Dementia knowledge, prevalence, and risk factors in a community sample of older adults from iLembe District

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DECLARATION

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LIST OF ACRONYMS

AD: Alzheimer's disease

ADI: Alzheimer’s Disease International

APA: American Psychiatric association

DALYs: disability-adjusted life years

FTD: frontotemporal dementia

GAP: global action plan

HICS: High-income countries

KZN: KwaZulu-Natal

LMICS: low-middle-income countries

NCD: non-communicable disease

PHC: Primary health care
PWD: People living with dementia
SSA: Sub-Saharan Africa

VaD: vascular dementia

WHO: World Health Organization

YLDs: years of life lost due to disability

LIST OF PAPERS

Paper 1: Mfene, X. P., & Pillay, B. J. (2024)

Screening for dementia and associated factors in older adults from low socioeconomic communities in iLembe, KwaZulu-Natal', *Health SA Gesondheid* 28(0), a2437. doi. org/10.4102/hsag.v28i0.2437

Paper 2: Mfene, X. P., & Pillay, B. J. (2023).

Knowledge of dementia and dementia care in a cross-sectional sample of individuals living in rural and urban areas in KwaZulu-Natal, South Africa. *South African Journal of Psychology*, *53*(2), 265-274. doi:10.1177/00812463221139651

Paper 3: Mfene, X. P., & Pillay, B. J. (2023).

Dementia-friendly communities: Exploring terms used to describe dementia, attitudes and reactions towards people with dementia in iLembe District, South Africa. *Dementia*, *22*(5), 964-977. doi:10.1177/14713012231165112

Paper 4: Mfene, X. P., & Pillay, B. J. (Submitted to *Behavioural Neurology*).

Investigating the multidirectional relationship between Anxiety, depression and instrumental activities of daily living and cognitive decline in a sample of older adults.

ABSTRACT

The rapidly increasing life expectancy in South Africa has made dementia a growing concern. Although several studies have been conducted worldwide, few surveys have investigated the prevalence of dementia in South Africa. This study aimed to estimate dementia prevalence in a community sample in the iLembe District, KwaZulu-Natal, and to evaluate its association across several socio-demographic and clinical characteristics. Lastly, it explored the caregivers' awareness and different conceptions of dementia and dementia care practices. This was a cross-sectional one-phased household study with 320 adults aged ≥60 years and 300 caregivers, randomly selected from the iLembe District. The research used a biographical questionnaire, a brief clinical interview schedule, and a neuropsychological test battery to collect data from the 320 participants. An informant interview was conducted with the caregivers, using an open-ended questionnaire on the participant's health and living circumstances and the caregiver's dementia health literacy and awareness. Demographic data were analysed using descriptive statistics. The dementia prevalence was based on the DSM-5 criteria for major neurocognitive disorders. Binary logistic regression was used to predict the likelihood of dementia by demographic factors. Chi-square tests ($\chi2$) of independence were used to compare the socio-demographic distribution and caregivers' dementia awareness and knowledge. The study results showed that 43 (13.4%) participants had dementia (95% CI 9.7–17.5), and 91 (28.4%) participants screened positive for mild neurocognitive dementia (95% CI 23.8–33.4). Depression and anxiety were incidentally also found to be high in this sample. The risk factors for dementia were old age, low education levels, not having a partner, and depression. Only 12% of the caregivers recognised and labelled dementia symptoms using the term dementia. Most participants identified symptoms as an illness of aging, mental illness, and unspecified sickness. It was found that most of the participants' home languages did not have a name appropriately synonymous with dementia. Although the participants knew that professional interventions would most likely help someone with dementia, their treatment preference was home or family care. To conclude, the number of older adults with dementia globally is increasing, and therefore, an increase is also expected in South Africa. Although there is no cure for dementia, multi-disciplinary care can help manage the impact of the disease on the quality of life of those with the condition and their families.

CHAPTER 1

INTRODUCTION

The number of persons over 60 is predicted to more than double between 2013 and 2050, reaching more than 2.1 billion globally by 2050 (Alzheimer's Disease International [ADI], 2015; World Health Organization [WHO], 2022). Furthermore, the WHO (2022) predicts that by 2050, approximately 80% of older people will live in low-middle-income countries (LMICs). South Africa is no exception. In 2015, the country had the third-highest number of older persons 60 years or older in sub-Saharan Africa (Statistics South Africa, 2017). South Africans aged 60 years or older in 2022 were estimated at more than five million people, representing 9.2% of the overall South African population (Maluleke, 2023). Although an increased life expectancy is good, it raises concerns about age-associated health conditions like dementia.

The increase in the ageing population will mean a rise in dementia. Studies predict that the increase in dementia cases will affect LMICs, such as those in Sub-Saharan Africa (SSA), more than in developed countries (ADI, 2015; Kalula & Petros, 2011; Nichols et al., 2022). The significant increase in the number of older people in South Africa and the increasing life expectancy infer that the prevalence of dementia will increase, making dementia a public health concern for South Africa.

1.1 Problem Statement

The global prevalence of dementia is predicted to rise from 57.4 million cases to 152.8 million cases between 2019 and 2050 (Nichols et al., 2022). Dementia is the seventh leading cause of death and a significant cause of disability and dependency among older people worldwide (WHO, 2023). In addition, dementia was one of the 15 leading causes of disability-adjusted life years (DALYs) among older people in 2010 and ranked as one of the ten leading causes of disability in the ≥75 years age group in 2015 (WHO, 2015). In 2017, it accounted for 11.9% of the years lived with disability due to non-communicable disease (NCD) worldwide (WHO, 2017). In SSA, dementia was the 33rd leading cause of death, causing 2.4% of DALYs and 3% of deaths in people aged ≥70 years (WHO, 2015), making dementia a significant public health problem in the SSA region. In South Africa, dementia is considered one of the top 50 causes of mortality (WHO, 2021) and is responsible for 1.27% of total deaths in older adults and 0.46% years of life lost due to disability (YLDs) and 0.4% DALYs (Institute for Health Metrics and Evaluation [IHME], 2019).

Dementia also contributes significantly to the social, economic, and psychological burden on people living with dementia (PWD), their families, communities, and the country's healthcare system (Hugo & Ganguli, 2014; WHO, 2017). Regarding the economic and healthcare burden, dementia results in a higher disability burden than other health conditions in older adults, given the progression of the disease (Langa et al., 2017; Lisko et al., 2021; WHO, 2017). A higher disability burden means that people with dementia are highly dependent on healthcare, raising the costs of care as the incidence of the disease increases (Sontheimer, 2015). The costs of care continue to burden the public healthcare system, which is already experiencing heavy demands because of HIV, TB, and the COVID-19 pandemic in LMICs. When healthcare institutions are overburdened and are unable to adequately care for PWD, the burden of care falls on the family and community. Approximately 50% of dementia costs are attributable to informal carers, who provide, on average, five hours per day of care and supervision to those with dementia (WHO, 2023). As families absorb the responsibility of the day-to-day care for PWD, this results in increased social and psychological strain on family and caregivers, and in this way, dementia continues to indirectly contribute to costs on the healthcare system (Wimo et al., 2017).

To address the growing psychological, socioeconomic, and health impact of dementia, the WHO (2017) developed a global action plan (GAP) for dementia adopted by all member countries. The GAP has seven action areas aimed at decreasing the impact of dementia and improving the lives of PWD, their families and communities. These are:

i. Treating dementia as a public health priority
ii. Increasing dementia awareness and friendliness
iii. Dementia risk reduction
iv. Dementia diagnosis, treatment, care, and support
v. Increased support for dementia carers
vi. Developing information systems for dementia
vii. Advancing dementia research and innovation.

Adopting the 2017–2025 WHO GAP will help countries improve their response to dementia. The resulting dementia research and innovation will lead to countries developing specific and suitable policies on dementia diagnosis, care, and support, and to creating programmes to improve knowledge and awareness of dementia in communities. Further, country-specific strategies to reduce dementia risk and prevalence will be developed.

1.2 Significance of the Study

As the number of older South Africans increases, the need to accurately determine the burden of dementia in the country and the resources needed to support and care for PWD, their families, and caregivers also increases (De Jager et al., 2017). The best way to do this is through prevalence studies, which help index the disease's burden (Hugo & Ganguli, 2014). Therefore, this study will firstly contribute to the literature gap in this field of study in South Africa, as there are limited studies on dementia prevalence, risk, and knowledge in South Africa. Secondly, the data on dementia prevalence and risk will assist with understanding the trends of dementia prevalence, which is essential in formulating tailored policies and strategies to combat dementia risk for the South African population. Lack of knowledge and awareness about dementia leads to barriers to seeking healthcare and stigmatisation of people with dementia in communities. The publication of local data will help communities to better understand dementia, and possibly open new avenues of dementia care and decrease stigma associated with dementia.

1.3 Aims and Objectives of the Study

This study investigated the risks, prevalence, and knowledge of dementia among older people in four communities of iLembe District, KwaZulu-Natal (KZN), South Africa.

1.3.1 Research Questions

The research questions in this study are:

i. What is the prevalence of dementia among people aged ≥60 years in the iLembe District?
ii. What are the risk factors associated with dementia in the iLembe District?
iii. How do people in the iLembe District conceptualise dementia and dementia care?

1.3.2 Research Objectives

The objectives of the current study were to:

i. To investigate the prevalence of dementia in those ≥60 years in the iLembe District.
ii. To identify the factors associated with dementia in the iLembe District.
iii. To explore the community's awareness and conceptualisation of dementia and dementia care practices.

The prevalence and risk factors of dementia in those ≥60 years in the iLembe District were investigated through a quantitative survey. The community's awareness and conceptualisation of dementia and dementia care practices were explored using a qualitative research design.

1.4 Thesis Outline

This chapter highlighted the concerns associated with dementia, the disorder's impact on families and communities, and the aims and objectives of the study. Chapter two provides an overview of the literature on dementia, including the literature on epidemiology and the conceptualisation of dementia. Chapter three contains the study's methodological framework, including the study sample, inclusion and exclusion criteria, data collection and analysis, and ethical considerations of the study.

The results are presented in Chapter four. The results are introduced with specific study objectives addressed in four published peer-reviewed papers. Papers one and two respond to objectives on the prevalence and associated factors of dementia, whereas papers three and four respond to the objective on community awareness and conceptualisation of dementia.

- Paper 1 addressed the prevalence and factors associated with dementia in the iLembe District.
- Paper 2 focused on the relationship between anxiety, depression, and cognitive decline.
- Paper 3 considered the community's knowledge and understanding of dementia.
- Paper 4 explored the stigma and terms used to describe PWD.

Lastly, Chapter five provides a synthesised discussion of the results based on the existing research related to the dissertation topic. The chapter also includes the study's limitations and conclusions, highlighting future priorities for dementia research and practice in South Africa.

CHAPTER 2

LITERATURE REVIEW

2.1 Defining Dementia

Dementia (major neurocognitive disorder) is an umbrella term for several conditions caused by progressive brain degeneration that impairs cognitive functioning and behaviour, and significantly interferes with a person's daily functioning (APA, 2022; Creavin et al., 2016; WHO, 2017). The term 'people living with dementia' (PWD) is commonly used to reflect that having dementia is not a death sentence and that one can have a reasonable quality of life with dementia (Swasffer, 2015; Low et al., 2018). Dementia symptoms include impairment in one or more cognitive functions such as complex attention, executive functions, learning and memory, language, motor-visual perception, and social adaptation (APA, 2022; WHO, 2019). Mild symptoms are observed at the onset of dementia, but as dementia progresses, there is a decline in instrumental and basic activities of daily living, such as feeding, self-hygiene, and carrying out household tasks, to name a few (Grand et al., 2011). At the end stages of dementia, core functions such as breathing are affected (Laban, 2007), making it fatal and shortening the life expectancy for a PWD to eight to ten years from the onset of symptoms (Sontheimer, 2015).

2.2 Common dementia subtypes in older adults

Dementia encompasses a spectrum of subtypes, each with distinct characteristics, causes, and manifestations. The most common forms of dementia in older adults (those ≥60 years) are Alzheimer's disease (AD), followed by vascular dementia (VaD), and less common frontotemporal dementia (FTD) (Arvanitakis et al., 2019; Borenstein et al., 2016).

2.2.1 Alzheimer's disease

AD accounts for more than 50-60 % of all dementia cases worldwide (Alzheimer's Association, 2019; Borenstein et al., 2016). It is characterized by the accumulation of abnormal protein deposits, such as beta-amyloid plaques and tau tangles, in the brain. Alzheimer's typically progresses gradually, starting with memory loss and eventually affecting language, reasoning, and other cognitive functions (Alzheimer's Association, 2019; Borenstein et al., 2016).

2.2.2 Vascular dementia

VaD accounts for 10-50% of global dementia cases and is considered the second most common type of dementia (Borenstein et al., 2016). The clinical manifestation of VaD more often includes an abrupt onset and a stepwise cognitive decline caused by a cerebral insult (Borenstein et al., 2016). The heterogeneity of VaD has made it difficult to understand the underlying cause, which most often has been considered sporadic and related to cardiovascular risk factors such as hypertension, diabetes, and heart disease (Guerreiro et al., 2020). However, the pathophysiological link between cardiovascular risk factors and cognitive impairment remains undetermined.

2.2.3 Frontotemporal dementia

FTD is believed to be underdiagnosed in the older population due to misclassifications (Sontheimer, 2019). It is a progressive neurodegenerative disorder, and patient history usually reveals a gradual change over several years before the first formal assessment and diagnosis (Sontheimer, 2019). FTD primarily affects the frontal and temporal lobes of the brain, leading to changes in personality, behavior, and language (APA, 2013). Unlike Alzheimer's, FTD often occurs at a younger age, typically between 40 and 65 years. Subtypes of FTD include behavioral variant FTD, semantic variant primary progressive aphasia, and non-fluent variant primary progressive aphasia (Borenstein et al., 2016).

The spectrum of dementia subtypes reflects the diversity of underlying causes, symptoms, and disease progression patterns. Recognizing and understanding these subtypes is crucial for accurate diagnosis, appropriate interventions, and advancements in research and treatment.

2.3 Screening and diagnosis of dementia

Early neurocognitive screening is crucial for identifying potential dementia cases and facilitating effective disease management (Arvanitakis et al., 2019). When screening for dementia, a combination of tests is recommended due to the lack of a single accurate screening test (Arvanitakis et al., 2019). A comprehensive neuropsychological battery of tests needs to include multidomain assessments. Although various batteries are used in different settings, a simple neuropsychological battery commonly consists of multidomain instruments such as the Mini-Mental Status Examination (MMSE), MOCA or others combined with other specific cognitive domain tests. The DSM-5 details six cognitive domains which may be affected in a person with dementia (APA, 2022). Typical neuropsychological batteries must include tests for these cognitive domains: learning and memory, executive functions, language, complex attention, motor and visual perception, and social adaptation (APA, 2022). Neuropsychological tests must have high sensitivity and specificity to avoid false negatives and positives (Ashford et al., 2007; Kvitting et al., 2012; Ramlall et al., 2013). In addition to the cognitive assessments, objective memory assessments, like the Eight-item Interview to Differentiate Aging and Dementia (AD8), offer reliable alternatives, mainly when information from key informants is considered (Galvin et al., 2006). Assessing activities of daily living (ADL) is valuable and can be done through objective instruments such as Lawton's IADL scale. Subjective memory complaint tests have limitations, including diagnostic uncertainty and definition inconsistency (Arvanitakis et al., 2019). During the screening process, the focus is not on diagnosis but on identifying potential cognitive deficits and once impairment suggestive of probable dementia is established, the patient can be referred for further diagnostic work up process.

The dementia diagnosis process typically involves a clinical interview, physical examination, and neuropsychological assessments supported by laboratory tests like CT scans or MRIs (Arvanitakis et al., 2019; Hugo & Ganguli, 2014). Laboratory tests are necessary to rule out other potential causes of cognitive impairment. A standardized classification system such as DSM-5-TR and ICD-11 is often employed (APA, 2022; Hugo & Ganguli, 2014; WHO, 2019). Table 2.1 indicates the two most common diagnostic criteria for dementia.

Table 2.1: Diagnostic criteria for dementia

DSM IV-TR CRITERIA	ICD-11 CRITERIA
There is evidence of substantial cognitive decline from a previous level of performance in one or more of the domains listed below, based on the concerns of the individual, a knowledgeable informant, or the clinician; and a decline in neurocognitive performance, typically involving test performance in the range of two or more standard deviations below appropriate norms (i.e., below the third percentile) on formal testing or equivalent clinical evaluation.	Marked impairment in two or more cognitive domains relative to that expected given the individual's age and general premorbid level of neurocognitive functioning, which represents a decline from the individual's previous level of functioning.
The cognitive deficits are sufficient to interfere with independence (i.e., requiring minimal assistance with instrumental activities of daily living).	Evidence of neurocognitive impairment is based on: Information obtained from the individual, informant, or clinical observation; and Substantial impairment in memory performance as demonstrated by standardized neuropsychological/cognitive testing or, in its absence, another quantified clinical assessment.
The cognitive deficits do not occur exclusively in the context of a delirium.	Behavioural changes (e.g., changes in personality, disinhibition, agitation, irritability) may also be present and, in some forms of Dementia, may be the presenting symptom.
The cognitive deficits are not primarily attributable to another mental disorder (for example, major depressive disorder and schizophrenia).	The symptoms are not better accounted for by disturbance of consciousness or altered mental status (e.g., due to seizure, traumatic brain injury, stroke, or the effects of medication), Delirium, Substance Intoxication, Substance Withdrawal or another mental disorder (e.g., Schizophrenia or

	Other Primary Psychotic Disorder, a Mood Disorder, Post-Traumatic Stress Disorder, a Dissociative Disorder).
	The symptoms result in significant impairment in personal, family, social, educational, occupational, or other important areas of functioning.

Primary health care (PHC) settings, especially in low- and middle-income countries (LMICs), lack formal guidelines for dementia screening, diagnosis and management (Arvanitakis et al., 2019). Functional imaging, biomarker measurements, and extensive neuropsychological testing are not readily available in primary healthcare (PHC) diagnostic procedures (Arvanitakis et al., 2019). Neuropsychological tests are often not standardized or normed for diverse populations, leading to reliability and validity concerns (Ferri & Jacobs, 2017). The absence of standardized protocols and methods contributes to variations in dementia prevalence estimates, hindering data comparisons between countries (Ferri & Jacob, 2017). Research has also noted variations in methods as contributing to different prevalence rates (ADI, 2015). In addition, consistent and standardized interpretation of neuropsychological test results must consider the patient's ethnic group, gender, age, and education (Hugo & Ganguli, 2014). Cultural biases in commonly used cognitive tools and limitations in linguistically diverse and low-educated populations highlight challenges in screening for dementia in many African populations. (Arvanitakis et al., 2019).

2.4 Prevalence of Dementia

Worldwide, the prevalence of dementia is more than 55 million people, and it is predicted that this rate will increase to 150 million by 2050 (Akinyemi et al., 2022; WHO, 2022). While the estimates of PWD show a global increase, prevalence predictions point towards higher growth in LMICs (Akinyemi et al., 2022; Nichols et al., 2022; WHO, 2022) such as Asia, Latin America, and Africa, compared to high-income countries (HICs) such as Europe and North America. Currently, 60% of the estimated 55 million with dementia live in LMICs (Nichols, 2022; WHO, 2022). Regional estimates of dementia show that, between 2020 and 2050, dementia will rise from 0.40 to 0.96 million in Australia, 12.71 to 21.6 million in Europe, and 5.01 to 11.10 million in North America. In contrast, in LMICs, it will increase from 29.23 to 81.75 million in Asia and 5.30 to 17.22 million in Africa. Over the next 15 years, the trajectory of dementia will increase by 71% in Latin America, 66% in Asia, 64% in Africa, 47% in Oceania, 41% in North America, and 23% in Europe (Ferri & Jacob, 2017).

A meta-analysis of 47 studies from Asia, Africa, South America, Europe and North America found that the prevalence of dementia was higher in Europe and North America than in Asia, Africa, and South America (Cao et al., 2020). Studies in the USA and UK reported a prevalence between 3.21% and 11.2%. For example, a study conducted with 5 330 Americans and 3 147 English participants found a prevalence of 11.2% in the USA and 9.7% in England (Arapakis et al., 2021). Another longitudinal study from the UK found a dementia prevalence of 3.21% in 9,938 participants (Rusmaully et al., 2017).

Firstly, the variations in the prevalence estimates between regions are attributed to multiple factors such as increasing life expectancy and population growth (Ferri & Jacob, 2017). Over two-thirds of the world's population aged ≥ 65 are from LMICs (UN, 2020). Secondly, the variations could be attributed to differences in sample characteristics in the different studies. Lastly, the variation could also be due to the lack of representative data for most LMIC regions (ADI, 2015). For example, in Africa, most data on dementia prevalence are extrapolated, as there is still a paucity of studies covering the continent. In addition, there is a scarcity of resources such as healthcare and education resources in LMICs compared to HICs, contributing to a higher risk profile for dementia. More needs to be understood about dementia prevalence in LMICs, and longitudinal studies with vigorous methods covering most regions would provide more reliable information about dementia in LMICs.

2.4.1 Dementia Prevalence in Africa

Approximately 1.9 million people in Africa are estimated to live with dementia (WHO, 2022). Although an increased prevalence in African regions is indicated in global studies (ADI, 2015; Nichols, 2022), multiple studies conducted in Africa reported lower estimates of dementia compared to other world regions, such as the USA and UK (Akinyemi et al., 2022). African studies of dementia in older adults estimate a prevalence between 2.6% and 10.1%. For example, prevalences between 2.6% and 3.7% were reported in two studies conducted in Benin (Guerchet et al., 2009; Paraïso et al., 2011), 5.7% to 6.7% in Congo, 6.6% to 8.5% in the Central African Republic (Guerchet et al., 2010), 2.8% to 10.1% in three Nigerian studies (Gureje et al., 2011; Ogunniyi et al., 2016; Yusuf et al., 2011), 6.4%

to 8.9% in Tanzania (Longdon et al., 2013), and 2.3% to 5.1% in Egypt (Akinyemi et al., 2022) and 6% to 12.5% in South Africa (Van der Poel et al., 2012; Farina et al., 2023).

African data was chiefly from studies in Western Africa, particularly Nigeria, projecting a skewed prevalence. Also, the data from HICs reported in this study does not account for all studies conducted in these countries and, therefore, should be cautiously interpreted. A projected dementia prevalence for SSA is presented in Table 2.2 (ADI, 2015, p. 24).

Table 2.2: Estimated Dementia Crude Prevalence and Proportionate Increases (2015–2050)

Region	**Over 60 population (millions, 2015)**	**Crude estimated prevalence (%; 2015)**	**Number of people with dementia (millions)**			**Proportionate increases (%)**	
			2015	**2030**	**2050**	**2015–2030**	**2015–2050**
SSA, Central	5.21	4.41	0.23	0.39	0.85	70	269
SSA, Eastern	20.08	4.53	0.91	1.57	3.62	72	298
SSA, Southern	5.36	5.41	0.29	0.41	0.76	41	162
SSA, Western	17.70	3.95	0.70	1.11	2.39	59	241
SSA	**48.35**	**4.40**	**2.13**	**3.48**	**7.62**	**63**	**257**

(ADI, 2017, p. 24)

Based on Table 1, the estimates of PWD across the sub-Saharan region show an increase in numbers from 2015–2050 (ADI, 2015; UN, 2020). In 2015, the number of people with dementia in sub-Saharan Africa was estimated at 2.13 million, with a proportional increase of 257% expected between 2015 and 2050 (ADI, 2015). In countries from the Southern region of the SSA, such as South Africa, the estimated number of people with dementia was

0.29 million, with a projected proportionate increase of 162% from 2015–2050 (ADI, 2015). Newer estimates by ADI (2017) show that PWD will increase from 0.25 million to 0.42 million in the Southern region of SSA by 2030.

In South Africa, approximately 450,000 are currently living with dementia (Farina et al., 2023). This number has multiplied compared to the 187,000 people reported in 2016, which is expected to increase exponentially by 2030 (ADI, 2017; De Jager et al., 2017). Due to the limited number of studies on dementia in South Africa, it is challenging to study the trajectory of prevalence and risk in the country. A survey of 200 people in an urban Bloemfontein community found a 6% prevalence of dementia (Van der Poel et al., 2012). Another study was conducted in a group of nursing homes in KwaZulu-Natal and reported a prevalence of 7.9% (Ramlall et al., 2013), whereas a study conducted with 1 394 rural Xhosa-speaking participants aged ≥60 years from the Eastern Cape reported a prevalence of 11% (De Jager et al., 2017). Lastly, a newer study compared the prevalence of dementia across two South African sites (Limpopo and the Western Cape) and Indonesia and found that the prevalence was 12.5% in South Africa and 27.9% in Indonesia (Farina et al., 2023). These four studies show that South Africa has a pooled prevalence between 6% and 12.5%. This prevalence is concerning, and South Africa needs to heed the call by WHO (2017) to treat dementia as a health priority and implement focused intervention policies and risk-reduction strategies.

2.5 Factors associated with dementia

Several factors are associated with higher odds of developing disease and elevated proportions of prevalence (Hugo & Ganguli, 2014). However, observed risk factors do not automatically mean that one will develop the disease; instead, they predict one's vulnerability to developing the illness. Whether or not one does develop the disease depends on the timing and duration of exposure to other precipitating and perpetuating factors (Hugo & Ganguli 2014). This is because, rather than arising from a single risk factor, dementia is most likely to be the result of an interplay of multiple modifiable and non-modifiable risk factors over a life course (Alzheimer's Association, 2019).

2.5.1 Modifiable Factors

Modifiable risk factors refer to factors that can be managed, altered, or manipulated to prevent dementia, accounting for around 40% of worldwide dementias (Livingston et al., 2020). Some modifiable risk factors include vascular factors such as hypertension, smoking, obesity, and diabetes; socioeconomic status (SES) factors such as less education, rural settings, undernutrition, and low social contact; and mental health factors such as depression (Livingston et al., 2020).

Multiple vascular factors and medical conditions such as hypertension, diabetes, high cholesterol levels, high homocysteine levels, cerebrovascular disease, cardiovascular disease, smoking, and obesity have been associated with dementia (ADI, 2015; Akinyemi et al., 2021; Livingston et al., 2020; WHO, 2017). According to Guo et al. (2018), dementia risk increases six-fold five years after a stroke, with the highest risk occurring within one year. Hugo and Ganguli (2014) reported that cardiovascular disease was a risk factor for vascular and degenerative dementias, particularly Alzheimer’s dementia. In addition, conditions in midlife, such as hypertension, high cholesterol, obesity, and diabetes mellitus, are associated with an increased risk of dementia in late life (Hugo & Ganguli, 2014), demonstrating the importance of risk exposure decades earlier. Yusuf et al. (2018) also confirmed that, in their study, dementia was higher in adults with diabetes mellitus than those without.

Some socioeconomic status (SES) factors associated with dementia include education, rural settings, undernutrition, and low social contact. Several studies found that dementia risk was lower among individuals with higher levels of education (Alzheimer’s Association, 2019; Dekhtyar et al., 2015; Yusuf et al., 2018). Low formal educational attainment and undernutrition in many African countries are indexes of low socioeconomic status and health disadvantage (Ojagbemi et al., 2021). Education is a crucial determinant of cognitive health. Studies have shown that higher levels of education are associated with reduced risk and delayed dementia onset (Clouston et al., 2019; Paddick, 2014; Olivier et al., 2018). This is because education may promote ‘natural reserve’, which protects against late-life cognitive impairment. The cognitive reserve theory suggests that cognitively stimulating activities through formal education have protective and enhancing cognitive effects (Hugo & Ganguli, 2014) and contribute to the brain's resilience by providing a cognitive buffer against the effects of aging and neuropathological changes, reducing the risk of cognitive decline and dementia (Clouston et al., 2019; Olivier et al., 2018; Ramlall et al., 2013; Yusuf et al., 2018). The theory emphasises that cognitive reserve needs to be enhanced during early life to prevent late-life cognitive decline (Livingston et al., 2020). In Africa, however, there are disparities in educational opportunities, with many individuals facing limited access to quality formal education. Therefore, improving education access must be prioritized in Africa to mitigate the rising dementia burden. In addition, due to the disparities in formal education in Africa, more research is needed to specifically explore the concept of cognitive reserve in populations where formal education is less prevalent and other indigenous forms of education are dominant.

People living in rural areas are reported to be more vulnerable to dementia than those in urban areas (Gureje et al., 2011; Rahman et al., 2020). Literature shows that the rural and urban disparities in dementia risk are significant (De Jager et al., 2015; Gureje et al., 2011). The differences indicate that living in a rural area is linked to a poorer socioeconomic status (SES), making it difficult to afford adequate nutrition and healthcare for diseases related to dementia (e.g., hypertension, diabetes, and cardiovascular disease) (Cai et al., 2021; Olivier et al., 2018; Rahman et al., 2020). In addition, people living in rural areas usually have limited income, which affects their access to appropriate and quality education, and may impact their lifestyle and nutrition choices, and living conditions (poor housing, unemployment, and challenging physical environment) (Cai et al., 2021; Olivier et al., 2018; Rahman et al., 2020). This is particularly true in South Africa; due to the past apartheid laws, marginalised race groups were relocated to rural areas and had poor quality, or limited access to, formal education, poor living conditions, and limited access to healthcare, which have over a person's lifetime contributed to higher rates of chronic conditions, such as hypertension, diabetes, and dementia in older people living in rural areas (Maphumulo & Bhengu, 2019).

The older people living in the rural areas now (60 years and above) are mainly from the marginalised racial groups unjustly affected by the apartheid laws. According to the literature, apartheid impacted the health outcomes of South Africa's older population in various ways, and the impact of these health outcomes on the cognitive functioning of older black South Africans who lived in rural areas and lived through apartheid has been insufficiently studied (Kobayashi et al., 2019). Another possible reason for rural-urban disparities is that rural populations are, on average, older than urban populations. This could be an impact of the migration or relocation effect, as younger people tend to migrate to urban areas to explore better study and living opportunities, leaving older people behind. The rural-urban disproportions may decrease if confounding factors such as low household income and poor access to healthcare, undernutrition and education are modified. Longitudinal studies are needed to explain the rural-urban disparities and their impact on cognitive functioning within the South African context.

Other factors associated with dementia risk in older people are loneliness and isolation (Gureje et al. (2011; Ogunniyi et al., 2016; WHO, 2022). Loneliness and isolation increase dementia risk by up to 50% (National Academies of Sciences, Engineering, and Medicine, 2020; Yusuf et al., 2018). This is because loneliness has been associated with depression, cardiovascular disease, hypertension, hearing loss and functional decline, which are also associated with dementia (Pagan, 2020). Loneliness also increases the risk of mortality and morbidity in older people (Pagan, 2020).

Loneliness is also associated with hearing loss, which is also related to cognitive decline (Lin et al., 2023; National Academies of Sciences, Engineering, and Medicine, 2020). Although research on the relationship between hearing loss and cognitive decline is still scarce, it is increasingly recognized as a risk factor. More research is needed in this area, and modifications such as reducing exposure to noise in early and middle adulthood and access to hearing aids are recommended (Lin et al., 2023).

Mental health conditions such as early life depression and anxiety are also associated with dementia (De Jager et al., 2017; Gimson et al., 2018; 2017; Ramlall et al., 2013). A South African study conducted with 1,394 Xhosa-speaking community dwellers in the rural communities of the Eastern Cape found that depression was associated with dementia in this sample (De Jager et al., 2017). Depression has a bi-directional relationship with dementia. When major depression occurs in early adulthood, it increases dementia risk in later life (Brenowitz et al., 2021). In contrast, depression occurring later in life is considered an early symptom of vascular or Alzheimer's dementia (Byers & Yaffe, 2011). The association of depression with dementia has various psychological or physiological mechanisms. Depression can be part of the prodrome and early stages of dementia, while depressive symptoms can also result from dementia neuropathology that occurs years before clinical dementia onset (Byers & Yaffe, 2011). To explain depression as a prodromal syndrome for dementia, a meta-analysis by Geerlings and Gerritsen (2017) found that people with depression had hyperactivity in the area of the brain that stimulates the adrenal glands to produce more glucocorticoids, such as the stress hormone cortisol, which can damage the hippocampus, a part of the brain that is important for cognitive function and memory. A systematic review of case-control and cohort studies conducted by da Silva et al. (2013) concluded that, while depression may be a prodrome or a risk factor for the development of dementia in older people, mood disorders in general (both depression and bipolar disorder) confer increased risk for dementia.

2.5.2 Non-modifiable Risk Factors

Non-modifiable factors, such as age, gender, and genetic factors, cannot be changed. The chief risk factor for dementia is old age (Prince et al., 2015; WHO, 2017). The estimated age of onset for dementia is >60 years, and the prevalence of dementia increases with age, with the highest rate of dementia expected from people who are ≥70 years (Prince et al., 2015). The overall prevalence estimates for dementia are 1–2% at age 65 and as high as 30% by age 85 (APA, 2013). In addition, after 65 years, the risk of dementia doubles every five years, reaching nearly one-third after age 85 (Alzheimer's Association, 2019; Hugo & Ganguli, 2014).

According to Hugo and Ganguli (2014), increasing age is not only the chief risk factor for dementia but also the only risk factor consistently identified after age 80. Studies conducted in sub-Saharan Africa also confirm that dementia proportions increase with age (Guerchet et al., 2009; Gureje et al., 2011; Ogunniyi et al., 2016; Paraïso et al., 2011). The risk of dementia due to advanced age might be due to various contributing factors across the life course that may differ between high- and low-income regions (Ramlall et al., 2013). For example, older people from LMICs are more likely to suffer from comorbid illnesses such as hypertension, stroke, diabetes, and hypercholesterolemia (Gorelick et al., 2011; Huang et al., 2015), which increases the risk of older persons developing dementia. This is because older people from LMICs usually live in poor conditions and with poor access to good infrastructure and healthcare services.

A mixture of genetic factors, including family history, are associated with an increased dementia vulnerability. People with first-degree relatives with dementia, such as parents and siblings, have a more significant predisposition to the disease (Prince et al., 2015; Olivier, 2018). Approximately 40% of individuals with frontotemporal dementia have a family history of another early-onset neurocognitive disorder, and an estimated 10% show an autosomal dominant inheritance pattern (ADI, 2017; Hugo & Ganguli, 2014). While several genes are associated with increased susceptibility to Alzheimer's disease, apolipoprotein E (*ApoE*) is the most established genetic risk factor (Hugo & Ganguli, 2014; Lisko et al., 2021). The *ApoE ε4* allele is more susceptible to hypercholesterolemia and heart disease and is also associated with most types of dementia (Tsuang et al., 2013; Yin et al., 2012). Although this gene is a risk factor for dementia, it is not a diagnostic marker as it is neither necessary nor sufficient for diagnosis, and its effect on risk appears to wear off in individuals older than 80 (Hugo & Ganguli, 2014).

Another non-modifiable risk factor is gender. Females are more at risk for dementia than their male counterparts (ADI., 2015; Guerchet et al., 2009; Gureje et al., 2011; Paraïso et al., 2011). Sixty-five percent of deaths due to dementia are in women, and DALYs due to dementia are 60% higher in women than in men (WHO, 2022). This might be because there is a higher number of older females and higher life expectancy in females than males (ADI, 2017; Hugo & Ganguli, 2014). For example, in South Africa alone, more than half (60.9%) of South Africa's older population is female, and they tend to live longer than males (Maluleke, 2023). In addition, a higher life expectancy in females predisposes females to other dementia risk factors, such as loneliness; for example, Stepler (2016) found that 37% of older females are more likely to be widowed and live alone compared to 13% of older males.

Some cases of dementia may be preventable or lowered through risk reduction (Nichols et al., 2022). Reducing modifiable risk factors such as education level, lifestyle diseases, and living conditions has contributed to a decline in dementia cases in HICs (Nichols, 2022; Langa et al., 2017; Matthews et al., 2013). According to the WHO (2022), risk-reduction strategies such as physical activity, avoiding substance abuse, weight control, eating a balanced diet, and managing blood pressure, cholesterol, and blood sugar levels must be employed from early life to prevent late-life cognitive decline. Although more research is necessary to study specific risks in Africa, presumably adopting and contextualising similar risk-reduction strategies in African countries can change the course of dementia in Africa. Evidence for the effectiveness of prevention programmes focusing on local contexts and modifiable risk factors must be strengthened to design effective interventions and public health policies appropriate for the local context (Ferri & Jacob, 2017).

2.6 Dementia Care and Management

As the prevalence of dementia increases, the demand for appropriate health services to diagnose, treat, and care for PWD will also increase. Although there is currently no known cure for dementia, care for PWD and management of the disease progression are still necessary. In South Africa, most older people depend on the public sector's primary health care (PHC) services for medical care (Peltzer & Phaswana-Mafuya, 2012). Although much work has been done recently to improve access to and quality of health services, healthcare at public hospitals and clinics is still inadequate (Maphumulo & Bhengu, 2019), particularly for older people (Kelly et al., 2019). In addition, there are many other concerns; these include complaints about the attitude of staff towards older patients, the shortage of medicines and assistive devices, the lack of transport, and long outpatient waiting times (Peltzer & Phaswana-Mafuya, 2012; Kelly et al., 2019). All these factors make the primary healthcare system unsuitable for addressing and providing for older people's healthcare needs (Kalula & Petros, 2011; Kelly et al., 2019).

Literature on dementia care strongly supports that older people should be *ageing in community or in place* (Grand et al., 2011), rather than in institutional settings. This is because, for PWD, the home or community environment promotes a sense of personhood, normalcy, and continuity in the face of the disconnection experienced due to multiple losses in functioning (Grand et al., 2011). Applying this concept of 'ageing in place' for PWD suggests that PHC needs to work towards providing routine outpatient services for PWD through community healthcare centres. This healthcare must be accessible and affordable to older persons, regardless of socioeconomic status. In the South African context, accessible, affordable, and prescribed norms and standards are inconsistent for older persons, especially the disadvantaged who rely on public healthcare. In addition, time resource constraints mean that many public healthcare professionals have limited time during doctor consultations and often miss or struggle to identify frailty and dementia (Kalula & Petros, 2011). In addition, limited knowledge of dementia is apparent in PHC services, leading to delays in offering referrals for further assessment to reach a diagnosis of dementia as PHC workers might see it as normal ageing (ADI, 2019; Jacobs et al., 2022; Oliviera et al., 2022). Older people with dementia require more comprehensive, holistic, and multidisciplinary interventions (Grand et al., 2011).

The expected increase in the prevalence of dementia demands a proactive PHC system, not one that acts as a bridge or defers dementia diagnosis and care to limited tertiary health care services (such as specialised memory clinics). Rather, a system is required that assesses and responds to the patient's needs and provides appropriate levels of support at different stages of dementia. Moreover, chronic care programmes, long-term care, and community support services geared toward the needs of older people at risk of dementia are needed within the primary healthcare system (Kalula & Petros, 2011). To be proactive in managing the rise in dementia, PHCs must develop efficient methods to assess patient care needs and provide flexible management plans and appropriate support systems, in keeping with those offered in tertiary institutions using the memory clinic model. This is because South Africa has few geriatricians and even fewer specialists in geriatric psychiatry, or memory clinics, most of which are urban and based in tertiary hospitals (Kalula & Petros, 2011; Ramlall, 2013).

The memory clinic model uses multidisciplinary teams (MDT) in the assessment and follow-up of people with dementia, making sure that care is holistic. The redistribution of dementia care services from tertiary to PHC in the public system is important because, currently, South Africa has a limited number of memory clinics and geriatric specialists in the public sector (Kalula & Petros, 2011). In districts where these services are available, they usually only operate for a few hours once or twice a month (Kalula & Petros, 2011). This means that PWD and their caregivers must be on a waitlist for appointments, thereby delaying diagnosis and care. To facilitate healthcare services that are accessible, equitable, affordable, and meet the prescribed norms and standards of dementia care, dementia screening and monitoring, at the very least, need to be integrated into PHC services and not just available at a few tertiary healthcare institutions (Kvitting et al., 2013). This was also recommended in a South African study by Ramlall (2013). Lastly, more resources, such as multidisciplinary teams and laboratories, must be allocated for the healthcare of older persons in PHC.

2.7 Knowledge and Conceptualisation of Dementia

Disease knowledge includes recognising symptoms, understanding risk factors and causes, and knowing available professional care and self-treatment (Jorm, 2012). The literature on dementia knowledge and awareness shows that the general population has insufficient knowledge and understanding of dementia (Ogunniyi et al., 2005). It is important that sociocultural meanings of illness are considered when dealing with different ethnic and cultural groups. This is because individuals sometimes use culturally specific explanations about how health and wellness are achieved, and the meaning of symptoms and causes of distress and illness (Dinos et al., 2017). This is important because, as seen in much of dementia literature, the conceptualisation of dementia symptoms, risk factors, and care are commonly based on personal experiences, and sociocultural beliefs and perceptions (Hindley et al., 2016). Differences in cultural and social backgrounds influence how people process their experiences and what illness means. Considering that social realities differ between different societies, social groups, and even individuals, this theory argues that these differences affect people's beliefs about and reactions to sickness and how they choose and evaluate the effectiveness of the available healthcare practices (Dinos et al., 2017). Therefore, knowledge about illness is not static or a single construct, but can be fluid, multi-layered, and complex (Dinos et al., 2017).

According to Patel (2011), in African communities, illness can be conceptualised as being medical while also having sociocultural implications or vice versa, supporting the idea that disease knowledge can be fluid and multi-layered. In several African studies, some participants conceptualised dementia as biomedical (i.e., natural and expected part of aging, mental illness, and medical disorder) (Hindley et al., 2016; Khonje et al., 2015; Mkhonto & Hanssen, 2017; Ogunniyi et al., 2005; Owokuhaisa et al., 2020), while others believed that dementia was caused by cultural and spiritual entities such as being possessed by evil spirits, retribution from God or the ancestors, not praying enough, not having sufficient faith to ward off evil spirits, and witchcraft (Cipriani & Borin, 2014; Hindley et al., 2016; Mkhonto & Hanssen, 2017; Mushi et al., 2014; Ndamba-Bandzouzi et al., 2014; Sayegh & Knight, 2013). These studies suggest that it is common among African populations to hold both Western and traditional or spiritual conceptions about dementia; expressing these multi-layered beliefs and perceptions does not necessarily imply a lack of or inaccurate knowledge, and also one belief is not held over the other.

Kleinman's theory infers that people's explanatory models of illness, whether biomedical, sociocultural, or mixed, influence their healthcare preferences (Alexander et al., 2013). In a South African Xhosa-speaking urban community, Khonje (2015) found that participants often relied on traditional healers to manage dementia rather than Western care practices, and this matched some of the participants' knowledge about dementia. However, other studies have shown that some African participants also prefer family care (Berwald et al., 2016; Raghavan & Patel, 2018), while others prefer spiritual or religious interventions and traditional ancestral connections for care (Hindley et al., 2016; Nwakasi et al., 2019). According to Alexander et al. (2013), having sociocultural beliefs about illness is not a problem; however, using only sociocultural models to explain disease has also led communities to look to traditional remedies and faith healing, which do not necessarily guarantee recovery from medical problems. When communities only use supernatural beliefs to understand dementia, faith healing and traditional medicine are usually preferred over medical treatment, then this constitutes poor knowledge and awareness about the biomedical aspects of disease and the benefits and importance of medical care (Alexander et al., 2013). In such cases, awareness-raising is needed.

2.8 Stigma and the Social Exclusion of People with Dementia

People with dementia often experience stigma, abuse, and discrimination within their communities (Hung et al., 2021; Khonje et al., 2015; Mkhonto & Hanssen, 2018). Stigma and discrimination include negative attitudes or behaviour, such as negative language or terminology, stereotyping, alienation, and intolerance towards PWD and their families (Mukadam & Livingston, 2012; Swaffer, 2014). According to Evans (2018), three types of stigma impact PWD. Self-stigma is the internalisation of negative stereotypes that people with an illness have about their condition. In contrast, public stigma involves discrimination and devaluation of people with illness by others, while stigma by association is when the effects of stigma are extended to families and friends of people linked to an ill person (Evans, 2018; Pattyn et al., 2014). People living with dementia also suffer from structural stigma, such as when systems, policies or services discriminate directly or indirectly against people living with dementia, poor healthcare provision for dementia through lack of investment in appropriate services and in training for health and social care providers, who continue to be unprepared to diagnose and to provide care and support for people living with dementia (Oliviera et al., 2022).

Stigma against those with dementia can discourage people from seeking help and can also trigger feelings of shame in the families of PWD. To prevent these feelings, people choose not to inform others that they have the disease or withdraw from community activities they were previously interested in (Adebiyi et al., 2016; Evans, 2018; Pattyn et al., 2014). A study that included one family member and seven nurses caring for patients with severe dementia in nursing homes in Tshwane, South Africa, found that relatives of PWD hide the status of their loved ones for fear of prejudice or violence from the community (Mkhonto & Hanssen, 2018). Communities with prejudicial attitudes toward dementia perpetuate the isolation and exclusion of PWD and their families from the community. A UK report found that 33% of those living with dementia lost friends after diagnosis, and 39% felt lonely and excluded in their communities (Alzheimer’s Society, 2013). Stigma against PWD, especially women, in South African communities is rife and can lead to families being ostracised (Gurayah, 2015; KwaZulu-Natal legislature, 2022; Mkhonto & Hanssen, 2018). In KZN and Eastern Cape, older women suspected of dementia may be accused of witchcraft, and their lives can be in danger (KwaZulu-Natal legislature, 2022), as they can be abused, exiled, and/or murdered by community members (de Jong et al., 2022; Mkhonto & Hanssen, 2018).

One of the ways that dementia stigma is enforced is through the colloquial language used to refer to dementia (Swaffer, 2014). Language toward people with dementia, such as *demented*, *crazy*, *possessed*, *loss of mind*, and *having a confused head*, have been used in communities and research (Berdai Chaouni & De Donder, 2019; Cipriani & Borin, 2015; Swaffer, 2014). These terms may be part of everyday social language, but they also implicitly reinforce stigma, social exclusion, and intolerance towards PWD. As other studies have pointed out, in most African communities, there is no term synonymous with the biomedical concept of dementia (Khonje et al., 2015; M’belesso et al., 2016); hence these damaging terms are coined. Inclusive and appropriate dementia language will help communities replace harmful terms that associate dementia with shame and reinforce stigma. When the language is inclusive, non-judgmental, and person-centred, it can help change community perceptions and attitudes towards PWD, improving their quality of life and encouraging communities not to socially exclude PWD (Swaffer, 2014). The WHO encourages countries to create dementia-inclusive communities to decrease public stigma against those with dementia and stigma by association for their families.

2.9 Theoretical Framework

This study used the biopsychosocial theory to understand the interaction between risk factors and dementia. It also employed Kleinman's (1987) theory of explanatory models to understand the knowledge and conceptualisation of dementia among the iLembe District population and how this influences treatment-seeking behaviour.

2.9.1 Biopsychosocial Theory (Engel, 1977)

In understanding dementia and dementia risk factors, the biopsychosocial model of disease was used. The framework's primary idea is that interactions between biological, psychological, and social factors determine the cause, manifestation, and prognosis of illness (Bayne & Shune, 2022; Engel, 1977). The biopsychosocial model argues that one factor is not sufficient to explain disease; however, it is the dynamic interplay between people's genetic makeup (biology), mental health and behaviour (psychology), and sociocultural environment that determines the course of health-related outcomes (Spector & Orrell, 2010).

Dementia results from the interplay between biological, psychological, and environmental factors (Cohen-Mansfield, 2000). The use of the biopsychosocial model to describe dementia was first done by Cohen-Mansfield (2000) and later adapted by Spector & Orrell, (2010). It was applied to dementia as an approach to ground and increase understanding of the factors that play a role in causing dementia, affect prognosis and to illustrate the role of psychosocial factors in the context of biological processes (Spector & Orrell, 2010). The adapted model by Spector and Orrell (2010) proposed that the impact of biological, psychological, social, and environmental domains change throughout disease progression. and they also identified fixed and tractable biopsychosocial characteristics experienced by those with dementia (Bayne & Shune, 2022; Spector & Orrell, 2010).

The biopsychosocial model in this study was used to understand the causes of dementia. The biological domain applies to the biomedical understanding of dementia as a neurocognitive disorder emanating from problems within the brain. Regarding the causes and risk factors of dementia, this domain supports that biomedical processes such as aging, depletion of neurotransmitters, brain atrophy, and genetic factors negatively affect the person's cognitive functioning (Keady et al., 2013). However, as the theory suggests, it is important to note that biomedical factors alone do not account for all aspects of the disease. Instead, certain non-biological (such as environmental) factors trigger and express the disorder in those with a pre-existing biomedical risk.

The psychological component of the biopsychosocial model includes potential psychological factors that may contribute to the development of dementia. These include a history of mental illness such as depression and psychosis, stressful life events (e.g., trauma), and personality (Burke et al., 2018; Spector & Orrell, 2010). Alternatively, psychological factors may exacerbate a biological predisposition by putting a genetically vulnerable person at risk for other risk factors (Spector & Orrell, 2010).

In comparison, the sociocultural domain includes socioeconomic status, culture, and religion. For instance, differences in the circumstances, expectations, and belief systems of different cultural groups contribute to different prevalence and symptom expressions of disorders. Cultural factors can even differ across a single city, from lower-income to higher-income areas, and rates of disease and illness vary across these communities. The sociocultural factors encompass the importance of the person with dementia maintaining a valued social identity, one where language is used positively to socially position the person as someone of intrinsic worth and value (Keady et al., 2013).

The biopsychosocial model not only highlights factors influencing the development of dementia but also factors that are protective against the disease. Lastly, it is important that the model is not only seen as a theoretical framework but also as an approach to care in dementia (Bayne & Shune, 2022; Spector & Orrell, 2010). Therefore, this model can be applied in research and clinical settings.

2.9.2 Explanatory Models of Illness (Kleinman et al., 1978)

Explanatory models of illness were first developed by Kleinman et al. (1978) and refer to socio-culturally determined perceptions and believes that individuals use to understand illness and distress. The beliefs ascribe meanings to symptoms, evolving causal attributions, and expressing suitable expectations of treatment and related outcomes (Dinos et al., 2017; Kleinman et al., 1978). They provide culturally specific explanations about health and wellness and distress and illness (Dinos et al., 2017; Kleinman, 1978). It should be noted that explanatory models do not consist of coherent beliefs but refer to various explanations simultaneously and rapidly taken up or dismissed (Tirodkar et al., 2011). 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 behaviour, and they are socially constructed. Explanatory models also influence how people choose and evaluate treatment options.

To understand a community's beliefs and perceptions about dementia, one needs to explore that population's subjective explanations about the concept of interest. These explanations must display the conceptualisation of the illness, the causes, and the treatment-seeking behaviours. PWD, their caregivers, and communities attach particular meanings to the experience of dementia by creating narratives describing its causes (aetiology), how it is manifested (symptoms), how it affects the body or person (pathophysiology), how it is expected to proceed (course), and what should be done about it (treatment preferences). When we understand people's explanatory models of dementia, they can be incorporated into existing approaches to care. 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. Apart from these clinical benefits, greater awareness of explanatory models about dementia may have beneficial effects on health policymakers, training of healthcare practitioners, and public awareness campaigns.

Therefore, in this study as we explore knowledge and conceptualisation of dementia among the iLembe communities, and we explore the explanatory models these communities use and how they influence treatment-seeking behaviour. In this study, this model of explaining dementia is suitable because, in African populations, it is not uncommon to understand illness from multiple perspectives, including a combination of biomedical, social, and cultural factors, as discussed in Section 2.5 above. Literature suggests that South African populations use multiple explanatory models of understanding symptoms and illness (Kometsi et al., 2019; Patel, 2011; Shai & Sodi, 2015).

Although this study uses the abovementioned theories to understand dementia and dementia conceptualization, it should be noted that other theories, such as the medical model, health belief systems and socio-ecological model, could also apply to this topic. However, the biopsychosocial theory was chosen for its ability to lend a multidomain lens to the understanding of dementia and dementia-associated factors.

2.10 Conclusion

The present study explored the prevalence and risk factors of dementia and explored the knowledge and awareness of dementia from the caregiver perspective in the iLembe District. This chapter reviewed dementia research, which included defining the symptoms and diagnostic features of the disease. It further examined the epidemiology of dementia by looking at the global and sub-Saharan African prevalence and risk factors. Towards the end of the chapter, the literature on knowledge of dementia and stigma was reviewed. The literature review supports the view that dementia is a significant public health problem. A projected rise in prevalence is expected in the coming years, with increasing projections reported by 2050, especially in Africa. However, there is a blink of hope, as literature has shown that managing modifiable dementia risk factors can lower risk profiles. The next chapter presents the methodology of the study.

CHAPTER 3

METHODS

3.1 Introduction

This study explored the prevalence of dementia and risk factors in older adults aged ≥60 years. Further, the study examined how communities from the iLembe District understand and conceptualise dementia and dementia care. This chapter gives an outline of the research methods that were followed in this study, such as the research design and approach and the sampling strategy. It also explains the instruments and procedures used for data collection and analysis. Lastly, the chapter discusses the ethical considerations of the study.

3.2 Research Design and Approach

This was a mixed methods study. A mixed-methods approach combines qualitative and quantitative research techniques into a single study (Creswell, 2015; Zheng, 2015). While using a mixed-methods approach ensured that the study objectives were met, it also improved the validity and consistency of the findings through methodological triangulation (Barnes, 2012).

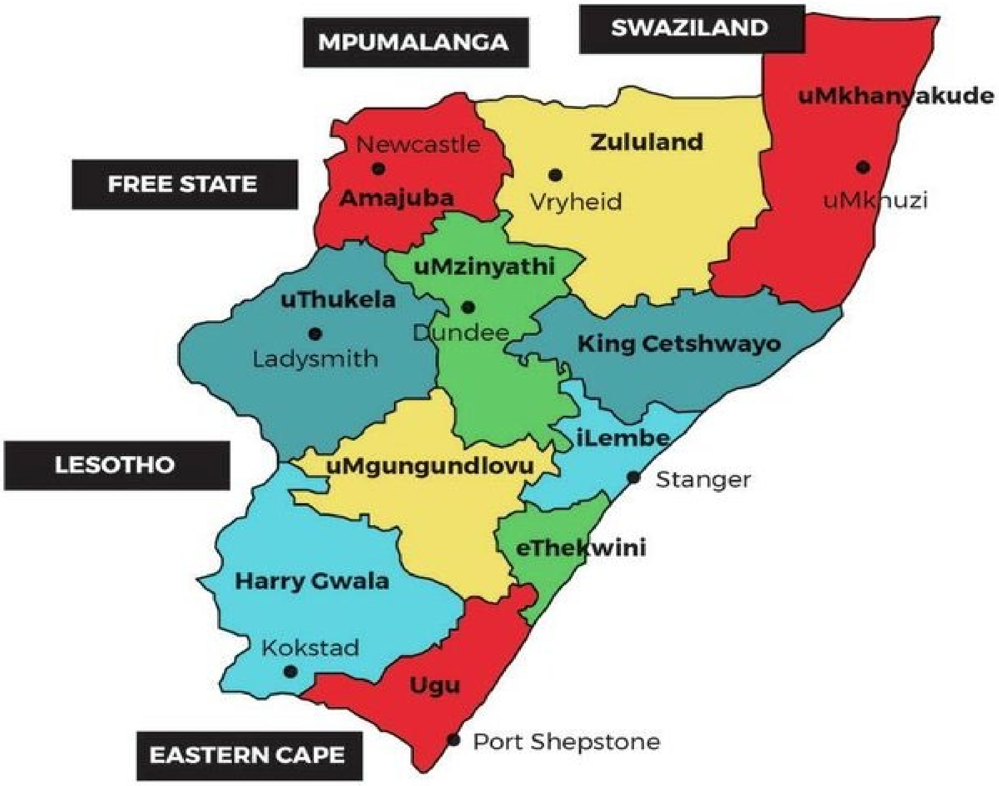
The quantitative component of the study used a descriptive cross-sectional design to characterise the prevalence of dementia in older adults and to explain the relationship between dementia and other social and clinical variables. In a cross-sectional design, data is collected on one or more variables from a selected sample at a single point in time (Aggarwal & Ranganathan, 2019; Zheng, 2015). In addition, cross-sectional studies are also valuable for population-based surveys that assess the prevalence of diseases and for researching knowledge on health-related topics (Setia, 2016). The generalisability of cross-sectional studies is generally good because they are representative of the studied population. Therefore, a cross-sectional design was appropriate for this study as it explored the prevalence and knowledge of dementia but also examined how dementia is associated with the sample risk factors.

The qualitative component of the study adopted an interpretive approach to achieve the objective of dementia awareness and conceptualisation. An interpretive design enhanced the researcher's understanding of the participant's experiences and conceptualisation of dementia. Interpretivism assumes that reality is subjective, multiple, and socially constructed. That is to say, we can only understand someone's reality through their experience of that reality, which may be different from another person's shaped by their historical or social perspective. Interpretive approaches rely on questioning and observation to discover or generate a rich and deep understanding of the phenomenon being investigated.

3.3 Study Location

The study was conducted in the iLembe District, situated in the South African province of KwaZulu-Natal (KZN). KZN has the second-largest population in South Africa, estimated at 11.5 million (Statistics South Africa, 2022). ILembe District is the smallest of the province's districts, and it is situated on the east coast of KwaZulu-Natal, nested between the eThekwini and King Cetshwayo Districts, as seen in Figure 1.

Figure 1: Map of KwaZulu-Natal showing the 11 districts of KZN (Christie & Monyokolo, 2018)



ILembe District is predominantly rural, led by tribal authority and characterised by subsistence farming (iLembe District Municipality, 2022). The district consists of four local municipalities: KwaDukuza, Mandeni, Maphumulo, and Ndwedwe, as seen in Figure 2. The capital city of iLembe is KwaDukuza (previously known as Stanger) and is the most urban compared to the three more rural municipalities. Most (82%) iLembe people are Black African and speak isiZulu (Statistics SA, 2016).

Figure 2: ILembe District map (iLembe District Municipality, 2022).

3.4 Sampling

A multistage cluster sampling technique was adopted in this study. These probability sampling techniques ensured that each member of the target population had an equal chance of being selected for the sample (Daniel, 2012). As a result, this increased the likelihood that the sample was representative of the research population and improved the ability to use the sample to draw inferences about the wider population. The target sample for this study was persons aged ≥60 years and their family members (called informants in this study), forming participant-informant dyads. The informants were needed to provide information about the participants and specifically for research objective three, which pertained to exploring the knowledge of dementia.

3.4.1 Sample Size

The number of people aged ≥60 years in iLembe District at the time of the study was 53 956 (Statistics South Africa, 2016). Cochran's formula for sample proportion was used to calculate sample size (Cochran, 1977):

$$\text{Formula:} \quad x = \frac{Z^2 pq}{e^2}$$

Where x = sample size, Z = confidence level of 95%, p = expected prevalence or proportion of dementia being 0.079% in this study, and e = precision (5%). The expected sample number was 320. For the 320 participants, 300 informants were included in the study.

3.4.2 Sampling Procedure

Using multistage cluster sampling, in the first stage, the researcher selected three districts from the Map of the KZN province, showing a layout of the 11 districts. The three selected districts best represented the population and provided a cross-sectional gradient of KZN. The three selected districts were iLembe, uThukela, and Zululand. From there, the three districts were assigned numbers using a randomiser and the iLembe District was selected. To improve representativity of the district, all four municipalities from the iLembe District, namely Mandeni, Maphumulo, Ndwedwe, and KwaDukuza, were selected to improve sample representation. After that, two areas (communities) from each municipality were sampled from an area list provided by Statistics South Africa. After the areas were identified, the next step was selecting participant households. Statistics South Africa provided a district map that indicated the GPS location of ward areas within the iLembe District and the estimated household numbers of people meeting the sampling age criteria within those ward areas. The first household was selected from each area, and subsequent households were determined using a sampling interval of four households. The process was repeated until the needed sample size per area was reached. In some households, more than one participant was eligible for participation. In such a case, all eligible participants in a household were selected for the study.

Participant inclusion and exclusion criteria

The following criteria were used to include or exclude participants:

- Participants who were ≥60 years old with an informant (dyad) were included.
- Participants had to be able to hear and see sufficiently to respond to questions. Participants and informants were asked if there were any disabilities we should note, and if there were disabilities, these were recorded to be considered during data analysis.
- Participants with significant cognitive or physical impairments that compromised their ability to cope with questioning were excluded. One participant self-excluded as they were unable to complete the required tasks. The informant reported that the participant was suspected to have dementia and is receiving supportive care from a local clinic. The participant was observed to have severe impairment, as evidenced by inaudible speech, confusion and was unable to sit for the interview. Eventually, the interview was terminated as it was difficult to conduct. The candidate was unable to provide consent; although the caregiver provided assent, he could not sit for the interview due to the severe impairment. This candidate was not counted as part of

the people with probable dementia as we could not objectively confirm the suspicions.

- The informant was either a caregiver, a family member, or a close neighbour (≥18 years).

3.5 Data Collection

Data collection began following ethical approval from the University of KwaZulu-Natal's Humanities and Social Sciences Research Ethics Committee (HSSREC) (Appendix I: ethical clearance letter). Before data collection, the participants were informed about the study using the information sheet (Appendix II: information sheet), and those who agreed to participate in the survey were requested to sign a consent form (Appendix III: consent form).

3.5.1 Instruments

Data were collected using a survey questionnaire (Appendix IV: Survey Questionnaire) and a semi-structured interview schedule (Appendix V: Informant Questionnaire). The survey questionnaire was administered to the older participants, whereas the semi-structured interview schedule was administered to the informant. A summary of the structure and topics covered in each questionnaire is provided in Table 3.1.

Table 3.1: Summary of the questionnaires

Objective	Data used	Administered to	Analytic approach	Section in questionnaire
To investigate the prevalence of dementia in those ≥60 years in the iLembe District	Clinical data and psychometric tests	Older Participants and informants	Quantitative	A and C
To identify the risk factors associated with dementia in the iLembe District.	Clinical data	Older participants and informant	Quantitative	B
To explore the community's awareness and conceptualisation of dementia and dementia care practices.	Informant interview	Informants	Quantitative & Qualitative	Informant questionnaire

The quantitative survey instrument

The survey questionnaire had three sections. The first section of the first questionnaire covered demographic information. The demographic data included the participants' and informants' age, gender, language, marital status, setting, household income, and level of education. The second section of the questionnaire elicited the participants' clinical history, including past and current medical symptoms, conditions, comorbid illnesses, disease onset and severity, and family medical history. It also included questions on social functioning, such as involvement with social organisations. The questions in this section were developed using literature from Sadock et al. (2015), the community screening interview for dementia (CSI-D) (Hall et al., 2000) and other studies on dementia (Prince et al., 2007; Ramlall, 2013). The third section incorporated neuropsychological assessments to explore the participants' cognitive functioning and overall mental health. The tests in the assessment battery assessed cognitive domains such as memory, executive functioning, verbal fluency, perceptual reasoning, processing speed, attention and concentration, depression, anxiety, and daily functioning. These tests were selected mainly based on their utility in African settings and ease of administration to avoid participant fatigue. A summary of the tests used is included below, while a detailed description is presented after Table 3.2.

Table 3.2: Tests included in the neuropsychological battery.

Test	**Test developer**	**Domain of functioning**	**Who questions were asked to**	**Study cutoff score**
Mini-Mental State Examination	Folstein in 1975	Multi-domain	Older participant	21 for participants <8 years of education 22 for participants with eight or more years of schooling
Rey Auditory Verbal Learning Test		verbal memory and learning	Older participant	Raw scores were converted to Z scores. Standard deviation of more than 2 from the mean indicated impairment.
Digit Span Test	WAIS	Attention and working memory	Older participant	
Rey-Osterrieth Complex Figure	Andre Rey in 1941	visual memory, visual construction	Older participant	
Clock Drawing Tests	Royall et al., 1998	Executive functions, visual spatial and construction	Older participant	<7 indicated impairment
The Lawton instrumental activities of daily living	Lawton and Brody in 1969	Activities of daily living	Informant	A decline is two or more areas of

				dysfunction.
Hospital Anxiety and Depression Scale	Zigmond and Snaith, 1983	Anxiety and depression	Older participant	normal (07), mild (8-10), moderate (11-14), severe (15-21)
Trail Making Test (A & B)	Ralph Reitan 1997	visual conceptual tracking and visiomotor tracking attention and psychomotor speed	Older participant	Raw scores were converted to Z scores. A Standard deviation of less than 2 from the mean is impairment.
Controlled Oral Word Association Test	Benton et al. (1983)	Verbal fluency	Older participant	Sum of all acceptable words
General health questionnaire -12	Goldberg and Hillier in 1979	Screening for psychiatric disorders	Older participant	12
AD8 dementia scale	Galvin et al., 2005	Informant dementia scale	Informant	>2

Ascertain Dementia Eight-Item Informant Questionnaire (AD-8)

The AD8 (Galvin et al., 2005) discriminates between signs of normal aging and mild dementia. The AD8 has both patient and informant versions. This study used an informant version to obtain objective and reliable information on the participant's cognitive functioning. The informant version contains eight items that test for memory, orientation, judgment, and function. A score >2 out of 8 signifies cognitive impairment. The AD8 has been used in other studies with participants with low education levels (Ong et al., 2021; Yan et al., 2021). In a study by the test developers the AD8 had a Cronbach alpha of 0.84 (95%

CI 0.80 to 0.87), suggesting excellent internal consistency and good intrarater reliability and stability (weighted kappa = 0.67, 95% CI 0.59 to 0.75) (Galvin et al., 2006). The AD-8 revealed good reliability (Rasch person reliability = 0.67, Cronbach's alpha = 0.89) in a USA study by Ham et al. (2022). Similarly, our study's internal consistency was good ($\alpha = 0.846$).

Clock Drawing Tests (CDT)

The CDT is a popular and easily administered tool used widely in screening for cognitive disorders, especially in older people (Chaves Mendes-Santos et al., 2015; Royall et al., 1998). It measures visuoperceptual and spatial abilities as well as executive functions (Lezak et al., 2012; de Paula et al., 2013). It has two components CLOX1 (free drawing) and CLOX2 (copying). CLOX 1 requires participants to draw a clock set to a time of 1:45 (Lezak et al., 2012). In CLOX 2, the participant must copy a clock that the examiner draws. The CDT has multiple scoring methods; Sunderland's 10-point system was used in this study (Chaves Mendes-Santos et al., 2015; Sunderland et al., 1989). A performance score of less than 7 indicated impairment. In a South African survey with older participants, the CDT had a sensitivity of 44.4% at a cut-off score of <6 and raising the cut-off score to <9 improved its sensitivity to 80% (Ramlall, 2013). Since this is a drawing test with no scale items, we could not calculate Cronbach's alpha.

Controlled Oral Word Association Test (COWAT)

The COWAT was developed by Benton et al. (1983); it is a verbal fluency test that measures the spontaneous production of words beginning with three designated alphabet letters (FAS) and words belonging to the same category (Animals) (Deist et al., 2023). For each of the three letters (FAS), the examinee has 60 seconds to produce words starting with that letter. All words are written down for scoring, including the repeated ones. The score is the sum of all acceptable words produced for the three letters during the 60-second trials (Deist et al., 2023). Various versions of COWAT have been used in different African studies, including a study by Nweke et al. (2022) in a Nigerian setting and demonstrated good intrarater reliability. The COWAT has demonstrated a strong internal consistency (0.83) and test–retest reliability coefficients (0.74) (Strauss et al., 2006). The COWAT had a reliability of 0.812 in our study.

Digits Span Test

The Digit Span test is a subtest of the Wechsler Adult Intelligence Scale (WAIS) (Lezak et al., 2012). It measures memory, cognitive flexibility, and attention. The Digit Span Forward and Digit Span Backwards trials were used in this study. In the forward task, numbers are read in sequence, and the subject is asked to recall them in that sequence, whereas, in the backward trial, the subject has to say the numbers read by the researcher in reverse order. Each trial has eight items to be completed, and the series of digits increase in length with each problem. When a sequence is repeated correctly, the examiner reads the following longer number sequence until the subject fails a pair of sequences (Lezak et al., 2012). The number of correct items is recorded. In an African study conducted in Nigeria, the digit span had moderate intra-rater reliability of 0.52 for the forward and 0.60 for the backward spans and a test-retest reliability index of 0.7 – 0.78 (Nweke et al., 2022). The digits span had a strong reliability of 0.80 and 0.77 for the forward and backward spans, respectively, in this research.

General Health Questionnaire (GHQ-12)

This test was developed by Goldberg and Hillier in 1979. It is a psychiatric screening questionnaire that can be used in both clinical and community settings to identify minor psychiatric disorders. It assesses the respondent's current state and compares if this differs from premorbid functioning. This study used the 12-item short version due to time limits in research settings. The twelve-item GHQ is intended to screen for general (non-psychotic) mental health problems (Anjara et al., 2020; Goldberg et al., 1997). Items on the GHQ-12 are rated on a 4-point scale using a timeframe of "in the last two weeks" (Anjara et al., 2020). The Likert scoring method (0-1-2-3), commonly used in research, was used in our study. The GHQ-12 has a cutoff score of 12 and has been validated in multiple countries by test developers, and it generally had good validity (Goldberg et al., 1997).

Hospital Anxiety and Depression Scale (HADS)

The HADS by Zigmond and Snaith (1983) is a well-established rating scale used to detect adverse anxiety and depressive states in clinical and non-clinical settings (Wondie et al., 2020). Also, it has been used as a screening tool for identifying emotional distress in non-psychiatric patients. The test focuses mainly on symptoms of generalised anxiety disorder and anhedonia (Djukanovic et al., 2017). The scale has 14 items divided between the two subscales (anxiety-HADS-A and depression-HADS-D). Each subscale has seven items, scoring 0-3 points (Djukanovic et al., 2017; Jerković et al., 2021; Rishi et al., 2017). The subscales are scored separately, with the scores ranging from normal (07), mild (8-10), moderate (11-14), to severe (15-21) (Jerković et al., 2021; Rishi et al., 2017). The higher the score, the worse the symptomatology. In a non-clinical sample of older adults, the internal reliability, assessed with ordinal alpha, was 0.92 for HADS Anxiety and 0.88 for HADS Depression, whereas using the traditional Cronbach's alpha, it was 0.87 for anxiety and 0.81 for depression (Djukanovic et al., 2017). Also, an African study from Ethiopia reported an internal reliability of 0.86 for anxiety, 0.85 for depression and 0.91 for the full scale (Wondie et al., 2020). Both these studies show that the HADS has strong internal reliability.

Lawton instrumental activities of daily living (IADLS)

The Instrumental Activity of Daily Living (IADL) scale evaluates impairment in daily activities (Lawton & Brody, 1969). It has eight items. For women, the scale score ranges from 0 (low function, dependent) to 8 (high functioning, independent), and from 0 to 5 for men (El-Tallawy et al., 2013). A decline is considered when a person has two or more areas of dysfunction. The IADL was done with the informant to get objective information on the participants' daily functioning. In a Turkish study of older adults, the adapted version of the IADLS produced an internal consistency of 0.843 for the whole scale with an intraclass correlation coefficient of 0.915 (Isik et al., 2020). This study had a strong internal consistency of 0.903.

Mini-Mental State Examination (MMSE)

The MMSE (Folstein et al., 1975) is a common test in clinical practice and research to assess multidomain cognitive functioning (Schutte et al., 2021). In patients with dementia, the MMSE has a good short-term test-retest reliability (Bernard & Goldman, 2010; Creavin et al., 2016). The test has eleven items, with a total score of 30; scores of less than 24 indicate severe cognitive problems (Creavin et al., 2016). An MMSE score should not be used as the sole score for diagnosing dementia since non-neurological reasons such as low education, difficulty with the English language, and visual or auditory difficulties can lead to low scores in this test (Bernard & Goldman, 2010). Instead, the score is used with the clinical history, the neurological examination, and other neuropsychological tests to diagnose dementia.

Also, adjustments to the cut-off scores are usually made in samples with low education, difficulty with the English language, and visual or auditory difficulties, as seen in other studies (El-Tallawy et al., 2013; Mao et al., 2018). In this study, the cut-off score was adjusted from 23 to 21 for participants with low levels of education (fewer than eight years) or suspected visual and auditory problems, and to 22 for participants with eight or more years of schooling. In a South African study of older adults, the MMSE had a specificity of 71.3% and a sensitivity of 82.3% (Ramlall et al., 2013). In a survey by Taumbaugh (1992), the MMSE had a Cronbach of 54.96. The MMSE showed good reliability in this study with a Cronbach's alpha of 0.703.

Rey Auditory Verbal Learning Test (RAVLT)

The RAVLT (Rey, 1964) is a word-recall test that assesses episodic memory, learning, and recognition (Bezdicek et al., 2014; Strauss et al., 2006). The RAVLT is widely used in South Africa (Blumenau & Broom, 2011). A list (List A) of 15 high-frequency and highimagery words is read at a rate of one per second (Lezak et al., 2012; Strauss et al., 2006). The list is repeated successively in five trials, and the number of recalled items is recorded each time. Following the five trials, a new list of words from a distraction trial is read (List B), and the subject is then asked to recall the original list (Lezak et al., 2012). After 20 minutes of distraction through other unrelated activities, a delayed recall of the original items is registered, followed by a recognition trial of the words from list A. The score for each trial is based on the number of words correctly recalled per trial (Lezak et al., 2012), with a maximum score of 15 points per trial. According to Strauss et al. (2006), the RAVLT scores can be affected by age, gender, educational level, and acculturation. A study conducted in South Africa also revealed the impact of language differences on test performance (Blumenau & Broom, 2011). In this study, the RAVLT had a reliability of 0.923 (*M* 24.78; *SD* 13.05) for trials 1-5, 0.480 (*M* 2.41; *SD* 1.83) for trial 6, 0.723 (*M* 5.60; *SD* 3.20) for trial 7, and 0.781 (*M* 3.79; *SD* 3.35) for the recall trial.

Rey Osterrith Complex Figure Test (ROCFT)

The ROCFT (Rey, 1941) measures visuospatial constructional ability, visual memory, and executive functioning (Lezak et al., 2012; Zhang et al., 2021). The task consists of two conditions; initially, the subject is given a complex figure to copy, and then after a 30-minute delay, they are required to replicate the figure from memory (Lezak et al., 2012). The ROCFT has various scoring techniques, but the one commonly used scores the drawing based on the placement, accuracy, and organisation of the individual features in the figure (Zhang et al., 2021). The maximum score for the test is 36 (Zhang et al., 2021).

The ROCFT had a Cronbach's alpha of 0.962 (*M* 15.74; *SD* 12.3) for the copy and .916 (*M* 6.367; *SD* 7.58) for the recall task in this study.

Trail Making Test (TMT)

The TMT is a test by Ralph Reitan that assesses visual search, scanning, attention, processing speed, executive functioning, and mental flexibility (Lezak et al., 2012; Reitan et al., 1997; Tombaugh, 2004). It consists of two parts, A and B. Trial A assesses simple cognitive processing speed, whereas Trial B assesses more complex executive functioning, requiring visual attention and task switching between letters and numbers (Tombaugh, 2004). In Part A, the subject is requested to make a trail from numbers 1 to 25 without lifting the pencil. In Part B, the subject makes a trail alternating between numbers and letters until they reach the final number 13 (Strauss et al., 2006). The scores are the time taken to complete the test, expressed in seconds (Tombaugh, 2004). In addition, the number of errors for parts A and B are recorded. The Trail Making Test A has shown test–retest reliability coefficients ranging from low (0.46) to high (0.94) (Reitan et al., 1997). It further showed an intrarater reliability of 0.80 in an African study (Nweke et al., 2022). Since this test does not have scale items, we could not calculate Cronbach's alpha.

Qualitative data collection instrument

A semi-structured interview schedule was used to collect data on the caregiver's awareness and conception of dementia, which is objective three of the study (Appendix V: Informant Questionnaire). The questionnaire included questions on knowledge, attitudes, perceptions, and treatment of dementia. These questions were directed to the informant.

This questionnaire was developed using existing literature on dementia knowledge and attitudes and beliefs about mental health problems (Berwald et al., 2016; Hindley et al., 2016; Jorm et al., 1999; Khonje et al., 2015; Ndamba-Bandzouzi et al., 2014; Owokuhaisa et al., 2020). The section started with a vignette presentation based on a person who presented with dementia symptoms (American Psychiatric Association, 2022; WHO, 2019). Since this questionnaire was open ended, the participants were asked to elaborate on their responses as needed to get richer responses.

3.5.2 Translation of Instruments

The researcher translated the questionnaire from English into isiZulu using a forward and backward translation process (Ozolins et al., 2020), with the assistance of two experienced bilingual clinical psychologists. The two assistants were involved in separate phases of the translation process. Firstly, one assisted with translating the questionnaire from English into isiZulu and administered the questionnaire to an isiZulu-speaking postgraduate student to test for accuracy. In the second phase, the second assistant, who was not involved in the first translation, helped to translate the isiZulu version back into English. Lastly, the translated versions were compared with the initial English version of the questionnaire. Any translation discrepancies were resolved through discussion and consensus between the researcher and the two assistants.

3.5.3 Validation of the Questionnaire

Two clinical psychologists were given copies of the questionnaire and the research questions to validate the questionnaire. These experts carefully reviewed the research questions and the questionnaire to ascertain the instrument's appropriateness and adequacy. They recommended that we use a common isiZulu name in the vignette used in the questionnaire on dementia knowledge. The name Sindi was used in the isiZulu version, and Cindy was used in the English version of the vignette. Furthermore, the researcher submitted the choice of neuropsychological scales to the research supervisor and discussed these with the supervisor to validate the appropriateness of the instruments.

Once the initial validation process was complete, a pilot test was carried out on the instrument using five randomly selected older adults from a township called KwaNdengezi, which is not in the district where the actual research was conducted. The pilot test helped to explore whether the items were clear and easily understood by the general population and the feasibility of the proposed methods. Based on the pilot test, ambiguous items were replaced with appropriate words and concepts to enhance the clarity and meaning of the questions. Moreover, Cronbach's alpha (α) (Santos, 1999) was used to check the internal consistency of the neuropsychological instruments used in the main study. A reliability coefficient of 0.70 and was rated as low (0–0.2), moderate (0.3–0.6) and strong (0.7–1.0) above is considered 'acceptable' in most research situations (Tavakol & Dennick, 2011).

3.5.4 Data Collection Procedure

To collect data, the researcher worked with six research assistants who were postgraduate psychology students. The research assistants attended training on research ethics, neuropsychological tools, and the Mobenzi data collection technology (Mobenzi, 2021).

Data were collected between October 2018 and December 2019, through semi-structured interviews. The interviews were conducted in the participants’ households. The participants chose to complete the interview either in English or isiZulu. Most participants chose their home language. The first interview with the older participant was approximately 90 minutes using a survey questionnaire. The second interview with the informant was about 1 hour and used the qualitative data instrument. The Interviewers were cognizant of fatigue and closely observed participants. No fatigue was observed or reported. During the interviews, the researchers read out the questions and manually recorded the responses from the participants onto electronic mobile devices using the Mobenzi data collection technology (Mobenzi, 2021). The researchers recorded the responses to avoid significant errors in filling out the questionnaire. This was also because the questionnaires were electronic, and participants were not trained in the electronic program and devices used. This way, the reading of questions and recording of responses was standardized. After collection, data were exported from the Mobenzi server to Microsoft Excel and SPSS.

3.6 Data Analysis

The Statistical Package for Social Sciences (SPSS) version 27 (IBM Corp, 2020) and R (R Core Team, 2021) were used to analyse the quantitative data. Summative content analysis (Hsieh & Shannon, 2005) and reflexive thematic analysis (Braun & Clarke, 2019) were used to analyse qualitative data.

3.6.1 Quantitative data analysis

The prevalence of dementia was descriptively ascertained using the MMSE, AD8, and IADL combined scores. Once the prevalence was ascertained, Chi-square and Fischer's tests measured associations between dementia and sociodemographic factors. Lastly, multivariate logistic regression was used to determine the likelihood of dementia based on the sociodemographic and health factors as independent variables. Odds ratios (ORs), 95% confidence intervals (CIs), and *p* values (α) were calculated. Spearman's correlation was used to measure the correlation between independent and dependent variables. The dependent variables for the correlation were anxiety and depression, whereas the independent variables were ADLs and cognitive decline. All the neuropsychological tests were scored using cut-off scores mentioned under instruments. Raw scores were converted to *Z* scores using the following formula:

$$Z = \frac{x - \mu}{\sigma}$$

Where Z is the standard score, = observed value, μ = mean of the sample and σ = standard deviation of the sample. Statistical significance was set at <5% for all analyses.

Ascertaining dementia-probable cases

Dementia was ascertained using the criteria for Major neurocognitive disorder from the Diagnostic and Statistical Manual of Mental Disorders 5th Edition-Text Revised (DSM V). Dementia is characterised by a decline in cognitive functioning, which must be observable by other people and should affect daily functioning (APA, 2022). Therefore, the study participants were classified as having dementia if they had cognitive decline reported by the participant and which is also observable by others, decreased daily functioning, no other diagnosed mental illness and no delirium (APA, 2022; WHO, 2017).

To measure cognitive decline in one or more cognitive domains, the Mini-Mental State Exam (MMSE) and Eight-item Interview to Differentiate Aging and Dementia (AD8) (Folstein et al., 1975; Galvin et al., 2006) were administered. The AD8 was used to obtain information from reliable informants and to discriminate between signs of normal ageing and mild dementia. For AD8, a score > 2 signified cognitive impairment (Galvin et al. 2006). The Instrumental Activity of Daily Living (IADL) was administered to all subjects to confirm impairment in daily activities (Lawton et al., 1969). The summary score ranged from 0 (low function, dependent) to 8 (high function, independent) for women and 0 to 5 for men (Mao et al. 2018). Self-report items were used to assess if participants had delirium and any other mental illness that could account for the symptoms.

3.6.2 Qualitative data analysis

Qualitative data analysis can be either inductive or deductive. In an inductive approach, themes are strongly linked to the data itself, thus allowing the data to determine the themes (Braun & Clarke, 2006). While through the deductive approach, the researcher approaches the data set with preconceived themes one expects to find, which are informed by theory or knowledge; thus, theme identification is driven by a researcher's theoretical or analytic interest in the area (Braun & Clarke, 2006). Coding and analysis hardly fall exclusively into one of the inductive or deductive approaches and are, therefore, used in combination (Braun

& Clarke, 2021). The current study used deductive and inductive approaches to analyze and report themes from the data set. The data captured from the informants were approached with preconceived themes while appreciating the relationships of different information items within the data set. This was done to achieve detailed descriptions of the data.

Summative Content Analysis

This study employed the three phases of summative content analysis: data preparation, organising, and reporting (Hsieh & Shannon, 2005; Renz et al., 2018). Meaningful content or texts were identified and quantified during the data preparation stage to understand their contextual use. The analysis focused on counting the frequency of specific content and analysed hidden content to discover the underlying meanings of the words or the content (Hsieh & Shannon, 2005). In the organising stage, patterns in the data were identified, coded, and contextualised. Summative content analysis was used to turn qualitative data into frequencies of the responses for paper 2.

Thematic Analysis

Reflexive thematic analysis (RTA) analyses data by classifying the data into themes (Braun & Clarke, 2019). A 6-step guide by Braun and Clarke (2019) was followed in the thematic analysis, as described in Table 3.3 below.

Table 3.3: Steps Followed for Reflexive Thematic Analysis (RTA)

Analytic Phase	Actions
Data familiarisation	Recorded data were transcribed and read over and over while making notes.
Initial code generation	Initial codes were generated through labelling and organising data items into meaningful groups.
Generating (initial) themes	Codes were sorted into initial themes through diagrams or mapping. Defining properties and meanings of the themes were also noted.
Theme review	Overlapping themes were collapsed to ensure there was no redundancy and there was enough data to support a theme. Themes were also reworked and refined to ensure coherency in the patterns.
Theme defining and naming	The story of each identified theme was determined and fitted to respond to the research questions.
Report production	An argument that addresses the research questions using the themes was written and presented in a concise and exciting account of the story from the data.

Adapted from Campbell et al. (2021).

3.7 Ethical Considerations

Ethical approval was obtained from the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal (protocol reference: HSS/1016/017D). The study adhered to the ethical considerations proposed by the Declaration of Helsinki (World Medical Association, 2013). Firstly, the purpose of the study was explained to potential participants, and informed consent was obtained. The participants' information was kept confidential, and pseudonyms were used. Where the participants' cognitive functioning was suspected to be impaired, consent was derived from their caregiver. After participation, participants were shown appreciation for their time with a gift voucher of R150.00. Participants and caregivers of participants who were assessed as having cognitive decline were given feedback and provided with a referral letter to the nearest healthcare institution for follow-up. Data is stored in a locked researcher's office at the University of KwaZulu-Natal.

3.8 Rigour

Credibility, conformability, transferability, and dependability (Lincoln & Guba, 1985) were considered to ensure the study's rigor. A rigorous external review of the study design and procedures was conducted during the ethical clearance process. Secondly, during data collection, the researchers were in the field for a prolonged period. The researchers' long engagement and persistent observation ensured that they learned more about the culture, the social and natural setting of the participants and the topic of study (Patton, 2001). Moreover, triangulation (Cresswell, 1998) ensured the data accuracy. In addition, responses in IsiZulu were backward translated into English by the researchers and confirmation of the translation and meaning were reviewed by independent professionals for accuracy. Similarly, interpretations of the findings and some cultural explanations were verified with peers who were more familiar with concepts such as *amafufunyana*.

3.9 Conclusion

This chapter focused on the methodology that was used in this study. The research design, data collection, and analysis methods were discussed. This chapter discussed the measures followed during the data collection and provided information about the sample. The next chapter details the analysis process and describes the research results as published manuscripts.

CHAPTER 4

RESULTS

4.1 Introduction

This chapter presents the results of the study. The results are presented in four manuscripts that address the study's research objectives. The objectives of the study were to:

i. To investigate the prevalence of dementia in those ≥60 years in the iLembe district.
ii. To explore the factors associated with dementia in the iLembe district.
iii. To explore the communities' awareness and conceptualization of dementia and dementia care practices.

The study recruited 321 older participants and 300 informants. However, one participant was excluded as they had severe dementia and could not complete any of the tasks. This participant was not counted in the final sample of 320 or the prevalence of dementia, as explained in chapter 3. Therefore, the response rate was 99.7%, with only one participant excluded. Table 4.1 provides the sample characteristics.

Table 4.1: Sociodemographic profile of informants and participants

Demographic variables	**Informants (*N* 300)**		**Participants (*N* 320)**	
	n	***%***	***n***	***%***
Setting				
Urban	135	45	146	45.6
Rural	165	55	174	54.4
Age (years)				
18–39	160	53.3	-	-
40–59	78	26	-	-
60–79	58	19.3	282	88.1
80+	4	1.3	38	11.9
Ethnicity				
African	224	74.7	225	70.3
Coloured	3	1	6	1.9
Indian	70	23.3	84	26.3
White	3	1	5	1.6
Sex				
Male	86	28.7	79	24.7
Female	214	71.3	241	75.3
Education				
No formal education	12	4	62	19.4
Primary	50	16.7	159	49.7
Secondary	111	37	72	22.5
Matric	84	28	14	4.4
Tertiary	43	14	13	4
Marital status				
Single	192	64	54	16.9
Married	69	23	108	33.8
Divorced	7	2.3	10	3.1
Widowed	21	7	141	44
Cohabitating	11	3.7	7	2.2

4.2 Paper 1

This paper explored the prevalence and risk factors of dementia and is based on objectives 1 and 2 of the study.

Reference: Screening for dementia and associated factors in older adults from low socioeconomic communities in iLembe, KwaZulu-Natal', *Health SA Gesondheid* 28(0), a2437. doi. org/10.4102/hsag.v28i0.2437

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Screening for dementia and associated factors in older adults from low socioeconomic communities in iLembe, KwaZulu-Natal

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Background: Dementia is one of the leading non-communicable causes of disability and mortality in older adults, with recent research showing that it is increasing in low-middle-income countries compared to high-income countries. As such, multidisciplinary efforts are needed to effectively reduce the prevalence and risk of dementia through quick screening, diagnosis, and management of those with dementia and those at risk.

Aim: The study's objectives were to estimate the prevalence of dementia and measure the sociodemographic and clinical risks in older adults in low socioeconomic communities.

Setting: The study was conducted among older adults aged ≥ 60 from the iLembe district in South Africa.

Methods: This cross-sectional, one-phased, household study was conducted to screen for dementia over 8 months between October 2018 and October 2019. Demographic and clinical data were collected using a semi-structured questionnaire. In addition, the Mini-Mental Status Exam, Ascertain Dementia Eight-item questionnaire and Instrumental Activities of Daily Living Scale were administered to a multi-stage cluster sample of 320 participants to ascertain dementia prevalence. Frequencies and multivariate logistic regression were conducted to determine risk factors correlated with dementia.

Results: The prevalence of dementia was 13.4%. Participants aged 80 and above were 2.73 times more likely to develop dementia than participants younger than 80. Those with an education level of Grade 1–7 had a 69% less chance of developing dementia than those without formal education. Single participants showed an almost seven-fold increase in dementia. Lastly, depression increased the risk of dementia by two-fold.

Conclusion: Dementia was probable in over one-sixth of the sample. Dementia risk factors were both modifiable and non-modifiable.

Contribution: Dementia prevalence in South Africa is increasing and therefore it is crucial to develop a dementia plan that is specific to the South African context which will include strategies for early identification of the disease, reducing modifiable risks and strategic management of dementia associated medical conditions such as depression and vascular diseases.

Keywords: dementia; epidemiology; low-middle income households; major neurocognitive disorders; prevalence; sub-Saharan Africa; risk factors.

[AQ1]

Introduction

Dementia is one of the leading causes of disability and mortality in older adults (Alzheimer's Disease International [ADI] 2015). According to Nichols et al. (2022), more than 60% of people with dementia live in low-middle-income countries (LMICs), with the highest estimates in Asia and Africa (ADI 2015; Nichols et al. 2022). In Africa, the regional forecast of dementia prevalence in people ≥ 60 years ranges from 5.1% in North Africa to 20.0% in sub-Saharan Africa (SSA) (Akinyemi et al. 2022). In South Africa, dementia is reported to be between 6.3% and 12.5% (De Jager et al. 2017; Farina et al. 2023; Ramlall et al. 2013; Vanderpoel, Heyns & 10/66 Dementia [AQ2] Research Group 2012). The prevalence of dementia in LMICs, such as in South Africa, has been predicted to increase, and the increase is associated with low interventions aimed at risk reduction in these countries (ADI 2015; Nichols et al. 2022).

A combination of non-modifiable factors, such as age and gender, and modifiable factors, such as depression, hypertension, education, and socioeconomic levels, are associated with dementia

(ADI 2017; Geaorge-Carey et al. 2012; Mavrodaris, Powell & Thorogood 2013; Olanyika et al. 2014; Paddick et al. 2014). In Africa, increasing age continues to be a significant risk factor, with the highest rate of dementia expected from the 70–80+ age group (ADI 2017; George-Carey et al. 2012; Gorelick et al. 2011; Mavrodaris et al. 2013; Olanyika et al. 2014). In addition, women are considered more at risk than men (ADI 2017; De Jager et al. 2017; Yusuf et al. 2018), because women have a higher life expectancy and increased neurobiological vulnerability during the postmenopausal period (Podcasy et al. 2016). Another risk factor, mainly in LMICs, is related to regional settings. For example, people in urban areas seem less vulnerable to dementia than those in rural areas (De Jager et al. 2015; Gureje et al. 2011). This is because commonly rural populations are older and because of poor access to health, they have higher rates of poorly managed chronic conditions, such as hypertension, diabetes, hyperlipidaemia, and depression compared to urban populations (Olivier, Cacabelos & Naidoo 2018; Rahman et al. 2020). The combination of these risk factors make rural communities disproportionately vulnerable to dementia.

There is a paucity of dementia prevalence and risk studies in Southern Africa; therefore, a need was identified for epidemiological studies in South Africa (De Jager et al. 2015). The authors identified two community-based studies estimating dementia prevalence in South Africa (De Jager et al. 2017; Ramlall et al. 2013; Vanderpoel et al. 2012). The two studies varied in methods used and were in different provinces. One study was conducted in KwaZulu-Natal (KZN) nursing homes, but there were no community studies (Ramlall et al. 2013). Therefore, the authors conducted a community study in one of the 11 districts of KZN province. This study estimated the prevalence of dementia and measured the sociodemographic and clinical risks in older adults in low socioeconomic communities in the iLembe district. It is important to measure dementia prevalence and identify risk factors in people with dementia to develop reduction strategies and improve the longevity of older adults.

Research methodology

Study design and setting

A one-phase, cross-sectional community study was conducted in the iLembe district. iLembe is located about 75 km north of Durban, in KZN, South Africa. It is mostly a rural district, with agriculture as the main economic activity. Four local municipalities constitute the district: Mandeni, KwaDukuza, Ndwedwe, and Maphumulo. It comprises four ethnic groups, with a majority of IsiZulu speakers. Most households are low-middle income, earning just the minimum wage of ZAR R3500.00 per month and dependent on government grants and state health care.

Study population and sampling strategy

The targeted population for this study was older adults ≥60 years. ILembe district has approximately 53 956 older adults (Statistics South Africa 2016). The sample was recruited using multi-stage cluster and simple random sampling techniques. In the first stage, using simple random sampling, the iLembe district was selected from other districts in KZN. In the second stage, eight areas were randomly selected from the four municipalities in the iLembe district. In the third stage, the first household was selected in each area, and subsequent households were determined using a sampling interval of 5. From the population, 320 participants who were ≥60 years old were recruited. All participants had to give consent to be included in the study. Participants also needed to have an available caregiver or informant to provide collateral information. This sample type is a participant-informant dyad, and 300 informants were recruited.

Inclusion criteria

- For participants: All participants had to be ≥60 years old. The participants did not need to be literate but had to be able to see and hear well enough to do the tests.
- For the informants: Informants needed to be family members, caregivers or close neighbours, ≥18 years old, who were well-informed of the participants' daily activities and health status, and could provide collateral information.

Data collection

Procedure

The interviews were conducted in the participants' homes by well-trained field workers. A semi-structured clinical interview was conducted with both the participants and the informants. The participants were also administered a neuropsychological assessment battery, including the Mini-Mental Status Exam (MMSE). In addition, the informants answered questions about the participants functioning on the Ascertain Dementia Eight-item questionnaire (AD8) and the Instrumental Activities of Daily Living Scale (IADLS). The interviews were conducted in either isiZulu or English, depending on the participants' preferred language. The interviews with participants and informants took approximately 2 h.

Instruments

A clinical questionnaire was used to obtain information regarding biographical details such as gender, age, home language, education, and clinical variables such as medical history, lifestyle behaviours, psycho-social factors, and family history of the participants. The MMSE, AD8 and Lawton's IADL (Folstein, Folstein & McHugh 1975; Galvin et al. 2005; Lawton & Brody 1969) were administered to measure cognitive decline and changes in daily functioning. The MMSE is a commonly used test that assesses multidomain cognitive functioning (Schutte, Tsikane & Nchoe 2021). The test has 11 items, with a total score of 30 (Creavin et al. 2016). The cut-off score was adjusted for education level on the MMSE – for participants with no formal education, a score of < 21 was used, and < 22 for the rest of the sample, as similarly done in other studies with participants with low levels of education (El-Tallawy et al. 2013; Mao et al. 2018). In this study, the MMSE showed good reliability with a Cronbach's alpha of 0.703 (*M* 22.80; *SD* 5.06) and a specificity of 76.5%. In addition to the MMSE, the AD8 obtained information from reliable informants. The AD8 helps to discriminate between signs of normal ageing and mild dementia. The AD8 contains eight items that test for memory, orientation, judgement, and function. For AD8, a score > 2 signified cognitive impairment (Galvin et al. 2006). The AD8 has been used in other studies with participants with low education levels (Ong et al. 2021; Yan et al. 2021). The AD8 had a specificity of 54.2%. The IADLS was administered to informants to assess the participants' independence in performing daily functioning (Lawton & Brody 1969). The summary score ranged from 0 (low function, dependent) to 8 (high function, independent) for women and 0 to 5 for men (Mao et al. 2018). The IADLS had a specificity of 58.5. All three tests had a sensitivity of 100%.

According to the International Classification of Diseases (ICD 11) (World Health Organization [WHO] 2019), dementia is characterised by a decline in cognitive functioning, which must be observable by other people and should affect daily functioning. Therefore, study participants were classified as having dementia if they had cognitive decline based on the MMSE score of < 22, plus cognitive decline reported by caregivers based on the AD8 score of > 2, and decreased daily functioning on the IADLS. Self-report items were used to assess if participants had delirium and any other mental illness that could account for the symptom.

Data analysis

All information was captured onto hand-held tablet devices using the Mobenzi Researcher software (Mobenzi 2021). Data was exported from the Mobenzi Researcher database to Microsoft Excel.

The statistical data analysis was conducted in R statistical computing software version 3.6.3 of the R Core Team (2021). Dementia was ascertained using the combined scores of the MMSE, AD8 and IADL (Folstein et al. 1975; Galvin et al. 2005; [AQ3] Lawton & Brody 1969) and was reported descriptively. Chi-square and Fischer's tests measured associations between dementia and sociodemographic factors. Lastly, multivariate logistic regression was used to determine the likelihood of dementia based on the sociodemographic and health variables. Odds ratios (ORs), 95% confidence intervals (CIs) and *p* values (α) were calculated. Statistical significance was set at < 5%.

Ethical considerations

Ethical clearance was obtained from the University of KwaZulu-Natal's Human Research Ethics Committee (HSS/1016/017D). Written informed consent was obtained from the participants; where participants could not provide consent, assent was obtained from family members. Necessary steps were taken to preserve participant anonymity and confidentiality. Participants that had major disabilities which affected participation and cognitive decline were not included in the study. After data analysis, participants who screened positive for dementia were informed of the results and referred to their nearest healthcare centre for further assessments. The option of counselling was offered to participants as needed.

Results

A total of 320 participants were recruited. Of these, some participants were from KwaDukuza (86; 26.9%), KwaMaphumulo (40; 12.5%), eMandeni (128; 40%) and eNdwedwe (66; 20.6%). Most participants were black African (225; 70.3%) and isiZulu speakers (220; 68.8%). The mean age of the participants (*N* = 320) was 69.43 (standard deviation [SD] = 7.76), with a minimum age of 60 years and maximum age of 94 years (Table 1).

Dementia prevalence

Of the 320 participants, 43 screened positive for dementia, giving a dementia prevalence of 13.4%. Dementia was higher in those from KwaDukuza (14; 32.6%), from rural areas (25; 58.1%), in females (36; 83.7%), those with education levels between the Grades 1 to 7 (21; 48.8%), were widowed or divorced (24; 55.8%), and had a household income of < R3500 (39; 90.7%) (Table 2).

TABLE 1: Sociodemographic profile of informants and participants.

Demographic variables	Informants (*N* = 300)		Participants (*N* = 320)	
	n	%	*n*	%
Setting				
Urban	135	45.0	146	45.6
Rural	165	55.0	174	54.4
Age (years)				
18–39	160	53.3	-	-
40–59	78	26.0	-	-
60–79	58	19.3	282	88.1
80+	4	1.3	38	11.9
Ethnicity				
African	224	74.7	225	70.3
Coloured	3	1.0	6	1.9
Indian	70	23.3	84	26.3
White	3	1.0	5	1.6
Sex				
Male	86	28.7	79	24.7
Female	214	71.3	241	75.3
Education				
No formal education	12	4.0	62	19.4
Primary	50	16.7	159	49.7
Secondary	111	37.0	72	22.5
Matric	84	28.0	14	4.4
Tertiary	43	14.0	13	4.0
Marital status				
Single	192	64.0	54	16.9
Married	69	23.0	108	33.8
Divorced	7	2.3	10	3.1
Widowed	21	7.0	141	44.0
Cohabitating	11	3.7	7	2.2

Source: [AQ6]

TABLE 2: Participants' characteristics associated with dementia, $N = 320$.

Dementia	No dementia		Dementia		X^2
	$n = 277$	86.6%	$n = 43$	13.4%	p
Municipality					0.325
KwaDukuza	72	26.0	14	32.6	
Mandeni	115	41.5	13	30.2	
Maphumulo	36	13.0	4	9.3	
Ndwedwe	54	19.5	12	27.9	
Setting					0.594
Urban	128	46.2	18	41.9	
Rural	149	53.8	25	58.1	
Ethnicity					0.284
African	196	70.8	29	67.4	
Indian	70	25.3	14	32.6	
Other	11	4.0	0	0.0	
Sex					0.169
Female	205	74.0	36	83.7	
Male	72	26.0	7	16.3	
Age Groups					0.115
60–69yrs	168	60.6	21	48.8	
70–79yrs	80	28.9	13	30.2	
80+yrs	29	10.5	9	20.9	
Education					< 0.001*
Never attended	43	15.5	19	44.2	
Grade 1–7	138	49.8	21	48.8	
Grade 8+	96	34.7	3	7.0	
Marital status					0.008*
Married/Cohabitating	108	39.0	7	16.3	
Single	42	15.2	12	27.9	
Widowed/Divorced	127	45.8	24	55.8	
Total household income					0.334
R3 500 and below	236	85.2	39	90.7	
R3 500 above	41	14.8	4	9.3	
Hypertension					0.128
No	97	35.0	10	23.3	
Yes	180	65.0	33	76.7	
Blackouts					0.039*
No	256	92.4	35	81.4	
Yes	21	7.6	8	18.6	
Head injury					1.000
No	258	93.1	40	93.0	
Yes	19	6.9	3	7.0	
Frequent headaches					0.115
No	217	78.3	29	67.4	
Yes	60	21.7	14	32.6	
Angina					0.301
No	262	94.6	39	90.7	
Yes	15	5.4	4	9.3	
High cholesterol					0.361
No	217	78.3	31	72.1	
Yes	60	21.7	12	27.9	
Stroke					0.684
No	189	68.2	28	65.1	
Yes	88	31.8	15	34.9	
Diabetes Mellitus					0.088
No	191	69.0	24	55.8	
Yes	86	31.0	19	44.2	
Epilepsy					0.352
No	275	99.3	42	97.7	
Yes	2	0.7	1	2.3	
Depression					0.018*
No	250	90.3	33	76.7	
Yes	27	9.7	10	23.3	

Table 2 continues on the next column→

TABLE 2 (Continues…): Participants' characteristics associated with dementia, $N = 320$.

Dementia	No dementia		Dementia		X^2
	$n = 277$	86.6%	$n = 43$	13.4%	p
Alcohol use					0.448
No	213	76.9	33	76.7	
Used to but stopped	30	10.8	7	16.3	
Yes	34	12.3	3	7.0	
Tobacco use					0.849
No	223	80.5	36	83.7	
Used to but stopped	20	7.2	3	7.0	
Yes	34	12.3	4	9.3	

Source: [AQ6]

*, 0.05 level (2-tailed); **, 0.01 level (2-tailed).

Dementia was significantly associated with education, marital status, depression and experiencing blackouts, defined as momentary loss of consciousness (Table 2). Regarding sociodemographic factors, dementia was more prevalent in females, those from areas considered to be rural, those within the age group of 60–69, with level of education between Grade 1 and 7, widowed and those with an income of R3500 and below. Dementia was more prevalent in those with hypertension and depression.

Dementia risk factors

Table 3 shows that factors associated with dementia in this group of participants included age, education, marital status, and depression.

In the unadjusted model, participants aged 80 and above were 2.73 times more likely to develop dementia (CI = 1.08–6.50, $p = 0.026$) than participants younger than 80. In the backstep model, those with an education level of Grade 1–7 had a 69% less chance of developing dementia (OR: 0.31; $p = 0.003$) than those without formal education. Compared to married participants or those with a partner, single participants showed an almost seven-fold increase in dementia (OR: 6.92; $p = 0.001$) and nearly three-fold for widowed participants (OR: 2.92; $p = 0.037$). Lastly, depression increased the risk of dementia by two-fold (OR: 2.74; $p = 0.041$).

Discussion

This study investigated the prevalence and correlates of dementia in older adults in a community setting. The prevalence of dementia was 13.4%. This prevalence rate is a little higher compared to other community studies in South Africa, which reported a prevalence of 6.3% – 12.5% in older adults living in rural and urban settings (Farina et al. 2023; Vanderpoel et al. 2012). It is also a little higher when compared to other studies from other African and Western countries (ADI 2015; Guerchet et al. 2009, 2010, 2014; Gureje et al. 2011; Paraïso et al. 2011; Ogunniyi et al. 2016; Longdon et al. 2012; Yusuf et al. 2011). The different life expectancy rates and differences in research methods are some of the factors that might contribute to variable prevalent rates in some of the studies when compared to this study. With increasing life

TABLE 3: Multivariate regression analysis of factors associated with dementia.

Explanatory	Unadj†			FullAdj‡			Backstep§		
	OR	CI	α	OR	CI	α	OR	CI	α
Setting									
Urban^{R}	-	-	-	-	-	-	-	-	-
Rural	1.35	0.70–2.69	0.379	1.84	0.62–5.36	0.263	1.93	0.90–4.27	0.095
Sex									
Female^{R}	-	-	-	-	-	-	-	-	-
Male	0.58	0.23–1.30	0.218	1.38	0.35–4.97	0.627	-	-	-
Age group (years)									
60–69^{R}	-	-	-	-	-	-	-	-	-
70–79	1.43	0.66–3.01	0.354	1.34	0.51–3.45	0.544	-	-	-
80+	2.73	1.08–6.50	0.026*	1.61	0.49–5.21	0.426	-	-	-
Education									
No formal education^{R}	-	-	-	-	-	-	-	-	-
Grade 1–7	0.32	0.16–0.66	0.002*	0.29	0.12–0.70	0.006*	0.31	0.14–0.66	0.003*
Grade 8+	0.05	0.01–0.17	< 0.001**	0.05	0.01–0.21	< 0.001**	0.05	0.01–0.18	< 0.001**
Marital status									
Married/Cohabitating^{R}	-	-	-	-	-	-	-	-	-
Single	5.14	1.87–15.61	0.002*	13.28	3.46–60.59	<0.001**	6.92	2.25–23.78	0.001*
Widowed/Divorced	3.29	1.37–9.16	0.013*	4.16	1.26–15.74	0.025*	2.92	1.12–8.66	0.037*
Household income									
R3500 and below^{R}	-	-	-	-	-	-	-	-	-
R3500 above	0.45	0.11–1.33	0.203	1.27	0.24–5.14	0.750	-		
Hypertension									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	1.93	0.92–4.44	0.099	2.32	0.82–7.07	0.124	-	-	-
Head injury									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	1.13	0.26–3.55	0.849	0.83	0.15–3.43	0.805	-		
Migraines									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	1.91	0.92–3.82	0.073	1.10	0.42–2.78	0.847	-	-	-
Blackouts									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	2.50	0.93–6.08	0.053	2.56	0.70–9.06	0.146	-		
Cardiovascular									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	1.37	0.31–4.41	0.628	0.33	0.05–1.66	0.204	-		
Stroke									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	1.25	0.62–2.46	0.518	1.90	0.77–4.68	0.160	-	-	-
High cholesterol									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	1.49	0.69–3.03	0.285	1.02	0.35–2.81	0.977	-		
Diabetes Mellitus									
No^{R}	-	-	-	-	-	-	-	-	-
Yes	1.73	0.88–3.36	0.108	2.04	0.83–5.09	0.121	1.98	0.91–4.36	0.086

Table 3 continues on the next page→

expectancy in LMICs, it is expected that dementia prevalence will increase (Nichols et al. 2022). Hence, it is anticipated that dementia in South Africa might also increase. However, as seen in the dementia trends in high-income countries (Nichols et al. 2022), dementia increase in LMICs can also be lowered if priority is placed on reducing modifiable risk factors.

Risk factors associated with dementia in this study included ageing, depression, not having a partner and education. Low education, depression and loneliness have also been identified in other African studies (George-Carey et al. 2012; Mavrodaris et al. 2013; Olanyika et al. 2014; Paddick et al. 2014; Yusuf et al. 2018), confirming the prominent plight of these factors in older African populations. Not having a partner in this study increased the risk of dementia by seven-fold for those who are single and three-fold for those who are widowed. This speaks to issues of loneliness and isolation in older adults. Other factors associated with loneliness and isolation in older adults include living alone, losing family or friends, chronic illness, and hearing loss (National Academies of Sciences, Engineering, and Medicine 2020). These results suggest that it is important that older people are included in community activities to combat loneliness and isolation.

TABLE 3 (Continues...): Multivariate regression analysis of factors associated with dementia.

Explanatory	**Unadj†**			**FullAdj‡**			**Backstep§**		
	OR	**CI**	**α**	**OR**	**CI**	**α**	**OR**	**CI**	**α**
Depression									
No^R	-	-	-	-	-	-	-	-	-
Yes	2.70	1.11–6.12	0.021*	3.48	1.01–11.89	0.046*	2.74	1.01–7.11	0.041*
Drink alcohol									
No^R	-	-	-	-	-	-	-	-	-
Used to but stopped	1.66	0.63–3.94	0.274	3.25	0.71–14.69	0.123	-		
Yes	0.61	0.14–1.82	0.429	0.95	0.14–5.37	0.957	-		
Tobacco use									
No^R	-	-	-	-	-	-	-	-	-
Used to but stopped	1.04	0.23–3.25	0.957	1.78	0.20–13.76	0.590	-		
Yes	0.77	0.22–2.09	0.643	2.52	0.45–12.13	0.264	-		
Family health risks									
Heart condition									
No^R	-	-	-	-	-	-	-	-	-
Yes	0.81	0.37–1.65	0.575	0.45	0.14–1.31	0.154	-		
Hypertension									
No^R	-	-	-	-	-	-	-	-	-
Yes	0.71	0.36–1.36	0.304	0.92	0.35–2.40	0.864	-		
Diabetes Mellitus									
No^R	-	-	-	-	-	-	-	-	-
Yes	0.76	0.38–1.48	0.427	0.83	0.32–2.13	0.695	-		
Parkinson disease									
No^R	-	-	-	-	-	-	-	-	-
Yes	0.76	0.18–2.29	0.664	0.58	0.11–2.34	0.481	-		
Dementia									
No^R	-	-	-	-	-	-	-	-	-
Yes	1.41	0.50–3.42	0.480	1.60	0.40–5.81	0.484	-	-	-

[AQ6] *Source*:

Note: ^{R}reference group.

OR, odds ratio; CI, confidence interval.

†, risk between dementia and other variables entered simultaneously.

‡, risk of dementia with adjustment for confounding variable.

§, Risk of dementia with variables entered separately.

*, 0.05 level (2-tailed); **, 0.01 level (2-tailed).

Ageing is a primary risk factor for dementia (ADI 2015; De Jager et al. 2017; Longdon et al. 2012), doubling the risk of dementia in those aged < 80 years in this study compared to those aged 60–69 years. Alzheimer's Disease International (2015) reported that a person's risk increases as they age, doubling every 5 years. In addition, older people are more likely to live with other comorbid illnesses such as hypertension, stroke, diabetes, and hypercholesterolaemia, also associated with dementia (Guo et al. 2018; Huang et al. 2015), thereby increasing the vulnerability of an older person to developing dementia.

Identifying and reducing risks, such as increasing the quality and levels of education and improving the control of depression and cardiovascular diseases, can effectively lower the incidence of dementia (ADI 2015; Nichols et al. 2022; WHO 2017). Quality education and cognitive stimulation programmes must be prioritised in developing countries to build and enhance cognitive reserve from a younger age. Further, public health interventions should be prioritised at a grassroots level to educate people about dementia risk factors such as cardiovascular risks. Addressing risk factors through public health interventions is a pathway to reducing dementia prevalence and altering the trajectory of age-specific prevalence. Lastly, the treatment gap between people diagnosed with dementia and those undiagnosed but with dementia must be reduced. This means that public health screenings for dementia should be encouraged. Older people should be screened at community clinics when they routinely visit to collect medications. To achieve this, primary healthcare staff can easily administer assessment tests that are readily available, easy to administer, and not time-consuming. There is a greater need for using validated and simple neuropsychological tools for early diagnosis of cognitive impairment (Ramlall et al. 2013). These tests must be easily incorporated into the routine screening of older people in primary healthcare settings in conjunction with the DSM-5 and/or the ICD-11. Cases of dementia can be identified, and routine care commenced, including laboratory testing and symptomatic management.

Conclusion

This study's primary objectives were firstly, to measure the risk factors and prevalence of dementia in the iLembe district. Secondly, the study explored the usefulness of the MMSE, AD8 and IADL in measuring dementia in an African population. Dementia prevalence was 13.4%. Many people with dementia in South African communities likely remain undiagnosed, and do not have access to treatment, care and support that a formal diagnosis can provide. More longitudinal studies need to be done to ascertain the actual trajectory of dementia in South Africa. The identified risk factors for dementia were age, low levels of education, lack of a spouse and a history of depression. The early identification of cognitive impairment is important in devising possible interventions that can help to reduce the burden on those affected and impacted by dementia and to lighten the socioeconomic burden of the disease on the country's resources (Schutte et al. 2021).

Future research in South Africa needs to be more representative and include longitudinal studies. In addition, future research needs to focus on exploring and eliminating the modifiable risk factors mentioned for populations identified as being at risk, especially those in rural areas and low-income households. [AQ7] Thirdly, it is recommended that when tests such as the MMSE are used to screen for dementia, they are used with caution and in combination with other tests. This study used a combination of tests and only counted participants as having dementia if the combined test results corresponded with the Diagnostic and Statistical Manual of Mental Disorders (DSM) 5 and ICD 11 criteria for dementia instead of relying on the results of the individual psychometric tests. Combining the MMSE, AD8 and IADL provides better diagnostic accuracy in the absence of laboratory tests, and can be easily incorporated into routine care by primary healthcare providers for diagnosing dementia.

Limitations of this study include the cross-sectional design, which lessened the ability to establish causal-effect relationships between dementia and the independent variables. In addition, this study did not include laboratory testing. However, other studies have predicted dementia without laboratory testing, and those screened as positive for dementia were referred for further testing at their healthcare institutions. Lastly, this study was conducted in one district and was not a national study. Therefore, results should be generalised with caution to other communities in South Africa. Notwithstanding these limitations, the study provides insight relevant to issues related to dementia prevalence in South Africa and other developing countries.

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Competing interests

The authors have declared that no competing interest exists.

Authors' contributions

X.P.M. conceptualised the study and wrote the first draft of the manuscript. B.J.P. supervised the study and made revisions and recommendations for the manuscript.

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Data availability

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors, and the publisher.

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4.3 Paper 2

This paper explored the awareness and knowledge of dementia and dementia care, which covers objective 3 of the study. A copy of the manuscript published by the *South African journal of psychology* is inserted below.

Reference

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Article

Knowledge of dementia and dementia care in a cross-sectional sample of individuals living in rural and urban areas in KwaZulu-Natal, South Africa

Xoli Precious Mfene[1] **and Basil Joseph Pillay**[2]

Abstract

Knowledge of dementia is considered one of the facilitators of dementia risk reduction because it has been linked to early detection, diagnosis, and help-seeking in people with dementia. This study explored knowledge of dementia symptoms, causes, and care in a community sample of individuals living in rural and urban areas in KwaZulu-Natal, South Africa. A cross-sectional household study of 300 participants, ⩾18 years old, using semi-structured individual interviews was conducted. Of the 300 participants, 94% recognised the presence of the cognitive decline symptoms, and 12.4% identified the symptoms as dementia. Participants emphasised biological and medical risk factors over socio-cultural factors. Although the participants primarily adopted a biomedical understanding of dementia, with a small number acknowledging a traditional understanding, they preferred a multi-disciplinary approach to care. Participants advocated for a multidisciplinary care approach that included medical, family, social work, mental health services, and spiritual and traditional care for people with dementia and their families. Therefore, policy and care services for African people with dementia and their families need to holistically integrate multiple care approaches. This will maximise the benefit of public health interventions while also building capacity in our understaffed and burdened healthcare systems.

Keywords

Awareness, dementia, dementia care, knowledge, rural and urban communities

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Dementia is a public health concern (Alzheimer's Disease International [ADI], 2015; World Health Organization [WHO], 2017). In 2015, ADI projected that the prevalence of dementia would triple to 115.4 million by 2050 worldwide. Consequently, in 2017, the WHO published the 2017–2025 Global Action Plan on the public health response to dementia, encouraging countries to reduce dementia risk. Creating and improving knowledge of dementia is considered one of the facilitators of dementia risk reduction (WHO, 2017). This is because dementia awareness and knowledge are linked to early detection, diagnosis, and help-seeking in people with dementia (PWD) (Hindley et al., 2016; Khonje et al., 2015; Mkhonto & Hanssen, 2017; Mushi et al., 2014; Owokuhaisa et al., 2020). Sufficient knowledge about dementia includes recognising symptoms, knowledge of risk factors and causes, knowing how to seek appropriate information on self-treatments, and professional help available (Jorm, 2012).

In many Sub-Saharan African studies, dementia knowledge is considered limited or poor (Hindley et al., 2016; Khonje et al., 2015; Mkhonto & Hanssen, 2017; Mushi et al., 2014; Owokuhaisa et al., 2020). This is because participants from these studies could not recognise or understand the Western biomedical term dementia (Mkhonto & Hanssen, 2017; Mushi et al., 2014) and participants who adopt a socio-cultural understanding of dementia rather than a biomedical understanding of dementia as a neurodegenerative disorder, as defined in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM*-5; American Psychiatric Association [APA], 2013), are usually seen as having poor knowledge. While a biomedical view is necessary for detecting and diagnosing dementia, Alzheimer Europe (2018), emphasised that what is considered 'sufficient' dementia knowledge for different communities should also be unbiased and congruent with people's beliefs, traditions, and perceptions, while also encouraging timely diagnosis, and access to support and other necessary services.

It is not unusual for African communities to endorse both Western and traditional notions of dementia, because knowledge of dementia symptoms, risk factors, and care usually varies according to personal and socio-cultural experiences, beliefs, and perceptions about the presentation of the disease (Chung, 2000; Conrad & Barker, 2010; Hindley et al., 2016). For example, some African studies reported that dementia was understood to be a natural part of ageing, a mental illness, and/or a medical disorder (Hindley et al., 2016; Khonje et al., 2015; Mkhonto & Hanssen, 2017; Owokuhaisa et al., 2020). While other studies reported the belief that dementia is the work of evil spirits, retribution from God (i.e., for past personal or family sins, not praying enough, not having sufficient faith to ward off evil spirits, or displeasing God), punishment from ancestors, and witchcraft (Cipriani & Borin, 2014; Hindley et al., 2016; Mkhonto & Hanssen, 2017; Mushi et al., 2014; Ndamba-Bandzouzi et al., 2014; Sayegh & Knight, 2012). An illness can be understood as medical while also having socio-cultural and spiritual meanings (Patel, 2011). A socio-cultural understanding does not constitute a lack of or poor knowledge and/or discounting the biomedical basis of the disease.

Since people may understand dementia from both or either a biomedical or a socio-cultural perspective, services and interventions for PWD should consider integrating different approaches into care. Communities would be less resistant to engaging with healthcare systems if interventions were tailored to their perceptions and beliefs. Community-tailored and diverse intervention approaches are crucial in reducing dementia risk and stigma, fostering dementia-friendly communities and providing caregiver support in non-Western, low/middle income, and multi-ethnic communities such as South Africa. Studies reported that some communities relied on traditional healers (Khonje et al., 2015), family care (Berwald et al., 2016; Raghavan & Patel, 2018; Shai & Sodi, 2015), spiritual interventions such as prayers or calling for a pastor, indigenous religious beliefs, and ancestral connections (Hindley et al., 2016; Nwakasi et al., 2019) to manage dementia, rather than Western care practices. The studies suggest that communities prefer several types of care, based on their understanding and cultural beliefs about the causes of dementia. It is suggested that a complementary healthcare system is essential, as communities believe in and use both medical and indigenous care (Patel, 2011).

Exploring people's knowledge of dementia is integral for reducing risk, developing care interventions and fostering dementia-friendly communities. This study aimed to explore the knowledge of dementia and dementia care in a community sample of individuals living in rural and urban areas in KwaZulu-Natal, South Africa. This study focused on dementia in the elderly and not dementia resulting from illnesses such as HIV and Huntington's or traumatic brain injury.

Method

A cross-sectional mixed methods (Creswell, 2003) household survey was undertaken in iLembe district, KwaZulu-Natal. ILembe district has four municipalities, namely Ndwedwe, Stanger, Maphumulo, and Mandeni, consisting mainly of rural communities.

Participants

We recruited 300 participants aged $\geqslant$ 18 years using probability multi-stage cluster sampling and simple random sampling (Terre Blanche et al., 2006). In the first stage, the iLembe district was selected from 11 KwaZulu-Natal districts using a simple random method; this was the primary sampling unit. In the second stage, eight ward areas were randomly selected from the four iLembe municipalities. Finally, the participants were selected by sampling the first household in the ward area and thereafter sampling every fifth household. Participants were not required to have prior knowledge of a person with dementia.

Instruments

A semi-structured questionnaire was used that included biographical details and dementia knowledge and care questions based on existing dementia literature (Berwald et al., 2016; Hindley et al., 2016; Khonje et al., 2015; Mushi et al., 2014; Ndamba-Bandzouzi et al., 2014; Owokuhaisa et al., 2020) and mental health literacy (Jorm, 2012). The questionnaire was administered digitally using the Mobenzi Researcher data collection and capturing tool (Mobenzi, 2021). Mobenzi Researcher is a mobile data collection tool used extensively to collect baseline data and conduct household surveys, patient interviews, and healthcare facility audits. Before the interview, a description of dementia symptoms was given in a vignette[1] about an older woman who met the *DSM*-5 criteria for dementia. Case studies are commonly used in medical research (Hindley et al., 2016; Jorm, 2012; Starman, 2013), including research on dementia knowledge and care (Berwald et al., 2016). A diagnosis of dementia requires significant cognitive decline in one or more cognitive domains that interfere with activities of daily living. The cognitive impairment must not only be during delirium but also be better explained by another mental disorder (APA, 2013). The questionnaire assessed the participants' knowledge of dementia symptoms, risk factors, and care options; Table 1 lists the questions used during the interviews.

Procedure

Face-to-face interviews were conducted at the participants' homes by the research team. The team included the first author and six research assistants with postgraduate qualifications in psychology. The interviews took approximately 45 min and were conducted in either isiZulu or English, depending on the participant's preferred language.

Table 1. Questions about knowledge of dementia and dementia care.

1. Is there anything wrong with the person in the vignette? If yes, what would you say is wrong?
2. What is the name of the illness? (The correct name is given to the participant following their answer).
3. Have you ever heard about dementia before? If yes, where did you hear about it? (Participants were allowed to give multiple responses.)
4. Do you know of anyone in your family who has experienced similar symptoms or dementia? If yes, who?
5. What type of people do you think suffer from this illness?
6. Do you think a person with these symptoms (dementia) can be helped?
7. How do you think they can be helped?
8. Who do you think can help? (Participants were allowed to give multiple responses.)
9. If you or your family member had similar symptoms, would you seek help?
10. Where do you think a person with dementia can be best cared for and by whom?
11. Do you feel that you would be able to care for someone with dementia?
12. Do you know any services that care for PWD difficulties in your community?
13. Are there any services in your community that care for older adults?

PWD: people with dementia.

Ethical considerations

The University of KwaZulu-Natal Humanities and Social Sciences Research Ethics Committee approved the study (HSS/1016/017D). Participation was voluntary, and informed consent was obtained before data collection.

Data analysis

Data were imported from the Mobenzi online server into a password-protected Microsoft Excel file and then exported into the Statistical Package for Social Sciences version 27 (IBM Corp, 2020) for statistical analysis. Descriptive statistics and summative content analysis were used in this study. Descriptive statistics were used to analyse participant characteristics and responses about dementia awareness and care practices. For the qualitative data, we used a summative content analysis involving counting and comparing keywords from participant responses to create frequencies and interpret the underlying context of the responses (Hsieh & Shannon, 2005). Data extracts were used to support the interpretations made from the summative content analysis.

Results

Sociodemographic data

The sample ($N = 300$) was primarily Black African (74.7%), females (71.3%), single (64%), and had secondary education (37%). The participants had a mean age of 40.7 years (range = 18–83 years, $SD = 18.27$). Table 2 presents the demographic variables of the participants.

Knowledge of dementia symptoms

Two hundred eighty-two (94%) participants identified the symptoms presented in the vignette as abnormal behaviour, while 6% did not recognise anything wrong with the person presented in the case vignette. Of the 282 participants, 35 (12.4%) interpreted the symptoms as dementia, 99 (35.1%) as old age, 85 (30.1%) as mental illness, and 56 (19.9%) as a medical illness. Of the

Table 2. Demographic variables ($N = 300$).

Demographic variables	*n*	%
Setting		
Urban	135	45
Rural	165	55
Sex		
Male	86	28.7
Female	214	71.3
Age (years)		
18–39	160	53.3
40–59	78	26
60–79	58	19.3
80+	4	1.3
Ethnicity		
African	224	74.7
Coloured	3	1
Indian	70	23.3
White	3	1
Marital status		
Single	192	64
Married	69	23
Divorced	7	2.3
Widowed	21	7
Cohabitating	11	3.7
Educational level		
No formal education	12	4
Primary	50	16.7
Secondary	111	37
Matric	84	28
Tertiary	43	14
Religion		
Christian	241	80
Hindu	26	8.7
Shembe	14	4.7
Islam	6	2
None	13	4.3

participants who identified the symptoms as mental illness, 24.3% could not specify the type of mental illness, while 2.7% reported stress, 1% depression, and 0.3% reported that: 'The person is losing her mind'. A further 2% of the 282 participants recognised the symptoms as representing forgetfulness or memory loss, and 0.3% as an ancestral problem: '*Unenkinga yabantu abadala*' (Literally: 'She has a problem of older people' [in this case, this was confirmed by the participant as referring to the ancestors]).

Fifty-six (19.9%) of the participants understood the symptoms to represent a medical disorder. However, most of them (53) could not specify the type of medical illness, and the prominent responses were: 'This person is sick'; 'She has a sickness'. One participant stated that: 'She is diabetic and possibly has BP'.

Table 3. Perceived risk factors for dementia (*N*=258).

Risk factors	Frequency of responses	
	n	%
Biological		
Old age	129	50
Diabetes	22	8.5
Hypertension	3	1.2
Alzheimer's disease	3	1.2
Disabilities	2	0.8
Unspecified medical illnesses	11	4.3
Head injuries	1	0.4
Psychological		
Stress	16	6.2
Mental illness (including depression, psychosis, and trauma)	18	7
Memory problems/forgetful	6	2.3
Lots of problems and thinking a lot	6	2.3
Social		
Loneliness or isolation (especially in old age and when one has problems).	6	2.3
Lots of problems like poverty	1	0.4
Spiritual		
Not praying enough	1	0.4
Ancestral problems	1	0.4
Combined		
Old age and mental illness	5	1.9
Old age and suffering abuse/neglected	4	1.6
Old age and hard-hearted	1	0.4
Old age with stress	6	2.3
Old age with diabetes/hypertension	14	5.4
Stress and working with too many people	1	0.4
Neglecting your health and not going for check-ups	1	0.4

Seventy-seven (25.7%) of the 300 participants had a relative who had dementia and assumedly had some knowledge of dementia before the study. Of the 77 participants who had relatives with dementia, 13 (16.9%) identified the cognitive symptoms in the case study as dementia, while the rest reported that the symptoms presented some form of mental illness 25 (32.5%), an illness of old age 23 (29.9%), and 16 (20.8%) as a form of medical illness. One hundred twenty-two (40.7%) of the total participants reported that they knew about dementia from various sources, such as hospitals or clinics: 36 (29.5%), radio: 35 (28.7%), television: 39 (32%), internet: 12 (9.8%), newspaper or magazine: 17 (13.9%) or school: 16 (13.1%).

Knowledge of dementia risk factors

The participants identified multiple risk factors that predispose people to dementia. These included biological, psychological, and social risk factors. Some participants (12.4%) combined explanations to show that dementia can be associated with multiple factors. Table 3 shows the perceived factors that predispose people to dementia.

Old age (50%) was identified as the primary risk factor for dementia. The participants also identified that medical illnesses (16.4%) and psychological issues (17.8%) were risk factors for dementia. Furthermore, a few participants attributed dementia to social (2.7%), spiritual, and traditional (0.8%) issues, and 12.4% identified that a combination of factors, such as being old and having diabetes or hypertension, increases the likelihood of dementia. For example, one participant stated that: 'People that have old age [have] been through trauma and suffering from deep anxiety get dementia'.

Knowledge of dementia care and support services

Two hundred sixty-three (87.7%) participants reported that if a family member had dementia they would seek help, while 37 (12.3%) were unsure. Of the participants, 44% preferred that care be provided at home by a relative, 39% believed care is better at a nursing home or hospital, 11% of the participants believed that a person with symptoms of dementia is better cared for at home but by a hired carer, and 6% did not have a preference. More than two-thirds of the participants (75.3%) reported they would be able to take care of a relative with dementia. A small portion (9.7%) of the participants reported receiving caregiver training. Ninety-one participants (30.3%) reported that their communities had services for PWD, while 33% of those who have relatives with dementia ($n = 77$) had access to dementia community services, and 13% had received caregiver training.

Of the participants who indicated they would seek help ($n = 263$), 86.7% chose multi-disciplinary care as their preferred way to manage dementia, with 19.8% preferring a multi-disciplinary care team, which includes family, doctor, mental health services, social worker, and pastor. Some participants (8.7%) included the traditional healer as part of the care team, while 13.3% preferred a single form of help such as either medical help (6 %), family (4.6%), or social work (2.7%).

Discussion

This study explored knowledge of dementia in South African rural and urban communities in the iLembe district. About 94% of the participants were able to recognise cognitive decline. A small number of these participants were able to identify the illness as dementia (12.4%). Some participants identified the symptoms as old age (35.1%), mental illness, (30.1%) or medical illness such as diabetes and hypertension (19.9%). These results indicate that recognition of dementia symptoms as an illness was high. In contrast, most studies reported that dementia knowledge was poor in Sub-Saharan African countries as participants could not recognise or understand the term dementia, and therefore could not describe the disease (Mkhonto & Hanssen, 2017; Mushi et al., 2014; Owokuhaisa et al., 2020; Raghavan & Patel, 2018). Our participants adopted a biomedical view of dementia, with fewer than 1% of the participants reporting that dementia was associated with punishment from ancestors. Exposure to information about dementia, such as having relatives diagnosed with dementia, getting information from the broadcasting media, community clinics, and schools, might have contributed to the participants' increased biomedical knowledge of dementia. These platforms may be useful for promoting dementia awareness programmes, especially in rural areas.

While many participants could not recognise the symptoms as dementia, they had a biomedical understanding of the risk factors that lead to dementia. For example, most participants referred to dementia as a disease of old age and identified ageing as the primary cause of dementia. Although old age is not synonymous with dementia, it is the leading risk factor (ADI, 2015). Similarly, and also mentioned in the literature (ADI, 2015), the participants identified medical illnesses (e.g., diabetes and hypertension) and mental illnesses (e.g., depression) as other prominent risk factors for dementia. A small number of the participants also believed that 'not praying enough' and 'having ancestral problems' can cause dementia, which is also reported in other studies (Cipriani & Borin, 2014; Owokuhaisa et al., 2020; Sayegh & Knight, 2012). Unexpectedly, some participants identified psychosocial factors like loneliness, isolation, and abuse as posing a risk for dementia. Recent literature (National Academies of Sciences, Engineering, and Medicine, 2020; Yusuf et al., 2018) has also considered loneliness and isolation as risk factors for dementia and these are associated with up to a 50% increase in dementia risk. Further research is needed to investigate the association between dementia and loneliness and explore whether loneliness is a determinant or a consequence of dementia.

Most participants reported that they would seek help if their relatives had dementia. They acknowledged that caring for a person with dementia requires help from multiple sources such as medical, social, psychiatric, pastoral, and traditional care. According to Patel (2011) and Shai and Sodi (2015), South African populations commonly prefer multiple care pathways for illness, particularly those living in rural areas where care often includes traditional and spiritual interventions. Our sample demonstrated that they preferred both socio-cultural and spiritual interventions, as well as biomedical care. Caregivers of PWD can sometimes be overburdened and stressed (Gurayah, 2015); therefore, the support and care that the multi-disciplinary services can provide is essential.

Understanding dementia knowledge extends the pathways for policy development and public health initiatives for risk reduction and improving care for PWD and their caregivers. Public health initiatives may include adequate community-based multidisciplinary team services for early detection, support, care, and rehabilitation for patients and their families. Community-based services can provide much-needed relief to the crippled South African healthcare system that is overburdened and under-resourced. The public healthcare system in South Africa lacks adequate human, medical, infrastructural, and pharmaceutical resources for the elderly (Kalula, 2011; Ramashala, 2012), especially those with dementia. According to Kalula (2011), there are no dedicated or specialist services for older people at the primary healthcare level, meaning that older people must compete for services with younger age groups. In addition, older patients are marginalised at the clinics, and very few are referred to secondary or tertiary levels for investigation and management of diseases such as dementia (Kalula, 2011; Kelly et al., 2019).

The increase in dementia prevalence raises the demand for resources to diagnose, treat, and care for those affected in the communities where people live and where it would be more accessible and convenient. As the first line of contact to health care, primary care services need to be accessible and adapted to the needs of older adults. The public primary healthcare sector needs to establish multidisciplinary teams (MDTs) for older persons at community healthcare facilities and adopt a participatory model of care, so that PWD and their families are included in the discussions and planning of their care. Such a collaborative approach would promote, support, and allow the public healthcare personnel to monitor and plan for the continuation of care, including assisted living.

One limitation of the study is that it was conducted in one district in KwaZulu-Natal, and the results should only be cautiously applied to other populations in the rest of South Africa. Another limitation is that being primarily a quantitative study, the closed questions used in the questionnaire did not adequately explore the participants' in-depth knowledge of dementia. Future studies should use more open-ended questions to explore participants' knowledge of dementia in greater depth.

Conclusion

Participants adopted a biomedical understanding of dementia symptoms and risk factors in this study. However, they also preferred a holistic and multi-disciplinary approach to care, including socio-cultural care. Dementia risk reduction and care initiatives in rural African communities need to consider the community's knowledge of dementia, creating new avenues for care and support. The public health system must work with all stakeholders in the community to support caregivers and adopt a participatory health model. Hospitals, schools, and the media can be used effectively to raise awareness and share knowledge about dementia.

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Note

1. The vignette used in this study can be requested by email from the corresponding author.

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4.4 Paper 3

This paper is an extension of objective three and looks at how communities describe dementia based on their knowledge of the disease and how conceptualizations of dementia by different communities contribute to stigma. This paper was published by *Dementia: the international journal of social research and practice* and is under review. A copy of the manuscript is inserted below.

Reference: Mfene, X.P., & Pillay, B.J. (2023). Dementia-Friendly Communities: Exploring Terms used to Describe Dementia, Attitudes and Reactions Towards People with Dementia in iLembe District, South Africa. Dementia, 22(5):964-977. https://doi.org/10.1177/14713012231165112

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Dementia-Friendly Communities: Exploring Terms used to Describe Dementia, Attitudes and Reactions Towards People with Dementia in Ilembe District, South Africa

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Abstract

Background: People with dementia often experience stigma, abuse and social exclusion in their communities. Thus, developing dementia-friendly communities is a priority in the fight against dementia.

Objectives: This study investigated communities' attitudes towards people with dementia by exploring the colloquial terms referring to dementia and the social tolerance toward people with dementia.

Methods: A cross-sectional household study, using individual interviews, was conducted in the iLembe district, South Africa, with 300 participants aged ≥18 years. Data was collected between 2018 and 2019. Data was analysed using descriptive and reflexive thematic analyses.

Results: Two themes related to local dementia terms were identified: (i) There are no known local terms synonymous with the term dementia; (ii) Communities use inaccurate and stigmatizing terms to describe dementia. The terms identified did not accurately describe dementia, and others had negative connotations toward people with dementia. Although most participants reported being tolerant, neighbourly, and friendly towards people with dementia, their tolerance decreased when

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personal interaction was required with a person with dementia. Most participants reported a more agreeable attitude when considering being neighbours rather than family members of people with dementia, and 50.3% reported that their communities discriminate against older people with dementia.

Conclusion: The identified dementia terms did not promote dementia-friendly societies. Appropriate dementia terms are crucial for changing social intolerance and negative perceptions of people with dementia and promoting a dementia-friendly culture in South African communities. Terms that encourage and perpetuate stigma against people with dementia must be replaced with terms that promote inclusion and tolerance.

Keywords

attitudes, dementia, dementia-friendly communities, dementia language, social tolerance and inclusion, and stigma

Background

People with dementia often experience stigma, abuse, and social exclusion in their communities (Hung et al., 2021; Khonje et al., 2015; Mkhonto & Hanssen, 2018). Evans (2018) refers to three forms of stigma that impact people with dementia: self-stigma, public stigma, and stigma by association. Stigma and discrimination include intolerance of people with dementia and their families, negative attitudes, or behaviour such as the use of negative language or terminology, stereotyping, alienation, isolation and exclusion, and lack of access to essential care and support services (Link & Phelan, 2001; Mukadam & Livingston, 2012; Swaffer, 2014). Developing dementia-friendly communities is a priority area in the fight against dementia stigma, and it is one of the seven 2017–2025 guidelines in the World Health Organization's (WHO) public health response to dementia (WHO, 2017). According to the WHO (2017), a dementia-friendly society provides an inclusive and accessible community environment, with enhanced opportunities for participation, health, and safety for all people, to ensure a good quality of life and dignity for people with dementia and their families. Dementia-friendly communities further create opportunities for awareness about dementia, provide support, make people with dementia feel confident about contributing to the community, and foster social inclusion and tolerance of people with dementia (Hung et al., 2021; Wu et al., 2019).

Communities' attitudes and stigma against people with dementia can be apparent in the colloquial language used to refer to dementia (Swaffer, 2014). When used correctly, language can reduce stigma, promote social inclusion and show respect for the personhood of someone with dementia. However, when used prejudicially, language harms and stigmatizes people with dementia. Therefore, to create dementia-friendly communities, it is important to start changing the negative everyday terms used to describe dementia or those with dementia.

In the past, researchers have used derogatory, dehumanising, stigmatising, and discriminatory language toward people with dementia, such as 'demented', 'victims' and 'not all there' (Swaffer, 2014). Stigmatising colloquial terms, such as "crazy, possessed, spoiled 'fsoesh', or as having a confused head" (Berdai Chaouni & De Donder, 2018: p. 8), and '*kharaf*' (translated as 'loss of mind') (Cipriani & Borin, 2015), were also used to refer to people with dementia in different communities where they live. Further terms such as 'mental' or 'getting off your brain' (Alzheimer's Europe, 2018; Antelius & Plejert, 2016; Lawrence et al., 2011), ageing disease, disease of insanity, disease of forgetfulness, madman, and dull brain (Adebiyi et al., 2016) were also used. While these terms might be part of everyday social language, they also implicitly reinforce the stigma, social exclusion, and intolerance of people with dementia. Swaffer (2014) stated that if the language used is inclusive, non-judgmental, and person-centered (rather than centered on the disease), the social care system and language trends can help people with dementia to have better health outcomes and quality of life.

Dementia is a Western biomedical construct and as such many African languages do not have terms synonymous with the biomedical concept of dementia as found in other studies (Khonje et al., 2015; M'belesso et al., 2016). For example, researchers found that there are no dementia synonymous terms in Brazzavillean Sango, Lingala or Kituba (M'Belesso et al., 2016), Asian Punjabi (Alzheimer's Europe, 2018), South African Xhosa (Khonje et al., 2015) and Tanzanian Swahili (Hindley et al., 2016), to name a few. The lack of appropriate terminology leads to the persistent use of inappropriate terminology in non-Western communities. Berdai Chaouni & De Donder (2018) advocate for diverse ethnic communities to construct appropriate terminology and produce dementia information in their languages. Developing simple, inclusive, and positive language can help communities replace harmful and negative terms that make the disease to be associated with shame and reinforce stigma towards people with dementia.

In some communities, dementia is associated with shame and embarrassment and because of this, some people prefer not to know or let others know that they have the disease (Adebiyi et al., 2016; Evans, 2018). Also, some relatives of people with dementia hide the status of their loved ones for fear of prejudice or violence from the community (Mkhonto et al., 2018). Therefore, societies that show prejudice and negative attitudes towards people with dementia perpetuate the isolation and exclusion of those with dementia and their families from the community. Excluding people with dementia from community interaction robs them of a good quality of life (Cohen-Mansfield & Parpura-Gill, 2007). The value of social interaction, community participation, and good social relationships with family, friends and neighbours are key elements of quality of life for older people (Bowling, 2011), regardless of their health condition. A UK report found that 33% of those living with dementia had lost friends following the diagnosis, and 39% felt lonely and not included in their communities (Alzheimer's Society, 2013). Maintaining social inclusion and community engagement can be particularly challenging for people with dementia and their families when communities are not dementia friendly.

This study explored communities' attitudes towards people with dementia by considering the colloquial terms referring to dementia, the social tolerance toward people with dementia and the availability of dementia-inclusive services in South African communities.

Methods

Study Design and Setting

This was a mixed method, cross-sectional household study conducted in the iLembe district. iLembe district is one of the 11 districts in KwaZulu-Natal (KZN), South Africa. It has four municipalities: KwaDukuza, Mandeni, Ndwedwe, and Maphumulo. It is predominantly a rural district, with isiZulu-speaking and black African population.

Participants

We recruited 300 participants aged ≥18 using multi-stage cluster sampling with simple random sampling (Terre Blanche et al., 2006). As this study was part of a more extensive study on dementia prevalence and care, a simple random method was used to select iLembe from the 11 KwaZulu-Natal districts. Secondly, two ward areas were sampled from each of the four iLembe municipalities. After that, the participants were selected by sampling the first household in the area, followed by every fifth household. Ethical approval for the study was obtained from the University of KwaZulu-Natal (UKZN)'s Humanities and Social Sciences Research Ethics Committee (HSS/1016/017D), and the participants provided informed consent.

Procedure

Data was collected for a period of 6 months between October 2018 and November 2019. In some communities, households were too far apart, which prolonged the data collection process in those communities. Interviews were conducted at the participants' homes in either isiZulu or English. A semi-structured questionnaire with biographical and study specific questions were used. The questionnaire included a vignette of a person with symptoms of dementia. The vignette was designed using the DSM-5 criteria for dementia (APA, 2013), which included symptoms of memory loss and other cognitive and behavioural difficulties noticed by family members and others. The following questions were asked to explore the colloquial terms used by participants to refer to dementia, as well as participants' attitudes toward people with dementia:

(1) Is there a name used to refer to dementia or people with dementia in your language or community?
(2) What is the name?
(3) Would you have a problem with being neighbours, friends, and family/date a person with dementia?
(4) How do you think other people in your community would treat a person with dementia?
(5) In your community, are there services for people with dementia?

The participants' responses were captured using Mobenzi Researcher software (Mobenzi, 2021), which is a digital data collection tool that captures data electronically during fieldwork. After collection, data was exported into a password-protected Microsoft Excel file for cleaning and analysis. Responses in IsiZulu were translated into English by the first author and reviewed for accuracy by two independent professionals who are bilingual.

Data Analysis

The Statistical Package for Social Sciences 27 (SPSS) was used for descriptive analysis of participant characteristics and question responses (IBM Corp, 2020). Qualitative data was analysed using reflexive thematic analysis (RTA) following the stages of familiarisation, generating codes and themes, sorting, reviewing data extracts, and writing up (Braun & Clarke, 2019). RTA focuses on "the researcher's reflective and thoughtful engagement with their data and their reflexive and thoughtful engagement with the analytic process" (Braun & Clarke, 2019, p. 594). Through the RTA, themes are not predefined to 'find' codes. Instead, themes are produced by organizing codes around a relative core commonality, or 'central organizing concept,' that the researcher interprets from the data (Braun & Clarke, 2019 Campbell et al., 2021).

To ensure the rigour of the study, credibility, conformability, transferability, and dependability (Lincoln & Guba, 1985) were considered. Firstly, a rigorous external review of the study design and procedures was conducted during the ethical clearance process. Secondly, during data collection, the researchers were in the field for a prolonged period. As suggested by Patton (2001), the researchers' prolonged engagement and persistent observation ensured that they learned more about the culture, the social and natural setting of the participants and the topic of study. Moreover, the use of triangulation (Cresswell, 1998) by the researchers ensured the accuracy of the data – i.e., this study was part of a larger study on dementia prevalence and care, where both quantitative and qualitative data was collected from multiple sources. In addition, responses in IsiZulu were backward translated into English by the researchers and confirmation of the translation and meaning were reviewed by independent professionals for accuracy. Similarly, interpretations of the findings and some cultural explanations were verified with peers who were more familiar with concepts such as amafufunyana.

Findings

A total of 300 interviews were conducted. The mean age of participants was 40.7 years. Most of the participants were African (74.7%), female (71.3%), single (64%), from a rural area (55%), and with secondary education (37%), as shown in Table 1.

The Colloquial Terminology Used to Describe Dementia

Two themes emerged concerning the local terms used to describe dementia: (i) There are no known local terms synonymous with the term dementia; (ii) Communities use inaccurate and stigmatizing terms to refer to dementia, as shown in Figure 1 of the thematic map. In the extracts, the participants are identified by their municipality (KwaDukuza, Mandeni, Maphumulo, Ndwedwe), ethnicity (Black, Coloured, Indian, White), gender (female or male) and their participant number (e.g., KFB66 = KwaDukuza, female, black and participant number 66 and MaMB22 = Mandeni, male, black, participant number 22).

Theme 1: No known local terms are synonymous with dementia

Most participants (n = 256; 85.3%) reported that there was no term synonymous with the biomedical term dementia in their languages and communities. A small proportion of the participants (n = 44; 14.7%) reported a term used in their communities to describe dementia. Nine colloquial terms were reported, as seen in Figure 1. These were primarily reported in the participants' language, and from these descriptions, four subthemes emerged and are presented below.

Theme 2: Communities use inappropriate and stigmatizing terms to refer to people with dementia

Of the 44 participants reporting a term, 72.7% reported terms that were not accurate and sometimes stigmatizing. Four subthemes emerged and participants used terms such as loss of mind', 'sickness of the mind', 'twisting of the mind', culture-bound illness, crazy or mad, and 'abused mind' as seen in the subthemes below.

Dementia as a Mind Disturbance

The participants reported this subtheme as illustrated in the following extracts:

Table 1. Participants' Sociodemographic Profile (*N* = 300).

Demographic variables	*n*	%
Municipality		
KwaDukuza	76	25.3
Mandeni	123	41
Maphumulo	39	13
Ndwedwe	62	20.7
Setting		
Urban	135	45
Rural	165	55
Ethnicity		
African	224	74.7
Indian	70	23.3
Other	6	2
Gender		
Male	86	28.7
Female	214	71.3
Age (years)		
18–39	160	53.3
40–59	78	26
60–80+	62	20.7
Marital status		
Single	192	64
Married	69	23
Divorced	7	2.3
Widowed	21	7
Cohabitating	11	3.7
Level of education		
No formal education	12	4
Primary	50	16.7
Secondary	111	37
Matric	84	28
Tertiary	43	14.3

> KFB66: "Sikubiza ngokuphambana umqondo." [We call it twisting of the mind.]
>
> KFI38: "It is called losing your mind."
>
> MFB53: "Kunjengokuhlukumezeka komqondo, so sikubiza kanjalo." [It is like an abuse of the mind, so that is how we call it.]

The excerpts imply that dementia alters a person's mind, leading to the person losing their mind or the mind getting twisted or abused. Although these descriptions do not adequately describe the construct of dementia; they indicate that the participants understand dementia as a disease that affects and changes a person's mind.

Some participants moved beyond the notion of dementia affecting the mind but recognised that it was also a sickness, which is involuntary. They also recognised that calling it a sickness of the mind is not its name, but they use this description in the absence of a name:

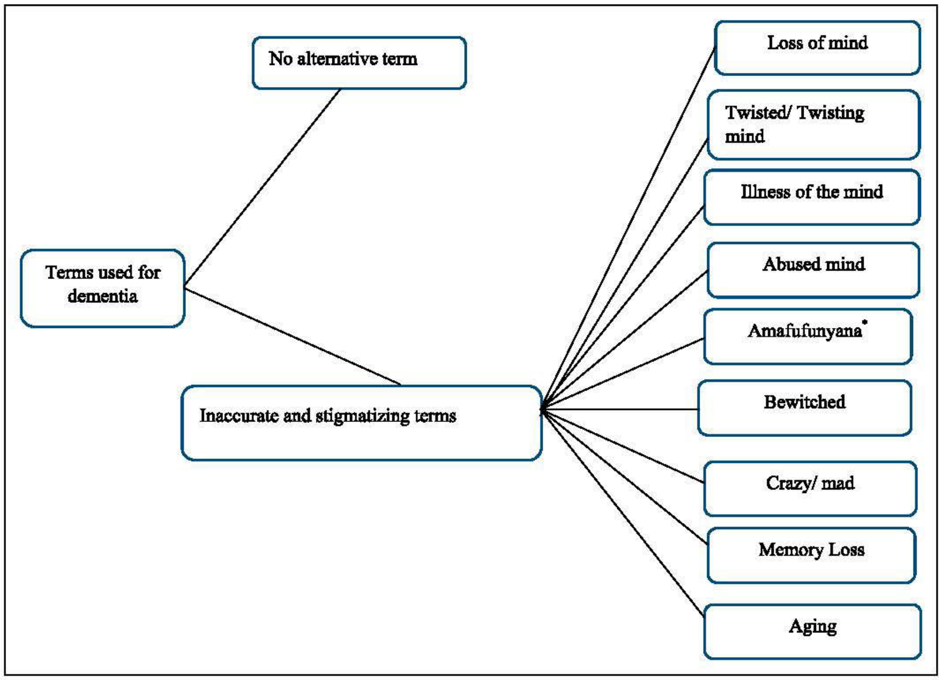

Figure 1. Thematic map demonstrating the themes and terms. *Amafufunyana means that a person has been bewitched to be possessed by an evil spirit that changes their behavior.

> NFB29: "Noma kungasilona igama kodwa sikubiza ngokugula…ukugula ngomqondo." [Although it is not a name, but we call it being sick, being sick in the mind.]

People with Dementia were Referred to as "mad" or "crazy"

Some participants referred to dementia as being called mad or crazy in their communities. The term was presented in different languages by the participants, with one Tamil-speaking participant calling it *paittiyam* and isiZulu-speaking participants calling it *ukuhlanya*:

> NMB71: "Kuyafana nomuntu osuke ehlanya, ukuhlanya." [It is like a person who is crazy…it is being crazy.]

> KFI61: "Oh, we call it like a mad person, like paittiyam in our language."

> MaFB158: "Ukuhlanya lokho." [That is being crazy.]

The notion that having dementia is the same as being crazy is usually associated with understanding dementia as a mental or mind illness. However, negative undertones suggest that some lose control of themselves (being mad or crazy), which could also imply a loss of autonomy, and in this way, dementia is seen as a dehumanising illness.

Dementia is Culturally Constructed

The terms reported in this subtheme were bewitched, witchcraft and *amafufunyana*; the latter refers to an African cultural illness that results when people are possessed by evil spirits through witchcraft, and therefore present with aberrant behaviour and psychological concerns. These words described the concept of dementia as a culture-bound illness:

> NFB47: "Sithi amafufunyana." [We call it amafufunyana.]
>
> MMB34: "Kuvame ukuthi kube izifo zabantu njengokuthi uthakathiwe." [It is usually illness caused by other people, such as being bewitched.]

The participants suggested that, in some African communities, people with dementia are seen as people who have been bewitched because they exhibit behaviours usually associated with possession by an evil entity. When dementia is equated to *amafufunyana*, it means that person has been bewitched to be possessed by an evil spirit that causes them to present with dementia symptoms. Also, attributing dementia to a particular cultural construct implies that dementia might only occur within that culture and not in other cultures. On the other hand, these terms show that although dementia is a western biomedical construct, the experience of it may vary across cultures.

Dementia is Identified based on its Characteristics

In this theme, 27.3% of the 44 participants reported that dementia was called *ukuguga* or ageing, memory loss or forgetfulness. These participants identified dementia based on when and how it occurs.

> MMB42: "Angithi yenziwa ukuguga, sikubiza ngokuguga." [It is caused by old age; it is called ageing.]
>
> KFI53: "It is called memory loss."

Dementia commonly affects older people, making the community believe it is an ageing disease. The terms 'memory loss' and 'ageing' focus on the characteristics of dementia rather than the disease itself. Although these terms describe some aspects of the disease such as that dementia affects old people and one of its primary symptoms is memory loss, they do not give a complete picture of what dementia is.

Community Reactions and Attitudes Towards People with Dementia

One hundred and 51 participants (50.3%) believed that people with dementia would be discriminated against in their community, 66 (22%) reported they would be treated well in their community, 45 (15%) believed they would not be discriminated against, and 38 (12.7%) participants were unsure how they would be treated in their community.

As presented in Table 2, 94.7% of the participants were willing to be neighbours with a person with dementia, whereas 5.3% were not. Moreover, 89.3% reported they would be friends with people with dementia, whereas 10.7% would not be friends. Lastly, 38.3% reported no problem being related to a person with dementia, whereas 61.7% of the 300 participants were not comfortable being related to someone with dementia. Almost two-thirds (64%) of those who reported dementia as being crazy and 50% of those who reported dementia as culturally constructed were unwilling to be personally associated with people with dementia.

Of the 300 participants, 77 (25.7%) reported having a person living with dementia in their families. Of these 77 participants, 51.9% reported ambivalence and shame about being related to a person with dementia. In addition, of these 77 participants, 49.4% believed their communities discriminated against people with dementia. Of all participants, less than a third (30.3%) reported that their communities had services for people with dementia.

Discussion

This study investigated communities' attitudes toward people with dementia by exploring how people spoke about people with dementia and their reactions towards people with dementia. It was observed that stigma existed in the studied communities, which might act as a barrier to creating dementia-friendly communities. Most participants reported the lack of adequate dementia synonymous terms in their communities. The lack of appropriate dementia terminology has also been reported in other African countries (Hindley et al., 2016; Khonje et al., 2015; M'belesso et al., 2016). When appropriate terms are unavailable, communities commonly develop their own colloquial terms based on their understanding of the symptoms and experience of the disease. For example, in this study, communities created their own terms or descriptions because there were no official terms. Some of these descriptions, i.e., dementia being called 'crazy', 'madness', 'twisting or loss of mind', 'witchcraft' and *amafufunyana,* had negative connotations and stigmatised people with dementia. Communities are encouraged to construct simple, inclusive, and accurate dementia terms in their languages to replace harmful terms that devalue people with dementia and reinforce their social exclusion in South African communities (Berdai Chaouni & De Donder, 2018).

Secondly, the participants understood that dementia occurred in older people and that the symptoms included forgetfulness; therefore, they described dementia as old age or forgetfulness. When symptoms of dementia are normalised as part of ageing, they depict ageing as being unhealthy. Therefore, older people are treated as different and with prejudiced. Older people are

Table 2. Social Tolerance and Community Reactions to People with Dementia (N = 300).

	Frequency of responses	
Social tolerance and community reactions	*n*	%
Neighbour		
Yes	284	94.7
No	16	5.3
Friend		
Yes	268	89.3
No	32	10.7
Family		
Yes	115	38.3
No	185	61.7
Community treatment		
Good	66	22
Bad	151	50.3
No problem	45	15
Unsure	38	12.7

already marginalised in most communities due to age (Evans, 2018). This is commonly known as ageist discrimination (Evans, 2018) and often crosses with other forms of stigma and discrimination (Jacobs et al., 2022). This means that older people then experience double stigmatisation - discrimination because of their age and dementia. Also, when dementia is recognized simply as ageing, it is normalised and not seen as a disease. Therefore, families might be reluctant to seek help when their loved ones start presenting with dementia symptoms (Jacobs et al., 2022). Normalizing dementia symptoms also means that the development and provision of services for people with dementia might not be prioritised in these communities because of the perception that the demand for services is low. Dementia community-based services in South African communities are already limited, as only a third of the participants reported having dementia services in their communities.

In many African communities, dementia has also been associated with cultural syndromes or being culture-bound (Berwald et al., 2016; Milne, 2010; Mkhonto & Hanssen, 2018; Mukadam & Livingston, 2012; Sayegh & Knight, 2013). In this study, dementia was also referred to as *amafufunyana*. *Amafufunyana* as a cultural construct is usually observed in African cultures. In addition, people with dementia were associated with other cultural phenomena, such as witchcraft (being bewitched or being a witch). This was also seen in another South African study (Mkhonto & Hanssen, 2018). Although witchcraft is not particular to Africa, in South Africa, it is a phenomenon that is associated with specific African traditions and cultures (de Jong et al., 2022). In South African communities, it is not uncommon for older women suspected of dementia to be accused of witchcraft and murdered by their communities (de Jong et al., 2022; KwaZulu-Natal Legislature, 2022), particularly in KZN and Eastern Cape provinces. Mkhonto & Hanssen (2018) reported that when people with dementia are associated with witchcraft, their lives are in danger as they can be abused, ostracised, and even killed. When dementia is associated with phenomena related to particular cultures, it discriminates against those with the disease and entire cultural groups.

Some families may prefer to conceal dementia within their families as they are afraid of being stigmatised or associated with the disease – stigma by association (Evans, 2018). Almost a third (61.7%) of the participants shared this view; they would prefer being neighbours over being related to a person with dementia. More than half of the participants (51.9%) with family members living with dementia reported negative reactions to being connected to a person with dementia. In addition, 64% of those who described dementia as a disease that affects the mind and 50% as a culture-bound syndrome were unwilling to be personally associated with people with dementia. Showing a link between the terms used and the participants' perceptions and attitudes towards people with dementia. When people with dementia and their families are stigmatised, it can impede help-seeking and increase feelings of low self-esteem, shame, and dehumanisation (Urbańska et al., 2015), as well as increase loneliness and isolation (Mukadam & Livingston, 2012).

Although some terms captured characteristics of dementia (i.e., dementia is a brain disease characterised by memory loss that can affect older people), some terms were offensive and discriminatory. Discriminatory terms seemed normalised and shared in some communities, indicating the possibility of unveiled or implied stigma (Adebiyi et al., 2016) against people with dementia. Stigma leads to social exclusion and rejection, making these communities unfriendly and unsafe for people with dementia.

Social tolerance and inclusion of people with dementia are crucial to creating dementia-friendly communities. The study found that tolerance of people with dementia was high when participants were asked to consider people with dementia as neighbours (94.7%) and friends but lower (38.5%) when they had to consider them as relatives or loved ones. This showed that, possibly due to social desirability, communities might display an attitude of tolerance towards people with dementia while simultaneously harbouring stigma. This was also suggested by 49.4% of the participants with relatives diagnosed with dementia. These participants reported that people with dementia were discriminated against in their communities. The discrimination of families might be one of the reasons why more than half of the participants (51.9%) who have a family member with dementia reported ambivalence and shame about being related to a person with dementia. Dementia discrimination can lead to families being socially excluded and ostracised (Gurayah, 2015; Mkhonto & Hanssen, 2018), and because of this, caregivers are likely to resent their role (Brodaty & Donkin, 2009), hide relatives with dementia and not seek help from formal health institutions and community services (Mukadam & Livingston, 2011; Jacobs et al., 2022).

There is an urgent need to reduce the stigma and negative connotations associated with dementia to improve the lives of people with dementia and their families, especially in low- and middle-income countries such as South Africa. Communities need to encourage acceptance and friendliness towards people with dementia. The South African government, in particular ministries of health, needs to prioritise dementia education and awareness, especially in KZN and Eastern Cape provinces, where dementia is still strongly associated with witchcraft and other negative perceptions.

Limitations

Data were not audio-recorded but were manually written into the data collection tool; audio-recording the interviews could have improved the richness of the extracts. This is because although all research assistants received training and captured data as verbatim as possible, some researchers wrote more information than others; for example, when participants were asked to give a name for dementia, some responses had more detail, whereas others just gave the term. It is unclear if this was because the participants did not elaborate or because of how data was captured. It is recommended that a voice recording function is added to the Mobenzi software.

Conclusion

The study found that some South African communities lack relevant and accurate terms to describe dementia. Most of the terms reported in this study showed that the communities have negative attitudes and might perpetuate stigmatisation of people with dementia. The terms were also inappropriate and did not correctly present or describe what dementia is. Updated and representative terms, and public awareness about dementia, might significantly reduce the stigma associated with dementia. The terms used to describe dementia need to focus on the abilities (rather than the deficits) of people with dementia and promote dignity while accurately depicting the disease. Tolerance of people with dementia might be superficial, with participants wanting to look or seem appropriate, but the language used shows the implicit presence of socially accepted public stigma. More intentional efforts are needed to use dementia-friendly terms and include services for people with dementia in South African communities.

Author Contributions

All authors listed contributed to the study's conceptualisation and writing of this article.

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4.5 Paper 4

This paper explored the relationship between depression, anxiety, and cognitive and daily functioning. This paper was submitted to the *Journal of behavioral neurology* and is under review. A copy of the manuscript that is in peer review is inserted below.

Investigating the multidirectional relationship between anxiety, depression, cognitive decline and the instrumental activities of daily living in a sample of older adults.

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Abstract

Background: Anxiety and depression are common psychiatric conditions affecting older adults and they are linked to low quality of life and other comorbidities like dementia.

Aim: To investigate depression and anxiety in older adults and their correlation with cognitive functioning and instrumental activities of daily living.

Setting: The study was conducted in low socioeconomic communities in the iLembe district, KwaZulu-Natal, South Africa.

Methods: A total of 320 participants, ≥60 years from the iLembe district, were assessed using the Mini-Mental Status Exam, Hospital Anxiety and Depression Scale and Instrumental Activities of Daily Living scale.

Results: In total, 16.6% of participants exhibited mild anxiety, and 21.9% had moderate to severe anxiety. As anxiety increased, cognitive impairment also increased, but no significant correlation was found between anxiety and instrumental activities of daily living. Additionally, 30% endorsed depression, with 18.8% reporting mild depression and 11.2% moderate to severe depression. Increased depression levels were correlated with increased anxiety. Moreover, as depression increased, cognitive functioning and independence in instrumental activities of daily living both declined.

Conclusion: Results indicate a high prevalence of anxiety and depression in older adults, highlighting the impact on cognitive functioning and daily activities. The findings emphasize the urgency of early detection and intervention to prevent adverse outcomes and reduce the burden on healthcare systems. Strengthening mental healthcare support for older individuals and promoting early identification and treatment is imperative for fostering healthy aging.

Keywords: anxiety; depression; cognitive impairment; activities of daily living; mental health.

Introduction

Anxiety and depression in older adults are common and increase the likelihood of adverse outcomes in daily functioning, disability, and mortality.[1-5] Globally, 13% of adults aged 70 experience anxiety and depression.[6] In Western countries, 1–3% of older adults exhibit major depression, 8–16% have clinically significant depressive symptoms,[2] and between 3.7% and 43% have anxiety.[3] Studies from the SSA region suggest an increased risk of depression in old age [4,6]. Depression and anxiety prevalence varies, with rates for depression ranging from 2.7% -9.7% in South Africa, 38.1% in the Central African region (CAR) and 41.8% in Ethiopia,[1-2,6,8] and anxiety reported to be 7.7% in CAR[1].

Anxiety and depression in older adults often coexist and are comorbid with other mental, medical, and neurocognitive disorders, such as dementia, psychosomatic disorders, and vascular disorders in older people.[2,5,8] A study conducted in Congo and Central African republic showed that anxiety and depression have a 5.7% comorbidity.[1] Severe comorbid symptoms correlate with cognitive impairment, with depression prevalence higher (44.1–49.6%) among those with cognitive decline, compared to 14.5% among those without cognitive decline.[3,9-11] Anxiety prevalence in people with mild cognitive impairment (MCI) is 14.3% in community samples and 31.2% in clinical samples.[12] Both anxiety and depression were linked to a high conversion rate of 25% - 28% of MCI to dementia,[13,14] A

Tanzanian study found that in dementia cases, anxiety (47.4%) and depression (33.3%) were amongst the most frequent symptoms.[16]

Depression negatively impacts instrumental activities of daily living (IADLs), and accounts for approximately 6% of years lived with disability among older people (WHO, 2017) .[15]Decline of IADLs in older adults with depression leads to dependence on family and caregivers[15], resulting in poorer quality of life. Therefore, monitoring activities of daily living in older people with depression is important, as it may indicate the severity of their depression and the need for alternative care arrangements. This may include medication, inpatient care, and the use of paid home care, especially in those with comorbid disorders such as anxiety, cognitive decline, and dementia.

Anxiety and depression in older adults have not been extensively studied in South Africa. Existing studies in South Africa on depression report varying prevalence rates. This research addresses the gap by measuring anxiety and depression in older adults and their correlation with cognitive and daily functioning in the South African context.

Research methods and design

Study design and setting

This cross-sectional study employed a door-to-door household survey in the rural and low socioeconomic iLembe District, situated about 75km north of Durban.

Study population and sampling strategy

We randomly sampled 320 participants aged ≥60 years. The sample was predominantly African, representative of the population of the iLembe district.

Data collection

Data collection occurred between October 2018 and December 2019. A biographical questionnaire was used to obtain the participants' characteristics, such as gender, age, home language, and education, while a clinical interview schedule assessed depression symptoms and comorbidities. Examples of the questions included 'Do you have problems with memory?', 'Have you been previously diagnosed with depression?', 'Do you have any chronic conditions such as stroke, angina, diabetes, arthritis, and asthma?', and 'What medications are you taking?'.

The Hospital Anxiety and Depression Scale (HADS)[17,18] was used to detect anxiety and depressive states. The HADS has two subscales, anxiety and depression, with each subscale scored separately. The score ranges for each subscale are: normal (0-7), mild (8-10), moderate (11-14), and severe (15-21).[18,19] Although many other scales assess depression and anxiety in older adults, most of these scales are individual scales assessing either or, whereas the HADS measures both factors. In addition, the HADS has been used in several studies as a screening tool to measure emotional distress, anxiety and depression in non-clinical settings, including those in Africa [20] and in older adults and has shown good specificity and sensitivity.[21-23]

Cognitive functioning was measured using the Mini-Mental State Examination (MMSE),[21] with a cut-off score of 21 for participants with education levels below grade 08 and 22 for those with grade 08 and above. These scores were used based on other literature where participants had low education levels.[22,23] This scoring adaptation was necessary as the MMSE tends to yield high false positives in samples with low education.[23] Lawton's Instrumental Activities of Daily Living Scale measured daily functioning.[24] Women were scored on all eight functions, whereas food preparation, housekeeping, and laundering were excluded for male participants. The scores range from 0 (low function, dependent) to 8 (high function, independent) for women and 0 to 5 for men. A decline is considered when a person has two or more areas of dysfunction. The validity of the IADLS has been reviewed in several studies.[25]

Data collection took place in the participants' homes in Ndwedwe, KwaDukuza, Maphumulo, and Mandeni, making up the four primary areas of the iLembe district. The interviews were conducted in either isiZulu or English, depending on the participant's preferred language.

Data analysis

Data were analyzed using the Statistical Package for Social Sciences-Version 27.[26] Depression and anxiety were ascertained using the HADS-D scores. Descriptive statistics are shown as frequencies and percentages for nominal variables. Chi-square tests (χ^2) of significance were used to compare the relationship between socio-demographic variables and anxiety and depression prevalence. Spearman's correlation (r) was used to assess the correlation between depression, anxiety, cognitive impairment, and instrumental activities of daily living. Significance was set at $p<0.05$.

Ethical considerations

Ethical clearance was obtained from the University of KwaZulu-Natal's Humanities Research Ethics Committee (reference: HSS/1016/017D). Written informed consent was obtained from the participants.

Results

Three hundred and twenty participants were recruited. The participants' ethnicity was African 225 (70.3%), Indian 84 (26.3%), Coloured 6 (1.9%) and White 5 (1.6%). The sample demographics, anxiety and depression scores are presented in Table 1.

Table 1. Sample characteristics, anxiety, and depression groups

Demographics	Anxiety N=123 (%)	p-value	Depression N=96 (%)	p-value	Overall N=320 (%)
Sex		0.026*		0.932	
Female	101 (82.1)		72 (75)		241 (75.3)
Male	22 (17.9)		24 (25)		79 (24.7)
Age group		0.474		0.013*	
60-69yrs	76 (61.8)		54 (56.2)		189 (59.)
70-79yrs	31 (25.2)		23 (24.)		93 (29.1)
80+yrs	16 (13)		19 (19.8)		38 (11.9)
Education		<0.001*		0.265	
Never attended	36 (29.3)		25 (26.)		62 (19.4)
Grade 1-7	59 (48)		44 (45.8)		159 (49.7)
Grade 8-11	25 (20.3)		21 (21.9)		72 (22.5)

Grade 12	1 (0.8)		2 (2.1)		14 (4.4)
Tertiary	2 (1.6)		4 (4.2)		13 (4.1)
Marital status		0.945		0.031*	
Married	44 (35,8)		30 (31.3)		108 (33.8)
Living together	3 (2.4)		3 (3.1)		7 (2.2)
Single	21 (17.1)		8 (8.3)		54 (16.9)
Divorced	3 (2.4)		5 (5.2)		10 (3.1)
Widowed	52(42.3)		50 (52.1)		141 (44.1)
Total household income		0.046*		0.606	
R1000-R3500	114 (92.7)		85 (88.5)		275 (85.9)
R3 501 -R5000	7 (5.7)		7 (7.3)		31 (9.7)
R5001 -R10000	2 (1.6)		4 (4.2)		12 (3.8)
R10000+	0		0		2 (0.6)
Hypertension		0.014*		0.019*	
No	31 (25.2)		23 (24)		107 (33.4)
Yes	92 (74.8)		73 (76)		213 (66.6)
Migraines		<0.001*		0.005*	
No	79 (64.2)		64 (66.7)		246 (76.9)
Yes	44 (35.8)		32 (33.3)		74 (23.1)
Cardiovascular disease		0.006*		0.006*	
No	110 (89.4)		85 (88.5)		301 (94.1)
Yes	13 (10.6)		11 (11.5)		19 (5.9)
High cholesterol		0.022*		0.014*	
No	87 (70.7)		66 (68.8)		248 (77.5)
Yes	36 (29.3)		30 (31.2)		72 (22.5)
Diabetes mellitus		0.875		0.363	
No	82 (66.7)		61 (63.5)		215 (67.2)
Yes	41 (33.3)		35 (36.5)		105 (32.8)
Depression diagnosis		0.015*		0.024*	
No	102 (82.9)		79 (82.3)		283 (88.4)
Yes	21 (17.1)		17 (17.7)		37 (11.6)
Dizziness and falling		0.001*		0.700	
No	85 (69.1)		74 (77.1)		251 (78.4)
Yes	38 (30.9)		22 (22.9)		69 (21.6)
Alcohol use		0.194		0.729	
No	92 (74.8)		73 (76)		246 (76.9)

Used to but stopped	19 (15.4)		10 (10.4)		37 (11.6)
Yes	12 (9.8)		13 (13.5)		37 (11.6)
Tobacco use		0.576		0.829	
No	103 (83.7)		76 (79.2)		259 (80.9)
Used to but stopped	7 (5.7)		7 (7.3)		23 (7.2)
Yes	13 (10.6)		13 (13.5)		38 (11.9)

Anxiety and depression

Among the 320 participants, 38.4% exhibited anxiety, of whom 16.6% (53) had mild anxiety, 17.2% (55) had moderate anxiety and 4.7% (15) had severe anxiety. A significant relationship was observed between anxiety and sex (*p*.026), education (*p*<.001) and household income (*p*.046). Anxiety was in 41.9% of females and 41.5% of those with a household income of R1,000 –R3,500. Anxiety was also associated with hypertension, migraines, cardiovascular disease, high cholesterol, and dizziness, as seen in table 1 above.

Depression was endorsed by 30% of the participants, with 18.8% (60) exhibiting mild depression, 8.4% (27) moderate and 2.8% (9) severe depression. Suicide ideation was reported by 28.2%. Of the 320 participants, 11.6% (37) confirmed a clinical diagnosis of depression and of the 37, 45.9% (17) had also endorsed depression on the HADS. A significant association was observed between depression and age (*p* .013) and marital status (*p*.031). Depression was more prevalent among widows than single and married participants. Medical conditions associated with depression were hypertension, migraines, cardiovascular disease, and high cholesterol.

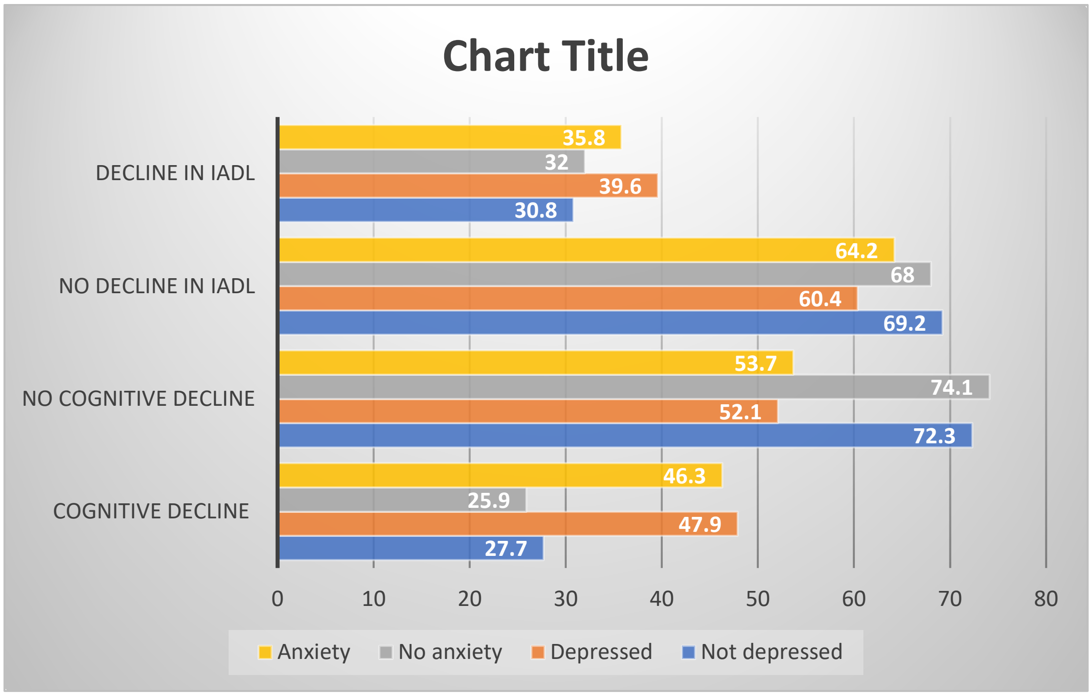

Figure 1. Anxiety, depression in relation to cognitive and daily functioning

Correlation between anxiety, depression and cognitive decline, activities of daily living

On the MMSE, 108 (33.8%) participants screened positive for cognitive impairment and of 320 participants, 241 (75.3%) reported experiencing unspecified memory difficulties, with 95 (39.4%) indicating that these memory difficulties occurred often. Of the 241 participants experiencing memory problems, 98 (40.7%) screened positive for cognitive decline. Of 320 participants, 33.4% had two or more areas of dysfunction on the IADLs, indicating a decline in daily functioning.

Of the 123 participants with anxiety, 57 (46.3%) also screened positive for cognitive impairment (figure 1). There was a small negative correlation between anxiety and cognitive decline (r= -.174, p=.002), indicating that higher anxiety levels correlate with lower cognitive functioning levels (Table 2). Whereas 44 (35.8%) of those with anxiety also experienced difficulties with IADL. There was a small positive correlation between anxiety and instrumental activities of daily living (r=.018, p=.748), suggesting that increased anxiety was not associated with a decline in IADL.

Table 2. Correlation between anxiety, depression, cognitive impairment, and daily functioning

Scale	1	2	3	4	5
1. Cognitive impairment (MMSE)	—				
3. Depression (HADS-D)	-.275**	.261**	—		
4. IADLS	.135*	-.239**	-.116*	—	
5. Anxiety (HADS-A)	-.174**	.212**	.356**	.018	—

**Significant at 0.05 level (2-tailed) ** Significant at 0.01 level (2-tailed)*

Of the 96 participants with depression, 46 (47.9%) also screened positive for cognitive impairment. There was a small negative correlation between depression and cognitive functioning (r=-.275, p=.000); thus, higher levels of depression correlated with lower levels of cognitive functioning. In those with depression, 38 (39.6%) also had a decline in IADL. There was a small, negative correlation between depression and IADL (r= -.116, p.039); depression increased as IADL decreased.

Of the 123 participants with anxiety, 60 (48.8%) also indicated depression. There was a medium positive correlation between anxiety and depression (r=.356, p=.000), meaning that as depression increases, anxiety also increases. Instrumental activities of daily living had a small, positive relationship with cognitive decline (r=.135, p .016), with higher levels of cognitive decline associated with decreased IADL.

Discussion

This study assessed the occurrence of depression and anxiety in older people aged ≥60 years. It further explored whether anxiety and depression were correlated with cognitive decline and decline in daily functioning. The results show that depression and anxiety are common in this group of older adults; anxiety was indicated in 38.4% and depression in 30% of the 320 participants. Depression occurred in 48.8% of the 123 participants with anxiety, confirming that these two disorders are usually comorbid, as reported by other literature.[1,2,5] This study's depression and anxiety rates are comparable to other global studies that reported high depression and anxiety rates in older adults,[1,3] but higher than those reported in other South African studies.[2,7] The high occurrence of depression and anxiety in older adults leads to higher healthcare utilization and costs, significantly burdening the healthcare system. The South African healthcare system is already overburdened and not coping with the population's healthcare needs, particularly for mental health.[27] This was evident in the Life Esidimeni tragedy, where people with chronic mental illness were displaced, and others died due to poor coordination and prioritization of mental healthcare in South Africa.[28]

Anxiety and depression in older adults were associated with cognitive decline, as found in other studies.[3,10-11] This means that as anxiety and depression increased, cognitive functioning decreased. In addition, cognitive decline was present in 47.9% of the 96 participants with depression and 46.3% of the 123 participants with anxiety, with other studies also reporting a high prevalence of between 44.1% and 49.6%.[3,10,11] Although depression and cognitive impairment can occur independently, they can also be comorbid. It is essential to consider that there is also a cause-and-effect relationship between depression and cognitive decline. Meaning that while depression can be a symptom of cognitive decline, it can also be a cause of cognitive decline. Therefore, there is a possibility that the high depression cases were, in fact, potential symptoms of dementia rather than independent conditions.

Increased depression was also correlated with an increased decline in IADLs. The association between depression, anxiety, cognitive impairment, and impairment in daily functioning suggests that, when older people with depression and anxiety do not receive early care, they risk a more aggressive cascade into functional disability, as well as the conversion of cognitive impairment into a more severe problem such as dementia, seriously decreasing their quality of life and life expectancy. According to WHO,[6] depression contributes to 5.6% of global years lived with disability (YLDs), and anxiety contributes to 3.4%. It is, therefore, important to actively reach out early to older people with depression and encourage treatment, as other studies have shown that treating anxiety and depression in older adults improves daily functioning and cognitive impairment, slowing the progression of MCI into dementia.[2,3]

Anxiety and depression contribute significantly to the overall cost of mental healthcare.[1] However, many healthcare systems are not well prepared to deal with these costs; for example, WHO[1] found that many countries, especially those in LMICs, had gaps in mental health information, governance (i.e., inadequate policies, plans, and laws) and allocation of resources to mental healthcare. In South Africa, the gaps in mental healthcare have been, for example, evident in budget cuts made by the KwaZulu Natal Department of Health, where a moratorium on the filling of posts of clinical psychologists and other allied healthcare professionals has been in place since 2008. This has limited the availability and accessibility of resources and services in the mental healthcare sector. The National Mental Health Policy Framework and Strategic Plan 2013–2020 was produced in 2012 to integrate mental health into general health services so that people needing treatment could access services at the community level; however, the plan has not been implemented to capacity because no budget has been made available.[27] Ongoing care efforts are essential in older people with anxiety and depression to ensure they remain actively engaged in their care to prevent, monitor, and manage the possibility of disease progression leading to cognitive and functional impairment. Ongoing care will alleviate depression and anxiety while improving the overall quality of life. However, ongoing care also calls for the health department to prioritize the mental healthcare of older adults by ensuring the availability and accessibility of the necessary professional services in primary healthcare institutions.

Due to the vast care gap for common mental health conditions such as depression and anxiety, WHO[6] recommends that countries diversify and scale-up care through non-specialist psychological counselling. In South Africa, this could be through employing registered psychological counsellors in areas where psychologists or psychiatrists are not readily available.

In conclusion, this study suggests that depression and anxiety in older adults are common and associated with cognitive and functional impairment. Depression significantly decreases cognitive functioning and IADLS, such as self-care and independence. Anxiety symptoms in older adults and the relationship between anxiety, cognitive functioning, and IADLs, have been studied less than depression and warrant deeper exploration. Older adults with comorbid anxiety and depression seem to display higher rates and more severe symptoms of depression and anxiety, with poorer adaptive and cognitive functioning. Literature.[1] also shows significantly more use of healthcare services, with a slower response to treatment in older adults with depression and anxiety. The high prevalence of depression and anxiety in older people emphasizes the need for early detection and treatment to reduce the possibility of adverse cognitive and functional impairment and increased costs for care. South Africa must strengthen support for older people and promote early identification and treatment of mental illness. In addition, to avoid the repeat of incidents such as Life Esidimeni, WHO[6] recommends the use of community-based mental healthcare, which is more accessible and acceptable than institutional care, helps prevent human rights violations, and delivers better recovery outcomes for people with mental health conditions, a sentiment echoed by the families of those who died in this incident.[27]

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Competing interests

The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article.

Author contributions

X.P.M. made an extensive contribution to the concept and design of the article, collected data and drafted the article, and finalised the version to be published. B.J.P. assisted with overseeing, made substantial remarks on the prepared article and approved the final version to be published. F.N. assisted with the statistical analysis.

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Data availability

The data supporting this study's findings are available on request from the corresponding author, [X.P.M]. The data are not publicly available due to their containing information that could compromise the privacy of research participants. Secondly, data is part of an ongoing PhD study.

Disclaimer

The views expressed in the submitted article are those of the authors and not an official position of UKZN or UCDP.

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CHAPTER 5

DISCUSSION

5.1 Introduction

The study investigated dementia prevalence and risk factors in adults who were ≥60 years old in the iLembe District, KwaZulu-Natal. In addition, the relationship between cognitive decline and anxiety and depression was further explored. Moreover, the study examined the communities' awareness and conceptualisation of dementia and dementia care practices. This chapter discusses the research results presented in Chapter 4. Lastly, research conclusions, limitations, and recommendations are provided.

5.2 Prevalence of Dementia

The prevalence of dementia in this study was 13.4%. Although there are no previous studies in the iLembe District to compare to, this rate was higher when compared to most South African studies, such as 11% in the Eastern Cape (De Jager et al., 2017), 6% in Bloemfontein (Van der Poel et al., 2012), and 7.9% in a nursing homes study in KwaZulu-Natal (Ramlall et al., 2013). However, this rate is comparable to another 2023 study conducted across two South African provinces, Limpopo and Cape town and reported a prevalence estimate of 12.5% (Farina et al., 2023). The variations in prevalence are expected, as the studies differed in sample characteristics such as education, district, and setting. For example, we conducted this study in a primarily rural district, whereas the two studies with the lowest prevalence (Ramlall et al., 2013; Van der Poel et al., 2012) were conducted in urban areas with samples that had a higher education mean when compared to our study. In addition, because the studies were conducted in different South African districts, differences in population growth trends might have contributed to the prevalence variations. For example, the province of KwaZulu-Natal has 937 000 older people compared to 291,000 in the Free State (Maluleke et al., 2023). It can be concluded that since ageing is a significant risk factor for dementia, a district with more older adults would have a higher prevalence of dementia. Lastly, the study with a comparable prevalence is newer like ours and has almost a similar sample size, which might be a confirmation that dementia is increasing as recent studies are showing higher estimates when compared to older studies. Although these two studies used different instruments, they both included reports from informants and older participants.

Although there are variations in the prevalence estimates, the results of this study suggest that dementia is high in the iLembe community, and it is projected that this might also mean it is steadily rising in South Africa due to similar trends of increased growth in numbers of older people and life expectancy throughout the country. The ageing index in SA for people 60 years and above increased from 30 in 2017 to 33 in 2022; the higher the index, the older the population (Maluleke, 2023). Also, the results suggest that dementia is elevated in community samples. This means that more people with dementia remain in communities undiagnosed and are not receiving care. This trend is expected in LMICs as there is a shortage of dementia services and facilities; therefore, people are taken care of by families and do not receive a formal diagnosis. Literature also speaks about the detection gap for dementia in communities of low socioeconomic status (Lang et al., 2017).

Lastly, of the 13.4% of participants with dementia in this study close to 58.1% were from rural communities, compared to 41.9% in urban communities, suggesting that dementia is more prevalent in rural than urban communities. Previous studies have reported that dementia was more prevalent in urban areas (De Jager et al., 2017; Van der Poel et al., 2012). One of the reasons for this contrast may be the lack of studies from rural areas in South Africa. In addition, it must be noted that although there was a positive association between dementia and rural settings on the Chi-square, the association was not reflected in regression models. The significance of the Chi-square test may reflect the higher number of participants from rural communities rather than a higher prevalence. With potentially increasing numbers of dementia, more than ever, the country must invest in reducing future disease risk and conducting more studies in rural areas to establish if there is a clear causal link.

This study indicated a higher prevalence when compared to other LMIC African countries such as Benin (2.6%–3.7%), Congo (5.7%–6.7%), Nigeria (2.8%–10.1%), the Central African Republic 6.6%–8.5%, Tanzania 6.4%–8.9%, and Egypt 2.3%–5.1% (Akinyemi et al., 2022; Guerchet et al., 2009; Gureje et al., 2011; Longdon et al., 2013; Ogunniyi et al., 2016; Paraïso et al., 2011; Yusuf et al., 2011). The prevalence was also higher compared to international studies in HICs such as the USA and UK. Dementia prevalence was 9.7% in England and 11.2% in the USA (Arapakis et al., 2021). Another longitudinal study from the UK found a dementia prevalence of 3.21% (Rusmaully et al., 2017). These results show that South Africa has a disproportionately high risk for dementia, when compared particularly to other African countries. This could be due to the increasing life expectancy rates in South Africa compared to other African countries such as Nigeria, CAR, DRC and Lesotho (Statista, 2023).

5.3 Factors Associated with Dementia

Risk factors associated with dementia in this study were ageing, education, depression, and not having a partner. Participants 80 years and above were 2.73 times more likely to develop dementia (*CI* 1.08-6.50, p=0.026) than participants below 80. Finding that age was associated with dementia was not surprising because this has been confirmed previously in multiple studies (ADI, 2015; de Jager et al., 2017; Longdon et al., 2012). All the participants were ≥60 years old, but the risk was higher in those who were ≥80 years old compared to the other age groups, which means that dementia is more prevalent in the 'older old'. Literature also confirms that a person's vulnerability to dementia increases as they age, doubling every five years from age 65 (Alzheimer's Association, 2019), with the risk snowballing after 80 years (Hugo & Ganguli, 2014).

Low levels of education were associated with increased dementia risk in this sample. Other studies in South Africa (de Jager et al., 2017) and SSA (Yusuf et al., 2011) have also reported an association between dementia and education. This study assessed educational attainment as the years of formal education completed. Those with the education level of Grades 1–7 had a 69% lower chance of developing dementia (*OR* 0.31; p=0.003) than those without formal education. The cognitive reserve theory suggests that high education reduces the risk of cognitive impairment and mild cognitive impairment (MCI) progression to dementia (Kvitting, 2019; Olivier et al., 2018; Ramlall et al., 2013; Yusuf et al., 2018). Enhancement of cognitive reserve could delay the onset of dementia (Borenstein et al., 2016). This is because a higher cognitive reserve "preserves metabolism and increases connections between the temporal and frontal lobes," meaning that "people in otherwise good physical health can sustain a higher burden of neuropathology without cognitive impairment" if they have a high cognitive reserve (Livingston et al., 2020, p. 416). The theory emphasises the importance of acquiring a good quality and high level of education in early life to prevent cognitive decline in late life (Clouston et al., 2019; Livingston et al., 2020). In contrast, in our study, 49.7% of the sample had less than eight years of education, and 19.4% had no formal education, contributing to low cognitive reserve and a higher risk of dementia.

Education is also used as an SES indicator (Ojagbemi et al., 2021), and with 69.1% of participants having less than eight years of education in one district, South Africa must aggressively develop and employ strategies to combat the lack of education in the country to reduce the risk of dementia and improve the SES of many South Africans. In addition, in most of SSA, because of a steady socioeconomic difference in health across the lifespan, the disadvantage of belonging to a low economic status may accumulate over the life course (Ojagbemi et al., 2021). This accumulation may, in turn, translate to significant risks to health, including the possibility of dementia by the age of 65 (Ojagbemi et al., 2017; Ojagbemi et al., 2021).

Being single and widowed in this study also increased the risk of dementia by three- and seven-fold, respectively. Literature shows that not having a spouse is linked to poor social engagement, loneliness, and isolation in older adults (National Academies of Sciences, Engineering, and Medicine, 2020; Ojagbemi et al., 2021; Yusuf et al., 2018). Other factors associated with loneliness and isolation in older adults include living alone, losing family or friends, chronic illness, and hearing loss (National Academies of Sciences, Engineering, and Medicine, 2020). In this study, 20% reported not having a partner, 44% had suffered a partner loss, and most participants had one or more chronic conditions. These results suggest a high rate of loneliness and isolation in our sample. Loneliness and isolation are associated with up to a 50% increase in dementia risk (National Academies of Sciences, Engineering, and Medicine, 2020).

Salinas et al. (2022) found a three-fold increase in the risk of subsequent dementia among lonely Americans older than 60 but younger than 80 years. Their study used a neuropsychological battery and MRI scans of the brain, and they found that loneliness in these participants was associated with poorer executive function, lower total cerebral volume, and more significant white matter injury, indicating vulnerability to cognitive decline (Salinas et al., 2022). There is enough evidence in the literature to suggest that older people who are lonely or isolated are more vulnerable to dementia than those who are not lonely (National Academies of Sciences, Engineering, and Medicine, 2020; Ojagbemi et al., 2021; Yusuf et al., 2018). Fortunately, loneliness and isolation are modifiable risk factors. They can be improved to protect against mental ageing by mobilising social support and programmes for older people in their communities and encouraging children or relatives to stay with older relatives after losing a spouse.

The last factor associated with dementia in this study is depression. Depression increased the risk of dementia by two-fold (*OR* 2.74; *p*=0.041). Depression in older adults is common and even more so in older adults with cognitive impairment (Di Iulio et al., 2010; Ma, 2020; Phung et al., 2014). In this study, 11.6% self-reported having depression, and 30% endorsed depression symptoms on the HADS-D. Depression can be an antecedent for dementia or a symptom of dementia (Brenowitz et al., 2021; Ramllal, 2013). As a dementia risk factor, depression in earlier adulthood appears to increase the risk of dementia in later life by 59% (Brenowitz et al., 2021). Some of the possible biological pathways linking depression to dementia include vascular disease, alterations in glucocorticoid steroids, and hippocampal atrophy (Byers & Yaffe, 2011). According to Geerlings and Gerritsen (2017) and Byers and Yaffe (2011), depression increases activity in the hypothalamus, which then stimulates the adrenal glands to produce more glucocorticoids, such as cortisol, damaging the hippocampus, which is responsible for cognitive function and memory.

If early-life depression is a risk factor for dementia, it must be aggressively treated to decrease rates of late-life cognitive impairment. Our participants reported late-life depression, and in contrast to early-life depression, the onset of depression in late life is believed to be an early sign of vascular or degenerative disease that causes dementia (Byers & Yaffe, 2011). This would suggest that 30% of the study participants are at significant risk of dementia. This is a high number and, as stated by Ramlall (2013), the multifaceted relationship between depression and dementia means that assessing and treating depression is essential when evaluating cognitive decline in older adults.

Another psychological factor explored in this study was the association of anxiety with cognitive impairment. The study found that anxiety was high in this sample and commonly occurred with depression in older adults. Anxiety was also high in those with cognitive decline and as anxiety increased so did cognitive impairment, showing a clear nexus between the two factors. Based on these results and as anxiety is commonly associated with cognitive decline in older adults, more research to explore anxiety in dementia is needed.

Other known dementia correlates not found in this study include but are not limited to gender and vascular risk factors (ADI, 2015; WHO, 2017). Although a higher frequency of dementia was found in women in this study, it was not significantly associated with dementia in this study. Possibly, the high frequency might be due to the large number of female participants compared to male participants and not necessarily a high dementia prevalence in females since a within-group analysis was not done. Vascular diseases have also been associated with an increased risk of dementia (ADI, 2015; Akinyemi et al., 2021; Livingston et al., 2020; WHO, 2017). Despite this, our study found no significant relationship between these two factors and dementia. Perhaps our overall sample size was not large enough, and our study did not measure vascular risk as a factor. Still, we measured the risks of each vascular-related problem, such as hypertension, cardiovascular disease, raised cholesterol, diabetes, and stroke. As assumed by the biopsychosocial theory, the results and literature suggest that dementia risk is not determined by a single factor in a single life period but by the complex interplay between genetic and environmental exposures throughout one’s life course (Boundless Psychology, 2015).

5.4 Knowledge and Understanding of Dementia

The last objective of the study was to explore the community’s awareness and conceptualisation of dementia, dementia care preferences, and attitudes toward PWD. It was essential to explore knowledge and understanding of dementia, as they affect healthcare preferences and attitudes toward PWD. In this study, 94% of the participants identified that cognitive decline was a symptom of illness. However, only 12% of participants could specify that the symptoms were of a condition called dementia. Most participants named the symptoms of cognitive decline as an illness of old age (35%), while 30.1% referred to them as mental illness and 19.8% as other forms of vascular disease.

Dementia knowledge in sub-Saharan African countries is regarded as poor (Ogunniyi et al., 2005). One of the reasons is that participants could not recognise or understand the term dementia (Mkhonto & Hanssen, 2017; Mushi et al., 2014; Owokuhaisa et al., 2020; Raghavan & Patel, 2018). In this study, although only a few participants used the term dementia to refer to symptoms, most identified that the symptoms represented an illness. This is important because when people understand symptoms as an illness, they are more open to seeking help or healthcare. People’s conceptualisation of symptoms and illness allows them to develop meaningful patterns of health promotion, care preferences and health-seeking behaviour (Ogunniyi et al., 2005; Patel, 2011). This is because people’s help-seeking behaviours usually correspond to their interpretations of the sources of wellness or causes of distress, as suggested by Kleinman’s theory of explanatory models of illness (Kleinman et al., 1978). Kleinman (1995) and Dinos et al. (2017) reported that people have different explanatory models for conceptualising illness, and these models provide culturally specific explanations about how health and wellness are achieved and the meaning of symptoms and causes of distress and disease. In addition, people’s conceptualisation of symptoms and illness allows them to develop meaningful patterns of health promotion, care preferences, and health-seeking behaviour (Ogunniyi et al., 2005).

Given that most of the participants were African and from rural areas, it was hypothesised that participants would prefer a sociocultural explanation of dementia over a biomedical explanation. However, most participants identified medical and mental illness (e.g., diabetes, hypertension, depression, and trauma) as risk factors for dementia, in keeping with a biomedical conceptualisation of disease. Fewer than 1% of the participants used a cultural explanatory model, reporting that dementia was caused by ancestral problems and by not being a prayerful person. In contrast to our findings, participants in other African studies had used a cultural model to explain dementia, such as that dementia is due to witchcraft, sinning, or that PWD are witches (Berwald et al., 2016; Cipriani & Borin, 2014; Owokuhaisa et al., 2020; Milne, 2010; Mkhonto & Hanssen, 2018; Mukadam & Livingston, 2012; Sayegh & Knight, 2013). The difference in how our participants conceptualised dementia compared to those in the cited studies might be because some participants knew or had been exposed to information about dementia before this study. For example, 40.7% reported hearing about dementia before this study, from hospitals, the media, and other sources, while 25.7% reported having relatives who have dementia. This rate included relatives who were not participating in this study. Again, this shows that dementia rates in the community might be higher than what was found in this study, as 13.4% is only limited to people who participated in this study.

Help-seeking intentions were high in our participants, as 87.7% reported that they would seek help if they or their relatives had dementia. Meanwhile, 86.7% reported that they would use multi-disciplinary services inclusive of medical and psychiatric care, as well as pastoral and traditional interventions. Since the participants had used a biomedical understanding of dementia, it was assumed that they would prefer biomedical interventions. However, South Africans often prefer multiple care services for illness (Patel, 2011; Shai & Sodi, 2015). The preference for MDT care was significant because the management of dementia reaches beyond just managing the patient's symptoms and extends to helping family members, caregivers, and support networks of those with the disease (Grand et al., 2011). This is because dementia has no medical cure, and most of the burden of care is social and falls on families and caregivers. With this burden of care, families and caregivers of PWD can experience increased emotional stress, depression, and health problems (Gurayah, 2015; Hugo & Ganguli, 2014), making the support and care provided by the MDT necessary to reduce the burden of dementia on both patients and families. This is also inline with the assumptions of the biopsychosocial theory, because dementia is caused by an interplay between multiple factors, it is sensible that management would be multidisciplinary.

Like other African studies (Hindley et al., 2016; Khonje et al., 2015; M'belesso et al., 2016), most of the participants in this study reported that there is a lack of adequate terms synonymous with dementia in their communities and in their languages. The participants used terms such as *old age illness*, *memory loss*, *crazy*, *madness*, *twisting or loss of mind*, *witchcraft*, and *amafufunyana* to explain what dementia is known as in their communities.

These results show that communities developed colloquial terms or descriptions based on how they conceptualised and experienced the disease. These terms were shared within communities, suggesting that they are socially constructed. Unfortunately, most of these terms have negative connotations and discriminate against dementia (the disease) and PWD. When discriminatory terms for an illness are normalised and shared in social groups, they can easily lead to stigma.

Stigma hinders the development of dementia-inclusive communities. This is because stigma leads to social exclusion and rejection, making these communities unsafe for PWD. The terminology used to refer to PWD led us to conclude that the studied communities held covert stigma against PWD, and some participants confirmed that PWD would be stigmatised in their communities. Due to stigma, families might be reluctant to seek help when relatives begin to show symptoms associated with dementia (Jacobs et al., 2022), and some may conceal the diagnosis due to fear of stigma by association (Evans, 2018). More than half of the participants (51.9%) related to PWD reported negative attitudes toward being associated with someone with dementia. Moreover, stigma perpetuates feelings of low self-esteem, shame, loneliness (Urbańska et al., 2015), and social exclusion (Mukadam & Livingston, 2012) of PWD and their families.

Social inclusion and tolerance of those with dementia are essential for developing dementia-friendly communities. Most of the study participants (94.7%) reported a negative attitude towards PWD when asked to consider people with dementia as neighbours. However, 38.5% had a tolerant attitude, considering a person with dementia as a relative or loved one. This showed that, due to social desirability and fear of exclusion and discrimination, communities might display an attitude of tolerance towards people with dementia while harbouring self-stigma.

To create dementia-friendly communities, educational programmes that increase knowledge and awareness about dementia must be prioritised. Increasing knowledge will not only increase help-seeking behaviour in PWD and their families, but it will also help to alleviate stigma and increase social cohesion and the inclusion of PWD into their communities.

5.5 Limitations

One of the limitations of the study is that it was conducted in only one district. Hence, the results do not represent other communities within South Africa. However, the results represent any homogeneous, low-income community similar to that of the iLembe District. A methodological limitation was that the study used a cross-sectional design. Since this design is a one-time measurement of exposure and outcome, it is challenging to derive causal relationships from cross-sectional analysis (Setia, 2016).

A second limitation was not conducting the within-group comparisons of significant differences for factors such as age groups, setting (rural/urban) and gender (female/male). Due to this, in particular for setting and gender, it cannot be specified whether or not dementia was associated with these factors. Although there is a significant difference on the Chi-square test, the difference could be attributed to large numbers of those within the female and rural groups. The regression models also did not confirm the association between these two factors. Therefore, the results must be read cautiously for these two factors.

Lastly, although the MMSE in this study had good reliability, sensitivity, and specificity, the use of the MMSE, particularly in populations with low levels of education and who are not English-first-language speakers, can result in false positive screening for dementia (Bernard & Goldman, 2010). The literature recommends that the MMSE is not used alone to diagnose dementia, but rather it is used with other instruments, and score adjustments are done according to participant characteristics (El-Tallawy et al., 2013). Following this recommendation, this study used a combination of tests that included informant reports of the participant's cognitive and daily functioning (AD8 and IADLS) and only counted participants as having dementia if the combined test results all indicated impairment in cognition or daily functioning corresponding with the DSM-5 and ICD-11 criteria for dementia.

Notwithstanding these limitations, the study provides insight relevant to issues related to dementia prevalence in South Africa and other developing countries. The strengths of this study include the random population-based sampling, with a high response rate and low rate of missing data. Our study population broadly represents older black populations in low-income rural regions of South Africa.

5.6 Recommendations

5.6.1 Recommendations for Reducing Future Prevalence and Risk

This study recommends that South Africa adopt a life-course model that uses modifiable risk factors to reduce future dementia prevalence and risk (Livingston et al., 2017; Livingston et al., 2020). This model has been used in HICs, where modifiable dementia risks are identified and targeted for management early to prevent cognitive impairment in late life. Identifying and reducing risks, such as increasing the quality and levels of education and improving the control of depression, can effectively lower the incidence of dementia (WHO, 2017). For example, a life-course strategy would include prioritising good education in childhood and adolescence to boost cognitive reserve in later life and prioritising reducing alcohol intake, smoking, and weight control in midlife, to prevent dementia in late life.

5.6.2 Recommendations for clinical practice

Due to the rise in dementia prevalence, the demand for accessible community resources to diagnose and care for those affected will also increase. As the first line of contact to healthcare, primary care services need to be accessible and to improve geriatric services. The PHC sector needs to adopt a collaborative model of care. A collaborative approach would promote, support, and allow the public healthcare personnel to monitor and plan for the continuation of care, including day care and relief for family members of PWD.

To effectively manage dementia, a PHC-focussed dementia intervention strategy is necessary as this primary-level approach will reach many potential referrals, especially those residing in rural areas (Kalula & Petros 2011). PHC must include efficient methods to assess patient care needs and provide flexible management plans and appropriate support systems, in keeping with those offered in tertiary institutions using the memory clinic model which uses MDTs. An integrated multi-disciplinary approach to diagnosing and managing dementia is highly recommended in PHC because no single healthcare specialty has the expertise to deal with the complex problems associated with dementia (Grand et al., 2011). In addition, older adults are identified as high-volume and high-frequency users of the healthcare system due to multiple comorbidities and other age-related illnesses (National Academies of Sciences, Engineering, and Medicine, 2020); this allows routine cognitive screenings to be incorporated at PHC level during regular clinic or hospital visits. For example, when fetching medications or appointments for other chronic conditions such as diabetes, older adults can also be screened for cognitive functioning. Incorporating dementia screening and care into primary healthcare will help reduce the treatment gap between people diagnosed with dementia and those living with dementia but undiagnosed. For this to be implemented, the country must invest more in prioritising the healthcare needs of older people. In addition, as Lisko et al. (2021) recommended, there needs to be close collaboration between multiple stakeholders such as researchers, clinicians, policymakers, and older adults. In addition, investment in and use of new technologies to support and manage dementia symptoms are needed to implement the research recommendations.

Moreover, in SSA research and clinical practice, there is no consensus on the best methods to test cognitive function and screen for dementia (Kobayashi et al., 2019). A recommendation made in a study by Ramlall (2013) is echoed in this study. Ramlall (2013) explored the usefulness of multiple neuropsychological tests to standardise testing and reach a consensus on the best tests for South Africans. We recommend that there is uniformity or agreement on tests used to assess dementia in South African hospitals. This will ensure that one standard assessment protocol is used in all districts and thereby reduce the degree of variation in dementia statistics.

In a setting like ours, where most of our participants had low levels of education, selecting neuropsychological tools must involve a thoughtful consideration of various factors to ensure their appropriateness and effectiveness. Although not always possible, given the lack of tools developed for South African older adults with low levels of education, as far as possible, the tools used in this study had to consider factors such as cultural sensitivity and adaptability. Most of the assessments used were oral-based assessments. This is because oral-based assessments may be preferred in poor literacy settings, where individuals may struggle with reading and writing. Tools that rely on spoken language rather than written responses can be more inclusive and better suited to the population's abilities. In addition, where possible, isiZulu versions of tests were used, for example, the IsiZulu MMSE, RAVLT and COWAT. The norms and usefulness of these versions will be measured in another paper.

Moreover, assessments such as the Trails and CDT provided a more flexible assessment approach that accommodates various levels of literacy as they have alternate response formats. Lastly, assessments that included information from informants such as the AD8 and the IADLS were also used to triangulate information. The goal was to comprehensively understand the participants' cognitive abilities while respecting their unique circumstances and challenges.

5.6.3 Recommendations for Improving Community Awareness and Fostering Dementia-Friendly and Inclusive Communities

There is an urgent need to create dementia-friendly communities and reduce the stigma associated with dementia, to improve the lives of those with dementia and their families. Building dementia-friendly communities entails involving PWD and their families in community activities and developing community care centres to support them. It would also include encouraging acceptance and dispelling stigma and false beliefs about PWD, such as the belief that people with dementia are witches or have been bewitched (de Jong et al., 2022; KwaZulu-Natal Legislature, 2022; Mkhonto & Hanssen, 2017). Mkhonto and Hansen (2017) recommend that awareness talks in churches, schools, and clinics, as well as facilitating support groups for carers of people with dementia, would assist in dispelling myths and misinformation about dementia.

This study found that most communities do not have African terms for dementia, and the terms used by African communities are frequently stigmatising. Therefore, as part of strategies to foster dementia and inclusive communities, an initiative is recommended to develop appropriate and non-discriminatory language.

5.6.4 Recommendations for Future Research

Research on dementia in South Africa is still limited and there is a lack of studies that are representative of all provinces. Secondly, there are no longitudinal studies to help ascertain the accurate trajectory of dementia in the country. Based on these, this study recommends that future dementia research include longitudinal studies to study the causal relationship between the identified modifiable risk factors and dementia. Such studies will assist us in developing and implementing robust strategies to modify risk factors to reduce dementia.

Another research recommendation is based on the results concerning the association between education and dementia. It was noted that most older African participants in this study had fewer than eight years of education, which might have affected the results. However, as suggested by Akinyemi et al. (2022), it is likely that this low level of formal education may not be an appropriate indicator of cognitive reserve, as many older Africans play key social roles and have community responsibilities; these better reflect their cognitive ability and likely play a role in maintaining cognitive reserve despite their having minimal formal Western education. Therefore, we recommend that future research on dementia explore the concept of cognitive reserve, including what it means and how it can be measured in African populations.

Lastly, as suggested above, the study found that South Africa does not have locally developed and standardised neuropsychological assessments to screen for dementia. This causes variation in the results of assessments conducted through research and clinical practice. Therefore, we recommend that future research be done on developing culture-sensitive tests for older South African people.

5.7 Conclusions

Dementia prevalence was higher than expected in this sample. This might be a confirmation that dementia is increasing in our population. Many PWD in South African communities remain undiagnosed and do not have access to the care and support that a formal diagnosis potentially provides. The identified risk factors for dementia were ageing, low levels of education, lack of a spouse, and depression. It is important to note that most of the present risk factors in our communities fall under modifiable factors. This gives reason to believe that the increase in dementia prevalence can still be managed. Dementia risk reduction in South African communities must start with improving the community's knowledge of dementia and include following a life-course risk-reduction model. Understanding how societies conceptualise dementia extends the pathways for policy development and public health initiatives for risk reduction and improving care for PWD and their caregivers. The public health system must work with all stakeholders in the community to support caregivers and adopt a collaborative health model. Public health initiatives may include incorporating MDT services into PHC for early detection, support, and care for PWD and their families.

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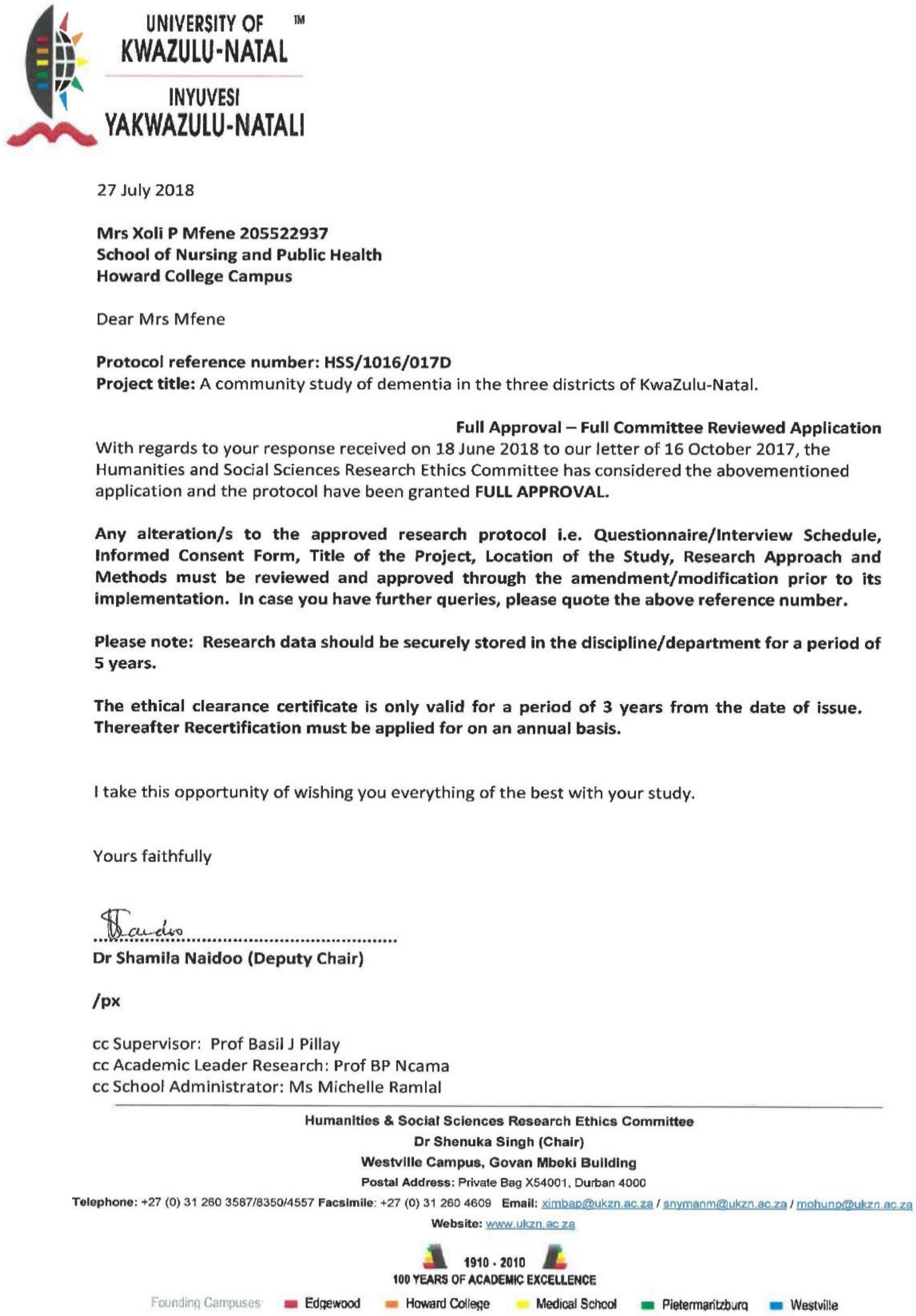
APPENDICES

Appendix I: Ethical clearance letter



UNIVERSITY OF KWAZULU-NATAL™
INYUVESI YAKWAZULU-NATALI

27 July 2018

Mrs Xoli P Mfene 205522937
School of Nursing and Public Health
Howard College Campus

Dear Mrs Mfene

Protocol reference number: HSS/1016/017D
Project title: A community study of dementia in the three districts of KwaZulu-Natal.

Full Approval – Full Committee Reviewed Application

With regards to your response received on 18 June 2018 to our letter of 16 October 2017, the Humanities and Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have 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 3 years 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 Shamila Naidoo (Deputy Chair)

/px

cc Supervisor: Prof Basil J Pillay
cc Academic Leader Research: Prof BP Ncama
cc School Administrator: Ms Michelle Ramlal

Humanities & Social Sciences Research Ethics Committee
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Appendix II: Information Sheet

Dear prospective participant,

My name is Xoli Precious Mfene. I am a Ph.D. candidate studying at the University of KwaZulu-Natal. I am currently conducting a study titled **Dementia knowledge, prevalence, and risk factors in a community sample of older adults from iLembe District**. The study aims to explore the occurrence and understanding of dementia.

Please note that:

- The information that you provide will be used for academic research.
- Your participation is entirely voluntary. You have a choice to participate, not to participate or stop participation in the study at any time. Non-participation or withdrawal from the study will not negatively affect you.
- Your views in this interview will be presented anonymously. Neither your name nor identity will be disclosed in the study; instead, codes will be used.
- The interview has three components: (i) an open-ended interview which will take approximately 10 minutes; (ii) A neuropsychological assessment to look at your cognitive functioning which will take approximately 60-90 minutes; (iii) An interview with your family member, this will take about 20 minutes.
- Following receipt of the completed questionnaires, the results will be analysed and will inform the proposed study. The results may also be communicated to the relevant stakeholders in the Department of Health and published in scientific

journals. You can request a copy of the results should you need them.

- The interview data will be stored in a password-protected file accessible only to the researcher and her supervisor. After five years, in line with the university's rules, data will be disposed of by shredding or burning.

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

If you have any problems, concerns/or questions, you may contact the researcher or the supervisor or the UKZN Humanities & Social Sciences Research Ethics Committee on the details below:

Ms Xoli Mfene, Clinical Psychologist/Researcher (033 260 5588), University of KwaZulu Natal, xolimfene@gmail.com

Professor Basil Pillay, Chief Clinical Psychologist, Department of Behavioral Medicine, University of KwaZulu Natal- Howard College (031 260 4324), Pillayb@ukzn.ac.za

Humanities & Social Sciences Research Ethics Committee, Research Office, Westville Campus, Govan Mbeki Building. Tel: 031 260 3587, ximbap@ukzn.ac.za

Thank you for your contribution to this research

Appendix III: Consent Form

I………………………………………………………………………… (*full names of participant*) confirm that I understand the contents of this document and the nature of the research project, and I agree to participate in the research project.

I understand that I can withdraw from the project at any time and will not be punished. I agree to participate.

I agree/do not agree to have this interview recorded.

…………………………………….   ……………………..
Signature of participant   Date

If the participant cannot give full consent, consent is required from the primary caregiver.

I………………………………………………………………………… (*Full names of caregiver*) confirm that I understand the contents of this document and the nature of the research project, and I agree to …………………………………………….. (*Name of participant*) participating in the research project.

I agree/do not agree to have this interview recorded (if applicable).

………………………………….   ……………………..
Signature of participant   Date

Appendix IV: Survey Questionnaire

Thank you for agreeing to complete this interview. It is important that you answer the questions to your best ability and knowledge; if you do not understand or do not want to answer any of the questions, please let me know. The first set of questions is about you and your living conditions.

SECTION A: DEMOGRAPHIC DATA

1. Name	
2. Sex	
3. What is your date of birth: (request the participant's ID book)	
4. Race	
5. What is your nationality?	
6. What is your home language?	
7. What is your religion?	
8. Highest level of education	
9. Occupation	
10. Marital status	
11. How many children do you have?	

12. Residential area: _____________ District _____________

Municipality___________

13. Setting: Urban [ ] Rural [ ] Semi-urban/Township [ ]

14. What is your phone number? ………………………………………………

15. What is your employment status?

Employed [ ] Unemployed but not pensioner [ ] Pensioner [ ]

16. What is the total monthly income for the household (range)?

R1000 - R3500 [ ] R3500 - R5000 [ ] R5000 - R10 000 [ ] ≥R10000 [ ]

17. Where does most of the income come from? Expect multiple selected options.

Pension [ ] Child support grant [ ] Salary [ ] Support from family/friends/other [ ]

18. Who is the head of the family?

Self [ ] Spouse [ ] Daughter [ ] Son [ ] Sibling [ ] Other [ ]

19. Have you always lived here?

Yes [ ] No [ ]

Skip when *Residence* Not Equal 'No'

20. What is the name of your last place of residence?

…………………………………...

21. Do you own or rent this home? ………………………………

22. Type of dwelling:

Formal [ ] Informal [ ] RDP /low-cost housing [ ] Out-building [ ]

Flat [ ] Semi-detached dwelling [ ] Other [ ]

23. My surname is xxxxxxxx. I would like you to repeat my surname for me.

Cannot repeat name [ ] Successfully repeats name [ ]

Now please remember my surname. I am going to ask you to say it again in a few minutes.

SECTION B: CLINICAL DATA

Thank you, now I would like to ask you some questions about your health. Over the last year, have you experienced any of the following, at least once a week?

25. Do you have any problems with memory or forgetfulness?

Yes [ ] No [ ] Unable to answer [ ]

26. Do you forget what you have just read or heard (e.g., in a conversation)?

Rarely or never [ ] Occasionally [ ] Often [ ]

27. Do you find it difficult to control what you say or do (impulses)?

Yes [ ] No [ ] Unable to answer [ ]

28. Do you have difficulties with making decisions?

Yes [ ] No [ ] Unable to answer [ ]

29. Do you have difficulty with planning and organising daily activities?

Yes [ ]   No [ ]   Unable to answer [ ]

30. At least once a week, do you feel you cannot cope when you have many things to do at the same time?

Yes [ ]   No [ ]   Unable to answer [ ]

31. Do you have difficulties with your concentration or attention?

Yes [ ]   No [ ]   Unable to answer [ ]

32. Do you have difficulty finding the right words when you speak?

Yes [ ]   No [ ]   Unable to answer [ ]

33. Do you find it difficult to understand what people are saying?

Yes [ ]   No [ ]   Unable to answer [ ]

34. At least once a week, do you have difficulty finding your way around your home?

Yes [ ]   No [ ]   Unable to answer [ ]

35. Do you have difficulty finding your way around other places (such as the shopping centre/home of a friend/relative/church etc)?

Yes [ ]   No [ ]   Unable to answer [ ]

36. Are you experiencing any of the following symptoms? Expect multiple selected options.

Stiffness (rigidity) [ ] Shaking limbs or head (tremors) [ ] Feeling slowed down in your movements [ ] None [ ]

37.1 Do you hear things which others do not seem to hear (clarify that these are hallucinations)?

Yes [ ] No [ ]

37.2 If yes, what is the hallucination?

38.1 Do you see things which others do not seem to see (clarify that these are hallucinations)?

Yes [ ] No [ ]

38.2 If yes, ask what they see.

39.1 Do you think or believe that other people are out to hurt or harm you?

Yes [ ] No [ ]

39.2 If yes, why?

Skip when *People out to harm you* Not Equal 'Yes'

39.3 Specify Harm

40 When did these difficulties start? ……………………………………..

41 Which problems started first? Expect multiple selected options.

Memory problems [ ]   Language/speech problems [ ]   Executive functioning[ ]

Hallucinations [ ]   Attention/concentration problems [ ]   Motor problems [ ]

Visual-perception problems [ ]   Unsure [ ]   No problems [ ]

If response includes 'No problems' then skip to *Compared to when you were younger [49].*

42 Were these problems

Gradual [ ]   Sudden [ ]   Unclear [ ]

43 How often do these difficulties happen?

Rarely [ ]   Occasionally/sometimes [ ]   A lot/frequently [ ]

44.1 When these difficulties started, was there a causing event or condition?

Yes [ ]   No [ ]

44.2 If yes, what was the trigger? ……. ………………………………………..

45 Do these problems make it difficult to perform your daily activities?

No [ ]   Occasionally/sometimes [ ]   A lot/frequently [ ]

46 How are your problems compared to others your age?

The same or better [ ]   Somewhat worse [ ]   Much worse [ ]

47 Rate your problems on a scale of 1-10 with 1 worst and 10 best.

9-10 [ ] 5-8 [ ] 1-4 [ ]

48 What is your understanding of what is happening to you? (What do you think having these difficulties means?) ……………………………………………………..

49 How is your functioning compared to when you were younger?

Same or better [ ] Somewhat worse [ ] Much worse [ ]

50 Do you have any of the following difficulties? Expect multiple selected options.

Frailty [ ] Urinary incontinence [ ] Falls [ ] Delirium [ ]

Pressure ulcers (e.g., bed sores) [ ] None [ ]

Skip when *Geriatric syndromes* Includes 'None'

51 When did they start? ……………………………………………………………..

SECTION C: PSYCHOMETRIC DATA

52 Mini Mental Status Exam (MMSE)

53 Please copy this design. [Display the intersecting circles on the stimulus form.] Score 1 point if the drawing consists of two circles that intersect to form a 1 figure.

54 Clock Drawing Test (CDT)

55 Europe Depression Scale (EURO-D)

56 Trails A&B

57 Hospital Anxiety and Depression Scale (HADS)

58 General Health Questionnaire-12

59 Rey Auditory Verbal Learning Test (RAVLT)

60 Can you please list your currently daily activities at home?..

61.1 Can you please select your current daily activities at home. Expect multiple selected options.

Washes dishes [ ] Cooks [ ] Sweeps the floor or yard [ ]

Gardening [ ] Takes out the trash [ ] Makes his/her bed [ ]

Washes laundry [ ] Other [ ] None [ ]

Skip when *Daily activities* Excludes 'Other'.

61.2 Please specify other: ………………………………………………………………….

62 Do you participate in activities outside the home, in the community?

Yes [ ] No [ ]

63.1 I am going to read a list of activities and I want you to tell me whether you do them and if you do the activity, how often. Expect multiple selected options.

Bicycle or hiking [ ] Doing hair [ ] Exercise [ ] Dance [ ]

Singing [ ] Fishing/hunting [ ] Neighbourhood association [ ]

Senior social club [ ] Volunteer [ ] Sports [ ] Church [ ]

Other [ ]

Skip when *Activities in the community* Excludes 'Other'.

63.2 Other activity……………………………………………………………………….

64.1 Do you drive a car?

Yes [ ] No [ ]

Skip when *Have car Not* Equal 'Yes'.

64.2 If yes, how often do you drive a car?

Daily or almost every day [ ] 3-4 times a week [ ] Once or twice a week [ ]

Once or twice a month [ ]

Skip when *Have car* Equals 'Yes'.

64.3 If no, why do you not drive?..

Now I am going to ask you a few questions about your family.

65 Who do you stay with at home? Expect multiple selected options (required)

Spouse/partner [ ] Children [ ] Siblings [ ] Parents [ ]

Hired carer [ ] Another relative/friend [ ]

66 Do you have close family members who have been diagnosed with a heart condition?

Condition	**Y/N**	**Who**	
High blood pressure			
Blackouts			
Head injury			
Frequent headaches			
Stroke			
Heart attack			
Angina			
High cholesterol			
Bouts of confusion			
Falls			

Diabetes Mellitus			
Epilepsy			
Depression			
Other: specify			

67.1 Have any of your close relatives (parents, siblings, or children) had the problem of serious memory loss?

Yes [ ] No [ ]

If response Equals 'No' then skip to *Relatives participating in this study [68.1].*

67.2 Was it so serious that they had to be taken care of in a nursing home/hospital?

Yes [ ] No [ ]

67.3 Who is the family member who had to be sent to a nursing home…………

68.1 Are any of your relatives participating in this study?

Yes [ ] No [ ]

Skip when *Relatives participating in this study* Equals 'No'.

68.2 Who? ……………………………………………

69 How is your life different because of your health?...

69.1 Do you currently drink alcohol?

Yes [ ] No [ ] Used to but has stopped [3]

If response Equals 'No' then skip to *Tobacco use [70].*

Skip when *Drink alcohol Not* Equal 'Used to but has stopped'.

69.2 Date of last use:

Skip when *Drink alcohol* Not Equal 'Yes'.

69.2 If yes, how often do you drink alcohol?

3-4 times a week [ ] Once or twice a week [ ] Once or twice a month [ ]

Skip when *Drink alcohol* Not Equal 'Yes'.

69.3 On days when you have alcohol, how many drinks do you usually have? (1 drink = 1 beer/1 glass wine/1 mixed drink)

More than 5 drinks [ ] 2 to 5 drinks [ ] 1 or 2 drinks [ ]

a. Do you smoke?

Yes [ ] No [ ] Used to but has stopped [ ]

If response Equals 'No then skip to *Forwards instruction.*

Skip when *Tobacco use* Not Equal 'Used to but has stopped'.

b. Date of last use:

Skip when *Tobacco use* Not Equal 'Yes'.

c. What type of tobacco do you use?

Cigarettes [ ] Cigars [ ] Pipe [ ] Chewing Tobacco/dagga [ ]

Snuff [ ] Other [ ]

Skip when *Tobacco use* Not Equal 'Yes'.

d. About how many do you have a day?

More than 5 [1]	2-5 a day [2]	1 a day [3]

Thank you, now we will do some activities.

71 Digit Span

72 RAVLT - delayed recall

73 Rey Complex Figure

74 Object Naming

I will show you a picture and I would like you to tell me what is in the picture. (Show the participant the picture on the cards.)

a. Picture 1:

b. Picture 2:

c. Picture 3:

d. Picture 4:

e. Picture 5:

75 Now I will tell you the name of something and I want you to describe what it is.

a. What is a bridge? Please score response for ‘bridge’. (Examples of correct answer: Something that goes across a river, canyon, road; something the dentist puts in your mouth. Examples of an incorrect answer are street, highway.)

0 [ ]	1 [ ]

b. What do you do with a hammer? Please score response for ‘hammer’. (Examples of correct answer: Drive nails, build things, bang things.)

0 [ ]   1 [ ]

c. What do people do in church? Please score the response for ‘people in church’.
(Examples of correct answer: Pray, sing, praise God, read, meditate, etc.)

0 [ ]   1 [ ]

d. Where do we buy bread?

0 [ ]   1 [ ]

76 Short Story Prose

77 Cowat (FAS)

78 Taylor figure recall

79 Short Story Prose (Recall)

80 Luria’s Three Step Test

Now I am going to show you a series of hand movements. (Demonstrate fist, edge and palm five times on your leg without verbal prompts.) Now I need you to repeat the movements for me.

0 [ ]   1 [ ]

81.1 No test, interviewer rate by observation and question if unsure:

a. Walking ability:

Unable to walk [ ]   Wheelchair as walking aid [ ]   Walker [ ]

Quadruple cane [ ]   Cane [ ]   Other [ ]   No aid [ ]

b. Has there been amputation (by observation)?

No [ ] One leg [ ] Both legs [ ] One arm [ ] Both arms [ ]

c. Is there paralysis or major weakness of the legs?

No [ ] One leg [ ] Both legs [ ]

d. Any other disability noted?

Yes [ ] No [ ]

Skip when *Any other disability noted* Not Equal 'Yes'.

81.2 If yes, please specify:

Thank you, we are finished with part 1 of the interview. Thank you so much. Now I am going to ask your caregiver a few questions.

Appendix V: Informant Interview Questionnaire

Thank you so much for agreeing to participate in this interview. We will start with questions about yourself and move on to questions about (name of participant)

1. Name	
2. Sex	
3. What is your date of birth: (request the participant's ID book)	
4. Race	
5. What is your nationality?	
6. What is your home language?	
7. What is your religion?	
8. Highest level of education	
9. Occupation	
10. Marital status	
11. How many children do you have?	

12.1 What is your relationship to participant?

Spouse [ ] Child [ ] Hired carer [ ] Parent [ ] Other [ ]

Skip when *Relationship to participant* Not Equal 'Other'.

12.2 Please specify other relationship:

Skip when *Relationship to participant* Not Equal 'Hired carer'.

12.3 If hired carer, do you receive payment?

Yes [ ]   No [ ]

13. How long have you known the participant (participant's name)?.........................

This section asks for information about (name of participant). I am going to ask you some questions about (name of the participant).

14.1 Have you seen a change in her daily activities in the past several years?

No change [ ]

Diminution in range of activities, and/or reduced ability to carry out activities [ ]

Skip when *Change in daily activities* Not Equal 'Diminution in range of activities, and/ or reduced ability to carry out activities'.

14.2 Describe change ……………………………………………………………………

15 Has there been a general decline in her mental functioning? ……………Please explain

16.1 Does she forget what she wanted to say in the middle of the conversation?

No [ ]   Yes [ ]

Skip when *Forget in middle of conversation* Not Equal 'Yes'.

16.2 If yes, how often does that happen?

Regularly [ ]   Sometimes [ ]

17.1 When speaking does she have difficulty saying the right words?

No [ ]   Yes [ ]

Skip when *Difficulty saying words* Not Equal 'Yes'.

17.2 If yes, how often does that happen?

Sometimes [ ] Regularly [ ]

18.1 Does she tend to talk about what happened long ago rather than the present?

No [ ] Yes [ ]

Skip when *Talk about past* Not Equal 'Yes'.

18.2 If yes, how often does that happen?

Regularly [ ] Sometimes [ ]

19.1 Does she get lost in the community?

No [ ] Yes [ ]

Skip when *Get lost in community* Not Equal 'Yes'.

19.2 If yes, how often does that happen?

Regularly [ ] Sometimes [ ]

19.3 Does she get lost at home, e.g., finding the toilet?

No [ ] Yes [ ]

Skip when *Get lost at home* Not Equal 'Yes'.

19.4 If yes, how often does that happen?

Regularly [ ] Sometimes [ ]

20 Does the interviewer think that the problem is primarily due to physical disability?

No, not due to physical disability [ ]   Yes, due to physical disability [ ]

21. Have you noticed a change in her ability to think and reason?

No [ ]   Yes [ ]

22. Does she have difficulty using the toilet?

No [ ]   Yes [ ]

23. Does she wet or soil herself?

No problems [ ]   Occasionally wets bed [ ]   Frequently wets bed [ ]

Double incontinence [ ]

24. Does she ever mistake you (or other family or friends) for someone else?

No [ ]   Yes [ ]

25. I am now going to ask you questions about (the participant's name) medical health. I will read to you a list of medical conditions. I want to know if a doctor has told (participant's name) that he or she has any of these conditions. Please answer YES or NO for each condition and tell me when it started and if she/he is on medication for the condition. (Both participant and informant can give answers here.)

Condition	**Y/N**	**Date of onset**	**On medication**
High blood pressure			
Blackouts			
Head injury			

Frequent headaches			
Stroke			
Heart attack			
Angina			
High cholesterol			
Bouts of confusion			
Falls			
Diabetes Mellitus			
Epilepsy			
Depression			
Other: specify			

25.1 Does the participant suffer from any of the following geriatric difficulties?

Expect multiple selected options.

Frailty [ ] Urinary incontinence [ ] Falls [ ] Delirium [ ] Pressure ulcers [ ]

None [ ]

Skip when *Geriatric syndromes* Includes 'None'.

25.2 Onset of geriatric syndromes

26.1 Have she/he had surgery/medical operations before?

Yes [ ] No [ ]

If response Equals 'No' then skip to *Hospitalised (98).*

Skip when *Surgery or medical operations* Equals 'No'.

26.2 If yes, what was the operation for and when was it? (Please list the procedures and the year of the procedure.)

27.1 Has she/he had any hospitalisations:

Yes [ ]   No [ ]

Skip when *Hospitalised* Equals 'No'.

27.2 When was she/he hospitalised and why? (Please list) ……………………….

28.1 Is the participant (name) currently on medication?

Yes [ ]   No [ ]

Skip when *on medication currently* Equals 'No'.

28.2 I would like you to list for me all the medication that she/he is taking regularly. Please include over-the-counter medicines, vitamins and herbal remedies that she/he has taken for more than one week.

Medication name	From participant	From bottle/packet	OTC	Prescription	Duration	How to take
e.g Panado	x		x		3weeks	2x daily

29. AD8 DEMENTIA SCALE

I am now going to ask if (name of participant) has had any of the following difficulties within the last year or several years. Please answer with yes/no/do not know.

30. Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE)

31. The Lawton Instrumental Activities of Daily Living Scale

Vignette

Cindy is a 65-year-old retired nurse with a history of diabetes. She is your neighbour. You have noticed that she has been having difficulty making decisions and counting her pension money. She sometimes is forgetful and does not remember her grandchildren's names. Her husband has also told you these difficulties have progressed over the past six to eight months. He has also noticed that she repeats things several times, has difficulty concentrating, and more commonly, is losing things. However, he thought this was a normal part of old age. He realised it was more serious when Cindy got lost for several hours last week after taking a neighbourhood walk. Since her retirement, Cindy has kept herself busy by volunteering at the church choir. The pastor recently told you that Cindy is confusing rehearsal times, forgetting songs, and having trouble following instructions. She has also had angry outbursts during choir practice and accused the members of changing songs without informing her, and last week she accused her husband of having an affair with the neighbour.

32.1 1 Do you think there is anything wrong with Cindy?

Yes [ ] No [ ] I do not know [ ]

If response Not Equal 'Yes' then skip to *older people services.*

32.2 What is the problem? ……………………………………………Please explain.

32.3 What type of people do you think usually have this kind of problem? …………..

32.4 From the following which ones do you think most likely explains the cause of Cindy's difficulties (you can choose more than one). Expect multiple selected options.

Mental illness [ ]   Stressful life events or trauma [ ]

Genetic or inherited problems [ ]   Evil spirits/sorcery/being possessed [ ]

Ancestral calling [ ]   Ancestral anger [ ]

Not following cultural rituals [ ]   Bad character [ ]

Brain disease [ ]   Due to family or parental sins [ ]

God's will [ ]   Sins she committed [ ]   She is a witch [ ]   None [ ]

33.1 Do you think Cindy can be helped?

Yes [ ]   No [ ]   I do not know [ ]

If response Equals 'No' then skip to *Family member.*

Skip when *Help (30.8)* Not Equal 'Yes'.

33.2 How do you think Cindy can be helped? ....

33.3 Who do you think can help Cindy? Expect multiple selected options.

Family/friends [ ]   Doctor/nurse/hospital [ ]   Mental health practitioner [ ]

Social worker [ ]   Pastor/church) [ ]   Traditional healer [ ]   Other [7]

I do not know [ ]

Skip when *Help* Equals 'Yes'.

33.4 Why do you think she cannot be helped?..

34.1 Has anyone in your family ever had dementia?

Yes [ ]   No [ ]   Do not know [ ]

If response Not Equal 'Yes' then skip to *Seek assistance for condition.*

34.2 Who? Expect multiple selected options. … … … … … … … … … … … … … .

35.1 If you or your family member had dementia similar to Cindy, would you seek help?

Yes [ ]   No [ ]   I do not know [ ]

Skip when *Seek assistance for condition* Equals 'Yes'.

35.2 What might stop you from seeking help? ……………………………

36. Do you think a person with dementia is better cared for at ……. ?

Home by a hired carer [1]   Home by the family [2]   In a nursing home [3]

36.1 Do you feel that you would be able to care for someone like Cindy?

Yes [ ]   No [ ]   I do not know [ ]

Skip when *Equipped to care for participant* Equals 'Yes'.

36.2 What do you think you would need to be able to care for someone with these difficulties?

Skip when *Relationship to participant* Not Equal 'Hired carer'.

37. List three most important needs which can contribute to your job satisfaction as the caregiver of the older person.

38. Do you know any services that care for people with dementia in your community?

Yes [ ]   No [ ]   I do not know [ ]

39. Are there any services in your community that care for older people?

40.1 Have you ever received any training on being a caregiver?

Yes [ ] No [ ]

Skip when *Caregiver training* Equals 'No'.

40.2 If yes, explain.

41.1 Knowing that Cindy has dementia, would you continue to be Cindy's neighbour?

Yes [ ] No [ ] Maybe [ ]

42.1 would you be friends with Cindy?

Yes [ ] No [ ] Do not know [ ]

42.2 Would you date or be family with someone like Cindy?

Yes [ ] No [ ] Maybe/do not know [ ]

43 How do you think that others would treat Cindy in the community, if they knew about her problems?

Discriminate [ ] Treat her well [ ] Would have no problem [ ] Don't know [ ]

44.1 Have you ever heard about dementia before this interview?

Yes [ ] No [ ] Do not know [ ]

Skip when *dementia* Not Equal 'Yes'.

44.2 Where did you hear about it? Expect multiple selected options. ………………

45.1 In your culture/language, is there a name for dementia or a condition like what Cindy has?

Yes [ ] No [ ] Maybe [ ]

Skip when *Culture* Not Equal 'Yes'.

45.2 If yes, what is it called?..

Skip when *Culture* Not Equal 'Yes'.

45.3 How is it managed in your culture? ……………………………………

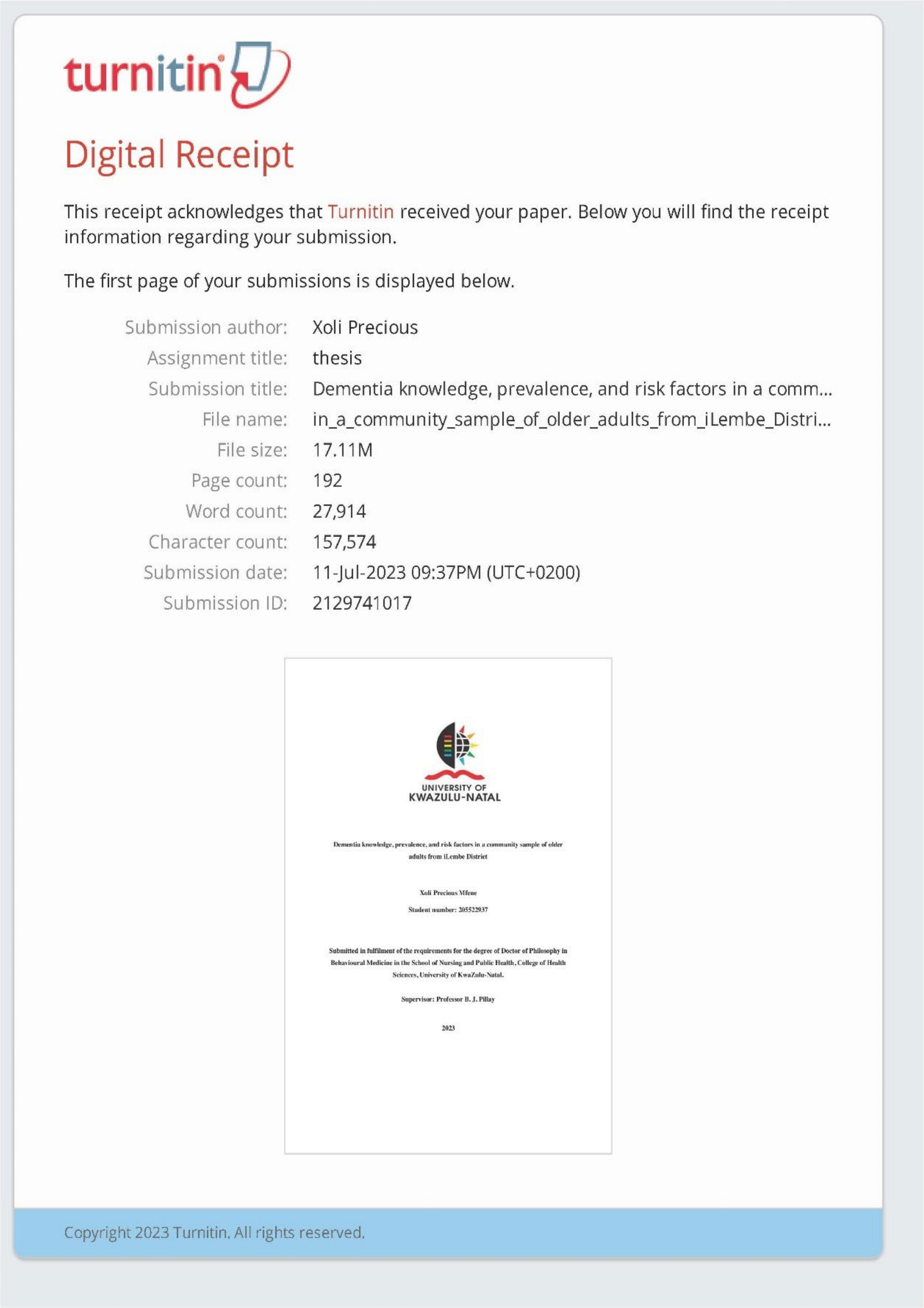
46 What is your understanding of the participant's cognitive difficulties?...........

47 As a person who stays with the participant and assists her/him, how do you cope with some of her difficulties? …………………………………………………

Conclude the interview. Thank the volunteer and give the airtime voucher when you give them the voucher, say the following: We appreciate your taking the time to have the interview today.

48 Interviewer remarks/observations.

Appendix VI: Turnitin Report



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Dementia knowledge, prevalence, and risk factors in a community sample of older adults from iLembe District

Xoli Precious Mfene

Student number: 205522937

Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Behavioural Medicine in the School of Nursing and Public Health, College of Health Sciences, University of KwaZulu-Natal.

Supervisor: Professor B. J. Pillay

2023

Dementia knowledge, prevalence, and risk factors in a community sample of older adults from iLembe District

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4	Paulus Anam Ong, Febby Rosa Annisafitrie, Novita Purnamasari, Chandra Calista, Noveline Sagita, Yulia Sofiatin, Yustiani Dikot. "Dementia Prevalence, Comorbidities, and	<1%

	Lifestyle Among Jatinangor Elders", Frontiers in Neurology, 2021 Publication	
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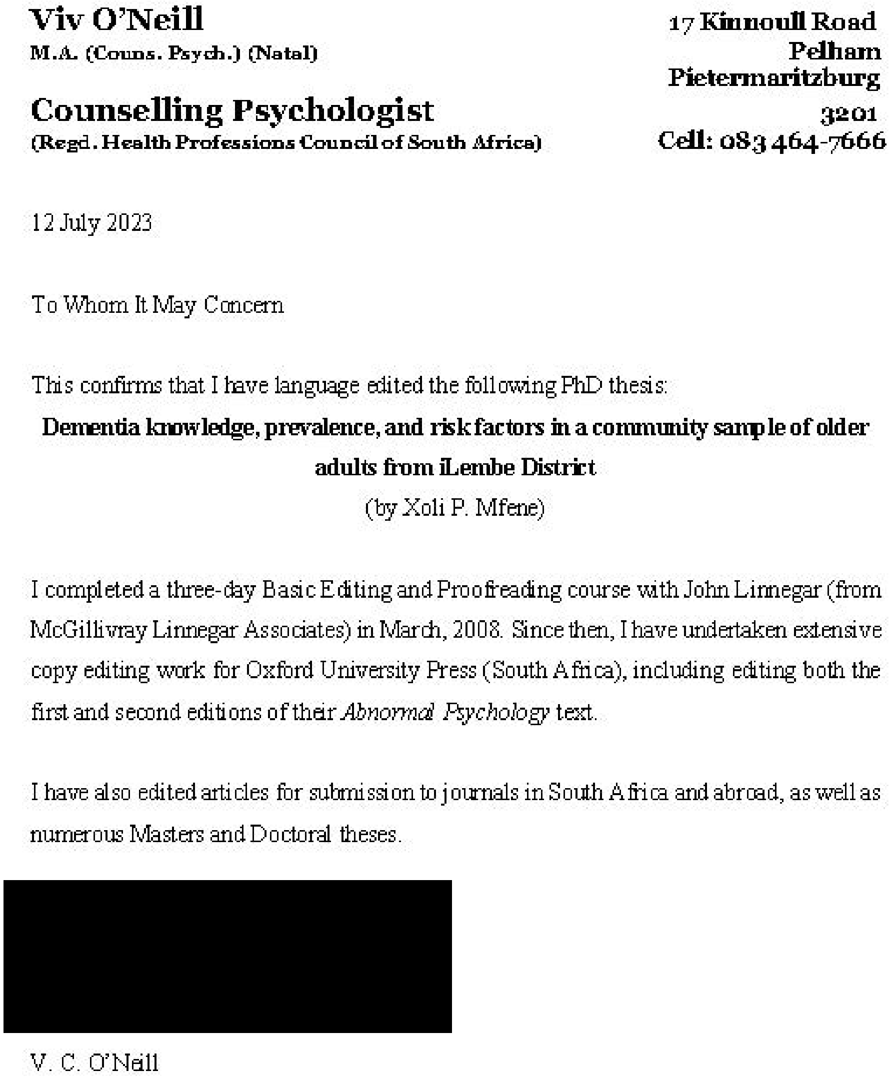

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12 July 2023

To Whom It May Concern

This confirms that I have language edited the following PhD thesis:

Dementia knowledge, prevalence, and risk factors in a community sample of older adults from iLembe District

(by Xoli P. Mfene)

I completed a three-day Basic Editing and Proofreading course with John Linnegar (from McGillivray Linnegar Associates) in March, 2008. Since then, I have undertaken extensive copy editing work for Oxford University Press (South Africa), including editing both the first and second editions of their *Abnormal Psychology* text.

I have also edited articles for submission to journals in South Africa and abroad, as well as numerous Masters and Doctoral theses.

[redacted]

V. C. O'Neill