

**A STUDY ON BELIEFS AND PERCEPTIONS OF MAJOR NEUROCOGNITIVE
DISORDER (DEMENTIA) IN A TOWNSHIP IN PIETERMARITZBURG – KWAZULU-
NATAL**

By

LUYANDA MEMELA

210510869

Supervisor

MRS X.P MFENE

**Submitted as the dissertation component in partial fulfilment of the requirements for the
degree of Masters in Social Sciences (Clinical Psychology)**

School of Psychology

University of KwaZulu-Natal

Pietermaritzburg

2021

DECLARATION

I, Luyanda Memela, declare that

- I. The research reported in this dissertation, except where otherwise indicated, is my original work.
- 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.
- IV. This dissertation does not contain another person's writing, unless specifically acknowledged as being sourced from other researchers. Where other written sources have been quoted, then:
 - a. Their words have been re-written, but the general information attributed to them has been referenced.
 - b. Where their exact words have been used, their writing has been placed in quotation marks and referenced.
- V. This dissertation does not contain text, graphics or tables copied and pasted from the internet unless specifically acknowledged, and the source being detailed in the dissertation and the References sections.

Signed:



Supervisor's approval of this thesis for submission:

As the candidate's supervisor I have approved this thesis for submission.

Mrs XP Mfene

Signed:



ACKNOWLEDGEMENTS

"I can do all things through Christ who strengthens me."

(Phil. 4:13)

Firstly, I would like to thank God almighty for his grace and for forever being faithful to me. This has been the most challenging academic year, but he has remained by my side until the end. For that, I will forever be indebted to God.

My sincere appreciation goes to Mrs X.P. Mfene (my supervisor) for her support, dedication and generosity in ensuring this work is a good piece.

To my family, especially my mother and my son, UnesuJehova, thank you for always being my pillar of strength even when I felt like I could not go on. I appreciate you.

Last but not least, I would like to extend my gratitude to my participants for their time, cooperation and valuable contribution to this research.

ABSTRACT

Dementia has been a public concern over the last few years. This concern is motivated by the population ageing in different countries. Because of this shift in the expected life span, there has been a rise in public health research focusing on dementia. Research has shown that there are different ways of understanding dementia in different communities and these impact treatment-seeking behaviors. This exploratory qualitative study investigated the perceptions of and beliefs about dementia held by study participants from Imbali Township (Pietermaritzburg). Secondly, it explored how their beliefs about dementia influence their treatment-seeking behaviors. Eight participants 18 years and over were recruited using a convenience sampling technique. Participants were interviewed in their households using a semi-structured interview schedule and data were analyzed using thematic analysis. The findings indicated that most of the participants perceive dementia as an illness while some did not regard dementia symptoms as constituting an illness. In addition the participants had different understandings of the terminology and causes of dementia. While some participants labelled the illness as dementia, others believed it is an old age sickness and illness occurring because of “*people’s doing*”. This diversity in understanding was also evident in treatment-seeking options and assumed recovery predictions. It was discovered that as much as people reside in a single township, they hold differing views about dementia. This shows the complexity of understanding a community, as people’s beliefs are influenced by their social and cultural context and prior experiences. It also shows that there can never be a “one size fits all” intervention if we cater to every person in our communities' spectrum.

Keywords: major neurocognitive disorders, dementia, sub-Saharan Africa, perceptions, beliefs, gender, Imbali Township

Table of Contents

DECLARATION	ii
ACKNOWLEDGEMENTS	iii
ABSTRACT	iv
ABBREVIATIONS	viii
CHAPTER ONE: INTRODUCTION	1
1.1 Problem statement	1
1.2 Purpose of the study	2
1.3 Objectives of the study	3
1.4 Research questions	3
1.5 Outline of research methodology	3
1.6 Definition of key terms	4
1.7 Outline of the study	5
1.8 Summary	5
CHAPTER TWO: LITERATURE REVIEW	6
2.1 Introduction	6
2.3 Age as a major risk factor	8
2.4 Dementia in Sub-Saharan Africa	9
2.5 Policies for elderly people	11
2.6 Management of dementia	13
2.7 Costs of dementia	14
2.8 Perceptions and beliefs about people with dementia	15
2.9 Theoretical framework	17
2.12 Summary	20
CHAPTER THREE: METHODOLOGY	21
3.1 Introduction	21
3.2 Objectives of the study	21
3.3 Research questions	21
3.4 Research paradigm	21
3.5 Study design	22

3.6 Study location and population	22
3.7 Sampling	23
3.7.1 Sampling strategy and sample	23
3.7.2 Inclusion and exclusion criteria	23
3.8 Data collection	24
3.8.1 Procedure	24
3.8.2 Instrument	24
3.9 Data analysis	25
3.10 Ethical considerations	26
3.10.1 Information sheet and informed consent	26
3.10.2 Confidentiality	27
3.10.3 Beneficence	27
3.10.4 Non-maleficence	27
3.10.5 Study benefits	27
3.11 Credibility, dependability, confirmability and transferability	27
3.11.1 Credibility	28
3.11.2 Transferability	28
3.11.3 Dependability	28
3.11.4 Confirmability	28
3.12 Limitations and challenges	29
3.13 Summary	29
CHAPTER FOUR: RESULTS	30
4.1 Introduction	30
4.2 Thematic analysis results	30
4.2.1 The participants' knowledge and understanding of dementia	30
4.2.3 Participants' understanding of dementia impact on treatment-seeking behavior	33
4.2.3.2 Relationship between participant's understanding of the causes of dementia and treatment-seeking behaviors	34
4.3 Summary	35

CHAPTER FIVE: DISCUSSION	36
5.1 Introduction	36
5.2 Knowledge and beliefs of dementia symptoms and causes	36
5.3 Treatment-seeking behaviors	38
5.5 Summary	38
CHAPTER SIX: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS	39
6.1 Introduction	39
6.2 Study summary	39
6.3 Conclusions	40
6.4 Study limitations	40
6.4.1 Participants' diversity	41
6.4.2 Literature reviewed	41
6.4.3 Data collection tool	41
6.5 Recommendations	41
6.5.1 Recommendations for future research	41
6.5.2 Recommendations for practice	41
6.5.3 Recommendations for policy/legislation	42
6.6 Summary	42
REFERENCES	43
APPENDICES	50
Appendix A: Information sheet	50
Appendix B: Consent form	52
Appendix C: Interview schedule	53
Appendix D: Ethical Clearance Letter	58
Appendix E: Letter from Child and Family Centre (psychological services)	59
Appendix F: Turnitin report	61
Appendix G: Proof of editing letter	67

ABBREVIATIONS

ADI	Alzheimer’s Disease International
ADK	Alzheimer’s Disease Knowledge Test
EMIC	Exploratory Model Interview Catalogue
HSSREC	Humanities and Social Sciences Research Ethics Committee
LAMIC	Low- and middle-income countries
MCI	Mild cognitive impairment
MDEMQ	Mental Distress Explanatory Model Questionnaire
MND	Major neurocognitive disorder
NCDs	Neurocognitive disorders
PWD	People with dementia
SSA	Sub-Saharan Africa

CHAPTER ONE: INTRODUCTION

1.1 Problem statement

The burden of disease has changed over the years, with non-communicable diseases becoming increasingly prevalent in recent years. Sub-Saharan Africa currently faces an increased burden of disease due to chronic and non-communicable diseases. The shift in the burden of disease resulted from lifestyle changes, with South African people adopting Western living patterns, urbanization and modernization (Guerchet et al., 2017). Urbanization and modernization affect development in different aspects of life, such as health services. Development comes with population ageing where mortality and fertility prevalence decrease, resulting in an escalation in old age diseases such as major neurocognitive disorders (MNDs) (dementia) (Guerchet et al., 2017). Based on the reviewed literature, there is a growing number of dementia cases and a lack of knowledge concerning the illness, especially in ethnic minorities (Giebel et al., 2019; Mushi et al., 2014).

Dementia has been cited as a global health concern especially given the worldwide population ageing trend. However, beliefs and attitudes towards dementia as an illness and people with dementia (PWD) have been problematic. A Nigerian study aimed at understanding the different types of stigma associated with dementia discovered that participants had inadequate knowledge about dementia (Adebiyi et al., 2016). In other parts of Sub-Saharan Africa (SSA), such as South Africa, dementia is perceived as a normal ageing process (Khonje et al., 2015). However, other people were more knowledgeable about dementia in some cases as they could highlight some specific symptoms, such as memory loss (Alzheimer's Society, 2013). These research examples give a synopsis of the gap in communities regarding dementia, especially in Sub-Saharan African countries. It is crucial to understand how dementia is perceived and how these perceptions influence treatment-seeking avenues.

Understanding people's beliefs, perceptions and experiences concerning illness helps understand help-seeking behavior and treatment choices (Dinos et al., 2017). Perceptions and beliefs are crucial aspects in understanding the nature of the problem at hand and developing intervention methods that meet the needs of the local people (Dinos et al., 2017). Understanding perceptions and beliefs is usually problematic to address in areas with minimal or no knowledge about the

illness under investigation. The Alzheimer's Society (2013) noted that there is no local term for "dementia" in African countries. Such information may suggest that there are places where dementia is not regarded as an existing illness. This could mean that people may produce their own perspectives on dementia and people living with dementia.

Due to the different beliefs about the etiology of dementia, people tend to respond differently to PWD. Some perceive dementia as normal for old age people and therefore feel that it is not worth spending money to manage the illness (Adebiyi et al., 2016). A report on dementia by the Alzheimer's Society (2013) showed that some people believed that dementia is a punishment from God. This belief influenced how someone with dementia is treated in their community. For example, a study of a Xhosa-speaking community in South Africa on their knowledge, attitudes and beliefs about dementia found that PWD are often stigmatized, discriminated against and socially excluded (Khonje et al., 2015). Moreover, Mushi et al. (2014) asserted that stigma exists with almost all neurological and psychiatric diseases in SSA.

Research done in Sub-Saharan countries such as Nigeria found that cultural differences, negative attitudes and a lack of knowledge about dementia in communities were problematic (Adebiyi et al., 2016). Among the identified challenges, it was found that some people had never heard of the term "dementia" while others associated dementia with embarrassment and shame (Adebiyi et al., 2016). These findings are similar to those of the above-mentioned South African study that explored knowledge, attitudes and beliefs about dementia in an urban Xhosa-speaking community. This study found that the understanding of dementia was poor, negatively affecting treatment-seeking behavior (Khonje et al., 2015). These examples show negative attitudes towards and limited and inadequate knowledge of dementia in the elderly population in some Sub-Saharan African countries, such as Nigeria and South Africa.

1.2 Purpose of the study

This study focused on perceptions and beliefs concerning dementia in the Imbali community. It is important to explore people's perceptions and beliefs in this regard because most of the literature has pointed out that there is a lack of knowledge around the topic of dementia, especially in low–

and middle-income countries and that this limited (and often inappropriate) knowledge affects how people living with dementia are perceived and treated in their communities. Research has also mentioned that people's perceptions impact treatment-seeking behavior (Dinos et al., 2017). This study explored the general understanding of dementia in Imbali Township (Pietermaritzburg) and how perceptions and understanding of dementia influence treatment-seeking behavior.

Understanding how people in townships perceive and comprehend dementia and how their ideologies influence treatment-seeking behavior will help identify gaps in township communities regarding dementia. This will influence the planning of health education and interventions in different communities, especially in townships.

1.3 Objectives of the study

1. To explore the participants' knowledge and understanding of dementia.
2. To explore how people's understanding of dementia affects treatment-seeking behavior.

1.4 Research questions

1. What is the participants' knowledge and understanding of dementia?
2. How does people's understanding of dementia affect treatment-seeking behavior?

1.5 Outline of research methodology

Chapter three of this study discusses the research methodology adopted. Within this chapter, several sub-sections speak, step-by-step, to how the research was conducted. These are briefly outlined below.

- Research paradigm: The lens through which this research was situated is the interpretative paradigm. It focuses on an individual or community's subjective interpretation of their own world.
- Study design: The framework of action for this research was embedded in the qualitative approach which, in turn, is associated with an exploratory method of enquiry.
- Location and population of study: This research took place in the Imbali Township in the Umgungundlovu District of KwaZulu-Natal. The population consisted of Imbali residents

with similar ethnicity but with heterogeneous variables such as education level, age and gender.

-Sampling: Participants were recruited from the Imbali Township, Sections 17 and 12. The sample comprised eight participants – four males and four females. Participants were selected using the convenience sampling method.

-Data collection: Data was collected using an interview schedule and through one-on-one interviews.

-Data analysis: Collected data was analyzed using thematic analysis.

-Ethical considerations: Ethical approval was issued by the Humanities and Social Sciences Research Ethics Committee (HSSREC) of the University of KwaZulu-Natal. All major ethical issues were carefully observed throughout the study as per research requirements.

-Research quality: To produce a qualitative study of quality, research credibility, dependability and transferability were ensured in the research.

-Limitations and challenges: The research's limitations and the challenges faced by the researcher were discussed in this, the final subsection.

1.6 Definition of key terms

Major neurocognitive disorder (MND): Previously known as dementia, a MND is a decline in mental ability severe enough to interfere with the independence and daily life functions (American Psychiatric Association, 2013).

Dementia: An old term for MND. It is used in this research interchangeably with MND (American Psychiatric Association, 2013).

Sub-Saharan Africa: This is an area that lies south of the Sahara Desert of the African continent (Bogueva, et al., 2018)

Perceptions: The way in which something is regarded, understood or interpreted (Lindsay & Norman, 2013)

Beliefs: An acceptance that something exists or is true, especially one without proof (Lindsay & Norman, 2013).

1.7 Outline of the study

This research sought to understand how the Imbali community conceptualizes dementia and if perceptions and understanding of dementia affect help-seeking behaviors. The remainder of the thesis comprises the following chapters:

Chapter two, the Literature review, consists of articles that relate to the topic of interest, such as ageing as a major risk factor for dementia. Dementia will be explained in depth by looking at it and related dynamics in a Sub-Saharan context. The Research methodology chapter follows in which the step-by-step procedures adopted to collect and make sense of the data obtained are described. Chapter four reports the research findings based on the methodology used to gather the data. In Chapter five, the discussion, the results are analyzed and discussed. Chapter six, the final chapter, summarizes the study, conclusions, and recommendations for further research, practice and policy/legislation.

1.8 Summary

This introductory chapter gave a synopsis of what to expect regarding the content of this thesis. The chapter specifically focused on the background literature that gave birth to the topic of interest. The problem statement and purpose of the study were discussed, and these were followed by a listing of the objectives and research questions underpinning the study. An outline of the research methodology was included to provide a clear picture of the research process. The chapter ended with definitions of key terms and an outline of the remaining chapters of the study.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

The literature review will first give an overview definition of dementia followed by a review on age as a major risk factor of dementia and the policies for older adults. The definition and epidemiology of dementia will be discussed and analyzed in the context of SSA. The literature on dementia management and costs will also be reviewed. The theory that underpins the study will then be discussed. In doing so, a brief definition of the theory, a history of its origin and how it links to the current study will be provided.

2.2 Defining dementia

The burden of disease has evolved over the years, with non-communicable diseases becoming increasingly prevalent. According to Kalaria et al. (2008), SSA currently faces an increased burden on ill-health due to chronic and non-communicable diseases. This shift in the burden of diseases results from lifestyle changes, adopting Western living patterns, urbanization and modernization. These changes include dietary changes with people consuming foods with high sugar and fats and alcohol intake thereby increasing risks to certain chronic illnesses such as diabetes, hypertension and dementia (Kalaria et al., 2008). In addition, Ferri et al. (2005) argued that 24.3 million people lived with dementia worldwide, which was expected to increase as the population ages. Such alarming figures show that dementia should be a public concern. It is, therefore, important to understand what dementia is (Ferri et al., 2005).

Dementia is defined as a syndrome in which there is deterioration in cognitive function beyond what might be expected from the usual consequences of biological ageing (WHO, 2021). According to WHO (2021) dementia results from various diseases and injuries that primarily or secondarily affect the brain. Alzheimer's disease is reported as one of the most common form of dementia and may contribute to 60-70% of cases (WHO, 2021). Dementia is currently the seventh leading cause of death among all diseases, one of the major causes of disability and dependency among older people globally (WHO, 2021). Kwok et al. (2011) described dementia as a degenerative and non-communicable condition commonly occurring in the elderly population. It

is characterized by progressive impairments in cognitive functioning such as memory, attention, reasoning and problem-solving. Kwok et al. (2011) added that behavioral problems such as wandering, depression, delirium and denial of symptoms are frequently reported.

The American Psychiatric Association (2013) defined dementia as acquired rather than developmental and that it is usually characterized by impairments in memory, speech, reasoning, intellectual function, and spatial-temporal awareness. These changes are often small to start with but for someone with dementia, they have become severe enough to affect daily life. The APA's definition emphasizes an important element about dementia: it is not a developmental illness, but it is acquired. WHO (2021) supported this premise and reported that although dementia mainly affects older people, it is not an inevitable consequence of ageing. The American Psychiatric Association (2013) also explained that dementia starts with delirium, followed by the major and mild neurocognitive disorders (NCDs) and etiological subtypes. The NCDs were previously referred to as dementia (American Psychiatric Association, 2013). The name change was motivated by the stigma and discrimination that the term "dementia" carried. There are multiple types of NCDs, but Alzheimer's disease is the most common form of dementia in older adults and possibly contributes to 60 - 70% of dementia cases (Alzheimer's Society, 2013).

The definitions discussed show that dementia is not just one biological condition but rather a syndrome defined by a measurable cognitive decline to the point where physical, social and intellectual functions are impaired (Duthey, 2013). Therefore, it is important to address multiple factors when discussing dementia and possible preventative methods. Haan et al. (2004) stated that identifying preventable or modifiable factors that influence the risk of dementia might lead to the evaluation of preventive interventions. The authors identified two nonexclusive stages in preventing dementia: primary and secondary. Primary prevention refers to preventing the condition before its biological onset or preventing disease risk factors, which is sometimes called primordial prevention. Secondary prevention refers to early detection of asymptomatic disease, usually through screening, leading to early treatment (Haan et al., 2004). Hence a role for early dementia screening in primary care has been proposed by several researchers. Primary and secondary prevention of dementia related to genetic factors logically focuses on modifying

environmental and lifestyle exposures that influence risk by interacting with genetic vulnerability (Haan & Wallace, 2004).

2.3 Age as a major risk factor

One of the 20th century's significant achievements was population ageing with most countries having reported a rising life expectancy and an ageing population. The notion of the ageing population is escalating worldwide and South Africa, in particular, has one of the most rapidly ageing populations in Africa (Vally, 2010). Population ageing is defined as an increasing median age due to declining fertility rates and increasing life expectancy (WHO, 2021). Economically developed and developing countries have produced reports on population ageing (Aboderin & Beard, 2015; Vally, 2010). These show the prevalence of population ageing in all parts of the world. According to the Alzheimer's Disease International (ADI) Report, people live longer because of improved nutrition, sanitation, medical advances, health care, education and economic well-being (Guerchet et al., 2017). Development in all aspects of life is expected globally, which means that more people worldwide are expected to live longer (Guerchet et al., 2017). However, an increasingly ageing population carries a new wave of illness associated with old age, such as MNDs (dementia) and other non-communicable diseases.

Population ageing has a significant impact on the rise of the global dementia epidemic (WHO, 2021). This means that population ageing and its complications are inevitable given the reported rise in population ageing. It is of paramount importance to discuss the notion of ageing when discussing dementia. Although age is the strongest known risk factor for dementia, but it is important to note that it is not an inevitable consequence of biological ageing (WHO, 2021). Moreover, dementia does not solely affect older people. There is also young onset dementia, that is defined as the symptomatic before the age of 65 year. WHO (2021) reports that young onset of dementia accounts for 9% of the cases. Studies have demonstrated that people can minimize their risk of cognitive decline and onset of dementia by being physically active, not smoking, avoiding harmful alcohol intake, controlling their weight, eating healthy and maintaining healthy blood pressure, blood sugar levels and cholesterol.

South Africa is not the only country that needs to pay careful attention to the health care needs of the elderly. An American article by Dilworth-Anderson et al., (2002) argued that America's elderly population is more likely to suffer from high blood pressure and high cholesterol and new evidence suggests that these conditions are major risk factors for Alzheimer's disease. This means that having one of the conditions increases the risk of developing the disease and having both places an individual at an even higher risk. Dilworth-Anderson et al., (2002) stated that despite being more at risk for Alzheimer's disease, the older population is diagnosed much later in the disease process and, consequently, faces significantly higher dementia-related conditions. The article further points out that minority elderly populations encounter barriers to social justice concerning Alzheimer's disease screening, diagnosis and treatment (Dilworth-Anderson et al., 2002). These barriers, amongst others, are structural (living in an inequitable geographical/regional location), economic (poverty) and social/clinical (health illiteracy). As a result, these barriers often limit access to care and discriminate against older minority populations, thereby exacerbating inequities in Alzheimer's disease care (Dilworth-Anderson et al., 2002).

2.4 Dementia in Sub-Saharan Africa

According to Olayinka et al. (2014), a survey conducted by the Harvard School of Public Health and the Alzheimer's Europe Consortium on Alzheimer's disease concluded that dementia is a significant cause of health concern among adults. Similar conclusions are predicted in most countries in SSA, where the proportion of older people is expected to rise over the coming years. Worldwide, the prevalence of dementia among those aged 60 years and above ranges from five to seven percent (Olayinka et al., 2014).

Several public health research projects have focused on dementia in developed countries McParland et al. (2012) conducted a study focusing on the community of Northern Ireland in which dementia knowledge and attitude were explored. A systematic review of the literature from developed countries entitled "Early-onset dementia: clinical and social aspects" was conducted in the United Kingdom (Werner et al., 2009). In Sub-Saharan African countries, research projects on dementia are scarce. Furthermore, the few available reports are inconsistent (Olayinka et al., 2014). According to Olayinka et al. (2014), these uncertainties may have far-reaching implications on

public health policies on dementia in the SSA region. Olayinka et al. (2014) reported that while some studies suggest a lower prevalence of dementia in some parts of SSA, other studies report prevalence rates comparable to those reported in Western countries. These differing reports may affect held knowledge about dementia and management strategies in SSA. Olayinka et al. (2014) explained that SSA is a vast territory with a population of 1.1 billion people, and the number of people aged 60 years and above is projected to rise to over 67 million by 2030. It is important to accumulate factual information to inform appropriate management strategies with such a highly dense population.

A possible reason for contradictory information on dementia in SSA is that the region consists of several ethnic groups with different cultures, languages and traditions (Olayinka et al., 2014). These diverse factors may impact the prevalence of diseases in unique ways. Literature has shown how culture can impact decision-making and perceptions. In addition to cultural factors, Sub-Saharan African countries are characterized by a relatively high prevalence of communicable diseases such as HIV/AIDS, low life expectancy at birth, a rising prevalence of cardiovascular risk factors such as hypertension and diabetes, and low literacy levels. These are important factors that are also reported to influence the epidemiology of chronic diseases such as dementia (Olayinka et al., 2014).

Based on the factors cited above, coupled with the limited amount of region-wide, standardized epidemiological studies in SSA, a call for studies on dementia in the region is encouraged. It is essential to identify the prevalence, incidence, and risk factors of dementia in SSA to understand this major public health concern (Olayinka et al., 2014).

Few studies of neurological illnesses have been conducted in Africa, resulting in concerns that this area of health has been neglected (Mshana et al., 2011). According to the Alzheimer's Society (2013), the population of SSA had few cases of dementia but this was due to the dearth of research aimed at understanding dementia in the African population. At that time, the evidence on dementia prevalence was inadequate and scanty in many world regions, especially in low-and middle-income countries (LAMIC) (Guerchet et al., 2017). Guerchet et al. (2017) argued that only three

epidemiological dementia studies were identified for the entire continent of Africa. As a result, the prevalence estimate for the African region was influenced by the one good quality study performed in Nigeria, which reported a strikingly low prevalence of dementia (Guerchet et al., 2017). It has been reported that black African populations have the lowest cases of neurological disorders such as Parkinson's disease, but it is unclear whether this is a true reflection of the African population's statistics (Mshana et al., 2011).

Due to the 10/66 Dementia Research Group (comprising researchers conducting population-based studies on dementia and non-communicable diseases), there is now an estimated prevalence rate of dementia in SSA. As with what has been found in developed countries, age is a major risk factor for dementia in SSA. Statistics provided by the Alzheimer's Society (2013) revealed that 2.13 million people were living with dementia in 2015 and it was estimated that this number will reach 3.48 million by 2030. However, despite the evidence of an prevalence and incidence of dementia there are still gaps with the topic of dementia in SSA. For instance, the assessment and diagnosis of dementia in some parts of SSA can be challenging because of a severe shortage of specialist physicians such as neurologists and psychiatrists (Alzheimer's Society, 2013). A gap in assessing an illness is crucial because the assessment informs diagnoses and intervention leading to proper management of a disease.

2.5 Policies for elderly people

The South African Constitution (Section 9) stresses the importance of equality for all South Africans and the absence of discrimination regardless of different characteristics. It states that "no persons may unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth" (Doron et al., 2016). This section of the South African Constitution shows that South Africa aims to ensure equality and protect people's rights, especially social minorities such as old age people. Furthermore, the African Union Charter on the rights of older persons makes specific provisions for protecting older people's rights (Doron et al., 2016). However, the reality is that some parts of South Africa are characterized by inequality, exclusion and the violation of human rights

concerning older people. The mistreatment of older people may hinder the chances of seeking proper health care when faced with dementia, compromising the quality of health for all citizens (Aboderin et al., 2015).

Understanding older people's health needs is crucial in preserving the South African Constitution and African Union Charter's terms relating to the protection of human rights. Families and communities are active agents in ensuring the proper implementation of Section 9 of the Constitution and the African Union Charter on the rights of older persons (Doron et al., 2016). However, some communities are reported to stigmatize and prejudice PWD (Mkhonto et al., 2018).

The presence of the above discussed policies and how they emphasize the importance of elderly people gave birth to the more specific policies on older persons, namely older person's Act 13 of 2006 and South African Policy for older Persons. The Older Person's Act 13 of 2006 aims to deal with unfavorable situations and experiences faced by older persons (Act of Older persons, 2013). This Act was established as a framework aimed at the empowerment and protection of older persons to promote and maintain their status, rights, well-being, safety, and security (Act of Older persons, 2013). This Act seeks to combat the abuse of older people, which can be due to lack of understanding older person's illnesses. As mentioned, other SSA countries tend to abuse elders who are suffering from dementia and other mental health issues.

On the other hand, the principle of the South African policy for older persons lies in the total transformation of ageing in South Africa. This policy acknowledges that older persons constitute an essential part of society (SA Policy, 2005). As a result, this policy places family structures as a non-negotiable and reciprocal support network throughout one's life cycle (SA Policy, 2005). Through this family context, this policy considers the importance of families of the elderly in ensuring active, healthy, enabling and supportive environment. Therefore, this policy seeks to strengthen family and community system to enable and cater to older persons. The communities can be strengthened by being health educated about mental health issues that affect elder persons

to better care for older persons in their households while eliminating discrimination and stigma around mental issues such as dementia.

2.6 Management of dementia

Family practitioners are usually the first port of call for families in need of medical assistance regarding a family member who is suspected of having dementia (Vally, 2010). Frank and Forbes (2017) stated that family physicians perform a considerable role in the diagnosis and management of dementia, and they emphasized that as the prevalence of dementia expands, this role is becoming even more crucial. Vally (2010) explained that in the early stage of suspected dementia, a full diagnostic criterion for dementia may not be necessary. Thus, the diagnostic label of “mild cognitive impairment” (MCI) may be used for those who present with symptoms of memory difficulties, whether subjective or objective. MCI usually progresses to Alzheimer’s disease (WHO, 2021). The early detection of MCI is crucial in delaying this seemingly natural progression towards developing Alzheimer’s disease (WHO, 2021). According to Frank et al. (2017), early and proper diagnosis of dementia and the disclosure and discussion of prognosis and management are essential and can significantly impact patients and their families. Family practitioners are best positioned to facilitate the early response towards MCI (Vally, 2010).

The management of dementia should be multidisciplinary. Upon diagnosing dementia, general practitioners need to contain and attend to the family’s pain and anxiety by providing health education on the patient’s diagnosis and an attentive and supportive space to voice their concerns and fears (Vally, 2010). Also, they will likely be responsible for communicating with the family around the arrangements for caregiving or institutionalization and for referrals to other disciplines where necessary (Vally, 2010). Frank et al. (2017) added that it might be necessary to refer to or work collaboratively with other health care professionals to organize support and services such as social workers for financial matters or psychiatrists for behavioral and psychological problems.

Many factors influence families of dementia patients to not utilize formal care for those patients. Culture plays a major role, where a large part of the belief about residential care is a firmly held view that families should be looking after PWD (Shanley et al., 2012). Another perception that

influences a decision not to utilize formal care is that formal/residential care often fails to cater for the specific needs of individuals and that some residential care staff are only focused on meeting the basic needs of the patients, such as feeding and washing laundry, rather than employing a holistic approach to care (Shanley et al., 2012). According to Shanley et al. (2012), some family members of dementia patients argued that the staff would neglect the patients, for instance, limiting the number of times the patients are taken to the toilet. Most family members asserted that placing their relatives in residential care was the last resort (Shanley et al., 2012). In addition to the above-mentioned factors that may influence the usage of residential care for dementia patients, Borochowitz (2011) reported that in general mental health care services in South Africa need serious review, as they are severely deficient in quality and quantity. In contrast to the findings of Shanley et al. (2012), Marais et al. (2006) mentioned that residential care services keep patients busy and expose them to entertainment depending on their abilities. It was also added that church ministers from different denominations usually visit patients, which is very important to the patients (Marais et al., 2006).

2.7 Costs of dementia

Health care and related costs are the primary causes of poverty in many low-income countries (WHO, 2021). Most of the current literature aims at determining how patient and caregiver characteristics and costs change with the progression of Alzheimer's disease only focuses on a single aspect of the disease, such as assessing cognition (Jones et al., 2015). Guerchet et al. (2017) stated that the costs of dementia should cover the paid professional home care, residential and nursing home care and informal (unpaid) care. Haan et al. (2004) argued that treating and managing dementia patients include direct medical care costs for acute care hospitals and long-term care. Long-term care is regarded as the most expensive component and is primarily paid out of pocket by the patients' families (Haan et al., 2004). Indirect costs such as lost wages and productivity, influenced by patient severity and length of survival with the disease, are one of the components often overlooked when discussing the costs of dementia. Patients with dementia are more likely to live in nursing homes than other elderly individuals (Haan et al., 2004).

Dementia, being a growing public health concern globally, was estimated to cost USD604 billion in 2010 (WHO, 2021). This figure may not be a true reflection of the actual costs of dementia because empirical research has shown that several countries have a poor knowledge of dementia, especially in SSA. This means that cases of dementia go undiagnosed and untreated. In addition, the constantly changing population demographics with declining mortality rates mean that the number of people living with dementia will continue to increase. This poses several challenges for governments, health and social care systems, individuals and families (WHO, 2021). Guerchet et al. (2017) added that to predict future trends in the cost of dementia, we need to estimate the actual number of people living with dementia. This may be a discouraging task considering the lack of empirical data from Sub-Saharan African countries regarding the prevalence of people living with dementia and the resources used in dealing with the condition.

2.8 Perceptions and beliefs about people with dementia

Perception is defined as the process, act, or faculty of perceiving and attaining awareness or understanding. In addition, it involves the ability to identify, interpret, and attach meaning. Thus, perceptions of dementia, particularly myths and fallacies, negatively affect early access, diagnosis, and treatment of Alzheimer's disease (Dilworth-Anderson et al., 2002). Moreover, cultural values and beliefs among different ethnic groups affect the meanings they assign to dementia and these cultural meanings help create barriers to seeking assistance outside the family system (Dilworth-Anderson et al., 2002).

Understanding a population's beliefs, perceptions and experiences concerning an illness and help-seeking behavior and treatment are vital aspects to understanding the nature of the problem at hand and developing intervention methods that meet the needs of local people (Dinos et al., 2017). The Alzheimer's Society (2013) stated that there is no local term for dementia in many African countries. A study conducted in Nigeria to understand the different types of stigmas associated with dementia found that some people had limited knowledge about dementia (Adebiyi et al., 2016). In other parts of SSA, such as South Africa, dementia was normalized, as it was seen as an "old age problem" (Khonje et al., 2015). However, people were more knowledgeable about

dementia in some cases as they could highlight some specific symptoms such as memory loss (Alzheimer's Society, 2013).

Due to different beliefs about the causes of dementia, people tend to respond differently towards those with dementia. Some people perceive dementia as normal for old aged people and, as a result, they feel it is not worth spending money to treat it (Adebisi et al., 2016). A report on dementia by the Alzheimer's Society (2013) showed that other people believed dementia is a punishment from God. This belief influences how one is treated in their community. For example, a study of a Xhosa-speaking community in South African on knowledge, attitudes and beliefs about dementia found that demented people are often stigmatized, discriminated against and excluded socially (Khonje et al., 2015). Moreover, Mushi et al. (2014) asserted that in SSA, stigma is attached to almost all neurological and psychiatric diseases.

Research done in Sub-Saharan countries such as Nigeria found that cultural differences, negative attitudes, and lack of knowledge about dementia in communities were problematic (Adebisi et al., 2016). Amongst the identified challenges was that some people had never heard of the term “dementia” while others associated dementia in old people with embarrassment and shame (Adebisi et al., 2016). A South African report (Borochowitz, 2011) that addressed the stigma and challenges of dementia illustrated a similar notion about dementia. The report described dementia as an illness that is still highly stigmatized, perceived as a myth in many South African communities, and associated with witchcraft (Borochowitz, 2011). Similar results were found in a study that aimed at exploring the dominant explanations of dementia given by the female family carers of PWD (Van Wezel et al., 2018). The study's collected data revealed that female carers believed that dementia is a normal ageing process, and that memory and behavioral problems are just a normal part of ageing. Moreover, some participants believed that dementia was a spiritual experience (Van Wezel et al., 2018).

The above examples show negative attitudes, limited and inadequate knowledge about dementia in the elderly population in some Sub-Saharan African countries such as Nigeria and South Africa. Another factor in African countries is that some Sub-Saharan cultures believe that the cause of

dementia is witchcraft rather than a disease (Mkhonto et al., 2018). This belief is prevalent in many South African townships and rural areas (Mkhonto et al., 2018).

This thesis focused on perceptions and beliefs about dementia in the Imbali community. It is important to explore people's perceptions and beliefs because notable literature has pointed out that there is a lack of knowledge around the topic of dementia, especially in LAMICs, and that this limited and often inappropriate knowledge affects how PWD are perceived and treated in their communities (Khonje et al., 2015). In addition, research has mentioned that people's perceptions influence actions, consequently impacting treatment-seeking behavior (Dinos et al., 2017).

2.9 Theoretical framework

According to Haidet et al. (2008), people hold differing views about illness and these differing views are known as explanatory models. The differing views of an illness or explanatory model are likely to cause difficulties in communication between the people concerned and yield poor disease outcomes (Haidet et al., 2008). Based on this brief introductory explanation, it is imperative to consider the person's understanding and interpretation of an illness when attempting to intervene to ensure improved clinical practice. The current thesis's objectives sought to understand the conceptualization/understanding of dementia among Imbali residents and how their understanding of dementia may influence treatment-seeking behaviors for themselves and their loved ones. Because of these objectives, this thesis was positioned within an explanatory model of illness theory. This theory was considered to be the best structure to support the objectives of the study.

An explanatory model is defined as a conceptual framework that provides an understanding of the process by which illness is patterned, interpreted, and treated (Bhui et al., 2002). This framework considers the differing notions about an episode of an illness and the treatments employed by all those involved in the clinical process. Bhui et al. (2002, p. 6) emphasized that a person's rich view of the world and their illness within that world gives rise to a better understanding of their illness, including its meaning to them and their expected recovery process." Dinos et al. (2017) further explains that "explanatory model of illness is the way people perceive, interpret and respond to

illness – these are mediated not only by the illness itself, but also by cultural and social contexts”. These definitions show that explanatory model of illness does not only focus on how a patient experience or understands the illness, but it also speaks to how general people understand illness. Another important element this model demonstrates is how culture and beliefs influence our perceptions and decision making in health issues. There are several studies in the literature that have employed an explanatory model. Mkhonto et al. (2017) conducted a study looking at cultural beliefs and perceptions of dementia in a general population. In this study it was found that cultural beliefs impacted on perceptions and people with dementia were seen as witches. In addition, Ciprian et al. (2015) undertook a study on understanding dementia in the sociocultural context. Both research studies were conducted with general population as participants and the yielded findings showed that the experience and understanding of dementia is not universal but is profoundly shaped by cultural beliefs.

Since establishing explanatory models of illness, several studies have adopted this theoretical framework. Giebel et al. (2019) conducted a study that explored in detail the perceptions of dementia (symptoms, causes, consequences and treatments) held by South Asians and discern how these understandings influence help-seeking behavior. The findings of this study yielded an important aspect in public health – it was found that there is unpredictability in the way South Asian communities perceive dementia. Also, through this kind of research, it was possible to identify specific areas where dementia awareness could be raised in South Asian subgroups to improve timely diagnosis, treatment outcomes and service access.

To understand a certain population’s beliefs and perceptions about an illness, one needs to explore that population’s subjective explanations about the concept of interest. These explanations need to display the conceptualization of the illness, the causes and the treatment-seeking behaviors. This was done in the study by van Wezel et al. (2018) where the Explanatory Model of illness was adapted to elicit perceptions of dementia from people with different cultural backgrounds in migrant communities. These communities included Turkey, Morocco and Suriname. The results showed that the explanatory model was a useful tool in understanding the conceptualization of

dementia. Turkish and Moroccan participants ascribed the causes of dementia to life events and personality traits, whereas Surinamese often mentioned physical aspects such as past dehydration.

According to Tirodkar et al. (2011), the establishment of explanatory models was motivated by the empirical evidence that suggested that patients are most satisfied when health practitioners share their model of understanding distress and treatment. Kleinman is regarded as a pioneer of the explanatory models – he proposed this mechanism for patient and practitioners to share information about the diseases (Kleinman et al., 1978). This proposed mechanism distinguishes traditional healing systems from Western biomedicine (Kleinman et al., 1978) and allows practitioners to incorporate a person's traditional beliefs with a Western medicine approach. It should be noted that explanatory models do not consist of a coherent set of beliefs but various explanations that are either simultaneously taken up or dismissed rapidly (Tirodkar et al., 2011). This clarification of explanatory models not being a clear-cut set of beliefs upheld by different people is one of the important components of this framework, especially when adapting this framework into a study located in one of the townships in South Africa. South Africa is known as a “rainbow nation”, where there are various variables such as education level, ethnicity and religion. It would be difficult to establish a single set of causal explanations related to behavior, diagnosis or adherence to medication treatment in a complex country like South Africa.

Due to the complexity of the world, we currently live in, there are significant concerns and pressures in public health interventions. Health care workers working in multicultural environments are expected to communicate and understand a wide range of cultural terms and expressions of disease if they aim to provide assessments and intervention measures that are effective. This may not be an easy task to do. As far as explanatory models are concerned, problems in health care work across different cultures are restricted to the assessment of and recognition of disease and extend to treatments and interventions that will be seen as culturally appropriate and not violate cultural beliefs.

According to Dinos et al. (2017), explanatory models can be described as culturally determined beliefs that individuals hold about misfortunes, suffering, illness and health. This means that

explanatory models are meanings that individuals have about their experiences of well-being, whether healthy or unhealthy. Individuals' cultural differences inform these meanings. Dinos et al. (2017) further explained that explanatory models shape societal expectations of the role of the sick, one's illness and help-seeking behavior. Understanding these models during assessment and treatment is a crucial component in a culturally sensitive practice. Research has shown that explanatory models are not fixed units but are complex and multilayered (Dinos et al., 2017). They can be influenced by several factors such as questioning, the relationship with the clinician, and mood (Dinos et al., 2017).

The current research project explored the conceptualization of dementia among the Imbali Township population and how this influences treatment-seeking behavior. It was important to employ an explanatory model of health and illness to explore how this population of interest understood dementia and how their knowledge influenced treatment-seeking behavior. This model was able to assist in unpacking valuable information on the significance of dementia and aid in building an understanding of the broader belief system.

2.10 Summary

This, the literature review chapter, clarified the definition of dementia and how it is perceived in the Sub-Saharan context. Various aspects of dementia were elaborated on, including age as a major risk factor, dementia management, and the costs of dementia. In addition, the theoretical framework that was used to understand and underpin the study, namely, the explanatory model of illness, was discussed.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

The study explored Imbali Township participants' understanding and perceptions of dementia. This chapter presents the research paradigm and design, followed by the study location and population. It also discusses the study methods, including the sample and sampling technique, and the data collection and data analysis processes. Lastly, it outlines the ethical considerations of the study and addresses the issues of quality and rigor of the research. The chapter ends with the limitations and challenges of the study and a summary.

3.2 Objectives of the study

1. To explore the participants' knowledge and understanding of dementia.
2. To explore how people's understanding of dementia affects treatment-seeking behavior.

3.3 Research questions

1. What is the participants' knowledge and understanding of dementia?
2. How does people's understanding of dementia affect treatment-seeking behavior?

3.4 Research paradigm

Kivunja et al. (2017) defined a research paradigm as a researcher's world view, the perspective or set of shared beliefs that inform the meaning or interpretation of collected research data. The authors further explained that the research paradigm is understood as the lens through which a researcher looks at the world (Kivunja et al., 2017). The research paradigm influences the methodological aspects of the research in determining the research methods and data analysis process (Kivunja et al., 2017). The current research employed an interpretative paradigm. This paradigm seeks to understand the subjective world of human experience and understand and interpret what the research participant is thinking (Kivunja et al., 2017). The emphasis is placed on understanding an individual or community and their interpretation of their world. The paradigm best fitted with this research because it (this research) sought to answer two questions: The first question aimed at providing a general understanding of dementia in Imbali Township

(Pietermaritzburg). The second question examined how perceptions and understanding of dementia influence treatment-seeking behavior. These two questions were explored deeply from the participants' points of view as the research aimed to interpret and understand the topic.

3.5 Study design

A research design is defined as a planned framework for action used to connect the research question and the actual implementation of the research (Terre Blanche et al., 2014). Furthermore, a research design informs the procedures for collecting and analyzing research data (Terre Blanche et al., 2014). This study employed a qualitative approach located within the exploratory method of inquiry. The qualitative approach attempts to explain and understand people's feelings and experiences in human terms rather than through measurements and quantification (Terre Blanche et al., 2014). This is evident, for example, in a qualitative study that aimed to understand student nurses' experiences of their clinical practice and was able to do so successfully (Sharif et al., 2005). Studies that employ a qualitative approach concentrate on small sample sizes selected purposively to saturate a phenomenon of interest (Patton, 2002), while exploratory studies are used to explore an unknown area of research (Terre Blanche et al., 2014). There are minimal studies that explore conceptualization and understanding of dementia in South African townships. This study will thus add to the body of knowledge by providing insight into the understanding and beliefs that people in Imbali Township have of MNDs.

3.6 Study location and population

This study took place in the Imbali Township in the UMgungundlovu District of KwaZulu-Natal. Based on observations of the different sections, it can be hypothesized that households within Imbali Township vary socio-economically, with most households being lower to middle class. The population is both homogeneous and heterogeneous. The population of Imbali Township is similar in ethnicity and that it is from the same communal setting. Furthermore, people have varying educational levels, and some have no exposure to formal education at all. Heterogeneity is also evidenced in age levels: the elderly, middle-aged, young adults, adolescents, and children. Based on the 2011 census report, females comprise 54% of the population and males 46%. The population

group is 100% Black African, with the vast majority (94%) being IsiZulu language speakers (StatsSA, 2012).

3.7 Sampling

3.7.1 Sampling strategy and sample

The targeted population of this study was residents of Imbali Township in Pietermaritzburg. Sampling is defined as a process of selecting a small portion of, for example, people from a larger population for inclusion in a study (Terre Blanche et al., 2014). The sample consisted of people from sections 12 and 17. The motivation behind studying the residents of Imbali Township and the selection of sections 12 and 17 is that Imbali Township is one of the oldest townships in Pietermaritzburg. Also, the selected sections present the desired diversity of Imbali Township. Various sampling techniques can be utilized when recruiting participants in qualitative research. This study employed non-probability convenience sampling. It is a method used to recruit participants who are easily accessible and convenient to the researchers (Patton, 2002) while still maintaining the integrity of the research. The integrity of this research was maintained by describing the recruiting process and inclusion and exclusion criteria before the data collection process. The participants' demographics matched those of the population considered for the sample. Also, the interview questions were not long to try and ensure that the participants remained interested and not fatigued. Using a convenient sampling method, the researcher visited residents' households, informed them about the study, and those interested in participating and meeting the inclusion criteria (see below) were included in the sample. The researcher entered the first houses in the street, discussed the study's information sheet and asked if an individual is willing to participate. If an individual is not interested, the researcher moved to the next house until the desired sample size was reached. Only one person (who met inclusion criteria) per house was interviewed.

3.7.2 Inclusion and exclusion criteria

1. Research participants consisted of both male and female residents of Imbali Township.
2. Participants who were 18 years of age and above.

3. Participants who could understand and sign the informed consent form (see Appendix C) participated in the study.
4. People who could not respond due to illnesses or any other cause were excluded from the study.

Eight (8) participants from the Imbali Township were sampled to partake in the study. Four of the participants were male, and four were female. Five participants were from Section 17 and three from Section 12 of the Township. For confidentiality purposes, pseudonyms were used to identify participants. The four females were identified as F01- F04, whereas the males were identified as M01 - M04.

3.8 Data collection

3.8.1 Procedure

Data was collected via one-on-one interviews using a semi-structured interview schedule. All interviews took place in the participants' homes in the Township. Each participant was given an information sheet (Appendix A) with all necessary study information to read. Once the participants had done so, they signed a consent form (Appendix B). Participants were given the option of being interviewed in either English or IsiZulu. Each interview took no more than 40 minutes to conclude.

3.8.2 Instrument

The data collection tool (Appendix C) was divided into two sections: The first section contained demographical information, namely, gender, age, marital status, race/ethnicity, level of education, occupation and home language. The second section comprised a case study about Mr Mkhize, a 68-year-old who presented with different symptoms associated with dementia. The interview schedule questions were drawn from the case study and focused on exploring participants' knowledge, beliefs, attitudes and perceptions of dementia. Questions aimed at eliciting people's perceptions and beliefs about dementia asked if participants thought there was anything wrong with Mr Mkhize, what they thought was wrong with him, the cause of his presentation, and the terminology of his condition. There were also questions concerning the type of treatment participants believed a person like Mr Mkhize should seek. These questions were generated from the different literature on dementia. The researcher formulated the case study based on the DSM-

5 symptoms of dementia as discussed in section 2.2 of the literature review. Similar questions to explore symptoms, causes, consequences, and treatment of dementia were used in the study by Giebel et al. (2019) on age, memory loss and perceptions of dementia in South Asian ethnic minorities. Case studies have been previously used in mental illness studies such as Jorm (2000), on his research on mental health literacy: public knowledge and beliefs about mental illness. Participants were showed vignettes of a person suffering from major depression and schizophrenia. Using case study approach the study was able to answer the research questions about mental health literacy successfully. Local research using similar case studies was seen in a study by Kometsi et al. (2020) on research exploring mental health literacy of depression. The advantages of using case study are that it provides a detailed analysis of the individual case and has their strength in obtaining detailed and relevant data (Krusenvik, 2016). The information in case studies cannot be taken out of context, and the study includes multiple variables and runs deep, which results in high internal validity (Krusenvik, 2016). Even though case studies have proven beneficial in the body of research, they also have disadvantages. One cannot generalize from a single case study. The case study usually contains a bias toward verification (Krusenvik, 2016).

3.9 Data analysis

Data were analyzed using thematic analysis. The thematic analysis identifies patterns or themes in qualitative research (Braun et al., 2019). Braun and Clarke's six-phase technique of thematic analysis was adopted (Braun et al., 2019). The first step was to become familiar with the data; here, the researcher familiarized herself with the raw data by reading and re-reading transcripts of the interviews. The second step was to generate initial codes. In this stage of analysis, the researcher looked for labeling ideas that emerged from the data. The third step was searching for themes. In this step, the researcher identified common labels and categorized them into themes. The following step was the review of themes, and this required the researcher to revisit identified themes. The identified themes were reviewed and checked if they made sense and whether the data supported all the identified themes and subthemes under the "major" themes. In the fifth step the themes were defined, that is, the themes were described and understood and where subthemes were assessed in terms of how they interacted with the main themes. The researcher achieved this by checking the essence of each theme, as well as the subthemes. The final step was the write-up. In

this regard, the researcher, based on the data analyzed, produced a report (this study) concerning the conceptualization of dementia in the population of Imbali Township and how this influences help-seeking behavior.

3.10 Ethical considerations

The protection of research participants through the application of appropriate ethical principles is important in all research. In a qualitative study, ethical considerations have a particular resonance due to the in-depth nature of the study process (Arifin, 2018). According to Arifin (2018), ethical issues become more prominent when conducting face-to-face interviews with vulnerable groups of participants who may become distressed while articulating their feelings or experiences during the research interviews.

Ethical clearance was obtained from the HSSREC at the University of KwaZulu-Natal (study reference: HSS/0458/019M) (See Appendix D). Data collection with the eight participants commenced once ethical clearance was obtained. During the data collection process, the following ethical guidelines were followed.

3.10.1 Information sheet and informed consent

The information sheet and informed consent form were given to potential participants. The forms were written in English and IsiZulu to ensure that respondents fully understood the nature of the study and the content of the informed consent. The use of both languages ensured that the participants could comprehend the information and were thus adequately informed about the research. Participants had the freedom to choose whether to participate in the study or not. Participants' agreement to participate in the study was thus obtained only after a thorough explanation of the research process. Contact details of the HSSREC, supervisor and researcher were available in the informed consent form.

3.10.2 Confidentiality

Confidentiality assurance was discussed with the participants before they participated in the research interviews. The participants were assured that their identities would not be made known. Pseudonyms were used to protect the participants' identities.

3.10.3 Beneficence

As part of “doing good” to the research participants, the researcher provided details whereby interested participants could find more information about dementia and support groups close to them.

3.10.4 Non-maleficence

No harm should result from participating in research. However, the interview questions enquired about dementia and there was the possibility that participants may have experienced/witnessed dementia at close range. As a result, these questions may have caused tension or being upsetting for participants. For participants experiencing such conditions, arrangements were made to be referred to the Child and Family Centre at the University of KwaZulu-Natal, Pietermaritzburg (see Appendix E). However, all the interviews went smoothly, and there was no indication that the participants needed subsequent counseling.

3.10.5 Study benefits

The current study generated knowledge of dementia in a Pietermaritzburg Township called Imbali. The findings of this study have the potential to contribute to the existing literature on dementia. There was no monetary or material compensation for participation.

3.11 Credibility, dependability, confirmability and transferability

In ensuring the quality and rigor of the study, the researcher ensured that four qualitative research criteria were maintained throughout the study. These are credibility, transferability, dependability and conformability (Pandey & Patnaik, 2014) and each is discussed in turn.

3.11.1 Credibility

Credibility was ensured by adopting research methods that could elicit information about the phenomenon of interest. This study chose a qualitative research route to understand beliefs and perceptions of a MND (dementia). The questions asked were largely open-ended and this enabled respondents to provide responses that best resonated with their beliefs, knowledge and understanding of dementia. In addition, participants were recruited from two different sections of Imbali Township, rather than having a sample of participants from the same ward. It is believed that the data reflected the beliefs and perceptions of the broader Imbali community members.

3.11.2 Transferability

The researcher ensured that enough contextual information about the study's fieldwork was displayed so that other interested researchers can relate to the study. Information included but was not limited to inclusion and exclusion criteria, and a description of the environment where the participants were recruited. Also, a thick description of the phenomenon of interest was provided via the literature review to ensure an in-depth understanding of interested researchers in the future. This will allow researchers to compare the study's settings with theirs.

3.11.3 Dependability

The researcher ensured that all the planned processes and executions were described in detail. For example, details of data collection were described in-depth so that subsequent researchers can repeat the study and hopefully reach similar findings.

3.11.4 Confirmability

Finally, the researcher also ensured that the research findings reflected the participants' experiences and knowledge rather than the researcher's preferences. An in-depth description of the data collection and analysis and research methods were demonstrated to permit the truthfulness of the research results. As outlined below, the researcher recognized the shortcomings of the chosen research methods and their potential effect on the results.

3.12 Limitations and challenges

This qualitative study was unconcerned with numerical generalizability but somewhat concerned with understanding a given problem using a few participants. Due to time constraints, the study recruited only eight participants. This figure may not be sufficient to accurately represent Imbali Township residents' beliefs and perceptions concerning dementia. The study utilized semi-structured interviews as the data collection tool. However, semi-structured interviews can be rigid, with minimal flexibility regarding interviewees' responses, and obtaining detailed data is difficult. Recruiting participants proved to be one of the most challenging features of the research. Going door-to-door was a challenge as people were concerned about their safety and did not open their doors easily.

3.13 Summary

This, the research methodology chapter, outlined the specific procedures used to identify, select, process, and analyze information about the topic of interest. In exploring the understanding and perceptions of the Imbali Township community towards dementia and how these impact treatment-seeking behaviors, this research adopted an interpretative paradigm. The study used a qualitative approach to explain and understand people's perceptions rather than a quantitative one. The research was located in the Imbali Township, Pietermaritzburg and the sample consisted of eight participants. Research participants were sampled conveniently, and inclusion and exclusion criteria were applied in their selection. Data was collected through one-on-one semi-structured interviews and analyzed using thematic analysis to understand the Imbali community's perceptions of dementia and how these perceptions influence treatment-seeking behaviors. The HSSREC approved the study and ethical issues were considered and applied to maximize participants' safety. Finally, the limitations and challenges were discussed.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter presents the findings of the study. The results reflect the data that was gathered from the one-on-one interviews with the research participants. As discussed in Chapter three, data were analyzed using thematic analysis. The interviewees' responses were transcribed, and the researcher identified emerging themes and codes using the six stages of thematic analysis. The results are presented in light of the research objectives and research questions. The latter were as follows:

1. What is the participants' knowledge and understanding of dementia?
2. How does peoples' understanding of dementia affect treatment-seeking behavior?

4.2 Thematic analysis results

4.2.1 The participants' knowledge and understanding of dementia

Seven of the eight participants were able to identify that the symptoms displayed by Mr Mkhize in the case study represented a sickness. In contrast, one participant did not see any problem with the presented symptoms. The findings thus show that the participants' identification and knowledge of the symptoms as an illness were good. The participants' understanding of dementia was categorized into understanding the type of illness and understanding the causes of dementia.

4.2.1.1 Understanding and naming of the illness

The participants' understanding of the illness varied as some of them recognized dementia symptoms as an illness. However, three themes were identified from the participants that identified dementia as an illness. These themes show that dementia symptoms are perceived as presenting an illness of (1) old age, (2) people's doing and ancestral neglect, and (3) brain disease or injury. As much as most participants identified dementia as an illness, the knowledge of the illness was inadequate. Most participants could not name the symptoms as dementia. Knowledge would have been satisfactory if participants could discern appropriate health care assistance should they or their family members need medical help concerning dementia. Each of the themes is elaborated on below.

Dementia as an illness of old age

Four of the participants understood that the symptoms were caused by old age. The following extracts from the interviews illustrate this:

F01: *“There is something wrong with Mr Mkhize, he is just getting old, so his mental functioning is deteriorating, hence he is forgetful and irritable.”*

F02: *“There is something not right with Mr Mkhize. He is experiencing ageing in his own way as people are unique, some people become very kind and friendly when they age. But others are just like this person because of old age, the brain is now getting slow.”*

M01: *“There is a problem with Mr Mkhize. It seems like he is sick, the chronic illnesses for the elderly.”*

F04: *“There is something wrong. He is growing old which is a normal process for every one of us.”*

The findings under this theme showed that the majority of participants understood dementia as an old age issue. Participants’ understanding of dementia seems to be based on the perception that dementia is an inevitable, normal ageing process and not an illness. This might also further mean that if it is normal for older adults to get dementia symptoms, it is expected that all older adults will get these symptoms.

Dementia as an illness of people’s doing

One participant described the symptoms as a result of people’s doing and the neglect of ancestors.

M03: *“There is something wrong with the person. He is like this because of other people's doings. People are very jealous when you have everything together. As I have mentioned that there are bad people out there.”*

The participant continued:

“You see, he may have neglected ‘umsamu’, ancestors cannot protect you when you have forgotten about them.”

This theme introduced a perception that dementia is caused by witchcraft by jealous people. However, one becomes vulnerable to this type of witchcraft when they have neglected their ancestors and they are no longer under the protection of their ancestors. When the ancestors disown a person due to not doing ancestral or traditional practices that person becomes unprotected against disease or witchcraft and that’s when they have dementia.

An illness of brain disease or injury

Two participants understood the symptoms as resulting from brain-related injury or disease, with one of the participants even naming the disease dementia.

M02: *“There is something wrong with Mr Mkhize, he has a problem of forgetting important stuff. The problem is known as dementia, it’s a disease that affects the brain.”*

F03: *“There is something wrong with Mr Mkhize. It seems like he was injured in his head, like maybe like, you know when you are a child you fall but you only get problems as you grow older. Other people become like this when they are involved in car accidents and get hurt in their heads. So, Mr Mkhize’s problem can be caused by one of these two issues.”*

This theme displayed an understanding of dementia as a disease or a medical perspective of dementia. Participants could identify dementia as resulting either from a brain disease process or from injury to the brain. One of the participants was able to even state the term ‘dementia’.

These extracts show that although the participants all received the same case study, they perceived the illness as being different, using different ways to understand the symptoms. Thus, half of the participants used a developmental model to understand dementia, one; a traditional model, and

two; used a biological/medical model. The findings under these themes indicate that while most participants identified dementia as an illness, they utilized different lenses to understand the cause.

4.2.3 Participants' understanding of dementia impact on treatment-seeking behavior

4.2.3.1 Treatment seeking behavior

Four participants reported that they would seek help if they or a loved one has dementia. Three participants stated that they would not seek help. The remaining participant asserted that they did not see anything abnormal with the dementia symptoms described in the data collection tool. Therefore, only seven of the participants were analyzed in terms of this objective. Two themes emerged from the data on treatment choices, and these are described below.

Medical help-seeking

Of the four participants who stated that they would seek help, three reported that they would seek help from medical professionals and medical institutions. Their responses are quoted verbatim below.

F03: *"I would seek help from a brain doctor and hospital."*

M02: *"I would visit a general practitioner."*

F01: *"I would go to the local clinic."*

Traditional health-seeking

One participant indicated that they would seek from a traditional practitioner.

M03: *"I would consult a traditional healer."*

Would not seek help

The three participants reported that they would not seek help if they presented with dementia symptoms because they saw dementia as a normal aging process and incurable, as seen on the extracts below:

F04: *“This is a normal process, there won’t be any change.”*

M01: *“Each and every elderly person experience chronic illnesses which are incurable.”*

F02: *“Ageing is a normal process.”*

4.2.3.2 Relationship between participant’s understanding of the causes of dementia and treatment-seeking behaviors

In ascertaining the relationship between participant’s understanding of the causes of dementia and treatment-seeking behavior, participants were provided with various treatment-seeking avenues. These responses were compared to their understanding of dementia, which was the first objective of this research. This analysis was drawn from the seven participants who identified dementia symptoms as an illness.

One participant who identified dementia symptoms as a result of people’s jealousy and neglect of ancestral rituals reported that he would seek help from a close family member, an isangoma (diviner), an inyanga (herbalist) and an uMthandazi (faith healer). Three participants reported that they would seek medical help from a doctor, a hospital and a local clinic. All three of these participants reported that dementia was due to either a brain disease, a chemical imbalance or stress. The remaining three participants claimed that they would not seek any help. These participants shared similar beliefs, regarding dementia as an inevitable and normal ageing process and God’s will.

Half of the participants believed that a person with dementia symptoms would partially recover but symptoms would re-occur, whereas three believed that the person would never recover. One participant believed that a person with dementia symptoms would recover fully with no

anticipation of further problems. Those participants who believed that the person could recover tended to regard dementia as a medical illness suggesting that they would seek help in dealing with the symptoms. The participants who did not believe that dementia was an actual medical illness would not seek assistance suggesting that a person with dementia symptoms would not improve their condition.

These findings confirm that the perceptions of dementia and beliefs about the causes of dementia influence beliefs concerning treatment. Participants who perceived dementia as a medical illness believed medical/biological factors caused it and also reported that they would seek medical treatment for the illness. A similar pattern was seen for those who perceived dementia as a traditional illness and who would prefer to seek traditional treatment for the illness. Those participants who understood dementia as being due to stress, God's will or ageing preferred not to seek help as they believed that the symptoms of dementia would not improve.

4.3 Summary

The results reported in this chapter provided an insight into how Imbali Township residents understand dementia and how their understanding influences treatment-seeking behaviors. This means that this study achieved its goal of providing detailed and in-depth data on the understanding of dementia by township residents and how perceptions and understanding of dementia influence their treatment-seeking behavior. The results showed that most participants could identify something wrong or abnormal with a person presenting with dementia symptoms. However, participants' understanding and knowledge of the terminology and causes of dementia and treatment-seeking behaviors and anticipated recovery of people living with dementia varied. Half of the participants associated dementia with old age, while two participants linked dementia symptoms with an illness of the brain or injury and the remaining one identified dementia as people's doings, jealousy and ancestral anger. Different treatment-seeking modalities were reported with three of the participants indicating that they would seek help from medical options, a further three indicating that they would not seek any assistance and one participant indicating that they would go the traditional route. Participants who identified dementia as a medical condition were likely to opt for medical treatment and they believed that recovery was a possibility.

Participants who viewed dementia as a normal ageing process did not believe in any form of treatment-seeking and anticipated that there would be no improvement in persons with the condition.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

The purpose of this chapter is to consider the meaning of the results gathered in the study. This will be achieved by focusing on explaining and evaluating what was found in the collected data. The chapter will discuss the importance and relevance of the results. The chapter will also show how the results relate to the literature review and research questions and will make an argument in support of the overall conclusion.

This study interviewed eight participants from the Imbali Township about their beliefs and perceptions of dementia symptoms, causes and treatment preferences.

5.2 Knowledge and beliefs of dementia symptoms and causes

According to the findings of this study, as much as the majority of participants could determine that the symptoms described in the case study presented a problem, most of them could not ascertain that the symptoms were those of dementia. This means that Imbali Township residents know dementia symptoms even though there was no identification of the term dementia. A study conducted in Western Pacific countries, namely Cambodia, Philippines and Fiji, showed that the sample population had low knowledge of dementia literacy (Leung et al., 2019). A local study by Khonje et al. (2015) that aimed at exploring knowledge, attitudes and beliefs about dementia in an urban Xhosa-speaking community also concluded that people seem to have a low level of knowledge about the condition of dementia. The findings of the current study thus support the hypothesis that has been made by different studies across the world, namely, that a significant number of people lack knowledge about dementia. The above findings respond to the first objective of the current study that sought to understand Imbali residents' understanding of dementia symptoms.

The insufficient knowledge of dementia was also seen in half of the participants stating that it is part of getting old, that is, ageing. One participant reported that dementia was an illness of people's doing- he explained that when people neglect their ancestors, they lose the protection of the

ancestors and become weak or vulnerable to bewitchment by other people who might be jealous of them, this way they present with dementia due to being bewitched by other people. The concepts of people's doing in this theme is seen as applying to the person with dementia being responsible for their own illness as they neglected ancestral practices and secondly as other people being responsible for causing dementia through witchcraft. The understanding of dementia as being due to witchcraft is common in South African communities as it was also reported in a study by Mkhonto et al. (2015). Also, Khonje et al. (2015) identified that in some communities perceived dementia symptoms as a sign of possession by evil spirits, or a punishment for sons. Similar understanding of dementia was also found in a study that was conducted in Tanzania, a country in Africa. Amongst other causes, dementia was also associated with curse or witchcraft (Mushi et al., 2014). Two participants stated that the symptoms were a brain disease (dementia). These findings show that people have different explanatory models for illness even when they are assumed to have the same ethnicity and be from the same community. The perception of dementia as an old age illness is problematic because it assumes that all older adults get these symptoms and are acceptable. Also, a traditional approach may be problematic because it would hinder people from seeking appropriate care, but only access traditional healers in an attempt to deal with 'people's doings and jealousy'.

The findings of the study thus revealed that people hold different perceptions and beliefs regarding dementia. The findings also showed that people have different attitudes towards the illness. This was evident when one participant reported that the dementia condition is due to chemical imbalances, while another participant claimed that the causes of Mr Mkhize's illness were likely due to God's plan. Some participants stated that the causes of dementia are likely due to stressful circumstances, while one participant added that it may be due to traditional circumstances. The variety of reasons given for the causal effects of dementia further show the lack of knowledge and attitudes people have towards dementia, supported by several studies. For example, research done in Nigeria found that cultural differences, negative attitudes, and the lack of knowledge about dementia in communities were problematic (Adebiyi et al., 2016). The findings also showed that some participants believed that while dementia presentation is an illness, it is also a natural part of

ageing. This finding is supported by the South African study of Khonje et al. (2015) that found that dementia was perceived as a normal aging process.

5.3 Treatment-seeking behaviors

The research findings revealed different views on how a person would seek assistance should they present with dementia-related symptoms. Participants' treatment-seeking measures were influenced by their beliefs about the causes of the illness. Some participants reported that they would opt for medical care, while others would access non-medical care. The motivation behind the choice of treatment-seeking avenues was due to the beliefs of the illness's causes. This study showed that participants perceived dementia as part of ageing, brain injury and tradition. Those who believed in ageing as a cause of dementia seemed to have poor perceptions about dementia with less chances of seeking health attention as it is deemed a normal ageing process. These findings are similar to several articles on Exploratory Model Inventories. Findings of a study that explored the use of Explanatory Models in nursing research and practice, provided an understanding of the complex linkages between beliefs and actions towards treatment-seeking behaviors (Sharif et al., 2005). These findings provide insight into how held knowledge and beliefs influence treatment-seeking behaviors. This discussion gives account to the objective of the current study that questioned if there is any link between people's understanding of dementia and their treatment-seeking behaviors.

5.4 Summary

This chapter comprised the discussion of the results of the study. The results were integrated with findings from the existing literature and the study objectives. The results showed that Imbali Township residents hold differing views about what dementia is and the causes of the illness. The results also indicated that there seems to be inadequate of knowledge on the topic of dementia. However, some participants were able to identify the problem as dementia. Therefore, the findings of this study were mostly in line with the existing body of knowledge regarding dementia.

CHAPTER SIX: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This, the final chapter, comprises the summary, conclusions, and recommendations of the study. It begins with a summary of the study which touches on all the issues covered including the methodology adopted. This is followed by the conclusion and the limitations of the study. Finally, the chapter ends with the study recommendations for future research, practice, and policy/legislation.

6.2 Study summary

To address the research objectives, it was considered important to review the literature related to dementia. Age as a major risk factor was discussed as it has been proven that life expectancy is increasing, giving rise to more illnesses related to old age. South African policies for the elderly were briefly discussed in order to give context to the study. Dementia was then discussed, and this included defining the condition and unpacking it in the SSA context. The management and costs of dementia were also discussed.

The study adopted a qualitative approach in addressing its objectives. Data was collected through one-on-one interviews with residents in the Imbali Township. The interview schedule consisted of semi-structured questions. The collected data were analyzed using thematic analysis. Different themes were identified, and these were compared to the existing body of knowledge.

The results revealed that the majority of participants lacked information on dementia. Their assumptions and beliefs influenced their proposed treatment-seeking measures. This finding is supported by the theoretical framework that underpinned the study. Urgency or lack thereof in terms of treatment is dependent on how a person views the condition. Participants' understanding of dementia seemed to be more influenced by their held beliefs about the illness.

6.3 Conclusions

The primary goal of this study was to explore beliefs and perceptions held by residents of a township of an MND (dementia). More specifically, the study explored the understanding of dementia in Imbali Township (Pietermaritzburg); and if perceptions and understanding of dementia influenced treatment-seeking behaviors. The study is believed to have added to the body of knowledge concerning mental health, especially knowledge related to the understanding of dementia in the South African context, an under-researched area. An explanatory model of illness was adopted to unpack and understand dementia and its dynamics in the South African context.

The findings provided important insights into people's understanding of dementia that might be useful for future policies and legislation concerning the illness in South Africa. The study findings agreed with most conclusions made by other studies worldwide that have attempted to explore dementia. The recommendations for future practice, policies and research will be discussed under 6.5 below.

Study findings indicate that personal and cultural beliefs about an illness will continue to be important factors. These factors could impact programs aimed at people living with and affected by dementia. Factors associated with dementia included the belief that dementia is part of the normal ageing process. It is interesting to note that half of the participants shared this belief. A quarter of participants believed that dementia is a brain illness or injury. One of the participants associated dementia with people's doing, a result, for example, of jealousy (witchcraft) and neglect of ancestral rituals. Held beliefs about the causes of dementia seemed to be directly linked to the treatment-seeking choices.

6.4 Study limitations

There were several potential limitations of the current study that are important to note and acknowledge.

6.4.1 Participants' diversity

Firstly, the size of the sample may be considered to be too small to permit population generalization. However, it should be noted that this was never the core purpose of the study – the study purpose was to gain a deeper understanding of the phenomenon of interest. Secondly, the sample was drawn from two sections of Imbali Township. Incorporating residents from other sections may have yielded more relatable findings.

6.4.2 Literature reviewed

The limited literature on dementia in the South African context was a major limitation of the study. Very few local studies were available and most of the literature consulted was from a Western context. Due to this, it is hoped that this study can contribute to the limited literature in the South African context.

6.4.3 Data collection tool

Data was collected using a semi-structured interview schedule. The schedule had a section with forced-choice responses that may have provided participants with responses rather than allowing them to provide personal experiences and perceptions.

6.5 Recommendations

6.5.1 Recommendations for future research

As noted in the participants' diversity limitation above, exploring similar objectives using a larger sample would be valuable. It is also recommended that similar studies be conducted in other townships and other contexts in South Africa. It is also recommended that a more open-ended data collection tool be used as this may yield important information that might not have been ascertained with the forced-choice questions that were asked.

6.5.2 Recommendations for practice

It is important to note that this study did not answer all the possible questions about dementia in a township context. However, it attempted to uncover and understand some factors relating to perceptions and understanding of dementia and treatment-seeking behaviors. The results yielded interesting information on how held beliefs determine decision-making in treatment-seeking interventions and the types of intervention. It is, therefore, vital to include personal and cultural beliefs when dealing with illness. Considering the study's findings, it is evident that Imbali Township residents had insufficient knowledge about dementia. There was no uniformity in their current understanding of the condition. Therefore, it would be beneficial to have tailor-made community-oriented programs to educate community members about mental illnesses, especially dementia. These programs should be informed by the different cultural beliefs held by the communities.

6.5.3 Recommendations for policy/legislation

Based on the findings of this study, it is important to state that policymakers are inevitably faced with the challenge of developing culturally sensitive policies. Policy should also accommodate investment in educating about dementia, not only within clinics but in the media generally, including television, radio and magazines. In this way, awareness and accurate information about dementia would reach an increased number of people.

6.6 Summary

In this concluding chapter, a summary of the study, conclusions and recommendations were put forward. The limitations of the study were also listed and described. The chapter ended with the study recommendations related to future research, practice and policy/legislation.

REFERENCES

- Act, O.P. (13). Of 2006. In 109th Congress Sess, (Vol. 2301).
- Aboderin, I. A., & Beard, J. R. (2015). Older people's health in sub-Saharan Africa. *The Lancet*, 385(9968), e9-e11.
- Adebiyi, A. O., Fagbola, M. A., Olakehinde, O., & Ogunniyi, A. (2016). Enacted and implied stigma for dementia in a community in south-west Nigeria. *Psychogeriatrics*, 16(4), 268-273.
- Alzheimer's Society. (2013). *What is dementia?* <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-dementia>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Washington, D.C.: American Psychiatric Association.
- Arifin, S. R. M. (2018). Ethical considerations in qualitative study. *International Journal of Care Scholars*, 1(2), 30-33.
- Bogueva, D., Marinova, D., & Raphaely, T. (Eds.). (2018). *Handbook of research on social marketing and its influence on animal origin food product consumption*. IGI Global.
- Borochowitz, K. (2011). Dementia: the stigma and the challenges: conference paper. *ESR Review: Economic and Social Rights in South Africa*, 12(1), 32-33.
- Bhui, K., & Bhugra, D. (2002). Explanatory models for mental distress: implications for clinical practice and research. *British Journal of Psychiatry*, 181(1), 6-7.

- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic analysis. In P. Liamputtong (Ed.), *Handbook of Research Methods in Health Social Sciences* (pp. 1-18). Springer Singapore. https://doi.org/10.1007/978-981-10-2779-6_103-1
- Ciprian, G. & Borin, G. (2015). Understanding dementia in the sociocultural context: A review. *Internal Journal of Social Psychiatry*, 61(2), 198-204.
- Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Disease & Associated Disorders*, 16, S56-S63.
- Dinos, S., Ascoli, M., Owiti, J. A., & Bhui, K. (2017). Assessing explanatory models and health beliefs: An essential but overlooked competency for clinicians. *BJPsych Advances*, 23(2), 106-114.
- Doron, I., Spanier, B., Lazer, O. (2016) The rights of older persons within the African Union. *Elder Law Review*, 10, 1.
- Duthey, B. (2013). *Background paper 6.11 Alzheimer disease and other dementias*. https://www.who.int/medicines/areas/priority_medicines/Ch6_11Alzheimer.pdf
- Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., . . . Huang, Y. (2005). Global prevalence of dementia: a Delphi consensus study. *The Lancet*, 366(9503), 2112-2117.
- Frank, C., & Forbes, R. F. (2017). A patient's experience in dementia care: Using the "lived experience" to improve care. *Canadian Family Physician*, 63(1), 22-26.

- Giebel, C. M., Worden, A., Challis, D., Jolley, D., Bhui, K. S., Lambat, A., & Purandare, N. (2019). Age, memory loss and perceptions of dementia in South Asian ethnic minorities. *Aging & Mental Health*, 23(2), 173-182.
- Guerchet, M. M., Mayston, R., Lloyd-Sherlock, P., Prince, M. J., Aboderin, I., Akinyemi, R., ... & Ezeah, P. (2017). *Dementia in sub-Saharan Africa: Challenges and opportunities*. London: Alzheimer's Disease International.
- Haan, M. N. & Wallace, R. (2004) Can dementia be prevented? Brain aging in a population-based context. *Annual Review of Public Health*, 25, 1-24.
- Haidet, P., Kimberly, K. J., Sharf, B. F., Gladney, A. P., Greisinger, A. J., & Street Jr, R. L. (2008). Characterizing explanatory models of illness in healthcare: development and validation of the CONNECT instrument. *Patient Education and Counselling*, 73(2), 232-239.
- Jones, R. W., Romeo, R., Trigg, R., Knapp, M., Sato, A., King, D., ... & Group, D. I. (2015). Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: the DADE study. *Alzheimer's & Dementia*, 11(3), 280-290.
- Jorm, A. F. (2000). Mental health literacy: Public knowledge and beliefs about mental disorders. *British Journal of Psychiatry*, 177, 394 – 401.
- Kalaria, R., Maestre, G., Arizga, R., Friedland, R., Galasko, D., Hall, K., . . . Antuono, P. (2008). Alzheimer's disease and vascular dementia in developing countries: Prevalence, management, and risk factors. *The Lancet Neurology*, 7. doi:10.1016/s1474-4422(08)70169-8

- Khonje, V., Milligan, C., Yako, Y., Mabelane, M., Borochowitz, K., & De Jager, C. (2015). Knowledge, attitudes and beliefs about dementia in an urban Xhosa-speaking community in South Africa. *Advances in Alzheimer's Disease*, 4(02), 21.
- Kivunja, C., & Kuyini, A. B. (2017). Understanding and applying research paradigms in educational contexts. *International Journal of Higher Education*, 6(5), 26-41.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Annals of internal medicine*, 88(2), 251-258.
- Kometsi, M. J., Mkhize, N. J., & Pillay, A. L. (2020). Mental health literacy conceptions of mental illness among African residents of Sisonke district in KwaZulu-Natal , South Africa. *South African Journal of Psychology*. 50(3), 347-358.
- Krusenvik, L. (2016). Using case studies as a scientific method: Advantages and disadvantages.
- Kwok, T., Lam, K. C., Yip, A., & Ho, F. (2011). Knowledge of dementia among undergraduates in the health and social care professions in Hong Kong. *Social Work in Mental Health*, 9(4), 287-301.
- Leung, A. Y. M., Leung, S. F., Ho, G. W., Bressington, D., Molassiotis, A., Lam, C., ... & Valimaki, M. (2019). Dementia literacy in Western Pacific countries: A mixed methods study. *International journal of geriatric psychiatry*, 34(12), 1815-1825.
- Lindsay, P. H., & Norman, D. A. (2013). *Human information processing: An introduction to psychology*. Academic press.

- Marais, S., Conradie, G., & Kritzinger, A. (2006). Risk factors for elder abuse and neglect: Brief descriptions of different scenarios in South Africa. *International Journal of Older People Nursing*, 1(3), 186-189.
- McParland, P., Devine, P., Innes, A., & Gayle, V. (2012). Dementia knowledge and attitudes of the general public in Northern Ireland: An analysis of national survey data. *International Psychogeriatrics*, 24(10), 1600.
- Mkhonto, F., & Hanssen, I. (2018). When people with dementia are perceived as witches. Consequences for patients and nurse education in South Africa. *Journal of Clinical Nursing*, 27(1-2), e169-e176.
- Mshana, G., Dotchin, C., & Walker, R. (2011). “We call it the shaking illness”: Perceptions and experiences of Parkinson’s disease in rural northern Tanzania. *BMC Public Health*, 11. doi:10.1186/1471-2458-11-219
- Mushi, D., Rongai, A., Paddick, S. M., Dotchin, C., Mtuya, C., & Walker, R. (2014). Social representation and practices related to dementia in Hai District of Tanzania. *BMC Public Health*, 14(1), 260. doi:10.1186/1471-2458-14-260
- Olayinka, O. O., & Mbuyi, N. N. (2014). Epidemiology of dementia among the elderly in sub-Saharan Africa. *International Journal of Alzheimer’s Disease*, 2014. <https://doi.org/10.1155/2014/195750>
- Pandey, S. C., & Patnaik, S. (2014). Establishing reliability and validity in qualitative inquiry: A critical examination. *Jharkhand Journal of Development and Management Studies*, 12(1), 5743-5753.
- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1(3), 261-283.

- Shanley, C., Boughtwod, D., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., & Rowland, J. (2012). A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. *BMC Health Services Research*, 12. doi:10.1186/1472-6963-12-354
- Sharif, F., & Masoumi, S. (2005). A qualitative study of nursing student experiences of clinical practice. *BMC Nursing*, 4(1), 6. doi:10.1186/1472-6955-4-6
- Statistics South Africa (2012). *Census 2011*.
- South African Policy for Older Persons (2005). Pretoria.
- Terre Blanche, M. J., Durrheim, K., & Painter, D. (2014). *Research in practice: Applied methods for the social sciences* (2nd ed.). Cape Town: Juta and Company Ltd.
- Tirodkar, M. A., Baker, D. W., Makoul, G. T., Khurana, N., Paracha, M. W., & Kandula, N. R. (2011). Explanatory models of health and disease among South Asian immigrants in Chicago. *Journal of Immigrant and Minority Health*, 13(2), 385-394.
- Vally, Z. (2010). The assessment and management of dementia. *South African Family Practice*, 52(5), 392-395.
- Van Wezel, N., Francke, A. L., Kayan Acun, E., Devillé, W. L., Van Grondelle, N. J., & Blom, M. M. (2018). Explanatory models and openness about dementia in migrant communities: A qualitative study among female family carers. *Dementia*, 17(7), 840-857.
- Werner, P., Stein-Shvachman, I., & Korczyn, A. D. (2009). Early onset dementia: Clinical and social aspects. *International Psychogeriatrics*, 21(4), 631.

World Health Organization (2021). *Dementia: a public health priority*.

APPENDICES

Appendix A: Information sheet

Good day Sir/Madam.

My name is Luyanda Memela. I am a masters' student from the school of Applied Human Social Sciences – Psychology Department at the University of KwaZulu-Natal (Pietermaritzburg Campus). As part of my degree, I am doing a research study to understand beliefs and perceptions of major neurocognitive disorder (dementia) in Imbali Township.

You are invited to consider participating in this study. This study has been ethically reviewed and approved by the UKZN Humanities and Social Sciences Research Ethics Committee (approval number: HSS/0458/019M).

The study will involve a one-on-one interview. If you choose to participate, the duration of your participation is expected to be between 30 to 45 minutes. Participation is voluntary and you may withdraw at any point of the interview without penalty.

Confidentiality will be maintained, as your name will not be used in any publication of the research, instead, a pseudonym will be used. The collected data will be stored at the supervisor's office in a lockable cabinet where only the researcher and supervisor will access the data.

It is hoped that the study will contribute to the generation of knowledge about dementia in the Pietermaritzburg Township and hopefully influence future policies around the topic of dementia.

In the event of any problems, concerns or questions, you may contact the researcher Miss Luyanda Memela at 073 021 7910 or Supervisor Mrs Xoli Mfene at 033 260 5588 or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

Phumelele Ximba Tel: 27 31 2604557– Fax 27 31 2604609 Email: HSSREC@ukzn.ac.za

Humanities & Social Sciences Research Ethics Administration,

Research Office, Westville Campus,

Govan Mbeki Building,

Durban 4000.

Appendix B: Consent form

I _____ have been informed about the study entitled “A study on beliefs and perceptions of major neurocognitive disorder (dementia) in a township in Pietermaritzburg-KwaZulu-Natal” by Luyanda Memela. I understand the purpose and procedures of the study and I hereby give consent to participate in this study. I have been informed and understand that my participation is voluntary and that I may withdraw at any time without incurring a penalty.

I have been informed about any available psychological assistance if any discomforts occur to me because of the content of the study.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher or the Humanities & Social Sciences Research Ethics Administration.

Additional consent

I hereby provide consent to:

Audio-record my interview

YES / NO

Signature of Participant

Date

Signature of Researcher

Date

Appendix C: Interview schedule

Record Time & Date of Interview Start:

Subject ID:

Thank you very much for agreeing to do this interview. This is an interview about how people perceive and understand illness, stress and distress. We are very interested in your personal beliefs, which means there are no right or wrong answers to the questions we are going to ask you. Please be honest and try not to report what you think we or other people might want to hear, but what you actually believe in.

Section 1: Biographical details

Age.....

Gender:

- 1. Female ☐
- 2. Male ☐

Marital Status

- 1. Single ☐
- 2. Married ☐
- 3. Separated/Divorced ☐
- 4. Widowed ☐
- 5. Living with a partner ☐

Race / Ethnicity

- 1. African ☐
- 2. Coloured ☐
- 3. Other ☐

Specify.....

What is your highest level of education?

- 1. Never went to school ☐
- 2. Primary ☐
- 3. Secondary ☐
- 4. Tertiary ☐

What is your occupation

- 1. Unemployed ☐
- 2. Employed ☐
- 3. Retired/pensioner ☐

What is your religious affiliation?

.....

Home Language:

- 1. isiZulu ☐
- 2. isiXhosa ☐
- 3. Other ☐

Specify.....

Section 2: Case study

Mr Mkhize is a 68-year-old married man with two children who has been attending a local clinic for the past 6 years for monthly checkups. Mr Mkhize was first seen by the doctors 6 years ago when his wife observed changes in his memory and behaviour and suggested that they seek medical advice. At that time, Mr Mkhize was still employed as a security guard at one of the government departments. During the couple's initial visit to a doctor, Mr Mkhize acknowledged that he had been aware of increasing memory problems for at least the past 2 years. He said that he frequently forgot his car keys or would go into the house to get something then forget what he wanted. He acknowledges that his memory problem is now embarrassing him. Mrs Mkhize noted that he changed from an outgoing, pleasant person to one who avoided conversation. She said that he also seemed hostile at times for no apparent reason. Mrs Mkhize asserts that Mr Mkhize takes longer to do things that need attention. In addition, he is experiencing difficulties knowing what to call things around the house. For example, during this morning when he wanted a spoon to eat his porridge, he could not remember what the spoon is called. Recently, he started to need supervision to look after his financial affairs and for driving. He has also forgotten how to use his cellphone and gets lost when he goes to church by himself. Before this, Mr Mkhize was in good general health and was not taking any medications. His alcohol consumption was limited to two to three beers a weekend. He had no significant medical or mental illness history.

1. Do you think anything is wrong with Mr Mkhize?

- a. Yes ☐ b. No ☐ (if no skip number 2 - 11)

2. What, would you say is wrong with Mr Mkhize?

.....

(If they did not give a specific term for the problem ask q4?)

3. What do you think is the cause of the problem/s?

.....

4. What would you call the problem?

.....

5. If you had a problem right now like Mr Mkhize, would you go for help?

a. Yes

☐

b. No

☐

If you responded “Yes” to Question 5 above: Answer Questions 6 & 7.

If you answered “No”, proceed to Question 7.

6. From whom would you ask for help?

.....

7. What might stop you from seeking help from this person/place?

.....

89. There are several people, some professional, some not, who could help a person with this illness, if you had this illness, who would you go to for help?

	Helpful	Harmful	Neither
a. Family GP / Doctor			
b. Pharmacist /Chemist			
c. A Counsellor			
d. Social Worker			
e. Telephone Counselling, like Life Line			
f. A Psychiatrist			
g. A Psychologist			
h. Help from close family member			
i. Help from close friends			
j. Isangoma (Diviner)			
k. Inyanga (Herbalist)			
l. uMthandazi (Faith healer)			
m. A Church Minister/Priest/ Pastor			
n. To deal with his problem on his own			

10. The next few questions ask what you think is Mr Mkhize's chances of recovery. What would be the likely result if he had the sort of professional help you think is most appropriate? Would you say.... (*Please choose one*)

- a. Full recovery with no further problems ☐
- b. Partial recovery, but problems would probably re-occur ☐
- c. No improvement ☐

11. What would be the likely result if Mr Mkhize did NOT have any professional help? Would you say.... (*Please choose one*)

- a. Full recovery with no further problems ☐
- b. Partial recovery, but problems would probably re-occur ☐
- c. No improvement ☐

12. What is the nearest place in your area that provides treatment for people with dementia?

.....

13. Is there any area in your community that caters for older people's needs?

.....

THANK YOU

Appendix D: Ethical Clearance Letter



UNIVERSITY OF
KWAZULU-NATAL

INYUVESI
YAKWAZULU-NATALI

15 October 2019

Ms Layende Memela (210510069)
School of Applied Human Sciences
Pietermaritzburg Campus

Dear Ms Memela,

Protocol reference number: NSS/0458/019M
Project Title: Beliefs and perceptions of major neurocognitive disorder (dementia) in Imball Township, Pietermaritzburg – KwaZulu-Natal (PMB-KZN)

Approval Notification – Full Committee Reviewed Protocol

With regards to your response received on 19 July 2019 to our letter of 01 July 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



Dr Rosemary Sibanda (Chair)

/ms

Cc Supervisor: Mrs X Mfene
Cc Academic Leader Research: Professor Ruth Teer-Tomaselli
Cc School Administrator: Ms Priya Komar

Humanities & Social Sciences Research Ethics Committee
Dr Rosemary Sibanda (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 350 3507/8390/8357 Facsimile: +27 (0) 31 260 4808 Email: ethics@ukzn.ac.za / rosemarysibanda@ukzn.ac.za / ndhup@ukzn.ac.za
Website: www.ukzn.ac.za



1918 - 2018



100 YEARS OF ACADEMIC EXCELLENCE

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

Appendix E: Letter from Child and Family Centre (psychological services)



07 May 2019

To whom it may concern

This letter serves to provide the assurance that should any research participant in the study by Ms Luyanda Memela (Psychology masters student) require psychological assistance as a result of any distress arising from the research project titled: *"Beliefs and perceptions of major neurocognitive disorder (dementia) in Imbali Township"*, the service will be provided by Psychology Masters students and/or Intern Psychologists at the Child and Family Centre, University of KwaZulu-Natal, Pietermaritzburg Campus.

I acknowledge that Ms Memela's project is under the supervision of Mrs Xoli Mfene.

Yours sincerely,



Dr Phindile L. Mayaba
Director: Child and Family Centre
University of KwaZulu-Natal
Pietermaritzburg Campus






CHILD AND FAMILY CENTRE

School of Applied Human Sciences

Discipline of Psychology

Postal Address: Private Bag X01, Scottsville, Pietermaritzburg 3209, South Africa

Telephone: +27 (0)33 260 5166/5374 Email: mayaba@ukzn.ac.za Website: psychology.ukzn.ac.za

Founding Campuses:  Edgewood  Howard College  Medical School  Pietermaritzburg  Westville

Research Project

by Luyanda Memela

Submission date: 11-Jun-2021 10:29AM (UTC+0200)

Submission ID: 1604597322

File name: MISS_L_MEMELA_RESEARCH DISSERTATION_2021.docx (62.79K)

Word count: 14171

Character count: 80059

Research Project

by Luyanda Memela

Submission date: 11-Jun-2021 10:29AM (UTC+0200)

Submission ID: 1604597322

File name: MISS_L_MEMELA_RESEARCH DISSERTATION_2021.docx (62.79K)

Word count: 14171

Character count: 80059

Research Project

ORIGINALITY REPORT

10%

SIMILARITY INDEX

%

INTERNET SOURCES

10%

PUBLICATIONS

%

STUDENT PAPERS

PRIMARY SOURCES

1

Olaniyi O. Olayinka, Nadine N. Mbuyi.
"Epidemiology of Dementia among the Elderly
in Sub-Saharan Africa", International Journal
of Alzheimer's Disease, 2014

Publication

2%

2

Mary N. Haan, Robert Wallace. "Can Dementia
Be Prevented? Brain Aging in a Population-
Based Context", Annual Review of Public
Health, 2004

Publication

1%

3

Peggye Dilworth-Anderson, Geraldine Pierre,
Tandrea S. Hilliard. "Social Justice, Health
Disparities, and Culture in the Care of the
Elderly", The Journal of Law, Medicine &
Ethics, 2012

Publication

1%

4

Z Vally. "The assessment and management of
dementia", South African Family Practice,
2014

Publication

1%

5	Timothy Kwok, Ko-Chuen Lam, April Yip, Florence Ho. "Knowledge of Dementia Among Undergraduates in the Health and Social Care Professions in Hong Kong", Social Work in Mental Health, 2011 Publication	1 %
6	B. Wu. "Gender Differences in Views About Cognitive Health and Healthy Lifestyle Behaviors Among Rural Older Adults", The Gerontologist, 06/01/2009 Publication	1 %
7	"Living with Dementia", Springer Science and Business Media LLC, 2021 Publication	1 %
8	Thavanesi Gurayah. "Caregiving for people with dementia in a rural context in South Africa", South African Family Practice, 2015 Publication	<1 %
9	"Gender Equality", Springer Science and Business Media LLC, 2021 Publication	<1 %
10	Kamaldeep Bhui, Dinesh Bhugra. "Explanatory models for mental distress: Implications for clinical practice and research", British Journal of Psychiatry, 2018 Publication	<1 %

11	Clarissa M. Giebel, Angela Worden, David Challis, David Jolley et al. "Age, memory loss and perceptions of dementia in South Asian ethnic minorities", Aging & Mental Health, 2017 Publication	<1 %
12	"Dementia Lab 2019. Making Design Work: Engaging with Dementia in Context", Springer Science and Business Media LLC, 2019 Publication	<1 %
13	Roy W. Jones, Renee Romeo, Richard Trigg, Martin Knapp, Azusa Sato, Derek King, Timothy Niecko, Loretto Lacey. "Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: The DADE study", Alzheimer's & Dementia, 2015 Publication	<1 %
14	Aqeela Mahomed, Chrisma Pretorius. "Availability and utilization of support services for South African male caregivers of people with Alzheimer's disease in low-income communities", Dementia, 2020 Publication	<1 %
15	Clarissa M. Giebel, David Jolley, Maria Zubair, Kamaldeep Singh Bhui, David Challis, Nitin Purandare, Angela Worden. "Adaptation of the Barts Explanatory Model Inventory to	<1 %

20	Vinay Kumar, Achintya Saha, Kunal Roy. "In silico modeling for dual inhibition of acetylcholinesterase (AChE) and butyrylcholinesterase (BuChE) enzymes in Alzheimer's disease", Computational Biology and Chemistry, 2020	<1 %
----	--	------

Exclude quotes	On	Exclude matches	< 20 words
Exclude bibliography	On		

Appendix G: Proof of editing letter

Athol Leach (Proofreading and Editing)



31 Park Rd
Fisherhaven
Hermanus 7200
Email: athollead@gmail.com Cell: 0846667799

13 June 2021

To Whom It May Concern

This letter serves to confirm that I have edited the following Masters in Social Sciences (Clinical Psychology) dissertation by LUYANDA MEMELA (210510869):

“A STUDY ON BELIEFS AND PERCEPTIONS OF MAJOR NEUROCOGNITIVE DISORDER (DEMENTIA) IN A TOWNSHIP IN PIETERMARITZBURG – KWAZULU-NATAL”

The dissertation was edited in terms of grammar, spelling, punctuation and overall style. In doing so use was made of MS Word’s “Track changes” facility thus providing the student with the opportunity to reject or accept the changes made on a chapter-by-chapter basis.

Please note that while I have checked both the in-text references and those appearing in the list of references for consistency in terms of format, I have not checked the veracity of the sources themselves.

Both the tracked and final documents are on file.

Sincerely



Athol Leach

(MIS, Natal)