazilalele abant' abasha.
>
> (Yes, and , these people (people with dementia) are precious to the world; they possess special things in them, which the youth should listen to.)

Another pastor expressed his perceptions and feelings about older adults with dementia:

Extract 34

> P04: Noma ungawumfundisi kuyena, kodwa uke asho ukuthi, "*Yes,* ungumfundisi kumina kodwa ungumntanami. Ake ngikhulume lezizinto zokuthi hlal' ebukhoneni mntanami, zikhon'izimo ezizofuna ukukushiyisa lento yokuthi uyakhonza."

(Even if you are a pastor to her, but she would say that, “Yes, you are a pastor to me but you are my child. Let me say these things that you must stay in the presence [God’s presence] my child, there are things that will force you to renounce your faith.”)

In addition to the statements above, P04 expressed his thoughts about the presence of elderly people in church:

Extract 35

P04: Sisuke sinethemba lokuthi khona isiyalo. Noma ngabe kuthiwa unalesisifo, kodwa sikhona isiyalo esiyimpande kuphila, int’ engasinika *iroot* yokuphila thina esingabantu abancane esingayithola kumunt’ omdala.

(We have hope that there is a lesson. Even though they have this disease, but there is a lesson which is a root of life, something that can give us the root of life as the youth, which we can get from an elderly person.)

Despite them being diagnosed with dementia, these extracts present older adults as having all the knowledge to help the youth in their spiritual lives and life in general. They can still pass on rich knowledge and groom those who follow behind them. However, the literature review highlighted that society in general might view people with dementia as facing ‘an endless funeral’. This view may be a factor that can lead to adults being devalued. There is also much stigma attached to mental illness, thus leading people with dementia to be stigmatized. In this way, their social position is devalued, as mentioned in the literature review, and consequently, their dignity is diminished.

Furthermore, people living with this illness are susceptible to social disconnection, as they eventually lose meaning in things, and this contributes to society’s discriminatory behaviour

against them. This means that people with dementia are often neglected and not listened to with respect, and thus society is not likely to pay attention to the valued knowledge their seniors may share with them.

4.3 Conclusion

This chapter firstly provided a brief overview of the study's objectives, followed by a description of the participants' characteristics. Next, the themes that were generated from the transcripts using NVivo were presented, with supporting extracts. The first section provided themes that elucidated how pastors understood dementia and the causes they attributed to the onset of this disease. The second section aimed to discover how pastors might provide care to those affected by dementia. The third section looked at how religious practices play a crucial role in the care of people with dementia, while the final section highlighted an emerging theme that the pastors raised across the dataset, in which they expressed how they perceived older people amid their deteriorating cognitive abilities.

Overall, a total of fourteen themes were identified in the dataset, and they corresponded with the research questions. As outlined above, these themes highlighted how pastors conceptualized dementia, how these conceptions influence how they provide care to those affected, and the contributory role of religious practices. The participants provided extensive discussions, and from their statements, a new theme emerged, which is based on how they perceived older people with dementia.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter discusses the findings of this study in relation to the literature and theoretical framework reviewed in Chapter 2 of the thesis. The main objectives of this study were to explore the following:

- Charismatic Christian pastors' conceptions of Major Neurocognitive Disorder;
- the influence of these conceptions in how they might provide care to those affected by this illness;
- how religious practices can assist in the management of this illness.

The social constructivist paradigm was adopted to help the researcher understand: a) the participants' context, b) how they create meaning about dementia, and c) how they engage their pastoral role in facilitating change for those affected by this illness. Commonly, when discourses around particular events emerge, it is expected that people might use their social context to make meaning of those events. Similarly, this study aimed at exploring religious and spiritual perspectives concerning dementia.

There is a commonality between the findings from this study and previous studies. Religious and spiritual healing has been proclaimed to be a practical approach in tackling mental and physical illnesses. However, there has not been much literature that presents pastors' notions about dementia. Therefore, where this study differs from available literature is the channel it took. Instead of interviewing people with dementia or their caregivers, pastors were recruited.

5.2 Conceptualization of Major Neurocognitive Disorder

It was clear that pastors had various understandings of dementia. It was also noted that pastors did not only use one way of understanding dementia; they used more than one aspect. For example, instead of just seeing dementia as an illness of old age, they would describe dementia as an illness of forgetting occurring in older people. Also, dementia was defined as a 'loss of mind' in older people, leading to disoriented behaviors such as losing a sense of time and place and wandering around at night. In addition, some adults are said to be found with no clothes on. Aging, forgetfulness, and loss of mind were seen as the prominent features of dementia. Aging was associated with those who are between sixty and ninety years. Forgetfulness was associated with older people misplacing objects, needing to be reminded about the date, forgetting what they wanted to say in the middle of the conversation, and failing to recall conversations they had had recently. These dementia features have been discussed in other literature as well.

Notably, their discussions reveal that their understanding of this disease is limited to spiritual and social factors affecting people with dementia. They lacked the biomedical discourse concerning this illness. Therefore, they are likely to overlook the biomedical sector's contribution to the management of dementia. Consequently, their understanding of this illness might increase the likelihood to alienate this sector and may not encourage people with dementia to consult medical practitioners where necessary. For example, when some people with dementia present with psychotic and behavioral features, religious units would likely perceive this presentation as supernatural instead of biomedical. Instead of seeking pharmacotherapy for these symptoms, they may resort to faith-based healing practices while the adults may progressively experience these symptoms. Therefore, due to delayed medical attention, this progression may further exacerbate the stigmatization of adults.

Hereema (2018) define dementia as a degenerative illness that entails memory loss and impairs the individuals' ability to to communicate and to perform day-to-day tasks. Taylor and Thoma (2003, as cited in Dening & Sandilyan, 2015) state that the most prominent clinical feature associated with this illness is memory loss that pertains to immediate recall and word finding. Sadock et al. (2015) state that memory decline is an early feature that indicates the presence of dementia. Sadock et al. (2015) and Prendecki et al. (2016) further state that this degenerative disease is estimated to affect fifty to sixty percent of individuals aged sixty to sixty-five years and over. These authors argue that the alterations that occur as the individual increases in age result in nervous system degeneration.

The definitions above elucidated how pastors understood dementia, but the pastors also reported how they believe the public views people with dementia. The explicated that society views people with dementia as practicing witchcraft because of the features associated with dementia. They revealed that society does not have a clear and accurate understanding of this disease. Due to older adults starting to behave in abnormal manner, the community starts to accuse them of witchcraft and respond violently to their bizarre behaviors.

Khonje et al. (2015) report on stigma and negative attitudes directed towards people with dementia. The underlying reason for these attitudes is a cultural perspective that people employ to conceptualize this disease. In some communal contexts, diseases are viewed as having spiritual explanations. These people attribute this illness to evil spirit possession, or punishment for sins (Khonje et al., 2015), or as evidence of witchcraft (Ferreira, 2005, as cited in Khonje et al., 2015). Consequently, people with dementia, especially women, become prone to becoming victims of violence.

P06 and P04 expressed similar stances to those reported by Khonje et al. (2015). P06 stated in Extract 20 that dementia is associated with evil spirits that aim at killing people, especially those who did not accustom themselves to prayer. P04 also spoke of communities accusing the elderly of witchcraft. Therefore, this study reveals that, at the foundation of the negative attitudes towards, and unfair treatment of, people with dementia lie culture-bound conceptions of this disease, which perpetuate violent acts towards people with dementia.

Corfield (2012) stated that dementia patients can be viewed as facing an 'eternal death' because they present with inexplicable behaviors, memory loss, disrupted communication abilities, and social detachment, leading to discrimination. Furthermore, Sadock et al. (2015) reported that a significant number of people with dementia may also present with depression and anxiety. An estimated fifteen percent of people over sixty-five years present with depressive symptoms, and this condition increases mortality (Prendecki et al., 2016).

5.2.1 Christian Pastors' Perceived Causes of Dementia

The participants believed that dementia is caused by emotional distress, neglect and aging. Firstly, emotional distress was associated with the grief of losing children, widowhood and older people being left with no one to take care of them in their time of need. This element of neglect is seen as both a cause of dementia and a maintaining factor in those who already have dementia. This factor is seen as most apparent in family settings, where family members may be seen withdrawing from providing care to the elderly. Dementia is a burdening disease to both people with dementia and their family caregivers. Thus, as the stress of caring for the elderly increases, caregivers are likely to experience burnout and become demotivated to provide care. Signs of burnout may include manhandling, and emotional and physical abuse directed to people with dementia (Yan & Kwok, 2011, as cited in Khonje et al., 2015). Also,

neglect may manifest as physical distance initiated by the caregivers, where they may maneuver for distance from their dependent elders. This maneuver is their coping mechanism, but it compromises the emotional well-being of those living with dementia.

Lastly, with aging as a risk factor, while the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychiatric Association, 2013) presents aging as a risk factor for dementia, other studies argue that dementia is not considered a normal part of aging, although it does primarily affect older people (LoGiudice & Watson, 2014). Similarly, Prendecki et al. (2016) argued that aging is not the cause of dementia. However, the neurodegenerative processes in the individuals' brains as they grow older are the identified causes of this disease.

Empirical studies perceive dementia as emanating from organic conditions such as Alzheimer's disease, vascular dementia, dementia with Lewy bodies, Parkinson's dementia, and Huntington's disease (Grover & Somani, 2016; Sadock et al., 2015). Furthermore, dementia is also perceived as emanating from molecular changes in the brain, impairing cognitive abilities (Prendecki et al., 2016). In contrast, participants in this study understood this disease as emanating from emotional responses from experiencing psychosocial stressors.

5.3 Pastoral Care as Influenced by Conceptions of Dementia

Based on the understanding that dementia is an illness occurring in older people, with features of forgetfulness and loss of mind caused by aging, neglect and emotional distress, the pastors believed that the church can provide support to the person with dementia and their family. This provides social support, where they not only cater to spiritual needs but also provide psychoeducation to families and the community of people with dementia who needed support.

The pastors also believed that the religious practices offer healing, spiritual connectedness and revival to those with dementia and their families.

Available literature reveals that caring for people with dementia is more stressful than other diseases (Brodaty & Donkin, 2009). Caregivers are identified as experiencing a constellation of feelings that include love, the need for spiritual fulfillment, a sense of duty, guilt, social pressures, and, consequently, emotional distress. Furthermore, family caregivers exhaust their spiritual, emotional, and financial resources in the process of caring for their elders (DETP, n.d.). Consequently, they are likely to harbor feelings of resentment which come from this caregiving experience. Thus, they may attempt to counteract this resentment because of guilt and may engage in self-sacrificial acts, further perpetuating resentment and emotional distress (Sadock et al., 2015). Furthermore, as family caregivers engage in this duty, they give up their leisure time, social interaction, and hobbies to maximize time spent with their family members with dementia.

The views from this study about the caregiving experience reiterate the importance of assessing the impact of dementia on people whose role is caregiving, as they are at high risk of developing emotional distress, including severe depression. As mentioned above, mental health practitioners tend to focus on the identified patients, forgetting that families are left with strained resources. Therefore, the scope of healthcare should be broadened to the wider family for it to be holistic and effective.

Pastors' scope of practice may be viewed as only limited to spiritual needs. However, this study reveals that their work is also centered around people's psychosocial needs. One of the psychosocial stressors that pastors aim to eradicate is poverty. They highlighted various

conditions that older adults bear in their old age, including the following: a) being neglected; b) their children leaving them with grandchildren; c) widowhood and being the female household head; and d) losing their children through death. These factors may significantly impact their socio-economic status, thus leaving the church responsible for taking care of their needs on this level.

Hansen et al. (2017) state that the psychosocial needs of people with dementia should be the focal point of caregiving. They identified physical needs, including nutrition, medication, hygiene, and help with domestic chores, as imperative. Participants in this study shared the same sentiments as previous studies and identified the importance of providing these families with food items and support. In addition to these needs, one of the pastors in this research reported that people with dementia often live under dire conditions, where their houses are dilapidated and, therefore, he saw a need to help in this regard.

As stated above, dementia is one of the illnesses that are misunderstood in society. Dementia as witchcraft is the most prominent misconception held by society. Also, seeing this disease emanates from spiritual forces and God's punishment will likely elicit negative attitudes, such as stigma and discrimination. An identified solution to misconceptions about this illness is psychoeducation, where information-sharing can be rendered. According to pastors, the targeted groups that need to be exposed to psychoeducation are the community and families affected by this disease.

Angry and depressed family caregivers are primarily identified to benefit significantly from psychoeducation (Hepburn et al., 2006). The psychoeducation scope proposed by these authors to reduce caregiver distress is as follows:

- Introduction to dementia, where an in-depth description of what this illness is and its causal factors could be rendered;
- introduction to strategies to be used with people with cognitive difficulties; and
- helping caregivers to be mindful of their emotional distress. This aspect is also highlighted by Sadock et al. (2015), describing the constellation of emotions involved in caregiving for people with dementia.

Though psychoeducation programs may potentially be of service in protecting people with dementia and their family caregivers, the practicality of these programs is limited in the South African context at this stage due to restricted community-based psychological services. So much work still needs to be done to promote outreach programs and facilitate change in how dementia is perceived in the lay communities. Once psychological services are made accessible in the communities, psychoeducational programs can thus help protect adults' physical and emotional well-being, where discriminatory actions against them may be eradicated through extending knowledge about this disease to society and addressing the misconceptions related to it. These are indicated in the statements about loss of mind and disorientation, as made in Extracts 12 and 13, which show that families do not only bear the burden of seeing their loved one's cognitions deteriorating progressively. They also bear the burden of dealing with negative labels directed at their family members living with dementia, as the community may stigmatize people with this disease. Therefore, pastors believe that the families needed support to deal with all the challenges of caring for people with dementia.

The results from this study and available literature share common views on the contributory role played by spiritual healing and revival, as they reveals that spirituality alleviates psychological, physical, and spiritual illnesses (Koenig et al., 2004; Parker et al., 2003; Powell

et al., 2003; Stuckey & Gwyther, 2003). These findings highlight the importance of the role played by religious practices in the lives of those affected by dementia. It is worth noting that the family caregivers also benefit from these practices, as they seek God for emotional and spiritual strength to endure the challenges of taking care of their loved ones.

The pastors' arguments endorsed the adherence to religious practices and perceived non-adherence as a predisposition to the onset and progress of dementia. For example, discussions made in Extract 20 are likely to ignite stigmatization of people with dementia as they may be perceived as not engaging in prayer and other religious practices, thus inviting spiritual forces to possess them. Consequently, the spiritual society may refrain from providing support to the older adults and their caregivers due to the expectation that they should protect themselves from illnesses through the use of these practices.

5.4 Perceptions about dementia patients

Seniors as the world's treasure and guides

Though older adults may suffer from this degenerative illness, pastors are still open to advice from them. Older adults are appreciated because of their inner treasure, which is the wisdom they hold and which pastors believe could serve as a compass for the younger generation. According to the pastors, they view older adults as people who, in their lifetimes, received something that cannot be taken away from them, and this is seen as a root of life. For this reason, they are seen as vessels from which others (including pastors) can drink and be fed with spiritual guidance and wisdom. Therefore, seniors are perceived to be of great value, and it is seen as a privilege to have them in society, despite the dementing illnesses they may be experiencing.

The above theme appears to be conditional. These perceptions speak to older adults who have a certain attribute and can overtly express it, which is spirituality and wisdom. It can be predicted that those who cannot express these attributes are likely to be devalued in society as the pastors' discourse does not provide a picture of how adults who can no longer express themselves are perceived. If spirituality and wisdom qualify people with dementia to be valued, what does this imply to people who are on the other spectrum, which is a lack of these attributes? Therefore, this raises questions of whether non-spiritual adults a) are worthy of respect, b) they should be valued and protected, and c) they deserve spiritual support. It appears that should spiritual movements focus their gaze on older adults who are affiliated with spirituality and able to share their wisdom, are likely to perpetuate discrimination against those who are non-spiritual.

5.5 Conclusion

Dementia is perceived as an illness associated with aging, forgetfulness, loss of mind, and supernatural processes. Perceived contributory factors to the onset of this illness are emotional distress, neglect, aging, and spiritual forces. Dementia is a disease that compromises the quality of life for older adults and their families, and it is left misunderstood by both the families and the general communities. Therefore, pastors argue that their role is to provide family support, social support and offer psychoeducation. Also, they report that they provide spiritual care through religious practices such as prayers, praise and worship, and the Word (reading of the scriptures). Pastoral care creates an atmosphere responsible for facilitating a feeling of safety, love, and a sense of belonging to people who may be undervalued due to their cognitive challenges.

Having comprehensible conversations and engaging in religious practices with people with dementia may be difficult, or even impossible, depending on the severity of the illness. Carr et al. (2011) argue that, although people with dementia may forget their personal history, they do not forget religious songs and prayers. They further argued that these practices are 'carved' in their minds. Similarly, in this research, participants reported that elders' awareness of spiritual and religious activities is deeply rooted in their souls, enabling them to comprehend the meaning of these activities as they participate in them. In addition, challenges in providing pastoral care were evident, but they are conquered by patience, love, empathy, and prayer.

Societal and familial negative attitudes towards people with dementia exacerbate factors that further deteriorate the elders' mental state. Though they may be subject to social rejection and be socially undervalued, people with dementia are seen as vessels that carry wisdom and counsel, which would greatly assist life's journey for the younger generations and their pastors.

CHAPTER 6: CONCLUSION

6.1 Conclusions

This study aimed at exploring pastors' conceptualization of dementia, the impact of these conceptions in providing care, and the contributory role of religious practises to support those affected by this illness. Findings suggest that pastors perceived dementia as emanating from psychosocial and supernatural forces, and it can be managed using various religious practices. Research findings also suggest that there is no uniform approach in providing care to people with dementia. In other words, effective care stems from multiple levels such as: social workers, doctors, mental health practitioners, religious leaders, communities, and families. The pastors' role is to advise families on how to take care of their seniors and to offer spiritual healing using religious practices. Their ministry is challenging. However, they overcome these challenges by heeding and employing calling-related virtues such as love and patience.

Pastors identified a direct relationship between emotional distress and dementia. When exploring the risk factors that contribute to the onset of dementia, pastors argued that emotional distress is likely to cause this illness. Furthermore, they identified gender differences in which they perceived dementia to be predominantly affecting elderly women. One of the pastors explained that older female figures are heading most households due to widowhood. This causes much pressure on older women as they have to care for their households and meet their family's needs. Therefore, dementia may not be attributed solely to neurological degeneration; rather, emotional factors could be responsible for the onset of this illness. However, how emotions are managed could differ across cultures.

Some cultural principles are likely to push women further to isolation by discouraging them from reaching out to services and people who can provide them with emotional support, resulting to a build-up of emotional distress. According to the pastors' views, factors resulting to emotional distress include abuse, heading households, restricted financial resources, and so on. Therefore, a socio-cultural aspect of gender differences, and the relationship between emotional distress and dementia seemed to emerge, as the data were critically analyzed.

6.2 Recommendations

Religious practices have received mass acceptance in relation to management of illnesses. However, there is restricted literature on these practices and how pastors conceptualize dementia from a religious perspective. Therefore, it is recommended that further research focusing on this topic be conducted.

Further research on gender differences and the emotional dynamics that affect women should be explored as the pastors identified these factors to seemingly impose on the onset of dementia.

One of Carr et al.'s (2011) findings is that effective care for people with dementia is often associated with being mindful of the individual's preferences. Therefore, if patients seem to be talking more about spiritual and religious topics, this could indicate that engaging in religious and spiritual activities could be what the seniors' souls long for. In this case, though they may be institutionalized, chaplains should be invited to offer prayer sessions. A collaborative approach should be encouraged between biomedical sectors, social welfare, religious avenues, families, communities, and traditional healing sectors in order to form this recommended collaboration. One of the six participants argued that dementia could result from spiritual

forces, and he mentioned that traditional healers are suitable caregivers. It is, therefore, important for health practitioners to be culturally competent when dealing with populations who believe in these cultural and traditional aspects.

6.3 Limitations and Areas for Further Research

This study has limitations, and they need to be explored further in future research. The scope of the study was on how dementia is conceptualized from a Charismatic Christian perspective. There is a paucity of previous research on dementia. The literature search for this study yielded a large pool of literature exploring other mental illnesses and psychosis. As a result, some articles were eliminated as their relevance to the topic at hand was minimal.

Furthermore, the area of research this study focused on appears not to have been explored sufficiently in recent research. Consequently, substantial literature reviewed in this study was found from the 1990s and early 2000s sources. Therefore, this is an area of research that needs further exploration, as perspectives shift with time.

The data collection instrument was not piloted due to financial implications as the study was not funded. Furthermore, an inquiry on the participants' highest level of education was not done in the demographic data. Finally, the study recruited male participants only. Meaning, it lacks a perspective from female pastors while their views may have potentially yielded to different themes concerning the topic at hand.

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APPENDICES

Appendix A - Information sheet

English version

Information leaflet

Dear potential participant

My name is Nompilo Khanyile, I am a Psychology Masters student at the University of KwaZulu-Natal, Pietermaritzburg campus. As part of my course, I am currently doing a research study, titled: Pietermaritzburg Charismatic Christian Pastors' Conceptualizations of Major Neurocognitive Disorder (dementia). This research will be conducted within the Pietermaritzburg area, and it primarily aims to discover how Charismatic Christian pastors conceptualize and provide care for congregants with dementia. You are invited to participate in this study. If you agree, please take note of the following information:

1. This study is voluntary and you will be allowed to withdraw from it at any time.
2. Withdrawing from the research will not yield negative consequences for you.
3. Please note that there will be no tokens or rewards offered for your participation in this study.
4. Please note that the information you will provide will be kept confidential; your name will not be disclosed, but pseudonyms will be used instead.
5. The interview will have to be recorded in order for the researcher to capture and transcribe the data as accurately as possible. The information you will provide will be accessed by the student researcher and her supervisor; it will be then shredded after a period of five years, as the university policy stipulates.
6. The interview consists of open-ended questions, and it is expected to take 50-60 minutes.

If you agree to participate, please sign the consent form.

In the event of any problems, concerns,or questions, you may contact the researcher or the supervisor or the UKZN Humanities and Social Science Research Ethics Committee.

Researcher: Miss Nompilo Khanyile, University of KwaZulu-Natal - Pietermaritzburg, (211558225@stu.ukzn.ac.za)

Supervisor: Mrs. Xoli Mfene, Discipline of Psychology, University of KwaZulu-Natal - Pietermaritzburg (033 260 5588, MkhizeX1@ukzn.ac.za)

Humanities and Social Science Research Ethics Committee Research
Office, Westville Campus, Govan Mbeki Building

IsiZulu version

Iphepha lolwazi

Sawubona

Igama lami ngingu Nompilo Khanyile, ngingumfundi wase Nyuvesi yakwaZulu Natali eMgungundlovu, ngenza iMasters kwi Psychology. Ngenza ucwaningo olunalesi sihloko esilandelayo: Pietermaritzburg Charismatic Christian Pastors'Conceptualizations of Major Neuro-Cognitive Disorder (dementia). Lapha ngihlose ukuthola ukuthi abafundisi bezenkolo yobuKristu bayiqonda kanjani i-dementia (ukukhathala komqondo) okuyisimo esivama ukuhlasela abantu abadala lapho imiqondo yabo seyifikelwa ukukhohlwa okudlulele. Lolicwaningo luzokwenziwa kubafundisi bezenkolo yobuKristu abahlala eMgungundlovu.

Uyacelwa ukuba ube yingxenye yalolu cwaningo. Uma uvuma, uyacelwa ukuba uqaphele lokhu okulandelayo:

1. Lolu cwaningo aluphoqelekile futhi uvumelekile uyeka ukuba ingxenye yalo noma kunini.
2. Ukuyeka kwakho ukuba ingxenye ngeke kube nemithelela emibi kuwe.
3. Ayikho inzuzo noma umklomelo ozowuhlomula ngokuba ingxenye yalolucwaningo.
4. Imininingwane ozoyikhipha ngeke idalulwe; igama lakho ngeke Iidalulwe kodwa kuyakusetshenziswa igama ozoqanjwa Iona. Uhlololwazi Iwakho luzokuqoshwa ngesiqopha mazwi ukuze umcwaningi akwazi ukubhala izimpedulo zakho zinjengoba zinjalo.
5. Umcwaningi kanye nombonisi wakhe yibona abazofinyelela emaphepheni anolwazi osinike Iona, ayobe esedatshulwa emva kweminyaka emihlanu njenganalokhu umgomo weNyuvesi usho.
6. Uhlololwazi lunemibuzo evulelekile, futhi kulindeleke ukuba luthathe imizuzu engamashumi amahlanu (50) kuya kwengamashumi ayisithupha (60).

Uma uvuma ukuba yingxenye yalolu cwaningo, uyacelwa ukuba usayine iphepha lesivumelwano.

Uma unemibuzo onayo mayelana ngalolu cwaningo, ungaxhumana nomcwaningi noma umaluleki wakhe. Noma ungaxhumana ne UKZN Humanities and Social Science Research Ethics Committee:

Umcwaningi: Miss Nompilo Khanyile, University of KwaZulu-Natal - Pietermaritzburg, (211558225@stu.ukzn.ac.za)

Umaluleki: Mrs. Xoli Mfene, Discipline of Psychology, University of KwaZulu-Natal - Pietermaritzburg (0332695588, MkhizeX1 @ukzn.ac.za).

Humanities and Social Science Research Ethics Committee
Research Office, Westville Campus, Govan Mbeki Building

Appendix B - Consent Form

English version

Consent by participant

I…….. (full name) hereby declare that I have read and understood the content of this research and I therefore voluntarily agree to participate, and I commit to provide as much information as I can.

Sign:..……

Date:……./……./……..

Consent by participants (Audio-recording)

I…… (full name) declare that the reasons and the importance of using an audio-recorder have been explained satisfactorily to me. I am aware that my discussions have to be recorded for the sake of transcription accuracy, and therefore I consent to be recorded.

Sign:..……

Date:……/……../…….

IsiZulu version

Iphepha lesivumelwano

Mina _____ (igama eliphelele) ngiyavuma ukuthi ngifundile futhi ngiyayinqonda imininingwane yalolu cwaningo. Ngakho ngiyavuma ukuba yingxenye yalolucwaningo futhi ngiyavuma ukunikezela imininingwane eyanele njengokolwazi enginalo ngalokho engizobe ngibuzwa kona.

Sayina: ..……

Usuku:……/……../……

Iphepha lesivumelwano (Isiqopha mazwi)

Mina _____ (igama eliphelele) ngiyavuma ukuthi ngichazeliwe ngokwanelisayo mayelana nesizathu kanye nokubaluleka kokusetshenziswa kwesiqopha mazwi ukuze umcwaningi ashicilele ulwazi engimnika lona ngokucophelela. Ngakho ngiyavuma ukuba iphimbo lami liqoshwe.

Sayina:..……..

Usuku: . . . ./. . . . . ../. . . ..

Appendix C - Data collection tools

Participant Pseudonym

Semi-Structured Interview Guide: English version

Thank you for agreeing to complete this anonymous interview.

1. Demographic data

Name			
Sex	Male ☐ Female ☐		
Date of birth		Age	
Race	African ☐ White ☐ Asian ☐ Colored ☐ Other ☐		
Nationality			
Language			
Religious denomination			
Name of church			
Position title			
Length of position			
Marital status	Single ☐ Married ☐ Separated ☐ Divorced ☐ Widowed ☐ Living together ☐		
Contact details			

Thank you, now we will talk more about dementia, and your understanding of this disease and how it can be managed.

Defining dementia:

1. Had you ever heard of dementia before this interview?
    a) If yes, where did you hear about it?
    b) If no, dementia is an illness where the individual's nerve cells have deteriorated resulting in impaired communication, memory loss and inability to perform daily activities. This condition mostly affects people who are 60 years old and above.
2. In your understanding, what is dementia?
3. What are the symptoms of dementia?
4. What kind of people do you think are affected by dementia?
5. Have you ever provided care for people with dementia?
    a) How many?
    b) Their age group?
    c) Their gender?

d) How would you know if a person in your church has dementia?
e) Have you had people with dementia in your church?
f) If yes, how many?
g) Have you had people with other mental illnesses in your church?
h) If yes, what type of mental illness and how did the church assist them?

Management of dementia

6. What impact do you think religion has on mental health?
7. What do you think leads people who are sick to seek religious/spiritual care?
8. What do you think are the causes or risk factors for dementia?
9. Are there any religious practices that you practice towards the helping of dementia?
   a) How do you think these practices can assist in managing dementia?
   b) Since dementia patients lose meaning in basic things, how would you assist them in seeing the value of religious practices?
10. Who, do you think, are most suitable people to care for people with dementia?
    a) Why?
11. What is the role played by religion in providing support for caregivers of demented individuals?
12. What is the role of religion especially in providing support to people with dementia?
13. How does the church at large respond to and treat people with dementia?
14. How do you overcome the challenges of providing care and/or counsel to persons who have lost meaningful communication?

Participant Pseudonym

Semi-Structured Interview Guide: isiZulu version

Ngiyabonga ngokuvuma ukwenza lenhlolovo engenakudalula igama lakho

1. Demographic data

Igama	
Ubulili	Owesilisa ☐ Owesifazane ☐
Usuku lokuzalwa	Iminyaka
Uhlanga	African ☐ White ☐ Asian ☐ Colored ☐ Other ☐
Ubuzwe	
Ulwimi	
Uhlaka lwezenkolo	
Igama lebandla	
Isikhundla	
Isinyaka ukulesisikhundla	
Umshado	Single ☐ Married ☐ Separated ☐ Divorced ☐ Widowed ☐ Living together ☐
Izinombolo zocingo	

Ngiyabonga, manje sizokhuluma kabanzi nge *dementia*, nangokuthi usiqonda kanjani lesi sifo nokuthi singalawuleka kanjani.

Incazelo ye dementia (ukukhathala komqondo):

1. Wake wezwa nge dementia ngaphambi kwalenhlovo?
   a) Uma kunjalo, wawuzwa kuphi ngayo?
   b) Uma kungenjalo, i-dementia isifo lapho ingqondo ikhathala khona, lokhu kuholela ukuthi Iowo muntu esimphethe ahluleke ukuba nengxoxo ephusile, akhohlwe futhi angabe esakwazi nokwenza imisebenza yansuku zonke. Lesi sifo sivama ukuhlasela abantu abaneminyaka engamashumi ayisithupha (60) nangaphezulu.
2. Ngokwazi kwakho iyini i-dementia?
3. Yiziphi izimpawu zalesi sifo?
4. Luhlobo luni Iwabantu ocabanga ukuthi bahlaselwa idementia?
5. Wake wasiza abantu abane dementia?
   a) Bangaki?
   b) Bangakanani ngokweminyaka?
   c) Bavama ukuba yibuphi ubulili?
   d) Ungathola kanjani uma kukhona one dementia ebandleni lakho?
   e) Kuke kwabakhona abantu abane dementia ebandleni lakho?
   f) Uma kunjalo, bangaki?
   g) Kuke kwaba khona abantu abanezinye izinhlobo zokuphazamiseka ngokomqondo ebandleni lakho?

h) Uma kunjalo, yiziphi lezo zinhlobo zokuphazamiseka ngokomqondo futhi ibandla labalekelela kanjani?

Ukulawulwa kwe dementia

6. Inkolo inamiphi imithelela esimweni soqondo womuntu?
7. Kuyini okwenza abantu bafune usizo Iwezenkolo?
8. Kuyini okuyimbangela ye dementia?
9. Ngabe zikhona izindlela zokukhonza enizisebenisayo ukwelapha lesisifo? (imithandazo, ukuzindla ngezwi)
   a) Uma ucabanga, lezi zindlela zokukhonza zingalekelela kanjani ekulawuleni idementia?
   b) Njengoba laba aba ne dementia bengakwazi ukuqonda izinto eziningi, ungabasiza kanjani ukuba baqonde ukubaluleka kwalezo zindlela zokukhonza enizisebenzisayo ekulawuleni lesisifo?
10. Ibaphi abantu ocabanga ukuthi yibo abakulungele ukusiza labo abane dementia? a) Ngobani?
11. Iliphi iqhaza elibanjwa izinhlongano zenkolo ukulekelela labo abangabanakekeli babantu abane dementia?
12. Yiliphi iqhaza elidlalwa yinkolo ukulekelela labo abaphethwe yilesi sifo?
13. Ibandla libaphatha kanjani labo abanalesi sifo?
14. Ubhekana kanjani nezingqinamba ezihambisana nokunakekela noma nokweluleka abantu abangasakwazi ukuba baxhumane kahle nabanye abantu?

Appendix D - Ethics Approval Letter

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

16 October 2019

Ms Nompilo Protecia Khanyile (211558225)
School of Applied Human Sciences
Pietermaritzburg Campus

Dear Ms Khanyile,

Protocol reference number : HSS/0525/019M
Project title: Pietermaritzburg Charismatic Christian pastors' conceptualizations of major neuro-cognitive disorder (dementia)

Approval Notification – Full Committee Reviewed Protocol

With regards to your response received on 16 September 2019 to our letter of 15 August 2019, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 1 year from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

[redacted]
.....
Dr Rosemary Sibanda (Chair)

/ms

cc Supervisor: Mrs Xoli P Mfene
cc Academic Leader Research: Professor Ruth Teer-Tomaselli
cc School Administrator: Ms Priya Konan

Humanities & Social Sciences Research Ethics Committee
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Appendix E - Turnitin Similarity Index Report

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by nompilo khanyile

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