# LAY KNOWLEDGE AND BELIEFS TOWARDS DEMENTIA: A STUDY AMONGST BLACK AFRICANS LIVING IN LONDON

A doctoral thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

Raphael Chinedu Mokwenye

College of Health, Medicine and Life Sciences

Department of Health Sciences

Brunel University London

September 2023

# Abstract

By 2025, dementia will affect over one million people in the UK. Many Black Africans live in the UK, and more than 850,000 people live with dementia in the UK. More than 25,000 people with dementia are from Black and minority ethnic groups. However, the dementia studies amongst Black Africans in the UK lack theory and empirical evidence, with limited research into Black Africans' ideas, meanings, and views. The previous data often did not separate the findings of the Africans from the Caribbean people. Therefore, the current research is an in-depth study exploring lay knowledge and beliefs about dementia amongst the Black African populations living in London. Overall, the study uses qualitative research design and methods to understand the lay concepts of dementia, perceptions of dementia risk factors, dementia help-seeking and caregiving, or treatment of people with dementia amongst the Black African populations living in London. The research is philosophically underpinned by social constructionism and sociological and anthropological lay concepts of health and illness. To generate rich data, the researcher interviewed 31 adult respondents, male and female, who identified as laypeople from the Black African community in London. The sample comprised first-generation migrants from West Africa and were churchgoers in the UK. The study utilised thematic data analysis informed by a grounded theory approach. The findings show that dementia is a complex phenomenon, and the researcher developed four key themes: social identity/sociocultural model, disease and illness, help-seeking, and caregiving. This study added witchcraft to the dementia literature and provided recommendations for policy and practice. The study concluded that the Black Africans living in London predominately do not lack knowledge of dementia. Still, more work is needed to enhance dementia awareness within the Black African population in the UK. This can be achieved through educational and training programmes aimed at reducing the stigma associated with dementia and improving outreach efforts to better support the Black community in dealing with dementia-related issues. This study recommended collaboration between medical doctors, community leaders, and applied medical anthropologists in dementia practice to help resolve the dementia stigma and dementia health disparity.

# Contents

# List of tables and figures

# Acknowledgements

I want to thank my supervisory team Dr Wendy Martin (principal supervisor), Professor Holly Nelson-Becker (supervisor), and Professor Meriel Norris (research development advisor) for their exceptional and excellent guidance and encouragement throughout this thesis. I am very grateful for working with the team, and I enjoyed every moment; it has been a fantastic experience.

I would particularly like to thank Professor Claire Donovan, who started this project with me as my first supervisor but moved to a different department before moving to another university in the UK.

I am grateful to my previous supervisors, Professor Christina Victor, Professor Nana Anokye, and Professor Subhash Pokhrel, for their guidance in the study. They resigned from the supervisory team just before the start of the fieldwork, and Brunel University London put together a new team for me to continue my study.

I would also like to thank all the participants who took part in the study. This thesis achieved success primarily with their support.

I sincerely thank my family, particularly my late parents, Ogbuenyi S. E. Mokwenye and Mrs M. E. Mokwenye, for being a pillar of love, growth, and spiritual strength. They funded my medical education through to my master’s degree. With their resources, my PhD study was possible. I love Dad and Mum! May they continue to rest in peace.

I also want to thank my children, Chisom Mokwenye and Udoka Mokwenye, for giving me valuable study time. Indeed, they are wonderful children.

Finally, I would like to thank the almighty God for giving me His support, strength, and protection throughout my journey in the research.

# Chapter 1

# Introduction

## Introduction

> *They would say it is either they are into witchcraft or that they are crazy . . . They are not knowledgeable enough to take the time to study and say no, that this person, this person has dementia and that the brain cells are dying. And the person needs to be treated with tender loving care, but they would rather stone them to death. Some people burn their mothers or fathers alive because they would say she is a witch, he is a wizard, but it is untrue. But they would cover up and say that woman was my mother, but a witch and that man was my father but a wizard. They would stone them and kill them, not realising that it is dementia and that those things they were saying were untrue. But a person from this society [London] would see it from a different perspective* (Yemi).

The above extract is an autobiographical account of a respondent in the current research. It offers insights into the intersection of geographical locations (the UK and Africa) and the experiences of dementia, which highlights an underexplored aspect in the dementia literature – witchcraft. The current study focuses on the lay knowledge and beliefs about dementia amongst Black Africans who were first-generation migrants and churchgoers from West Africa living in London and considered themselves laypeople.

The researcher’s working definition of lay knowledge about dementia encompasses comprehensive concepts or theories based on the knowledge and beliefs about the social patterning and functioning of the body (Helman, 2007, p. 134). Popay and Williams (1996) suggest that the social patterning of dementia can be extensive and not limited to the conventional distinctions between ‘non-science’ or ‘scientific’ concepts. Rather, it is based on a robust and holistic understanding of dementia in which individuals construct meaning for a ‘common sense’ experience of dementia. Therefore, lay knowledge and beliefs about dementia in the current study is an intersection of biomedical and non-biomedical experiences of dementia, history, and biography, as can be argued in social science (Popay & Williams, 1996; Popay et al., 1998). Drawing on the works of Popay and Williams (1996) regarding laypeople’s perceptions of health and illness, this study extrapolates lay knowledge about dementia in terms of risk factors, its classification as an illness or disease, its impact on disability, connection to gender, and association with curses or witchcraft as illuminated in the current research. In this study, *lay knowledge* is defined as the ideas, meanings, and perspectives of the Black Africans who were first-generation migrants from West Africa living in the UK and were churchgoers. It highlighted the concepts used to construct and interpret their experiences of dementia in their everyday life (Popay & Williams, 1996; Popay et al., 1998).

Furthermore, churches within the Black African community in the UK can be active in providing dementia services (Parveen et al., 2017; Berwald et al., 2016) and can be considered lay experts (Wilcox, 2010). Nevertheless, lay expertise can typify a combination of a nonscientific and scientific form of knowledge (Grundmann, 2017), experiential knowledge (Popay et al., 1998), ethical knowledge/practical wisdom/phronesis or 'non-scientificity' (Rothenberg, 2004). Thus, dementia *lay expertise* in this study is defined as a 'general cultural stock of knowledge' (Wilcox, 2010, p. 45) or a 'body of knowledge' (Grundmann, 2017) about dementia held by the Black African respondents in their communities in the UK. This knowledge serves as a guiding framework for their actions and decision-making processes related to dementia as illuminated in the current research.

Therefore, by drawing upon the work of Wilcox (2010), the present study positions the church community as a source of lay expertise within dementia services. This enables medical doctors and researchers to understand that lay expertise in dementia health is an integral part of faith, particularly through the practice of prayer, which can serve as therapy for dementia. Moreover, it promotes the dementia health of the Black Africans in the community, advocates for equitable access to dementia care as human rights and encourages to reform the unjust structures within dementia care and treatment in the Black community. It seeks to make the church a faith community for dementia that can collaborate with the NHS to improve the dementia care system for the Black African community in the UK. Churches in the UK can influence dementia behaviours, and involving churches in dementia services that incorporate spiritual and cultural contextualisation can be adequate (Campbell et al., 2007). Lastly, it encourages community leaders to address dementia health disparity by involving them in dementia service design and delivery in the Black African community in the UK. Indeed, a church setting can be pragmatic in public health and health promotion programmes (Wilcox et al., 2010; Baruth & Wilcox, 2013; Campbell et al., 2007).

Therefore, it was crucial to understand the participants' own ideas, meanings, and views about dementia. Thus, this chapter sets out the context and layout of the whole thesis. Firstly, the chapter provides the background, a brief on the literature review, the current research aims and design, and some reflections on the study. It further provides the thesis layout at the end of this chapter.

## Background

Dementia is a public health burden and can be considered a social or cultural phenomenon as much as a biological phenomenon. Indeed, dementia is a complex phenomenon that is questionable but observed to exist within sociocultural and biomedical contexts. Its causes and explanations are situated within social and cultural meanings, experiences, or as a biomedical reality. In the UK, 1 in 14 people over 65 has dementia, affecting 1 in 6 people over 80 (Alzheimer's Society, 2017). Thus, dementia can be considered one of the leading causes of death among women aged 60 and above. Two-thirds of people with dementia are women, and over 60,000 deaths yearly are directly attributable to dementia (World Health Organisation, 2017; Alzheimer's Society, 2017). The burden of dementia is set to become one of the biggest public health challenges in the world in the 21st century (WHO, 2017; Alzheimer's Society, 2017; Alzheimer's Association, 2022). The prevalence of dementia increases rapidly (WHO, 2017). The current evidence shows that the prevalence of dementia is rising rapidly, especially in countries with low and middle income, such as in Africa. The evidence suggested that 35.6 million people in 2010 lived with dementia worldwide, with about 58% living in low and middle-income countries. This proportion is anticipated to rise to about 63% in 2030 and 71% in 2050 (Prince et al., 2013, p. 69).

Moreover, even though the economic cost of dementia to the UK government is about £26 billion per annum (Alzheimer's Society, 2017), only a few dementia research has been conducted amongst the Black African population in the UK. Indeed, many Black Africans live in the UK and the US; more than 850,000 people are living with dementia in the UK, and more than 25,000 people with dementia are from the Black and minority ethnic groups (Alzheimer's Society, 2017), increasing dementia cases in the groups. Yet, we know little about dementia in the Black African community in the UK. Based on data from the 2021 Census, approximately 2.4 million Black individuals reside in the UK, which accounts for 4.2% of the population. Africans comprise more than half of this population, with 1.5 million people representing 2.5%, increasing from 1.8% in 2011. Black African people are the largest ethnic group within this population and are comprised mostly of Nigerians (0.5%), Somalis (0.3%), and Ghanaians (0.2%) (ONS, 2022).

## Literature review

The literature review shows that only a little dementia research has been conducted in the Black community in the UK, and little is known about dementia amongst Black Africans in the UK. The findings of the few previous studies on the Black and minority ethnic groups in the UK suggest that Black Africans in the UK lack the knowledge of dementia and rely on community, family, relatives, and friends for advice and dementia care (Berwald et al., 2016). Black African populations in the UK use churches for dementia support and are underrepresented in UK dementia services (Parveen et al., 2017). Notwithstanding, the authors concluded that Africans, like other minority ethnic communities in the UK, lack knowledge of dementia without an in-depth exploration of the Black Africans' own dementia ideas, meanings, experiences, or views. Nevertheless, dementia was viewed as a 'White, old White people's disease' (Berwald et al., 2016, p. 7). However, the data is limited in a particular culture and little do we know about dementia within the cultural perspectives of the Black African populations in the UK. The findings corresponded with observations from the literature as extracted:

> *We found that higher number of Africans reported a lack of knowledge of dementia and greater reliance on community, family and friends for support, advice and care. The majority of participants reported delaying help-seeking* . . . (Berwald et al., 2016, p. 5).

Likewise, Parveen et al. (2017) suggested that Africans in the UK used religious support, and the study illuminated a perceived lack of cultural sensitivity from GPs. Indeed, there was perceived tension between the groups and their GPs:

> *The African and Caribbean groups also made use of religious support from their church* . . . All groups perceived a lack of awareness and cultural sensitivity from services particularly from GPs. Many perceived that their GPs lacked dementia knowledge and were too busy to provide the care and support required. Some had experience negative interactions with their GPs (Parveen et al., 2017, p. 738).

Of course, the authors suggested that Black Africans in the UK lack knowledge of dementia. Nevertheless, it was unclear if the participants lacked biomedical and non-biomedical ideas and beliefs about dementia. Hence, this current research evaluated the qualitative studies by drawing on philosophical and evaluation discourses (Crewell, 2006; Schwandt, 2002; Scale, 1999), such as their epistemological concepts (Lather, 1986). Also, there appears to be an epistemic tension between lay knowledge and biomedical knowledge of dementia.

Nevertheless, the researchers did not reveal their positionality (epistemological and ontological stance) on the dementia phenomenon. Drawing on Holmes (2020), it can suggest that researchers come from different backgrounds to those they engage with, such as in dementia research in the community. Ontologically, the insider perspective on dementia is usually called an emic account, which privileges the local viewpoint. The outsider perspective on dementia is regarded as an etic view, which privileges the researcher's standpoint. Often, etic explanations of dementia tend to be formulated as biomedical or 'scientific theories' (Pool & Geissler, 2007, p. 24). Therefore, researchers' background and positionality impact their research approach and outcome (Wilson et al., 2022), and it determines whose voices are represented in their dementia outcome or policymaking (Pool & Geissler, 2007).

However, the literature review indicates a discrepancy and inequality in UK dementia services. Indeed, there is a disparity in power relationships between doctors (professional dementia service providers) and patients and their families (Black African [laypeople] dementia service providers). It appears there is a perceived difference in ideas and the meaning of dementia between doctors, patients, and their families eminent in the Black African community in the UK that might illuminate their social and cultural dementia reality that needs further exploration. In addition, the author concluded that the perceptions of dementia might be changing among minority ethnic communities in the UK about illness identity and causes (Parveen et al., 2017, p. 741). Moreover, most UK studies are to be updated and dependable, suggesting they lack trustworthiness criteria (Lincoln & Guba, 1985; Lincoln et al., 2011).

### Identified gaps in the literature

The understanding of lay ideas, meanings, and beliefs about dementia is lacking in the UK literature compared with the biomedical knowledge of dementia (see Chapter 2). The lay concepts of dementia, perceptions of dementia risk factors, and dementia help-seeking and barriers to help-seeking are not wholly known amongst the Black African population in the UK. Regardless, dementia is less known amongst Black Africans in the UK; presumably, the Black Africans in the UK are not living long enough to develop dementia, but life expectancy in Black African populations living in the UK has increased. It is expected to rise from about 65 years due to improved quality of life and access to essential health services (Wohland et al., 2015). Nonetheless, the current average life expectancy for Africans in Africa is 62 years

(Kamer, 2022). Indeed, it is expected that dementia will rise amongst Black Africans living in the UK (Pham et al., 2018). Therefore, there is a more substantial need to better understand the dementia phenomenon amongst the Black African populations in the UK.

## Research aims and objectives

The current study explores lay knowledge and beliefs about dementia amongst Black African populations living in the UK. The study's objective is to understand the lay concepts of dementia, perceptions of dementia risk factors, dementia help-seeking, and the caregiving or treatment of people with dementia amongst the Black African populations living in London.

## Research design

This study is qualitatively designed to explore the dementia phenomenon amongst the participants (see Chapter 4). Social constructionism and sociological and anthropological lay concepts of health and illness underpin the current study (see Chapter 3), and semi-structured interviews are used to collect empirical data (Braun & Clarke, 2013; Mason, 2018). To generate rich data, the researcher interviewed 31 respondents who identified as laypeople from the Black African community in London. The study used thematic data analysis (Braun & Clarke, 2019) and informed by a grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1994). The findings show that dementia is a complex phenomenon, and the researcher developed four key themes: social identity/sociocultural model, disease and illness, help-seeking, and caregiving. Thus, the Black Africans living in London viewed and narrated dementia as a social, cultural, and biological phenomenon embedded in sociocultural meanings, ideas, and experiences.

## Reflections

The development of this study supported the researcher's learning and professional development. The study evolved in a way which met the researcher's interest. Thus, this study adopted confessional and realist tales (Van Maanen, 1988). Indeed, the researcher's curiosity and academic background influenced how the study developed. However, even more important in shaping the study's direction were the participants' interests and concerns. The researcher is a community physician (MBBS, trained in Nigeria) and an applied medical anthropologist (trained in the UK). He has a PGDip in medical anthropology and MSc with merit in public health and health promotion, both from Brunel University London. His previous postgraduate research in medical anthropology utilised a qualitative design and methods to explore HIV/AIDS amongst the African population in the UK. Likewise, the MSc with merit in public health and health promotion used a qualitative design and methods to explore the views and perceptions of TB and its treatment amongst the sub-Saharan African people in London.

Furthermore, the researcher's personal experiences providing care for a family member with dementia and his professional background influenced the direction of the study. They also highlighted his positionality within the context of this dementia study. Moreover, it situated the researcher's insider perspective as a Black African (Tuffour, 2018), highlighting his lay position and an outsider's perspective (Holmes, 2020) as a medical doctor, which could either be an advantage (Tuffour, 2018) or a disadvantage (Kauffman, 1994) in the current study. Regardless, the researcher perceived himself as an insider and an outsider (Kauffman, 1994; Tuffour, 2018; Holmes, 2020) to the dementia culture and phenomenon. This insider-outsider duality (Merton, 1972) gave the researcher an advantageous position compared to some researchers in the field, as could be argued for and against (Hammersley & Paul, 1995; Weiner et al., 2012). Of course, each researcher's positionality and professional status mainly affect the research process and the interpretation of research outcomes (Smith, 1999). Therefore, the current study draws on the researcher's personal, clinical, and anthropology background, which intersects the lay knowledge and biomedical framings of dementia.

If not for these backgrounds, the current research would have developed differently; for example, it may have focused on the biomedical knowledge of dementia if the researcher's background had been in biosciences. However, the researcher was critically self-reflective about his clinical and medical stance on dementia, so the researcher's anthropological background influenced much of the development of the current study. Most importantly, this study is driven by the participants' views and narratives. All participants (the Black African population living in London) identified as laypeople and were churchgoers (see Chapter 5).

Lay knowledge and beliefs about dementia may be defined as general knowledge about dementia in non-biomedical ways or as non-scientific knowledge about dementia in a population group (Jonsdottir et al., 2022), such as amongst the Black Africans in the UK. However, lay knowledge about dementia can often be informed by 'scientific' concepts or the biomedical understanding of dementia and vice versa (Helman, 2007, p. 134). Nevertheless, it is usually not framed as such. Nonetheless, laypeople have multiple ways of understanding dementia depending on their sociocultural and demographic factors. Indeed, laypeople can use internal and external events and personal experiences to explain the occurrence of dementia (Chung, 2000). Laypeople’s explanation of the cause of dementia forms an essential aspect of their dementia narratives and views. Hence, the current study’s definition of lay knowledge about dementia is the broader concepts about dementia that differs from or intersects with biomedical knowledge of dementia amongst Black Africans in the UK. It challenged medical assumptions and enabled the researcher to learn how laypeople from the Black African community in the UK perceived and experienced dementia. Furthermore, a lay explanation is an essential explanatory model that can be applied to the dementia phenomenon.

However, the concept of the explanatory model found it difficult to reconcile different conflicting and contradictory systems of medical beliefs and practices covering a whole spectrum from modern medicine to folk medicine (Kleinman, 1980, 1988). They are, indeed, suggesting that an explanatory model for dementia can also be employed by all those engaged in the dementia clinical process. This suggests that explanatory models of dementia are held by doctors, patients, families, and friends. They guide choices of dementia and treatment and can give meanings and experiences to the dementia phenomenon. They can be deeply rooted in explaining the causes of dementia to the end of life (Downs et al., 2006). They can also explain the dementia phenomenon, which may include the causes of dementia, when and how the dementia symptoms first appeared, the nature of the symptoms, the course of the sickness, and treatment or caregiving.

## What is dementia?

Dementia is a complex phenomenon, and medical doctors do not know all about dementia (Assal, 2019). Therefore, to maximise the effectiveness of clinical reasoning, medical doctors need to carefully explore and learn from the dementia ideas, meanings, and experiences of others, particularly the laypeople in the community, and integrate their valuable learnings into the dementia practice (Neubauer et al., 2019). Despite this, most rarely do; some do, but many do not (Campbell, 2021). Presumably, those physicians that do not may assume they are more knowledgeable than others on dementia. Some medical doctors may believe that subjective dementia ideas, meanings, and experiences of laypeople are invalid or that the qualitative methods used in exploring dementia are unreliable compared to quantitative methods and objective data used in understanding the dementia phenomenon. Regardless, it is essential for medical doctors to learn about dementia from others and integrate their learning into practice (Neubauer et al., 2019). Indeed, many physicians approach dementia from an epistemological and more positivistic point of view (Davison, 2022; Kumar & Clark, 2021). Furthermore, they often adopt an ontological perspective rooted from a realist position (Green & Thorogood, 2018).

Nevertheless, as a physician and applied medical anthropologist, the subjective dementia ideas, meanings, and experiences of laypeople and the qualitative methods used in understanding the dementia phenomenon are credible and reliable (Braun & Clarke, 2013; Manson, 2018). Therefore, the lay dementia experiences, ideas, and meanings accurately represent those who share them. The lay and biomedical concepts of dementia may also postulate several factors acting together and may be closely linked (Ismail et al., 2020). So, then, what is dementia?

### The medical concepts and knowledge of dementia

The researcher reflected on his stance and medical training. Indeed, the medical knowledge of dementia is drawn from the biomedical concept of dementia as a disease (Kumar & Clark, 2021; Davison, 2014; Hofmann, 2002). In this context, dementia is a clinical syndrome rather than a particular disease (Kumar & Clark, 2021). Moreover, it is common for multiple diseases to contribute to any patient's dementia syndrome. Davison (2022) considered dementia a clinical syndrome characterised by a loss of previously acquired intellectual function in the absence of impairment arousal, defined as a global impairment of cognitive function, typically progressive and nonreversible.

However, Kumar and Clark (2021) considered dementia a clinical syndrome with multiple causes, defined as an acquired loss of higher mental function, affecting two or cognitive domains that may be progressive and reversible in some cases. Therefore, the word 'dementia' describes symptoms that may include progressive memory loss, difficulty in thinking, problem-solving, language difficulty, and changes in mood, perception, or behaviour (Davison, 2014; Kumar & Clark, 2021). As dementia progresses, the images and chemistry of the brain change, causing damage to nerve cells. Thus, the medical model generally considers dementia as a broad category of brain disease. Also, dementia as an organic disorder is regarded as a medical condition.

Nevertheless, physicians do not see dementia as a psychiatric disorder as it results from a degraded brain function rather than a psychiatric disorder. Indeed, dementia presentation tends to be more complex as comorbidity with organic and psychiatric disorders, and they can be familiar and grounded in nature (Hyman, 2021). Regardless, dementia is included in psychiatric classifications, such as the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) and Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), because of the behavioural and psychological manifestations in people with dementia. However, the DSM-5 is a rearrangement of psychiatric diagnosis and an agreed list of categorisations of mental health disorders approved by a panel over a lengthy period. It partially adopts a dimensional approach by introducing a new diagnosis and then harmonising it with the International Classification of Disease (Krawczyk & Swiecicki, 2020). Therefore, dementia can sometimes be misdiagnosed because it could often manifest with problematic behaviour. Diagnosis of dementia is generally based on testing, with some new tests such as computed tomography (CT), antinuclear antibody (ANA), and anti-double-stranded DNA (ant-dsDNA) (Davison, 2022, p. 1247), as well as Tau and Aβ42 measurement (Kumar & Clark, 2021, p. 881) that is recently approved.

Nevertheless, it is unclear why some people get dementia and others do not. Still, it may depend on many factors, including age and genetics (Alzheimer's Society, 2017, p. 12). Mild cognitive impairment (MCI) is intermediate between normal cognition and dementia (Kumar & Clark, 2021, p. 881).

## Types of dementia

Notwithstanding, there are many different types of dementia, and about 95% of people with a diagnosis will have one of the four main types: Alzheimer's disease (AD), vascular dementia (VD), and dementia with Lewy bodies (DLB) or frontotemporal dementia (FTD). Less common is dementia with Lewy bodies and frontotemporal dementia. Alzheimer's disease (AD) is the most common type of dementia, accounting for 60% to 80% of cases (Alzheimer's Association, 2022). The pathological hallmarks of Alzheimer's disease are the deposition of β-amyloid in amyloid plaques in the cortex and the formation of tau-containing intracellular neurofibrillary tangles. Indeed, this means that early pathological changes in the brain of a person with dementia include Aβ deposition (Kumar & Clark, 2021).

On the other hand, vascular dementia (VD) results from poor blood supply to the brain (ischaemic damage). It is the second most common cause of dementia and is a worldwide health concern (Bir et al., 2021). Indeed, most VD has mixed causes, but about 5% to 10% of individuals with dementia show evidence of vascular dementia alone (Alzheimer's Association, 2022). Moreover, symptoms will depend on the part of the brain that has been damaged (Kumar & Clark, 2021). However, dementia with Lewy bodies (DLB) is characterised pathologically by including Lewy bodies in the cortex. They disrupt brain functions, and about 5% of older individuals with dementia show evidence of DLB alone, but most people with DLB also have Alzheimer’s disease pathology (Alzheimer’s Association, 2022). Nonetheless, the pathological hallmarks of DLB include the deposition of Lewy bodies containing aggregates of the protein α-synuclein. It results in neurodegeneration which is clinically accompanied by behavioural and psychological changes (Pope et al., 2021).

Likewise, frontotemporal dementia (FTD) is a group of neurodegenerative disorders pathologically characterised by frontal lobe and temporal lobe atrophy. It is also called Pick’s disease. Unlike other dementias, onset is usually below age 65, and there is often a family history. FTD mainly affects people in their 40s, 50s, and 60s and is considerably less common than AD. The prevalence is approximately 10 per 100,000 before age 65 (Kumar & Clark, 2021). Some rare conditions cause dementia; they account for only 5% of dementia types. However, they are common in younger people and may include alcohol-related brain damage (ARBD) and prion disease (Davison, 2022; Kumar & Clark, 2021).

Indeed, prion disease is a transmissible neurodegenerative disorder with a long incubation period caused by misfolded native prion protein accumulation. Creutzfeldt-Jakob disease (CJD) is the most familiar prion disease in humans, and it may be sporadic, iatrogenic, or familial. Sporadic CJD is the most typical form occurring over age 50, with an incidence of approximately 1 per million. Iatrogenic CJD is transmitted from the neurosurgical instrument (prions are resistant to sterilisation) and has a long incubation period of several years. Familial CJD is rare and associated with native prion protein (PRNP) gene mutations. An epileptic seizure is a clinical feature of prion disease (Mbizvo et al., 2021). Nevertheless, more than 100 known dementia have different causes (Alzheimer’s Society, 2017; Davison, 2014; Kumar & Clark, 2021).

Furthermore, four main drugs have been developed to treat Alzheimer’s disease: donepezil, rivastigmine, galantamine (cholinesterase inhibitors for mild or early forms of dementia), and memantine (NMDA receptor antagonist for moderate to severe forms of dementia). Current clinical trials aim to develop drugs that could halt or slow the progression of early-stage dementia disease (Khan et al., 2020). They include anti-amyloid therapies, for example, monoclonal antibodies directed against Aβ and inhibitors of secretase enzymes that process amyloid precursor protein (APP) into Aβ fragments. Therefore, physicians may perceive the biomedical concept of dementia as ‘scientific’ (Pool & Geissler, 2007, p. 24) and believe that dementia is treatable with medicines. Indeed, the biomedical theories of dementia are less vital for the current study, although exciting and compelling, nonetheless, of a reductionist dementia view. Regardless, some Black African people living in London perceived dementia as a disease.

Nevertheless, no person with dementia has been cured of the disease. Preventing dementia through managing vascular and lifestyle-related risk factors may be a more realistic goal than treatment with medicines (Kenigsberg et al., 2016; WHO, 2017; Alzheimer's Society, 2017). Most importantly, public policies on dementia are more likely to engage in improving dementia education, providing good quality early dementia diagnosis and intervention for the Black African populations in the UK, and improving their quality of care from diagnosis to end of life, as well as using clinical and economic endpoints (Kenigsberg et al., 2016).

### The lay concepts and knowledge of dementia

The researcher reflected on layperson perceptions and lay theories about dementia and recognised that lay knowledge about dementia can be different from the scientific understanding of dementia (Jonsdottir et al., 2022). However, lay perspectives overlap with biomedical frameworks of dementia, an essential part of the current research. Therefore, lay and biomedical perspectives are not mutually exclusive; instead, lay and biomedical views are not the same but can intersect, as shown in the current study. In this study, the participants identified themselves as laypeople, and this research conceptualised a layperson as a non-medical person. Therefore, all the participants were nonmedical practitioners from the Black community in London. The laypeople's knowledge and beliefs about dementia were presented in the views and narratives of the Black African respondents who were churchgoers. They are first-generation migrants from West Africa.

Moreover, the lay ideas of dementia care included a set of dementia knowledge and beliefs. These are usually guidelines specific to the group or Black community about the perceived normal behaviour and treatment of dementia for themselves and others (Chung, 2000). They usually include beliefs about the spirit, body, and mind (Helman, 2007), including a prescription for help-seeking for dementia and care. Most dementia care in the lay sector occurs between people already linked to one another by ties of kinship, friendship, family, and neighbourhood or membership in work or religious organisation (Hughner & Kleine, 2004; Helman, 2007). It also means they shared similar assumptions about the dementia phenomenon, and nonconformity in their dementia knowledge and beliefs is rare. Thus, the lay sector comprises a series of informal and formal relationships, and their lay knowledge and beliefs about dementia are drawn from the lay concepts of dementia. Therefore, patients, families, friends, and relatives from the Black community produce their dementia knowledge and beliefs as their personal views and narratives of the dementia phenomenon. Dementia views and narrative can be considered a story that Black African patients, family, and friends tell, and many others retell to give coherence to the dementia illness. The narrative and views do not just reflect the dementia experience but can help to constitute dementia in the Black community (Patterson et al., 2018; Thorsen & Johannessen, 2021).

Understanding how dementia is constituted and constructed by laypeople and how they make sense of the meaning of dementia was an essential first step in developing practical interventions for people with dementia and their family in the Black community in the UK. Nevertheless, understanding the lay knowledge of dementia is daunting. Some of the significant challenges for an applied medical anthropologist, or indeed any doctoral researcher or researcher, are conducting research in clinical or community settings and finding ways to incorporate the applied research findings or the anthropological insights on the dementia phenomenon into practice while respecting the orientation and commitments of the medical doctors (Pool & Geissler, 2007; Helman, 2007). Therefore, the focus is often translating the dementia constructs, thus enabling medical doctors to use the anthropological insights discovered. Such lay knowledge and beliefs about dementia often involve negotiating the interconnecting medical and lay theories of dementia or the sociocultural constructions of the dementia phenomenon.

Nevertheless, lay concepts of dementia are based on more comprehensive theories about misfortune in general. They draw on beliefs about the structure and function of the body, spirit, and mind and how they can malfunction (Helman, 2007). Unlike the medical concepts of dementia, they are not based on scientific facts or positivism (Kumar & Clark., 2021). However, they usually have internal logic, which helps the person with dementia and their family ‘make sense’ of what happened and why (Helman, 2007, p. 134). Therefore, unlike medical theories, lay concepts of dementia are subjective and relativist ontologies (Green & Thorogood, 2018). In the Black African culture, they are part of a complex body of inherited folklore (Helman, 2007; Pool & Geissler, 2007). Regardless, dementia in the UK is increasingly influenced by the concepts borrowed from the media, the internet, and the medical and psychosocial model (Maslen & Lupton, 2019). Many participants in the current study acknowledged that media, internet use, and education and training influenced their views about dementia.

Interestingly, the lay knowledge and beliefs about dementia represented how laypeople understood the causes of dementia or the lay epidemiology of dementia. They provided an ideal measure of success and failure in education programmes (Bury, 1994). The lay epidemiology of dementia is considered a process in which dementia risks are understood and interpreted by laypeople. It is perceived as a barrier to public health and health promotion (Allmark &Tod, 2006), particularly when laypeople disbelieve or fail to act and align with public health and health promotion messages on dementia disease or appropriate policy. It can also be politically controversial and remains an epidemiologist debate (Cwikel, 1994).

### The individual world theory

An individual world theory is a distinct entity of individualised events (Betzel et al., 2022). In this way, an individual is conceptualised as a model with varying degrees of precision applied to various biological systems (Radzvilavicius & Blackstone, 2018), such as the brain and body. Therefore, the individual theory locates the dementia phenomenon within the individual intrinsic factors amongst Black Africans that can cause damage to the body or brain cells (Davison, 2014; Kumar & Clark, 2021). It includes systemic malfunctioning, including high blood pressure and diabetes as the cause of dementia in the Black community. Thus, the lay theories can also be linked to biomedical concepts, locating the lay knowledge of dementia within the body, mainly with malfunctions within the individual body and system related to changes in diet and behaviour (Takeuchi & Kawashima, 2021; Dominguez et al., 2021). Here, the responsibility for dementia is placed on the person with dementia and can be considered victim-blaming in many cases in the Black community. This means the tendency to make the individuals responsible for their dementia and misfortune (Genschow & Vehlow, 2021).

Nonetheless, some of the lay aetiological factors in the Black community can be located within the individual body but are considered not within the victim’s conscious control (Helman, 2007). Indeed, they include the understanding of lay vulnerability (Smith & Anderson, 2018), such as personality and physical, hereditary, and socioeconomic causes of dementia. The lay personality vulnerability refers to knowledge of the individual character, such as thinking, feeling, and behaviour. Thus, lay physical vulnerability is based on the knowledge of resistance and weakness or functionality, such as in the degeneration of the structure or function of the body organ such as the brain (Betzel et al., 2022), which can occur with ageing and older age.

Whilst the lay genetic vulnerability is based on the genetic causes of dementia, the socioeconomic causes of dementia are linked to hardship, poverty, and health inequalities. Still, on individual theory, lay aetiological factors for dementia include an imbalance in the brain system, perceived as a state of disequilibrium within the body (Jahn, 2019). It includes poor dietary intake and vitamin deficiency, lifestyle factors such as lack of exercise (Dominguez et al., 2021), and inversion of the body to foreign substances such as alcoholism and tobacco smoking (Arora & Bhagianadh, 2021). Others may include mechanical causes, such as abnormal brain functioning, as seen with falls and head injuries (Casey et al., 2020). Indeed, the individual theory is complex and can be interconnected with the medical view of disease but mainly focused on the individual as a particular person or human being contrasted with a social group, as perceived in the Black community in the UK (Berwald et al., 2016; Parveen et al., 2017).

### The social world theory

The social construction of dementia can be shared amongst the Black African populations in the UK as an illness embedded with social and cultural meaning (Bosco et al., 2019). Dementia illness can be socially constructed at an experiential level, based on how individuals in the community understand, build relationships, and live with the condition as sickness and illness (Conrad & Barker, 2010; Hofmann, 2002). For example, drawing from Helman (2007), blaming others for the cause of dementia is a common feature of the community where interpersonal conflicts may be frequent. The most familiar African forms are witchcraft, sorcery, shamanism, and the 'evil eye'. In witchcraft beliefs, certain people are believed to possess a mystical power to cause others to have dementia. In Africa, witches are believed to be 'different' from others in appearance or behaviour; for example, In Ghana, witches may carry out diabolical deeds (Adinkrah, 2019). Often, they are considered older men or women, ugly, disabled, or socially isolated. They are usually the deviants or outcasts of society on whom all the negative aspects of dementia cultures may be projected. The witches' malevolent powers are often unconsciously practised; however, not all witches are deviant. Anthropologists have pointed out that witchcraft accusations are expected during social change, sickness, uncertainty, and social conflicts (Helman, 2007; Mace et al., 2018). Competing factions within Black African communities can accuse each other of causing their sickness or misfortunes, such as dementia, by practising witchcraft (Brooke & Ojo, 2020; Spitted et al., 2021).

Nonetheless, sorcery may be similar to witchcraft accusations as the cause of dementia (Mushi et al., 2014; Hindley et al., 2017; Owokuhaisa et al., 2020). Sorcery is the power to manipulate and alter natural and supernatural events with the proper magical knowledge and perform rituals or shamanism (Whitaker, 2021). Indeed, the sorcerers may consciously exert their power to cause dementia, usually due to envy and jealousy. They can cause dementia by using spells, potion rituals, or shamanism. Likewise, an evil eye can cause dementia. The possessor of the evil eye may cause dementia unintentionally, and they are often unaware of their malignant powers, believed to be extraordinary and unable to control them (Berger, 2012). Similarly, in the UK, the lay theories of stress often play a similar role (Bougea et al., 2022). Indeed, blaming the cause of dementia on other people, for example, in a situation where a person with dementia or their family blames the cause of dementia on spouse and carers, employers or workmates, probably due to psychosocial stress, which may require psychosocial and psychoeducational interventions (Gilhooly et al., 2016; Mahomed & Pretorius, 2022).

### The supernatural world theory

In the supernatural world, dementia is attributed to the direct actions of paranormal entities, such as gods, spirits, or curses (Helman, 2007). Thus, dementia can be perceived as a divine punishment from God due to sinful behaviour. On this basis, the medical doctor might not be of any help in treating the dementia illness; instead, seeking help is the acknowledgement of sin, being sorrowful for having committed the sin, and a vow to improve one’s behaviour. Therefore, people may strategically endorse the supernatural world and punishment beliefs as intuitive tools of social control (Fitouchi & Singh, 2022). Hence, the person with dementia and their family may seek help from religion. Prayer may be helpful towards a remedy rather than seeking a medical doctor for medicine or, perhaps, as a syncretic practice (Rossiter-Thornton, 2002).

In addition, the cause of dementia can be linked to ‘spirit possession’, where the person with dementia is invaded by an ancestral spirit they have offended (Helman, 2007). It happens when the person with dementia and their families may be guilty of immoral or antisocial behaviour. Thus, spirit possession may refer to a broad range of phenomena whose primary defining feature is the involvement of an incorporeal agent with a human host in various ways (Bhavsar et al., 2016; Sharabi, 2021). These agents are commonly referred to as spirits. In Africa or Europe, these spirits may represent ghosts of departed ancestors, foreign visitors, divine beings, demons, angels, and spirits of fire (Rashed, 2020). As such, the diagnosis of dementia is through divination, where the sickness is perceived as punishment for transgressions, and the moral value of the group is reaffirmed. Whilst supernatural explanations for dementia as divine punishment or spirit possession are less common in the UK, the central equivalent may blame dementia on bad luck, fate, a star, or ‘an act of God’. For example, drawing on the ‘Law of Wisdom’ (Badanta et al., 2020), a law of health and wellbeing revealed by God for physical and spiritual benefit can lead some people in the UK to care for their dementia and have a network of support from church leaders, who may act as dementia health promoters (Badanta et al., 2020; Epps et al., 2020; Epps et al., 2021; Gore et al., 2022). The law advised good behaviours such as caring for older people or parents and avoiding substances such as alcohol and food unsuitable for the spirit, body, and mind. Such can include cigarette smoking. Indeed, in the Black community, the supernatural is interconnected with the social world theory.

### Identity theory

The lay knowledge of dementia amongst Black Africans can be framed through various theoretical perspectives, such as the mind/brain identity theory (Farrell, 1950; Smart, 1959), mind/body theory (Feigl, 1958), or an embodied identity (Myin & Zahnoun, 2018). Additionally, concepts such as personhood, which pertains to the idea of being an individual (Kitwood & Bredin, 1992; Kitwood, 1997), and the concept of selfhood (Kontos & Martin, 2013) are also relevant in this context. Hence, the identity theory of the mind/body problem or the dichotomy between mind/brain can hold that the processes of the mind can be identical to the state of the person and self or brain and the body (Farrell, 1950; Feigl, 1958; Smart, 1959). Thus, mental and physical properties are also impaired when the brain is damaged. Indeed, the concept of personhood has competing constructs. The existential construct acknowledges personhood as a state of being inherent to the individual as a person; that is, the individual is purely physical or functional, and the mind is just an elliptical way of referring to the brain (Taylor, 1985). The relational construct acknowledges personhood as a conditional state of value defined by society; that is, the individual is more than mental and physical properties, with the involvement of a metaphysical and moral status (Nobis, 2011). Therefore, dementia amongst Black Africans can be transcendental, and medical doctors in dementia services are not well-trained in asking patients about their interest in spirituality and religion (Nelson-Becker, 2017).

Moreover, social identity theory (Tajfel &Turner, 1979) can be based on the view that dementia identity is constituted through differences in social relationships and behaviour or as group members defined by their self-concepts and sociocultural factors. Thus, being a Black African living in London in a relationship with others in the Black community and the society at large can be considered a social identity. Likewise, it can support the intersectionality theory movement (Carbado et al., 2013) and its application in public health and health promotion research (Heard et al., 2020) and knowledge translation (Kelly et al., 2021). Nonetheless, this thesis positions dementia at the intersections of different aspects of identity, such as ethnicity, ageing, gender, religion and spirituality, disability/ability, socioeconomic status, education, and power relationships, showcasing how they mutually interact to shape individual and group identity (see Chapter 3). However, exploring intersectionality theory as the foundational theoretical framework for the current study can limit the research's theoretical and operational scope (Bauer, 2014; Holman et al., 2021). More so, there are no clear guidelines for incorporating the principle of intersectionality into empirical research (Kelly et al., 2021; Abrams et al., 2020; Green et al., 2017).

Regardless, the concept of intersectionality was first introduced by Kimberle Williams Crenshaw, an American scholar who studied critical legal race issues. In 1989, she used this term to describe the various types of discrimination Black women face, critiquing the 'single-axis framework', which focuses on the experiences of the most privileged members of the subordinate groups (Crenshaw, 1989). Intersectionality was used as a metaphor to help understand how multiple forms of inequality can combine to create obstacles that are not always easily recognised in a community.

Therefore, reflecting on intersectionality, it is possible to uncover how racism and sexism may be built into the biomedical dementia services in the Black African community in the UK and privileged over the lay knowledge about dementia amongst the marginalised groups. Indeed, the framework can be vital for understanding and responding to health inequalities and inequities experienced by the Black African community in the UK. It can reveal the interconnected power structures that create these issues and make them more visible by understanding the dynamics of the privileged biomedical dementia services and the disadvantaged lay dementia services amongst the marginalised churchgoers in the Black African community, bearing in mind that they are first-generation migrants from West Africa with lay expertise.

More so, it is possible to use the concept to promote a more equitable dementia health system in the UK. The intersectionality framework can consider various social and cultural factors such as race/ethnicity, gender, disability/ability, migration status, education, age, environment, professional status, religion/spirituality, and the power structures underpinning them at macro and micro levels as illuminated in the current study. Even so, the concept can be daunting and limiting for the present research (Bauer, 2014; Holman et al., 2021). Nonetheless, the theory that forms the basis of this study is holistic, as evidenced in the ‘dual-axis theoretical framework’ (see Chapter 3) used in the current study. They are interconnected and were utilised to investigate the overall perspective of Black African populations in the UK regarding their lay knowledge and beliefs about dementia.

Additionally, the researcher would like to acknowledge some of the published autobiographies of individuals living well with dementia, as they provide further insights into the research topic in the context of ‘lay expertise’ and ‘lay knowledge’ about dementia. These autobiographies were obtained from Dementia UK. The individuals are people from different walks of life diagnosed with young onset dementia. They have continued to share their experiences, advocate, and provide lay expert advice on insights into what day-to-day life with dementia is like as they live through and with dementia. Briefly, it includes ‘Slow Puncture’ (Berry & Bunt, 2021), ‘Dancing with Dementia’ (Bryden, 2005), ‘Dementia from the Inside’ (Bute, 2018), ‘Five Minutes of Amazing’ (Graham & Holden, 2016), ‘Somebody I Used to Know’ (Mitchell, 2018), ‘The Lewy Body Soldier’ (McNamara, 2016), ‘Dear Alzheimer’s’ (Oliver, 2019), and ‘Unforgettable’ (Thompson, 2022). These autobiographies provided interactions between lay and expert knowledge about dementia (Dementia UK). Furthermore, the primary research question is emphasised.

### Research question

- What are the lay knowledge and beliefs towards dementia amongst the Black African populations living in the UK?

Therefore, by focusing on the research questions, the researcher developed a theoretical framework (see Chapter 3), which further describes, explains, and discusses the theoretical components that underpin the thesis. It explores how the theories are related and interconnected. Finally, the layout of the thesis is as presented.

## Layout of thesis

### Chapter 1: Introduction

Chapter 1 presents the background and the importance of the study. It briefly positioned the researcher and situated the study on the lay concepts and knowledge of dementia as attached to a broader investigation. The chapter briefly described the research context and how this qualitative study developed.

### Chapter 2: Literature review

Chapter 2 provides a systematic review of the empirical studies on knowledge and beliefs about dementia using evidence synthesis (The Royal Society, 2018). The review identifies the literature relevant to this study, identifies gaps in the UK studies, and discusses how dementia is constituted and constructed amongst the African populations with justifications for the current study. Four themes emerged from the literature: (i) dementia witchcraft paradigm, (ii) dementia older age paradigm, (iii) dementia disease and illness paradigm, and (iv) Dementia identity paradigm.

### Chapter 3: Theoretical framework

Chapter 3 outlines the conceptual research framework. It describes, explains, and discusses the components of lay concepts of health and illness and social constructionism by focusing on the research questions. It explores how the theories are related and interconnected. The chapter also highlights the study’s strengths and limitations of the theoretical approaches.

### Chapter 4: Methodology

Chapter 4 outlines the methods used to meet this research aim and objectives. It describes the data-driven methodology approach, including the data analysis method. Details of the sample and recruitment and ethical considerations are included. The thematic data analysis process informed by a grounded theory approach is outlined in detail.

### Chapter 5: Social identity

Chapter 5 presents the interview findings of this study and showcases the empirical data. Firstly, this chapter provides the demographic characteristic of the participants. The respondents identify as churchgoers and laypeople from the Black African community in London. They are marginalised first-generation migrants from West Africa. The empirical findings illuminate the respondents' lay knowledge and beliefs about dementia. The data show that dementia knowledge and beliefs amongst the Black Africans living in London have evolved.

### Chapter 6: Sociocultural model

Chapter 6 presents the findings on the last five subthemes of the social identity/sociocultural model. It showcases the empirical data and provides in-depth explanations and interpretations. The results in this chapter highlight inequality and inequity associated with dementia, and it focuses on the other five subthemes: lay expertise, ethnicity, gender, older age, and disability/ability. The chapter informs the sociocultural model of dementia.

### Chapter 7: Disease and illness

Chapter 7 presents the findings of the thematic analysis of the interviews amongst the Black African populations living in London. It showcases the empirical evidence. Four subthemes emerge from the disease and illness theme: (i) dementia viewed as an illness, (ii) dementia viewed as ageing/older age, (iii) dementia viewed as a disease, and (iv) dementia viewed as forgetfulness. The chapter considers disease a biomedical concept, illness a lay concept, and sickness a social identity.

### Chapter 8: Help-seeking and caregiving

Chapter 8 presents the findings of the thematic analysis of the interviews amongst the Black African populations living in London by showcasing the empirical evidence. This chapter focuses on help-seeking and caregiving, as emerged from the study. It links dementia to stigma and labelling, separation and isolation, loss of status and power relationships, and discrimination and emotional reaction in people with dementia and their families.

### Chapter 9: Discussion

Chapter 9 combines all the interview findings, relating them to the original research question. The researcher discussed the results in relation to the existing literature, including what this study adds overall to the literature on dementia. The study is critically evaluated, and the strength and limitations are outlined and discussed. The study concludes that dementia in everyday life is complex but provides some recommendations for policy and practice.

## Summary

This introduction chapter outlined the research development through to the study findings. Overall, the researcher reflected on the medical concepts and knowledge about dementia from his medical background and training as a physician. The chapter briefly discussed the biomedical concepts and knowledge about dementia but focused on the lay concepts, knowledge, and beliefs about dementia. The biomedical concept of dementia is a reductionist approach to dementia on a cellular level as a disease and focuses only on the individual’s intrinsic bodily functions. However, the research essentially drew on the lay knowledge and beliefs about dementia within a broader sociocultural perspective from more expansive lay theories about dementia, including the individual, social and supernatural worlds, and identity theory. Indeed, dementia is a complex phenomenon. Again, on reflection, the study development supported the researcher’s learning and professional development. The study evolved in a way which met his interest. His good academic background in medicine, medical anthropology, public health, and health promotion influenced the current research development. However, the views and narratives of the respondents mattered the most. Furthermore, this chapter provided the layout of the thesis. The next chapter presents the literature review.

# Chapter 2

## Evidence Synthesis of Literature

### Introduction

This chapter systematically reviews the literature on knowledge and beliefs about dementia using evidence synthesis (The Royal Society, 2018). It identifies the literature relevant to this study (see Tables 3 & 4) and identifies gaps in the UK studies on dementia amongst Africans in the UK (see Table 5). The chapter evaluates and critiques the studies conducted in Africa and the UK with African populations as the respondents or a part of the participants. The literature is reviewed throughout the development of this study, through to the end stages of the analysis and write-up stages. The review focuses on African populations, representing a significant population in the UK. For example, about a million Black people live in London, with half of the Black population comprising Black Africans (Office for National Statistics, 2012). Therefore, the review excluded studies outside of the UK and Africa because the research is focused on the UK. The evidence provided in most studies in the United States was on Black Americans and did not apply to the UK context. In addition, the chapter presents a contextual definition of dementia knowledge and beliefs and the review question. This chapter also provides the literature review methods, including the studies evaluation, critique, and descriptive analysis. Firstly, the contextual definition of dementia knowledge and beliefs are illuminated.

### Research context

The definition of knowledge and belief is a matter of ongoing debate amongst philosophers. Nevertheless, the understanding is that knowledge and beliefs are essential representations (Phillips et al., 2020; Surtess & Todd, 2021). Indeed, it can suggest the representations of dementia amongst Black Africans. Furthermore, the dementia knowledge amongst Black Africans in the UK can be understood and depends on the prior representation of the diverse dementia beliefs that gave meaning to their life, which science cannot prove. Therefore, Black African people cannot be represented as knowing dementia if they cannot be described as believing in dementia. Thus, the Black African respondents in the current study can be treated as agents, knowing one mode of dementia representation or the other (Westra, 2021). Therefore, laypeople from the Black African community in the UK can know the lay representations of dementia through relativism or interpretivism or the biomedical representations of dementia through positivism or objectivism.

Nevertheless, a thematic or social constructionist analysis of the Black African's ideas, views, and narratives about dementia can illuminate some hidden biomedical constructs of dementia within their lay beliefs. Thus, their experiences, ideas, narratives, and views will define their shared knowledge and beliefs about dementia. Indeed, their lay knowledge and beliefs about dementia can be a potent sign of shared social attributes that can be socially meaningful.

Furthermore, the concept of dementia beliefs can allow for the guidance of behaviour in individuals and social groups, such as in the Black African community (Seitz et al., 2018). Therefore, knowledge is knowing, and belief is another way of knowing. However, intuitively, there may be a subtle difference between knowledge and belief, delineated as justified true belief (Gettier, 1963). Nevertheless, the Black African population can know dementia from instinctive feelings rather than conscious or clinical reasoning (Gruppetta & Mallia, 2020; Gagnon-St-Pierre et al., 2021). Hence, dementia belief must be understood from the 'native's point of view'. Only then can the seemingly irrational dementia constructions be understood, and only then can programmes of dementia education in the UK be developed to work within the local frame of reference (Pool & Geissler, 2007).

## Review question, aim, and objective

The researcher wanted to understand more about dementia services in the UK by exploring the dementia knowledge and beliefs amongst the African populations in the UK and Africa using evidence synthesis. The review aims to identify gaps in UK studies and explore how dementia is constituted and constructed amongst African people to inform dementia policy and practice. Therefore, the review question, aim, and objective are outlined:

- **Review question:**
  What are the knowledge and beliefs towards dementia amongst the African populations in the UK and Africa?
- **Review aim:**
  The review aims to identify gaps in the UK literature.
- **Review objective:**
  The review's objective is to understand how dementia is constituted and constructed amongst the African population in Africa and the UK literature.

## The review methods

This section provides the overall review methods, including the studies' search strategy and quality appraisal. The current study systematically reviews qualitative studies on knowledge and beliefs about dementia using evidence synthesis and are used to answer the review question highlighted above.

## Search strategy

This section covers two areas of literature search. Firstly, a comprehensive literature search on the research topic was performed using Google Scholar to overview the research topic. Google Scholar is a part of the popular WWW search engine, which means there were no limits on the languages covered, keywords allowed per search, and the list of covered journals (Falagas et al., 2008). Therefore, most of the literature was outside this study's scope, and it was not possible to systematically review them, given the vast amount of literature. Nevertheless, most of the studies on dementia in the African population were conducted in Africa, UK, and America. However, the researcher excluded studies conducted in the United States on the grounds of transferability since the focus is on UK studies. Regardless, dementia studies in the United States were mainly conducted on African Americans (Roche et al., 2020).

A systematic literature search was conducted in the second search to identify relevant studies (The Royal Society, 2018). Four databases were used to find peer-reviewed articles and provide literature on the topic. The databases were selected to enable a search strategy for research published in a broad disciplinary tradition. The study was updated from 6 May 2022 to 17 October 2022. Two previous searches were conducted from 19 October 2020 to 21 November 2020 and from 3 September 2017 to 16 October 2017. The researcher used search words as identified inductively from the literature, and they were 'dementia', 'Alzheimer's', 'culture', 'religion', 'anthropology', 'belief', 'perception', 'knowledge', 'lay', 'view', 'stigma', 'attitude', 'constructionism', 'Africa', and 'UK'. Each keyword and the phrase were initially used singly and combined using the Boolean operators 'AND' and 'OR'. Thus, the researcher undertook the search and launched the literature quality appraisal. A set of the combined search terms is indicated below and was used in each database.

**(Dementia OR Alzheimer*) AND (Cultur* OR Relig* OR Anthropol*) AND (Belief* OR Perception* OR Knowledge OR Lay OR View* OR Attitude* OR Stigma OR Constructionism) AND (Africa OR UK).**

The highlighted four electronic databases were searched: Scopus, Web of Science, Medline, and PubMed. Scopus was used because of the interdisciplinary nature of the topic of the study. Scopus delivers the world's research output in medicine and social sciences. Thus, Scopus covers life sciences, social science, and health science disciplines. It covers a broader journal range in keyword searching and citation analysis (Falagas et al., 2008). Web of Science was used because the database supports various scientific tasks across diverse knowledge domains. It covers the oldest publications and indexes, archived records dating to 1900 (Falagas et al., 2008). Hence, the researcher used PubMed and Medline because of the study topic's relation to clinical medicine and health science. PubMed focuses on medicine and biomedical sciences (Falagas et al., 2008), although it has an interface that searches Medline.

The four databases were selected to enable a search strategy for research published in various disciplinary traditions, including broader social sciences, clinical medicine, and health sciences. Therefore, these combined characteristics of databases enhance the utility for medical literature and social sciences academic and professional needs of this study. In each database, date limits were not applied to the search to consider a broader perspective. The set of papers on return was screened for eligibility to be included in the review. Nonetheless, this study literarily used only three electronic databases (see Table 1) because PubMed was an interface that searched Medline; Medline is the same as PubMed. The researcher used Google Scholar to overview the research topic. Nevertheless, the review augmented the electronic search with backward and forward reference searching of included articles and carried out manual book searches.

Table 1. Search strategy and results.

| Databases | Keyword search | Search with (Last searched on 17 October 2022) | Operators / Boolean / Phrase | Total number of hits |
|---|---|---|---|---|
| Scopus | Dementia, Alzheimer’s, Culture, Religion, Anthropology, Belief, Perception, Knowledge, Lay, View, Stigma, Attitude, constructionism, Africa, UK. | Article title, Abstract, Keywords | (Dementia OR Alzheimer*) AND (Cultur* OR Relig* OR Anthropol*) AND (Belief* OR Perception* OR Knowledge OR Lay OR View* OR Attitude* OR Stigma OR constructionism) AND (Africa or UK). | 120 |
| Web of Science | Dementia, Alzheimer’s, Culture, Religion, Anthropology, Belief, Perception, Knowledge, Lay View, Stigma, Attitude, constructionism, Africa, UK. | Topic | (Dementia OR Alzheimer*) AND (Cultur* OR Relig* OR Anthropol*) AND (Belief* OR Perception* OR Knowledge OR View* OR Attitude* OR Stigma OR constructionism) AND (Africa OR UK). | 79 |
| PubMed/Medline | Dementia, Alzheimer’s, Culture, Religion, Anthropology, Belief, Perception, Knowledge, Lay View, Stigma, Attitude, constructionism, Africa, UK. | All field | (Dementia OR Alzheimer*) AND (Cultur* OR Relig* OR Anthropol*) AND (Belief* OR Perception* OR Knowledge OR View* OR Attitude* OR Stigma, constructionism) AND (Africa or UK). | 284 |
| Total databases searched = 3 | | | | Total hits =483 |

## Eligibility criteria

To be included in the review, papers needed to meet the eligibility criteria for inclusion (The Royal Society, 2018), and papers that did not meet the eligibility criteria were excluded from the research (see Table 2). The papers included in the review were published peer-reviewed articles with available abstracts and full text written in English. Still, the review excluded studies outside the UK and Africa; as indicated, this study focuses on the UK. Therefore, studies outside the UK and Africa are excluded from the review since the current research focus is the UK. As noted, some of the few studies on African populations were conducted in the United States amongst African Americans, with the researchers not of African background (Roche et al., 2020). Therefore, the current study excluded papers conducted in the United States on the grounds of transferability. Indeed, the evidence provided in the studies conducted in the United States does not apply to the UK context.

Furthermore, the current study included only research reporting qualitative studies as this was the methodology appropriate to the review question. Therefore, quantitative studies are excluded. However, quantitative analysis can consist of expressions of attitude and epidemiology, and often close-ended and expressed numerically to ensure statistical representation (Bowling, 2018) rather than decisions gathered through contextualised inquiries or interviews to learn about feelings, meanings, attitudes, behaviours, and experiences (Braun & Clarke, 2006, 2013) of dementia. Therefore, the review included mixed method studies (Bowling, 2018) of dementia because when mixed studies are used, the data can gather the target audience’s demographic experiences, attitudes, feelings, behaviours, and meanings of dementia.

In addition, the inclusion and exclusion criteria are used when screening results from the initial database to ensure relevance to the review question. Moreover, the researcher utilised the APSO checklist, which he developed inductively from the papers, and finally, the current study used CASP qualitative checklist (CASP, 2018). The tools were an initial practical framework to appraise the evidence and ensure its relevance to answering the review question. The APSO checklist is demonstrated below (see Table 2 for more details on the inclusion and exclusion criteria).

## APSO checklist

The APSO checklist is developed inductively by considering the papers, and it is like the PICO strategy (da Costa Santos et al., 2007; Brown, 2020). Thus, the researcher wanted to ensure that studies considered for this review contained the right populations; nonetheless, this review is not about dementia intervention but dementia knowledge. Indeed, many UK papers were on BAME, but only a few had Black Africans as respondents or participants. Moreover, the researcher wanted to ensure the study's outcome was on dementia services. Therefore, using the APSO checklist ensures the appropriateness of the articles, population, study design, and outcome of the research and offers the ability to synthesise the evidence needed for the review. Thus, the researcher invented a set of questions inductively from the studies, as illuminated below, to determine the appropriateness of the included studies.

**A** = Article

**P** = Population

**S** = Study design

**O** = Outcome

### A (Articles)

- Is it a published journal article?
- Is the abstract available?
- Is the full text available?
- Is the article written in English?

### P (Population)

- Is the study conducted in Africa with African populations?
- Is the study conducted in the UK with African populations?

### S (Study design)

- Is it a qualitative study?
- Is it a quantitative study?
- Is it a mixed-methods study?

**O (Outcome)**

- What is the outcome of the study?
- Is the outcome relevant to the current study?

Table 2. Eligibility criteria for inclusion and exclusion using the APSO framework.

| Inclusion criteria | Exclusion criteria |
|---|---|
| **Articles (A):**<br>• Peer-reviewed articles<br>• Published journal articles (no date limit)<br>• Available abstract<br>• Available full text<br>• Papers written in English | **Articles (A):**<br>• Non-peer-reviewed articles<br>• Nonavailable abstract<br>• Nonavailable full text<br>• Papers not written in English<br>• Letters<br>• Commentaries<br>• Conference proceedings<br>• Media articles |
| **Population (P):**<br>• Studies conducted in Africa with African populations.<br>• Studies conducted in the UK with African populations. | **Population (P):**<br>• Studies with African populations conducted outside Africa.<br>• Studies with African populations conducted outside the UK.<br>• Studies with health practitioners. |
| **Study design (S):**<br>• Primary qualitative studies<br>• Primary mixed-methods studies | **Study design (S):**<br>• Quantitative studies<br>• Systematic reviews<br>• Traditional reviews |
| **Outcome (O):**<br>• Dementia services | **Outcome (O):**<br>• Not on dementia services |

### Identification of studies to be included or excluded

The study identification process is divided into two-stage operations: (i) level 1 screening and (ii) level 2 screening process. Level 1 was done using the publication modality, whilst the level 2 process was done using the APSO checklist as illuminated above, and then the CASP (2018) qualitative checklist for quality appraisal of the selected articles.

In the level 1 screening, the papers identified from the three central databases were assessed using the APSO checklist, for example, based on peer review journals, available abstract, available full text, and establishing that the papers were written in English (as illustrated in Tables 2 & 3).

In the level 2 screening, the researcher removed the duplicates, and the remaining papers were screened based on their relevance to the study using the APSO checklist (please refer to Table 3). The use of the APSO checklist by the researcher is essential because a clinical review or evidence synthesis needs to be directly relevant to the population of study and phrased in such a way as to facilitate answering the research question. Therefore, the APSO checklist made the literature review process more transparent and provided quality and rigour in the review process. Thus, it focused the evidence synthesis on peer-reviewed articles with African people as respondents or participants in the qualitative studies and excluded studies outside of the UK and Africa. More so, the researcher was interested in the outcome of the dementia services. Indeed, the researcher’s personal experiences of providing care for a family member with dementia, his clinical background, and being a Black African in the UK situated his positionality in the review and met his interest as an insider and outsider in the review process (Merton, 1972; Kauffman, 1994; Tuffour, 2018; Holmes, 2020).

Therefore, the inclusion and exclusion criteria were used when screening results from the initial database. In addition to the search and ensuring their relevance to the research question, the researcher used the APSO checklist (see Table 3) when reading titles and abstracts and the full article to ensure relevance and the ability to answer the research question. The included articles were then appraised using the Critical Appraisal Skills Programme (CASP, 2018) qualitative checklist (see Table 4). The researcher used these checklists to screen and appraise the papers methodologically and evaluate the quality of the included articles to review the literature and answer the research question. Indeed, 22 papers were included in the review (n=22), although Armstrong et al.’s (2021) and Mkhonto and Hassen’s (2018) papers were problematic. Armstrong et al.’s (2022) study explored the perspectives of Black and Asian people living with dementia and their carer in the UK. Of the 15 participants, seven were of Black ethnicity, and all were Caribbean. Some participants reported birth in African countries such as Kenya and Uganda, but all those who reported birth from the African countries defined themselves as South Asians. Nevertheless, the researcher included the UK study in the review because the paper contains Black Caribbean respondents. Whilst Mkhonto and Hassen's (2018) paper involved 19 nurses, even though the review excluded studies with a health professional, the researcher included the paper because the study involved 18 family members, 2 of the 18 family members were Black African background and were not health professionals.

Table 3. Screening of the included papers using the APSO Checklist

| | | Articles | | | | Population | Study design | Outcome |
|---|---|---|---|---|---|---|---|---|
| | | Journal | Abstract | Full text | English | | | |
| 1 | Adamson (2001) | Yes | Yes | Yes | Yes | African Caribbean | Qualitative | Dementia services |
| 2 | Adamson & Donovan (2005) | Yes | Yes | Yes | Yes | African Caribbean | Qualitative | Dementia services |
| 3 | Adebiyi et al. (2016) | Yes | Yes | Yes | Yes | Africans | Mixed | Dementia services |
| 4 | Agyeman et al. (2019) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 5 | Armstrong et al. (2022) | Yes | Yes | Yes | Yes | Africans Caribbean | Qualitative | Dementia services |
| 6 | Baghirathan et al. (2020) | Yes | Yes | Yes | Yes | African Caribbean | Qualitative | Dementia services |
| 7 | Berwald et al. (2016) | Yes | Yes | Yes | Yes | Black Africans | Qualitative | Dementia services |
| 8 | Botsford et al. (2011) | Yes | Yes | Yes | Yes | African Caribbean | Qualitative | Dementia services |
| 9 | Gurayah (2015) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 10 | Hindley et al. (2016) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 11 | Jacobs et al. (2022) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 12 | Kakongi et al. (2020) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 13 | Kehoua et al. (2019) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 14 | Lawrence et al. (2008) | Yes | Yes | Yes | Yes | African Caribbean | Qualitative | Dementia services |
| 15 | Mahomed & Pretorius (2022) | Yes | Yes | Yes | Yes | African | Qualitative | Dementia services |
| 16 | Mahomed & Pretorius (2021) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 17 | Mkhonto & Hanssen (2018) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 18 | Mukadam et al. (2011) | Yes | Yes | Yes | Yes | Africans or Caribbean | Qualitative | Dementia services |
| 19 | Mushi et al. (2014) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 20 | Nwakasi et al. (2021) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 21 | Owokuhaisa et al. (2020) | Yes | Yes | Yes | Yes | Africans | Qualitative | Dementia services |
| 22 | Parveen et al. (2017) | Yes | Yes | Yes | Yes | Africans and Caribbean | Mixed | Dementia services |

## Quality appraisal

The included studies were assessed against the Critical Appraisal Skills Programme (CASP, 2018). The CASP systematic review qualitative checklist highlighted ten questions to help make sense of the review papers as a quality measure. The appropriateness of the methodology, for example, research design, research methods, and findings, were considered (CASP, 2018). For instance, three broad issues were considered when appraising the included studies: (i) were the results of the study valid, (ii) what are the findings, and (iii) will the findings help in the understanding of dementia phenomena? With its categories of ‘YES’, ‘NO’, and ‘CAN’T TELL’, the articles were then judged subsequently as being of high, moderate, or low quality. There were no low-quality papers identified in the studies. The CASP (2018) qualitative checklist used in the quality assessment review is highlighted below.

**CASP (2018) checklist:**

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between the researcher and participants been adequately considered?
7. Has the ethical issue been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Table 4. Quality assessment of included studies using the Critical Appraisal Skills Programme – Qualitative Checklist

| Papers | Quality control | | | | | | | | | | | Quality outcome |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Total | |
| Adamson (2001) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 0 | 0.5 | 0.5 | 1 | 6 | Moderate |
| Adamson & Donovan (2005) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 0 | 0.5 | 0.5 | 1 | 6 | Moderate |
| Adebiyi et al. (2016) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Agyeman et al. (2019) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Armstrong et al. (2022) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 1 | 0.5 | 0.5 | 1 | 7 | High |
| Baghirathan et al. (2020) | 1 | 1 | 1 | 0.5 | 0.5 | 1 | 1 | 0.5 | 0.5 | 1 | 8 | High |
| Berwald et al. (2016) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 0.5 | 0.5 | 1 | 8 | High |
| Botsford et al. (2011) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 1 | 0.5 | 0.5 | 1 | 7 | High |
| Gurayah (2015) | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 5 | Moderate |
| Hindley et al. (2016) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Jacobs et al. (2022) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Kakongi et al. (2020) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Kehoua et al. (2019) | 1 | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 1 | 1 | 8 | High |
| Lawrence et al. (2008) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 0 | 0.5 | 0.5 | 1 | 6 | Moderate |
| Mahomed & Pretorius (2022) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Mahomed & Pretorius (2021) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 1 | 0.5 | 1 | 1 | 7.5 | High |
| Mkhonto & Hanssen (2018) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 1 | 0.5 | 1 | 1 | 7.5 | High |
| Mukadam et al. (2011) | 1 | 1 | 1 | 0.5 | 0.5 | 0 | 1 | 0.5 | 0.5 | 1 | 7 | High |
| Mushi et al. (2014) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Nwakasi et al. (2021) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Owokuhaisa et al. (2020) | 1 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 1 | 1 | 9 | High |
| Parveen et al. (2017) | 1 | 1 | 1 | 0 | 0 | 0 | 1 | 0.5 | 0.5 | 1 | 6 | Moderate |

## Quality assessment

Drawing on Roche et al. (2021), the researcher assigned a maximum of one point per item, with a possible score ranging from 0 to 10 (lowest to highest quality, respectively). He gave a partial point (0.5) if the study population was not entirely Africans but a multi-modelling of ethnicity and if the data analysis failed to provide separate findings for the African people in the study. Therefore, a score of 7 to 10 was judged as a high-quality study, a score of 5 to 6 was evaluated as a moderate-quality study, and a score below five was considered a low-quality study. Still, there was no low-quality paper identified in the study. Sixteen papers (n=16) were regarded as high quality, and five (n=5) papers were considered moderate-quality studies. Baghirathan et al.'s (2020) paper was the only study that assessed the relationship between participants and the researcher. Therefore, all the papers needed more positionality. Armstrong et al.'s (2021) and Mkhonto and Hassen's (2018) papers were a bit problematic, but the studies were included, and their findings were significant in answering the research questions.

### Evaluation of the included studies

This section evaluates the included studies (see Table 6: Appendix 12) by drawing on the philosophical and evaluation discourses (Crewell, 2006; Schwandt, 2002; Scale, 1999). For example, the research epistemological and ontological concepts (Lather, 1986) and the trustworthiness discourse (Lincoln & Guba, 1985). Therefore, the evaluation of the included research is guided by theory, methods, and empirical evidence (see Appendix 12).

Twenty-two studies (n=22) met the eligibility criteria and were appraised and included in the review (Table 4). All the UK papers were a multi-modelling of ethnicity in the study. Nine studies (n=9) (Adamson, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Botsford et al., 2011; Mukadam et al., 2011; Berwald et al., 2016; Parveen et al., 2017; Baghirathan et al., 2020; Armstrong et al., 2022) are studies conducted in the UK. Thirteen studies (n=13) (Gurayah, 2005; Mushi et al., 2014; Hindley et al., 2016; Adebiyi et al., 2016; Mkhonto & Hassen, 2018; Kehoua et al., 2019; Agyeman et al., 2019; Owokuhaisa et al., 2020; Kakongi et al., 2020; Mahomed & Pretorius, 2021; Nwakasi et al., 2021; Jacobs et al., 2022; Mahomed & Pretorius, 2022) are studies conducted in Africa (5 studies from South Africa, 2 studies from Tanzania, 1 study from Congo, 2 studies from Uganda, 2 studies from Nigeria and 1 study from Ghana) (Please refer to Table 3 & 4 for further details). The researcher considered all the studies valuable because the papers provided vital information regarding dementia services, although they were limited in some ways. For example, all the participants in the UK papers already accessed dementia services and knew someone was accessing dementia services or providing care for someone with dementia. Therefore, their dementia knowledge, beliefs, or attitudes would have been influenced by their attending dementia services or caring for a person with dementia. Therefore, participants' dementia knowledge and beliefs could have been affected by the biomedical understanding of dementia, yet the studies did not consider that. They were, indeed, lacking in the trustworthiness criteria (Lincoln & Guba, 1985). Nonetheless, the current research in the UK recruited participants from church sites, meaning that the respondents' dementia knowledge and belief would have also been influenced by religion and spirituality. Indeed, the current researcher employed a more objective judgement of quality in the empirical study (Lincoln & Guba, 1985; Crewell, 2006; Schwandt, 2002; Scale, 1999; Lincoln et al., 2011) drawing on his experiences, philosophical, epistemological, and evaluation discourses (see Chapter 4).

Moreover, Parveen et al.'s (2017) study participants were not purposively recruited. All the participants were recruited from roadshows and were found to have contacted or relied on support from their GPs, Alzheimer's Society, Age UK, or the local day centres as sources of support. It would have influenced their dementia knowledge, attitudes, or beliefs. Therefore, the participants' knowledge and beliefs about dementia would have been affected by such, thus making the study's outcome less reliable or lacking in credibility. However, the papers show that the African and Caribbean groups used religious and spiritual support from their churches (Parveen et al., 2017, p. 738). Although, the data did not separate the findings of the Black Africans from the Caribbean people. Therefore, the results were not compelling and could not make reliable conclusions about the Black African populations in the UK.

In addition, seven studies (n=7) from the UK defined the ethnic group as African-Caribbean (Adamson, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Botsford et al., 2011; Mukadam et al., 2011; Parveen et al., 2017; Baghirathan et al., 2020). Likewise, the data did not separate Black Africans from the Caribbean, as indicated in the UK studies. They were, indeed, lacking in transferability. However, a study (n=1) clearly defined the ethnic group as Black African (Berwald et al., 2016), although it did not provide separate data or findings for the Black African populations. Moreover, as previously illuminated, Armstrong et al.'s (2022) study explored the perspectives of Black and Asian people living with dementia and their carer in the UK. Of the 15 participants, seven were of Black ethnicity, and all were Caribbean. Nonetheless, some participants reported birth in African countries such as Kenya and Uganda, but all those who reported birth in the African countries defined themselves as South Asians. Therefore, we cannot make reliable conclusions about dementia knowledge amongst the Black African populations in the UK.

Furthermore, all the studies were different in the age range. Although the minimum age for respondents was 22 years, and the maximum was 100 years. The findings or data in the study were not distributed within age groups. Indeed, the distribution of meanings, ideas, and feelings about dementia will vary considerably with age range or age groups. Likewise, none of the studies provided separate findings with demographics or age groups, gender, education, and status, even though some of the studies, such as those by Mukadam et al. (2011), Kehoua et al. (2019), Nwakasi et al. (2021), Kakongi et al. (2020), Armstrong et al. (2022); Mahomed & Pretorius (2021), Jacobs et al. (2022) and Mahomed & Pretorius (2022) provided some vital demographic data.

More so, the total number of participants (n=222) in all the UK studies added together was 222, with only 38 participants (n=38) fluidly defined as Africans, constituting just about 17% of the total participants in the UK study. However, all the African studies were of African background, comprising 465 African participants (n=465) without the mixed methods quantitative data. Therefore, 17% is a meagre percentage, so we cannot consider the UK data valid or robust. Thus, the UK studies' findings are undependable and do not wholly inform us about the Black African population's dementia knowledge, attitudes, or beliefs in the UK papers.

In addition, five UK studies (n=5) were conducted more than ten years ago (Adamson, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Botsford et al., 2011; Mukadam et al., 2011). This suggests two things: firstly, dementia research is relatively new amongst Black African ethnic groups; presumably, Black Africans are not living long enough to develop dementia. Secondly, current research is required to investigate dementia knowledge and beliefs amongst the Black African ethnic groups. Black Africans' life expectancy in the UK is increasing, and it is expected to rise further from an average of 65 years due to improved quality of life and access to vital health services (Wohland et al., 2015). Therefore, it is likely that dementia may increase amongst Africans living in the UK.

Concerning methodology, all the studies included were qualitative. Still, two studies (Parveen et al., 2017 and Adebiyi et al., 2016) were of mixed methods; even though mixed methods do allow a nuanced understanding of phenomena in studies and the triangulation of perspectives, such as in the Adebiyi et al.'s (2016) study but were lacking in the Parveen et al.'s (2017) UK study. Indeed, Adebiyi et al. (2016) and Nwakasi et al. (2021) combined multiple empirical materials to understand the dementia phenomena in Nigeria. In addition, fifteen studies (n=15) made use of semi-structured interviews using a guide (mono-methods), and seven studies (n=7) were multi-methods, of which five studies (n=5) made use of focus groups and semi-structured interviews using a guide. Two studies (n=2) made use of unstructured interviews and case observations. Therefore, most of the qualitative studies used semi-structured interviews. Moreover, all the studies used interview guides except Kehoua et al. (2019), which used unstructured interviews and participant observations, and Agyeman et al. (2019), which used a series of case studies.

Therefore, drawing on Mahomed & Pretorius (2021) and using an interview guide during semi-structured interviews allowed for a more collaborative approach. The participant's ideas and language constructs were integrated into the questions. Nevertheless, there were three studies from the authors (Mahomed & Pretorius, 2021, 2022), but the two (Mahomed & Pretorius, 2022) explored dementia lived experiences from the same respondents. Thus, the researcher considered both studies the same even though one of the two concentrated on the contextual factors that impacted the dementia family caregiving experiences in the Soweto township in South Africa. In addition, Nwakasi et al.'s (2021) study used semi-structured interviews with participants in Nigeria. Afterwards, the findings were presented to focus groups of Nigerians living in the United States for more contextual insights into the results, presumably for confirmability. Nevertheless, unlike Nwakasi et al. (2021), the current study focuses on the UK rather than the United States.

Furthermore, a study (n=1) used case vignettes (e.g., Hindley et al., 2016), but no reason was provided for using the vignettes. Nevertheless, drawing on Helman (2007) would suggest that the same technique was developed by Greenhalgh and colleagues (Greenhalgh et al., 1998). They aimed to overcome 'deference bias' – the tendency of some respondents from disadvantaged backgrounds to agree automatically with any question the researcher asks, especially if the researcher comes from a more affluent or educated background (Helman, 2007, p. 461).

Nonetheless, the understanding is that vignette is a crucial tool (Sheringham et al., 2021), and using a vignette can provide an equal standard for all the participants during the interviews. It can be used to clarify people's judgement. Presumably, some researchers should have used a vignette to provide a cultural context for their study on dementia or, perhaps, a uniform standard for all the respondents in their dementia research. However, it may produce biased results (Sheringham et al., 2021).

Moreover, using semi-structured interviews may have allowed the researcher to prepare questions ahead of time and become more competent during the interviews (Braun & Clarke, 2013). More importantly, semi-structured interviews gave the participants the opportunity and freedom to express their views on their terms rather than in the capacity of unstructured interviews (Braun & Clarke, 2013). However, because unstructured interviews do not follow a guide, the interviewer may stray from the conversation, rendering the study findings inconsistent, as observed in Kehoua et al.'s (2019) study. Likewise, multi-methods must be carefully planned and implemented; otherwise, the approach can overstretch logistic and analytic resources (Braun & Clarke, 2013; Mason, 2018; Green & Thorogood, 2018).

Furthermore, fifteen studies (n=15) utilised purposive sampling, and two (n=2) used convenience sampling. Both methods are non-probability sampling (Braun & Clarke, 2013; Barbour, 2014). With purposive sampling, it could be easier to generalise the Africans in the study, but the sampling is open to selection bias and error (Braun & Clarke, 2013; Manson, 2018). Likewise, convenience sampling is prone to bias (Braun & Clarke, 2013), and the sample will not represent the entire African population in the UK. With convenience sampling, the result can only speak for part of the African people in the UK, but purposive would not. However, none of the studies provided separate findings for the African populations. Of course, it is not easy to generalise results to all the Africans in the studies, even those that used purposive sampling methods. Nonetheless, qualitative research is not aimed at generalisation. Still, contextualising the findings to the African population was not possible.

In addition, the study sample size ranged from five (n=5) for the qualitative to 313 (n=313) for the mixed methods studies. Most studies (n=16) used a sample size ranging from 11 to 56. Only one study (n=1) used a 5-sample size (Gurayah, 2015), which the researcher considered a shallow sample. In this case, the small sample size will reduce the power of the study and increases the margin of error, which can render the study less meaningful (Braun & Clarke, 2013; Miles et al., 2014; Barbour, 2014; Green & Thorogood, 2018; Mason, 2018). Nevertheless, the power of a study is primarily quantitative rather than qualitative. Regardless, Gurayah's (2015) evidence is not compelling. However, two studies (n=2) used a sample size ranging from 93 to 313 for mixed methods. Still, many factors are essential when considering the sample size for a qualitative study, including the quality of data, the scope of the research and data saturation (Braun & Clarke, 2013; Manson, 2018). Most importantly, in a qualitative study, researchers are interested in quality, not quantity (Braun & Clarke, 2013; Green & Thorogood, 2018).

Furthermore, the study participants were male and female, with a minimum stated age of 22 to a maximum of 100 years, as previously mentioned. Still, the researcher could not ascertain the total number of men and women in the study because some did not present demographic information on gender. However, all the interviews were audio-recorded, pseudonymised, transcribed verbatim, checked for accuracy and code for data analysis using NVivo 12, ATLAS.ti software, and Excel for data management.

Finally, a total of fourteen studies (n=14) made use of thematic data analysis, two studies (n=2) used content analysis, and five studies (n=5) made use of traditional grounded theory. One study (n=1) used a constructivist grounded theory. Thematic analysis is the most common method used to identify patterns of meanings or themes in qualitative analytical approaches (Braun & Clarke, 2013; Barbour, 2014; Mason, 2018). Specifically, Mahomed & Pretorius (2022) used reflexive thematic analysis. Jacobs et al. (2022, p. 7) and Mahomed & Pretorius's (2021, p. 639) studies show that phases of thematic analysis can include 'familiarisation', 'generation of initial codes', 'focus coding', 'searching for the theme', 'categorisation of themes', and 'production of the report', which can also include the similar process for reflexive thematic analysis (Braun & Clarke, 2006, 2019). Nevertheless, they are the methods for a grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1994).

Notwithstanding, the traditional and constructivist grounded theory is an approach 'grounded' in participants' own words and experiences (Barbour, 2014; Mason, 2018; Green & Thorogood, 2018; Braun & Clarke, 2019). Glaser and Strauss developed the grounded theory (Braun & Clarke, 2013, 2019). Regardless, most of the studies used grounded theory without being specific, but Botsford et al.'s (2011) study suggests that constructivist grounded theory is a flexible process and refers to the fact that the evolving theory was co-constructed by the researcher and participants (Charmaz, 2006). It can be considered a theoretically informed framework for research, unlike thematic analysis, which may be regarded as a broader approach rather than a precise method (Braun & Clarke, 2019; Manson, 2018). Regardless, most of the studies used a thematic approach for data analysis.

PRISMA

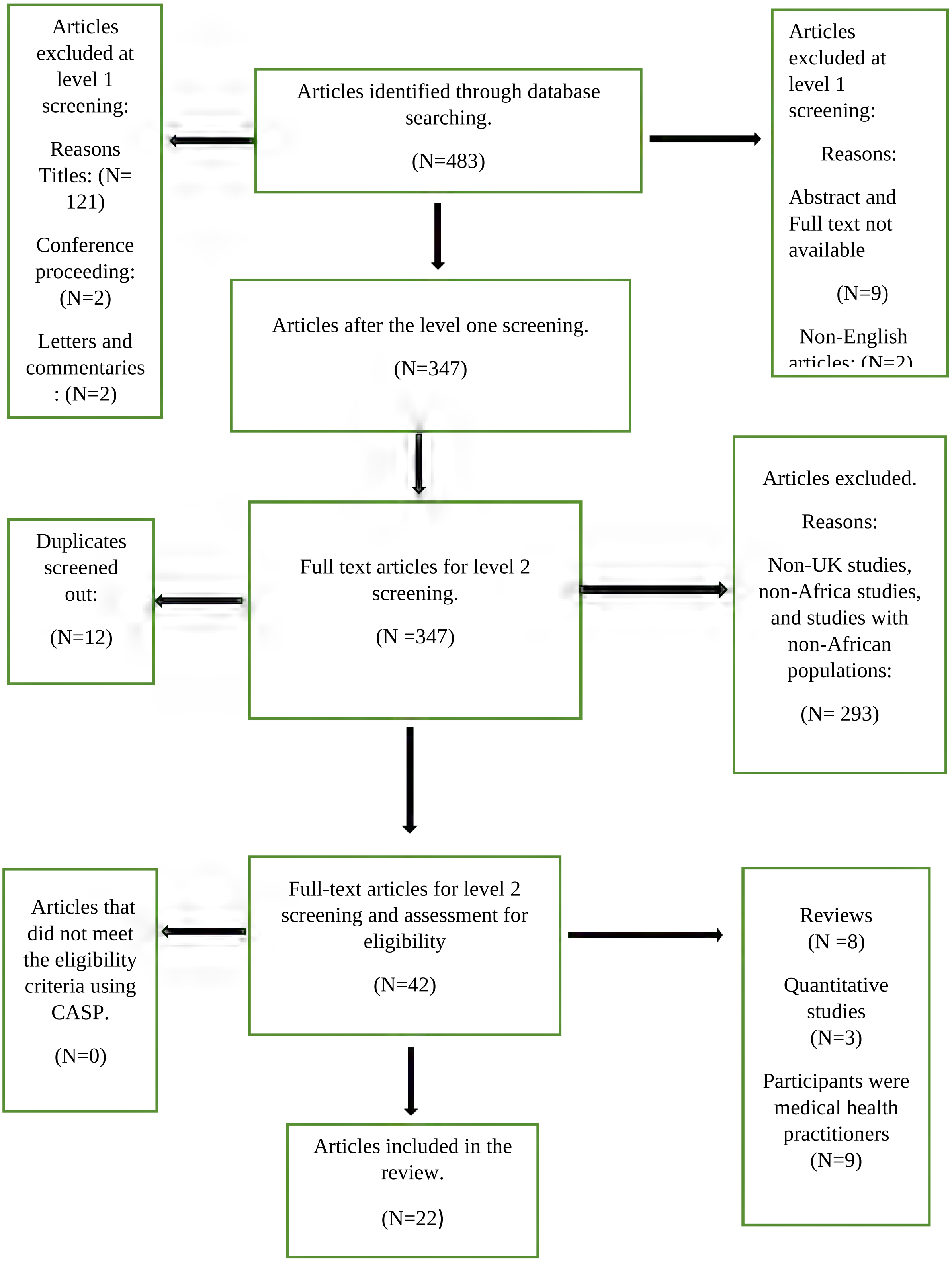


Figure 1. PRISMA diagram of the selection of studies

Table 5: Identified gaps in the literature and plans for the current study.

| No | Studies | Study design | Methods | Sampling | Sample size | Identified gaps | Plans for the current study | Data analysis for current study |
|---|---|---|---|---|---|---|---|---|
| 1 | All the UK studies | Qualitative | Semi-structured interviews | Purposive | 15 – 56 | All the studies were multi-modelling of ethnicity, and the results did not separate Africans from the Caribbean. Thus, the studies lack trustworthiness criteria (Lincoln & Guba, 1985). | To explore dementia amongst African populations in the UK. | Thematic analysis informed by a grounded theory approach. |
| 2 | All the UK studies | Qualitative | Semi-structured interviews | Purposive | 15 – 56 | The studies did not explore lay knowledge and beliefs about dementia amongst Black Africans in the UK. | To explore lay knowledge and beliefs towards dementia amongst African populations in the UK. | Thematic analysis informed by a grounded theory approach. |
| 3 | All the UK studies | Qualitative | Semi-structured interviews | Purposive | 15 – 56 | The studies were lacking in theory, methods, and empirical evidence. Thus, the studies lack clarity and validity (Lather, 1986). | To develop a conceptual framework for the current study and collect empirical data. | Thematic analysis informed by a grounded theory approach. |
| 4 | Armstrong et al. (2022) | Qualitative | Semi-structured interviews. | Purposive | 15 – 56 | All the participants who reported birth from African countries defined themselves as South Asian. | To explore lay knowledge and beliefs towards dementia amongst African populations in the UK. | Thematic analysis informed by a grounded theory approach. |
| 5 | All the African studies | Qualitative | Semi-structured interviews | Purposive | 15 – 56 | The studies were lacking in the researcher’s positionality (epistemological and ontological stance) | To highlight the researcher’s positionality. | Thematic analysis informed by a grounded theory approach. |

### Thematic content analysis

The procedure for the literature analysis adopted a thematic approach as used in the included studies (e.g., Mahomed & Pretorius, 2021; Jacobs et al., 2022). The thematic analysis (Braun & Clarke, 2019) is informed by a grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1994). The analysis is conducted to answer the review question thematically. The procedure was drawn upon in the thematic coding and analysis of the included studies and identifying the themes and patterns or meanings across the data (Glaser & Strauss, 1967; Braun & Clarke, 2019). Hence, the researcher analysed vital empirical data accessible in the included papers using thematic content analysis. The analysis was driven by the participants' own words rather than the researcher's interpretation of the data (Roche et al., 2021). The review question is to explore lay knowledge and beliefs about dementia amongst the Black African populations using evidence synthesis to identify gaps in the UK literature. The review's objective is to understand how dementia is constituted and constructed amongst the African populations in the study. Hence, the researcher included direct quotations from the UK and African studies in this analysis and coded the extracted data line by line and between as deemed necessary to answer the review question. The analysis utilised thematic content analysis outlined by Braun & Clarke (2013) and grounded in the participant's own words (Glaser & Strauss, 1967).

The method involved identifying theories through analysing the data (Glaser, 1992; Strauss & Corbin, 1994), which involved familiarising with the data, focus coding, theoretical coding, categorising, and thematic coding through inductive reasoning (Strauss & Corbin, 1994; Braun & Clarke, 2013; Mason, 2018). Indeed, as the researcher coded the included studies' empirical data, embedded concepts became apparent and emerged from the data. Then, the researcher deductively assigned theories to the data by drawing deductive inferences from the theoretical framework (see Chapter 4). Therefore, the grounded approach (Ralph et al., 2015) provided means of constructing methods (Leavy, 2020) to understand better how dementia is constituted and constructed by the Africans in the studies. Indeed, it enabled the researcher to understand the socially shared constructions that underline the individual's or group's behaviour and the dementia reality of the participants across the papers. The researcher coded the participants' words as evidence using colours and managed the data using Excel (see Appendix 13). Through an iterative and reflexive process of comparing the empirical data from the studies (Braun & Clarke, 2019), the researcher produced codes inductively based on the empirical evidence. For example, as demonstrated in the audit trail:

1. **Participants' own words as evidence:** *You know in the village, they will think that somebody is bewitching [or casting evil spell on] that person [with dementia]* (Nwakasi et al., 2021, p. 1452).

- **Focus coding:** Dementia is witchcraft
- **Theoretical coding:** Cultural construct
- **Category:** Spirituality
- **Theme:** Witchcraft paradigm

2. **Participants' own words as evidence:** *We call it old age, when a person becomes elderly, his knowledge reduces and he starts forgetting* (Owokuhaisa et al., 2020, p. 3).

- **Focus coding:** Dementia is old age
- **Theoretical coding:** Social constructionism
- **Category:** Body
- **Theme:** Older age paradigm

3. **Participants' own words as evidence:** *Another thing which causes forgetfulness among the elderly, there is when you find a person has suffered from a disease for a long time like cancer and he takes different types of medicine* (Owokuhaisa et al., 2020, p. 4).

- **Focus coding:** Dementia is a disease
- **Theoretical coding:** Biomedical concept
- **Category:** Mind
- **Theme:** Disease and Illness paradigm

4. **Participants' own words as evidence:** *And if you see her, you won't even know that she is having such sickness* (Nwakasi et al., 2021, p. 1453).

- **Focus coding:** Dementia is a sickness
- **Theoretical coding:** Identity theory
- **Category:** Body
- **Theme:** Identity paradigm

Nonetheless, the empirical data presented in the literature is a subsample of the whole dataset used in the included articles but was deemed valuable for the thematic content analysis (refer to Appendix 13 for further detail).

Finally, the researcher produced the report by discussing the emergent themes captured in a more analytical concept and synthesising the evidence on how dementia knowledge and beliefs are constituted and constructed amongst the African populations. Therefore, four themes are developed from the literature, as illustrated in table 7 (see Appendix 13) and are discussed. It included the following: (i) dementia witchcraft paradigm, (ii) dementia older age paradigm, (iii) dementia disease and illness paradigm, and (iv) dementia identity paradigm.

## Discussion

The focus of this section is to discuss the emerged themes reflectively. The synthesised evidence foregrounded sociocultural distinctiveness, illuminating how dementia knowledge and beliefs are constituted and constructed amongst the African populations as emerged from the literature review:

### Dementia witchcraft paradigm

Belief in witches' crafts is widespread in Africa (Mkhonto & Hanssen, 2018; Brooke & Ojo, 2019). The characteristic indicator of the witchcraft paradigm is when the dementia is undiagnosed, and the treatment for dementia does not provide the expected relief or cure. Many Black African populations believed witches could cause dementia. The knowledge about dementia and its causes can be contradictory and held simultaneously amongst people depending on the applied theory or concepts. For example, Owokuhaisa et al.'s (2020) investigation was based on explanatory theory. The explanatory model framework assessed how individuals from Southwestern Uganda perceived and named the dementia illness and described its causality and meanings. Explanatory theories are constructs used to make sense of complex phenomena such as dementia. Thus, Owokuhaisa et al. (2020) unified how dementia was constituted and constructed as 'witchcraft' in Southwestern Uganda. Therefore, an explanatory model of dementia is a way of understanding the process by which dementia is patterned, interpreted, and treated (Kleinman, 1980, 1988).

Furthermore, Mushi et al. (2014) used Kleinman's explanatory model to examine perceptions of the causes and symptoms of dementia and the meanings attached to the experiences of people with dementia and their carers in the Hai District of Tanzania. Kleinman's explanatory model can focus on answering the 'why', 'when', 'how', and 'what next' for dementia illness. Mushi et al. (2014) somehow used this model developed by Arthur Kleinman, a physician and anthropologist, to explore how dementia was constituted and constructed by the respondents in Tanzania as 'witchcraft'. Thus, in Owokuhaisa et al.'s (2020) and Mushi et al.'s (2014) study, they coherently unified the understanding of dementia amongst the participants as 'witchcraft'. However, the studies were lacking in empirical evidence. Generally, the African people's explanation of the cause of dementia forms an essential aspect of their dementia narratives and views.

Nevertheless, the concept of the explanatory model found it difficult to reconcile different conflicting and contradictory systems of medical beliefs and practices covering a whole spectrum from modern medicine to folk medicine (Kleinman, 1980, 1988). They are, indeed, suggesting that an explanatory model for dementia can be employed by all those engaged in the dementia practice or clinical process. Therefore, explanatory models of dementia are held by doctors, patients, families, and friends. They guide choices for dementia and treatment and can give meanings and experiences to the dementia phenomenon. They can be deeply rooted in explaining the causes of dementia through to the end of life (Downs et al., 2006). They can explain the dementia phenomenon, which may include the causes, when and how symptoms first appeared, the nature of the symptoms, the course of the dementia illness, and its treatment.

However, drawing on Young (1982) can suggest that the explanatory model approach for dementia may be limiting because it may focus only on the individual, for example, as a part of the lay explanatory model of dementia (see Chapter 3). As a result, how social relations shape and distribute dementia may be ignored. Indeed, the individual focus (individual phenomenon) can hide power relationships between groups, ethnicity, gender, and social class as a factor in dementia. It may need to include the social process through which behavioural and biological signs are given social meanings. In addition, the explanatory model may assume that a person with dementia and their family have only one kind of dementia knowledge. Therefore, it is vital to consider broader sociocultural relations beyond the person with dementia. More importantly, there should be more focus on the sociocultural understanding of dementia knowledge production using the lay concept of dementia, which focuses on holism, individualism, and relativism or pragmatism (see Chapter 3).

Likewise, Nwakasi et al.'s (2021) study focused on the everyday understanding of dementia in Nigeria. Moreover, the findings of dementia as 'witchcraft' resonated strongly in the study. Afterwards, the findings were presented to focus groups of Nigerians living in the United States for more contextual insights into the results. Nevertheless, all the 12 participants in Nigeria were women, but dementia knowledge and beliefs can vary with gender. Some of the participants in the study associated dementia with witchcraft. Regardless, the 21 participants for the focus groups in the United States were both men and women, and they linked dementia with witchcraft as illuminated:

> *You know in the village; they will think that somebody is bewitching [or casting evil spell on] that person [with dementia]* . . . (Nwakasi et al., 2021, p. 1452).

However, the current study is focused on the UK, and the United States study may need more research transferability and dependability in the UK. Of course, none of the included UK studies associated dementia with witchcraft. For example, Parveen et al. (2017) used Leventhal's model of self-regulation to explore the perceptions of dementia in ethnic communities in the UK. Illness representations are central to Leventhal's self-regulatory theory. However, Parveen et al.'s (2017) study was limited in many ways but suggested that Africans in the UK are using churches as support for dementia. Regardless, five of the included UK studies used grounded theory (e.g., Adamson, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Botsford et al., 2011; Baghirathan et al., 2020), but they were all limited in empirical data and theory. The grounded theory maintains an approach free of prejudices and preconceptions (Glaser, 1992; Glaser & Strauss, 1967).

Thus, grounded theory should produce the dementia knowledge and beliefs that lie in and emerges from the data, ultimately illuminating lay explanation of dementia, an explanatory model (Kleinman, 1980, 1988) for dementia knowledge amongst the Black African population in the UK. However, all the included studies conducted in the UK were a multi-modelling of ethnicity (e.g., Adamson, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Botsford et al., 2011; Mukadam et al., 2011; Berwald et al., 2016; Parveen et al., 2017; Baghirathan et al., 2020; Armstrong et al., 2022). Therefore, limiting knowledge in the cultures, none of the studies provided separate empirical findings and was limited in dementia theory for the African populations in the UK. In addition, the most recent study in the UK by Armstrong et al. (2022) explored the experiences of dementia care using an ecological model but was also limited in empirical findings. For example, all the participants who reported birth from African countries defined themselves as South Asian (Armstrong et al., 2022). Therefore, we cannot make a reliable conclusion about the African populations in the UK and their lay dementia knowledge and beliefs.

Furthermore, most of the UK studies were not methodologically robust. For example, studies did not report age range (e.g., Adamson & Donovan, 2005; Parveen et al., 2017; Baghirathan et al., 2020) or limited in age range (e.g., Botsford et al., 2011), and the data was not separated by age or demographic factors. As noted in the evaluation section of this study (see Table 6), all the respondents in the UK papers were already accessing dementia services, knew someone accessing services or caring for someone with dementia, or had an awareness of dementia beforehand. Therefore, it is essential to note that all the participants in the UK studies already had some level of dementia awareness or knowledge before the studies were conducted. However, this was not acknowledged even though some Black Africans and Caribbean communities thought that dementia was a White person's illness and, by implication, possibly not an actual disease for Black Africans (Berwald et al., 2016). Regardless, five UK studies (n=5) were conducted more than ten years ago (e.g., Adamson, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Botsford et al., 2011; Mukadam et al., 2011). Moreover, it may be outdated with current dementia knowledge amongst the groups, thus suggesting a need for urgent study in the UK with Black African respondents.

The thematic content analysis illuminated that the UK's studies were limited in empirical evidence due to the conceptual fusion of the African populations with other ethnic groups in the UK research, or due to the modelling of multi-ethnicity in the UK studies (e.g., Adamson, 2001; Adamson & Donovan, 2005; Lawrence et al., 2008; Botsford et al., 2011; Mukadam et al., 2011; Berwald et al., 2016; Parveen et al., 2017; Baghirathan et al., 2020; Armstrong et al., 2022). Still, the UK studies have some relevant findings and inform the current research. Although the studies lacked robust empirical evidence and theory, they were instrumental in knowing that the research on dementia amongst BAME in the UK was traditionally limited by the characteristics of people included in the dementia research and biomedical concepts of dementia. Indeed, lacking lay ideas of dementia or the sociocultural constructions of dementia. However, it suggested how inequality and inequity negatively impacted dementia services in the UK. For example, Parveen et al.'s (2017) study in the UK suggested that Africans were underrepresented in dementia services. The study explored perceptions of dementia and the use of services in minority ethnic communities in the UK using Leventhal's model of self-regulation. It conducted a series of dementia awareness-raising roadshows delivered between

August 2013 and April 2014 in the North of England, involving 62 British Indians, 50 Africans and Caribbean, and 63 East and Central Europeans. Informal discussions and a dementia knowledge quiz were conducted. Nonetheless, respondents were not purposively recruited.

Indeed, from a methodological perspective, the study relied on roadshows for sampling, naturally occurring data were hugely relied on, and the study lacked contexts; no information was collected in the context of age, gender, religion, demography, or socioeconomic status of participants. A quiz is not a sufficient and robust method to capture quantitative or qualitative data, but it is readily acceptable in medical education (Dengri et al., 2021). Nonetheless, evidence was obtained from the quiz concerning knowledge about dementia (Parveen et al., 2017, p. 739). However, the evidence provided was not compelling. All the participants were recruited from roadshows, and they were found to have contacted or relied on support from their GPs, Alzheimer's Society, Age UK, or the local day centres as sources of support. Therefore, the participants' knowledge and beliefs about dementia would have been influenced by such, thus making the study's outcome unreliable and lacking in dependability and credibility. Like other studies in the UK, the study utilised multi-modelling of ethnicity, thus limiting knowledge of the cultures. It provided no separate findings for the African populations in the study regarding the dementia illness representations.

On the contrary, Owokuhaisa et al.'s (2020) study in Uganda explored the community perceptions about people with dementia based on the explanatory model framework in December 2018, purposively recruiting and conducting 22 individual in-depth interviews and seven focus groups discussion within three separate districts in Southwestern Uganda. The study used traditional healers, local council leaders, community elders, and religious leaders. Both males and females aged 22 to 84 were involved in the study. Similarly, Kakongi et al. (2020) explored the understanding of care-seeking pathways for patients with Alzheimer's disease and related dementias across three psychiatry hospitals in Southwestern Uganda. The study showed that the hospital point of care was more frequent during initial healthcare visits, while places of worship took the lead during subsequent visits. Indeed, findings from both studies were not compelling but suggested that the respondents' dementia knowledge and beliefs were based on their reality that dementia is caused by satanic power and perceived as witchcraft. However, the evidence was not robust but can support or link to why the African respondents in the UK roadshows (Parveen et al., 2017) might use churches for dementia support. The findings corresponded with observations from the literature as illuminated:

> *Some are bewitched so when they become like that, we take them to churches to pray for them and they get better. We pray for him/her and he becomes fine, there are devils which can make a person like that but after praying it goes [away]* (Owokuhaisa *et al.,* 2020, p. 9).

Indeed, suggesting that the community dementia knowledge was informed by looking at the world from a familiar cultural perspective, and the categories or the lay concept used in understanding the dementia phenomenon in Southwestern Uganda was culturally bound. Like all the African studies reviewed, dementia was identified as witchcraft (Mushi et al., 2014; Gurayah, 2005; Mkhonto & Hassen, 2018; Kehoua et al., 2019; Kakongi et al., 2020; Hindley et al., 2016; Adebiyi et al., 2016; Agyeman et al., 2019; Mahomed & Pretorius, 2021; Nwakasi et al., 2021). Therefore, the lay knowledge of dementia as witchcraft can be considered a sociocultural construct, labelling, or stigma (Adebiyi et al., 2016). The findings from the studies have some consistency with the broader African literature on dementia. Although dementia labelling as witchcraft can be considered a ritual that changes the social identity of people with dementia, ultimately leading to stigmatisation, social isolation, and social death, in line with the empirical findings corresponding with the observations from the literature:

> *It may be difficult for you to go and see your friends or gather with people whether they are far or near* . . . (Owokuhaisa et al., 2020, p. 7).

Therefore, according to Goffman (1963), the understanding is that stereotyping can lead to stigma. Perhaps it is a circular process with stigma as the starting point for stereotyping, which could change the identity of people with dementia, their self-concept, and social identity. Of course, stigma led to a reluctance to seek help for dementia either due to dementia labelling as witchcraft (Mkhonto & Hassen, 2018) or labelling dementia as mad (Berwald et al., 2016; Adebiyi et al., 2016). Therefore, there was a reluctance to seek help for dementia due to perceived and associated stigma (Jacobs et al., 2022), and the dementia stigma created a barrier to seeking assistance outside the family system or structure (Baghiranthan et al., 2020; Mkhonto & Hassen, 2018; Agyeman et al., 2019; Nwakasi et al., 2021). Although the empirical evidence provided in the studies was not so strong and compelling, the evidence presented below suggested enacted and implied stigma for dementia in the community (Adebiyi et al., 2016; Mkhonto & Hassen, 2018; Nwakasi et al., 2021; Jacobs et al., 2022), as findings corresponded with the observations from the literature:

> *They [the villagers] called me asking and saying if it is madness that is happening to my grandma . . .* (Nwakasi et al., 2021, p. 1453).

However, it appears that the dementia stigma is not only associated with the sociocultural conceptualisation of dementia but also with the biomedical perception of dementia as a hereditary condition or the transmission of genetic information from parents to a child, as illuminated by this excerpt from the literature:

> *You know how it is in Nigeria. If someone is mad [dementia] in the family, they [outsider] will see it as one person [a younger family member] is going to be mad in your family. They won't want to marry you, and they will say . . . don't marry from that family . . .* (Nwakasi et al., 2021, p. 1453).

In addition, Jacobs et al. (2022) explored the experiences of stigma among people living with dementia and their carers through understanding their own knowledge, attitudes, and beliefs. The study involved 52 respondents (n=52) aged 26 to 90 across two provinces in South Africa. Findings illuminated high internalised and structural stigma levels, which limited access to dementia help-seeking and support. The study is rich in empirical data. However, the study did not explore lay conceptualisations of dementia. It did not provide an analysis of the indigenous cultural beliefs about dementia, although internalised stigma resonated strongly in the research as observed:

> *I have been trying to hide . . . it's fine . . . keeping this to myself, I didn't want to involve other people into it* (Jacobs et al., 2022, p. 11).

Undoubtedly, the studies reported pluralistic behaviours in seeking help due to the stigma. However, the stigma influenced and impacted respondents' health behaviour negatively, although some participants sought help from their GP or modern care (Berwald et al., 2016; Mushi et al., 2014), prayers from churches (Perveen et al., 2017; Hindley et al., 2016), spiritual home or traditional healers (Mushi et al., 2014; Kehoua et al., 2019; Hindley et al., 2016). Notwithstanding, the evidence suggests that most of the time, when respondents took patients to GP or modern care, it was not necessarily for dementia treatment but due to other medical conditions such as HIV, TB, or STI (Mushi et al., 2014; Berwald et al., 2016). Thus, dementia may be considered a chronic illness. Moreover, further evidence suggested that a delay in seeking help from GP was because the respondents' culture or religion encouraged them to initially turn to their family structure or pastors (Berwald et al., 2016), traditional healers, or faith healers (Hindley et al., 2016) for their help.

Nevertheless, prayer was helpful due to the nature of support and encouragement received through prayers (Berwald et al., 2016; Hindley et al., 2016; Kakongi et al., 2020), and collaboration amongst health providers can be considered effective in dementia help-seeking, behaviours, and dementia management. Although, Hindley et al. (2016) suggested that the lack of evidence of therapeutic efficacy of traditional remedies and evidence of harmful practices of the traditional healers with difficulties in aligning different health beliefs were often cited as arguments against collaboration amongst health providers (Hindley et al., 2016). However, a multidisciplinary and collaborative approach is crucial in dementia management.

Nevertheless, Hindley et al.'s (2016) study explored how traditional and Christian faith healers understood and treated people with dementia by purposively recruiting 11 traditional healers, 10 Christian faith healers, 18 people with dementia, and 17 family caregivers in Tanzania. A primary concern identified in the study was the incentive payment made to gatekeepers and the participants, which may have undermined informed consent. Therefore, a primary ethical concern arises because it is essential to consider key ethical questions concerning the incentives and to ensure the motivation was reasonable, not coercive, and did not undermine their voluntary consent. In addition, the interviews were partly conducted through an interpreter. Thus, subtleties and inconsistencies might have been missed during the translation. Regardless, it is unclear how dementia was stigmatised amongst the participants apart from the witchcraft accusation and labelling. Therefore, the evidence presented in the studies was not robust. However, it suggests a dichotomy between the biomedical knowledge of dementia and the lay conceptualisation of dementia (e.g., Mushi et al., 2014; Gurayah, 2015; Berwald et al., 2016; Adebiyi et al., 2016; Hindley et al., 2016; Kehoua et al., 2019; Agyeman et al., 2019).

Nonetheless, the studies did not detail the lay conceptualisation of dementia, stigma, and negative help-seeking behaviours. Also, it's important to note the limitations of Gurayah's (2015) study, which was primarily limited in sample size, wherein only five respondents (n=5) were purposively recruited for the study, thus providing inadequate empirical evidence, and was limited in age range (e.g., ages 46 to 68). Therefore, the degree to which the findings of these qualitative studies can be transferred to the UK context is daunting. Regardless, some of the studies only identified related terms used to externalise dementia causes and in looking for divine explanations such as satanic power (Hindley et al., 2019), punishment from God (Kehoua et al., 2019), possession by the devil (Kehoua et al., 2019), ancestral curses (Mushi et al., 2014), and curses and evil spirits (Owokuhaisa et al., 2020). As such, the evidence corresponded with the observations from the literature:

> *They use to give sacrifice to the ancestors so due to her age she cannot afford to give sacrifice to them so they get annoyed and cause all these problems* (Hindley et al., 2016, p. 133).

In addition, the witchcraft paradigm can be perceived as a construct of modernity that addresses tension or conflicts within the communities (e.g., Mushi et al., 2014; Mkhonto & Hassen, 2018; Agyeman et al., 2019) and provides explanations for events which have no logical reason in the biomedical construct of dementia as a disease of the brain. However, witchcraft as a lay concept or a sociocultural construct of dementia may logically explain Black African communities' events, such as an explanation for illness, sudden death, bad luck, or misfortune (e.g., Mushi et al., 2014; Mkhonto & Hassen, 2018; Owokuhaisa et al., 2020). Indeed, suggesting that the lay construct of the dementia illness as witchcraft places the causation of dementia within the individual, supernatural world, social world, or the natural world, as seen in the studies (Hindley et al., 2016; Kehoua et al., 2019; Agyeman et al., 2019). The dementia witchcraft labelling or constructs and narratives reflect core cultural values that express normative understandings of the African respondents about the nature and causes of disease and bodily dysfunction. Many lay explanations for dementia have multiple reasons but are deeply rooted in religion or the supernatural world (Hindley et al., 2016; Kehoua et al., 2019). For example:

> *The majority get the disease of forgetfulness and sometimes they think that they are invaded by Satan* (Owokuhaisa et al., 2020, p. 6).

Nonetheless, Owokuhaisa et al.'s (2020) study was focused on the rural communities in southern Uganda and did not capture perceptions of people with dementia in the urban part of Uganda. The findings of dementia as witchcraft were replicated and consistent in previous studies in other regions of sub-Saharan Africa (e.g., Gurayah, 2005; Mushi et al., 2014; Mkhonto & Hassen, 2018; Agyeman et al., 2019; Kehoua et al., 2019), including the most recent study in Nigeria (Nwakasi et al., 2021). Therefore, all the studies conducted in Africa identified the lay knowledge of dementia as witchcraft. Interestingly, Kehoua et al. (2019) suggested that the accusation of dementia as witchcraft came from the narratives of informal caregivers based on social facts, such as the death of a loved one, generational curses and incurable illnesses. However, only 29.6% of the rural people with dementia were accused of witchcraft, against 68.4% in the urban area. Therefore, the evidence is not compelling. However, amongst African communities, dementia beliefs can form part of a complex body of inherited knowledge or folklore that is actively constituted through their consciousness, narratives and experiences or perceptions (e.g., Mushi et al., 2014; Mkhonto & Hassen, 2018; Kehoua et al., 2019). On the one hand, Mkhonto and Hassen's (2018) study provided weak empirical evidence; all the eight interviewees who talked about witchcraft were seven nurses of African-Black background and a family member of African background. Only two of the 18 family members interviewed in the study had native Black African cultural backgrounds.

Again, drawing on Kehoua et al.'s (2019) study, which explored the perceptions and the social representations of people with dementia in the Republic of Congo. A total of 93 participants were interviewed in Brazzaville (urban) and Gamboma (Rural) using unstructured interviews and complemented with participant observations. Findings suggested the respondents' understanding of witchcraft was likened to direct or indirect harm to others, such as in physical or mental health-related problems and linked to lay knowledge that informed their dementia reality. For example:

> *I have already heard of dementia . . . but there are demons in all dementia: Matthew 17 verse 21: This type of demons comes out only through prayer and fasting* (Kehoua et al., 2019, p. 170).

Therefore, such knowledge was informed by their religious or spiritual reality or understanding of the Bible. However, the outcome may be positive, as religion can be a source of social and spiritual support for people with dementia (see Chapter 5), or negative, as witchcraft accusations were associated with people who demonstrated strange characteristics or behaviours (Mkhonto & Hassen, 2018; Kehoua et al., 2019). For example, the informal caregivers living in urban and rural areas identified accusations of witchcraft against their relatives; due to these accusations, families and individuals suffered physical, psychological, and financial abuse. Moreover, when a person accused of being a witch was diagnosed with dementia, they were labelled or stigmatised, avoided, or isolated (Mushi et al., 2014: Kehoua et al., 2019). Although Kehoua et al.'s (2019) study was limited in some ways, such as the study was conducted in six local languages (Lingala, Kituba, Teke, Mbochi, Lari and French), and the principal investigator had to speak these languages as to conduct unstructured interviews without an interpreter. Therefore, consistency in the interviewer would mean more time spent on the topic (Kehoua et al., 2019). Nonetheless, the dementia discourse in each society has its own narrative, symbolism, metaphor, and linguistic embodiments.

Linguistic embodiment is a cultural product and impersonal experience. Therefore, the absolute or subjective knowledge of dementia as witchcraft will vary from language to language, culture to culture, and amongst communities within Africa (Owokuhaisa et al., 2020; Agyeman et al., 2019; Nwakasi et al., 2021). Likewise, the lay concept of dementia as witchcraft included the understanding of witchcraft as a malevolent or harmful action carried out by the person with dementia presumed to have access to supernatural powers (Hindley et al., 2016) and the idea of witchcraft as a misfortune, an illness, or a loss of status or life (Kehoua et al., 2019). The beliefs in witchcraft also caused fear for people with dementia, and they feared for their property and processions (Mkhonto & Hassen, 2018), as observed in the literature:

> *They say 'that one has been bewitched' . . . they go to these old people, vandalise their houses, burn their houses . . . they accuse them of being witches* (Mkhonto & Hassen, 2018, p. 172).

Although, the perception of dementia as witchcraft became an essential theme in eight of the Tshwane interviews conducted in South Africa (Mkhonto & Hassen, 2018). All eight interviewees who talked about witchcraft were of a Black African background. The study explored and described the link between culture and dementia, focusing on the belief in dementia as witches. However, only 2 of the 18 family respondents had native Black African cultural backgrounds, and of the 19 nurses interviewed, all but one was a woman. The findings fluidly suggested that in South Africa, especially in townships and rural areas, dementia was often perceived and connected to witchcraft rather than disease.

### Dementia older age paradigm

A shift from the witchcraft paradigm shows that the knowledge about dementia was accepted as a problem of older age, and this was seen as identified in all the studies conducted in Africa (e.g., Mushi et al., 2014; Gurayah, 2015; Owokuhaisa et al., 2020; Kehoua et al., 2019; Hindley et al., 2016; Agyeman et al., 2019). Participants described dementia as a feature of older age. They identified it as 'akuzire', meaning 'old age' (Owokuhasia et al., 2020, p. 12). Hindley et al. (2016) explored how traditional and Christian faith healers understood and treated people with dementia by conducting semi-structured interviews with 11 traditional healers and 10 Christian faith healers using interview guides and vignettes in the Hai district of Tanzania between the 1 March and 31 May 2015. Findings show the conceptualisation of dementia by the healers as a normal part of the ageing process, like Agyeman et al.'s (2019) study, where symptoms of cognitive decline were commonly perceived as part of 'normal ageing'. Indeed, it resonated in most of the studies; for example, it was mirrored by Owokuhaisa et al. (2020), where dementia was described as a feature of older age. Therefore, older age has a symbolic socio-cultural significance for many Africans (Mushi et al., 2014; kehoua et al., 2019; Hindley et al., 2019; Agyeman et al., 2019), and culture varies widely in the status accrued by the older people as a form of respect. In many Black African communities, the respect accorded to older people could be higher or insignificant (Hindley et al., 2019). Older people are generally well cared for by their relatives (Mukadam et al., 2011) but are sometimes abandoned and abused (Kehoua et al., 2019). However, older age was considered synonymous with wisdom in Africa. Such a finding also corresponded with the observations from the literature as illuminated:

> *In Africa, when an old man dies, it is a library that burns* (Kehoua et al., 2019, p. 171).

Therefore, when an older person has dementia, it can cause fear and could be perceived as a loss of national treasure amongst the African people. Indeed, implying that older age was highly valued and not considered a disease condition but a way of life or a process of normal ageing (Agyeman et al., 2019). Nevertheless, older people depended on relatives for care, and being older was perceived by respondents as a part of gaining community status and respect within the Black African communities. Thus, relying on the community, kinships, or their children for support and respite was essential to managing dementia for Black Africans. Contrarily, the Western perception of older age may be individualised, contrasting it with non-Western societies where older age can be described as relational or sociocentric. Therefore, when an older person is diagnosed with dementia in Africa, it automatically leads to a loss of status for the individual and a loss of community knowledge acquisition.

Nonetheless, evidence in the UK study suggested that older age could be perceived as a type of chronic illness that does not have a cure but is alleviated through family responsibility (Lawrence et al., 2008). Indeed, Lawrence et al.'s (2008) study explored the caregiving attitudes, experiences, and needs of family carers of people with dementia from the three largest BME groups in London. It purposively recruited 10 African Caribbean, 12 South Asian, and 12 White British (7 men and 25 women, aged 33 to 87 years). Findings showed that participants conceptualised caregiving for older people as natural, expected, and virtuous. However, the study was limited in not providing separate results for the Black African populations in the UK. It must also be noted that the study was conducted more than ten years ago. However, Parveen et al.'s (2017) study is more recent and conducted in the North of England and suggested that

Africans lack the knowledge of dementia like the other minority groups in the UK. However, Northern England may be culturally distinct from Southern England, where the current research is conducted. Nevertheless, the study lacked age range and context, and findings illuminated that dementia was generally thought to be related to older age, even though the results were not provided separately for the Black African populations.

Regardless, Black communities often believe that families should look after their elders and that a diagnosis of dementia is needless (Mukadam et al., 2011; Botsford et al., 2011). Generally, in African communities, the family remains a natural framework where there are intergenerational relations, social solidarity, exchange of services, bounds and effectiveness (Kehoua et al., 2019, p. 171), and care for the older people is provided by families. Therefore, shifting the perceptions and experiences of dementia towards being old and a process of 'normal ageing' rather than a disease condition (Mushi et al., 2014; Gurayah, 2015; Agyeman et al., 2019) and needless consulting a doctor for forgetfulness associated with ageing (Berwald et al., 2016), and that the family should offer care in secrecy. Indeed, it highlights the dichotomy between the Western perception of older age and the non-Western perception of ageing. However, the UK study by Berwald et al. (2016) reported that respondents lacked knowledge of dementia with greater reliance on community, family, and friends for support, advice, and care, and attributed forgetfulness to the normal ageing process. However, there was no separate data for the African populations in the study, but the findings corresponded with the observations from the literature, as illuminated below:

> *Where I come from there's no definition of dementia, an old person is starting to forget, it's part of growing old* (Berwald et al., 2016, p. 5).

Hence, Berwald et al.'s (2016) study involved the Black African and Caribbean British communities but provided no separate findings for the Black African populations in the UK. Nevertheless, most Africans believe that memory loss is normal in older people (e.g., Mushi et al., 2014; Gurayah, 2015; Agyeman et al., 2019) and that ageing leads to physical changes, which causes both physical and mental weakness in the elderly. Drawing on Mushi et al.'s (2014) study, which explored the social representation and perceptions of dementia in the Hai District of Tanzania, 25 paired interviews were conducted with people with dementia and their caregivers, and 16 interviews with caregivers alone aged 70 years and older. Findings suggested that people with dementia and their carers perceived dementia as '*Ugonjwa wa uzeeni*', meaning disease of old age. However, Mushi et al.'s (2014) study were limited in the age range, and only participants aged 70 years and above were recruited and interviewed. Still, it may correspond roughly to the group who primarily experience dementia and caregiving.

Likewise, in the UK, Botsford et al. (2011) illuminated that many respondents from BME communities had culturally based knowledge of dementia associated with older age. However, the study was not entirely for the Black community. Botsford et al. (2011) conducted 43 in-depth interviews with 13 Greek Cypriot and the African Caribbean aged between 60 and 80 years in London. The study was delivered over 18 months between 2007 and 2009, and the data were analysed using a constructivist grounded theory approach. The study found that most of the participants expressed a general belief that changes associated with dementia were a normal part of older age. Indeed, most respondents believed that dementia was a part of ageing. However, the study illuminated how dementia was constituted in only two Black and minority ethnic groups and limited to the Greek Cypriot and African Caribbean communities in London. In addition, the study was also limited in age range (e.g., aged 60 to 80).

Furthermore, evidence in this review suggests that the dementia older age paradigm provided the meaning of caring for older people within the communities in the UK (Adamson & Donovan, 2005), with the Black population believing that caring for the elderly is a necessity and kind reciprocity, a routine duty for the ageing family members (Lawrence et al., 2008). The belief in dementia older age paradigm provided meaning to the ‘traditional’ caregiving ideology for the Black populations in the UK, which was rooted in cultural and religious beliefs and values (Lawrence et al., 2008, p. 241). However, Lawrence et al. (2008) explored caregiving experiences in three BME in the UK but lacked notably in African populations, just like many BAME studies in the UK. The study could be lacking in current facts; therefore, it is less dependable.

Contrarily, in some population groups, older age may be discriminated against and can be associated with stigma and social isolation (Mkhonto & Hassen, 2018; Hindley et al., 2019). Therefore, it is argued that culture or older age paradigms may be activated to stereotype and exclude older people in Black African communities (Gurayah, 2015; Berwald et al., 2016). Nevertheless, the older age construction can be challenged, altered, and resisted by some Black communities. This depends on specific epistemological viewpoints that can be broadly categorised as objectivist, such as biological ageing as a kind of reality, or interpretivism, such as social ageing. Indeed, it depends on the community or individual interpretations and understanding of ageing in context. Culture can influence perspectives on the interpretations of older age, meaning that different ethnicities can perceive ageing from different frames of reference beyond the biomedical lens (Berwald et al., 2016), and ageing or older age is considered a metaphor (Hindley et al., 2016).

Therefore, in most studies, respondents do not believe that dementia is a physical illness or a disease but a problem of older age and that the condition does not occur in the Black African community (Berwald et al., 2016). Finally, there was a belief that older people will have poor memory (Parveen et al., 2017; Owokuhasia et al., 2020). However, it is not essentially true that everyone older will have dementia, although, socially, that was how the respondents perceived it. Therefore, the degree to which the research findings can be confirmed (confirmability) is still being determined.

Nonetheless, Mahomed & Pretorius's (2022) findings suggest a shift in paradigm in the perception of dementia amongst Black Africans in the context of culture. In addition, Black Africans are increasingly predisposed to getting dementia, as the evidence corresponds with the observations from the literature. Still, based on the limited evidence provided by these studies, we cannot make a robust conclusion about their lay dementia knowledge and beliefs.

### Dementia disease and illness paradigm

Most of the included UK studies suggested that the Black community in the UK lacked dementia knowledge. It was inevitably associated with the lack of biomedical understanding of dementia as a disease. For example, by utilising the self-regulatory model of illness as a theoretical framework, Parveen et al. (2017) suggested that all groups in the study perceived a lack of knowledge about dementia as a disease. The respondents perceived a lack of awareness regarding dementia disease in the broader family and community, and the use of dementia support services was also reported to be limited to the respondents due to the lack of dementia knowledge as a disease (Parveen et al., 2017, p. 740). However, the study provided no separate findings for the Africans in the UK. Still, respondents attributed a biological cause to dementia and considered dementia as an illness of the brain. Dementia perceived as an 'illness' resonated in the most recent study in the UK as highlighted:

> *Then, when I was allowed, I was told, 'he is ill' . . .* (Armstrong et al., 2022, p. 9).

Although Armstrong et al.'s (2022) study explored the perspectives of Black and South Asian people living with dementia and their carers in the UK, all the participants born in Africa defined themselves as South Asian. Therefore, the study lacked the perspectives of Africans in the UK. However, findings corresponded with observations from the literature suggesting that respondents in Africa, for example, in Uganda and Ghana, used the term disease and illness as illuminated:

> *The majority get the disease of forgetfulness* . . . (Owokuhaisa et al., 2020, p. 6).

Nevertheless, Adamson (2001) showed that most participants from the Black populations in the UK were aware of the condition 'dementia' but used different terms to describe the disorder. Nevertheless, the study highlighted that many had not heard of the disease before their relatives developed it. Although, the study concluded that the knowledge of dementia as a disease was limited amongst the population groups (Adamson, 2001, p. 395). However, Lawrence et al. (2008) suggested that the Black populations in the UK were found to possess a traditional ideology towards knowing and understanding dementia based on culture. Therefore, every society has its own 'ethnomedicine', a part of its cultural system that deals with dementia as sickness or illness. Thus, knowledge of dementia as a disease is drawn from biomedicine which can be regarded as ethnomedicine in the Western world defined by biomedicine.

Therefore, within biomedicine, those practising medicines form groups with their values, concepts, and rules of behaviour. Thus, those outside the group may need help understanding these concepts and values. We expect lay people to use different terms or terminology familiar with biomedicine. Likewise, it is not surprising that the African respondents lacked biomedical knowledge of dementia as a disease. However, the two studies (Adamson, 2001; Lawrence et al., 2008) were limited in methods; for example, they were limited in age range, provided no data separated for age, education, and status, and did not provide separate findings for the Africans in the UK. Moreover, the two studies were conducted over ten years ago. Current views might have changed as many Africans in the UK now have access to quick information from many sources such as the internet and formal education and training.

In addition, the observations from the literature suggest that cultural perceptions, age, education, social status, and language influenced the understanding of dementia as a disease. Therefore, culture, education, and language were significant concerns in defining dementia. Indeed, all the UK studies were conducted in English, more or less a second language (e.g., Parveen et al., 2017; Berwald et al., 2016; Mukadam et al., 2011; Botsford et al., 2011; Adamson & Donovan, 2005; Adamson, 2001). However, culture supported most of the respondents to evaluate and reevaluate their knowledge and understanding of dementia as observed:

> *The African culture is vast . . . Culture plays an important role here [in Nigeria] . . .* (Nwakasi et al., 2021, p. 1453).

Of course, 'African culture is vast,' and the current study's findings acknowledge that religion and spirituality are parts of the Black African culture in the UK (see Chapter 5), even though all the participants were churchgoers (see Chapter 4). Nonetheless, in the previous studies, the cultural background of participants provided an understanding of how the meaning of dementia influenced their interpretation of the dementia phenomenon as a disease or illness (Parveen et al., 2017; Berwald et al., 2017; Baghirathan et al., 2020). Therefore, the current researcher needed to explore the dynamic nature of culture and linguistics with the understanding of dementia through an anthropological lens. Most of the UK studies are from the perspectives of researchers and not of Black African background, meaning that it can be argued that the researcher's skin colour, race, or ethnic background (Tuffour, 2018) can affect the totality of each of the studies and the research process either positively or negatively (Holmes, 2020). Thus, addressing positionality and reflexivity in the research can mitigate systemic racism and move the research towards equity (Walker, 2021). Nevertheless, the researcher believes that all qualitative researchers need to employ trustworthiness and a more objective judgement of quality in their empirical studies (Lincoln & Guba, 1985; Crewell, 2006; Schwandt, 2002; Scale, 1999; Lincoln et al., 2011).

Medical anthropology is a social and cultural branch deeply rooted in medicine, public health, and health promotion. It concerns a broader range of biological or cultural phenomena of illness and disease, such as dementia. Therefore, there is a need to balance the etic and emic perspectives of dementia in the Black African community in the UK. Indeed, most of the studies in Africa offered insights into how dementia is understood. However, these studies were limited in discourse and empirical data. They frequently relied on the prevailing older age paradigm and the witchcraft paradigm (e.g., Gurayah, 2015; Mkhonto & Hassen, 2018; Owokuhaisa et al., 2020; Nwakasi et al., 2021). Also, some of the lay knowledge on dementia identified it as '*awusse*', meaning 'rotten in the head'; '*atabukiire/okuhungutuka*', meaning 'mad' or 'mentally disturbed'; '*tayiine obwengye*', meaning 'lacks knowledge'; '*ebitekateko bikuzire*', meaning 'old thoughts'; '*nayebwayebwa*', meaning 'so forgetful'; and '*omwaga/oburomborombo*', meaning 'irritability' (Owokuhaisa et al., 2020, p. 3). Therefore, the empirical evidence from the review suggests that most participants in the study do not lack the cultural knowledge of dementia but the biological or biomedical understanding of dementia as a disease condition. However, some respondents in the UK studies (e.g., Berwald et al., 2016) acknowledged dementia as a disease but thought the disease was for White people, as highlighted.

> *When you talk about dementia . . . this is a White, old White people's disease, it's not seen as Black people have dementia* (Berwald et al., 2016, p. 7).

Furthermore, in Owokuhaisa et al.'s (2020) study, the participant's knowledge of the causes of dementia was also based on viral and bacterial infections like HIV, STI, and TB. They were identified as syphilis ('*ebinyoro*'), HIV, cancer ('*ekokoro*'), and allergy ('*efumbi*'). Thus, Africans liken dementia to a chronic illness. The symptoms of dementia were acknowledged as loss of memory (Owokuhaisa et al., 2020, p. 4). In addition, using Kleinman's explanatory model, respondents in Tanzania reported their knowledge of dementia symptoms as 'memory loss', 'forgetting things or places', 'forgetting people', 'repeating the same stories', 'forgetting the road or people, including their own children', 'forgetting to eat or to change clothes', 'lost in conversation', and 'talking stories of the past' (Mushi et al., 2014, p. 3). Indeed, the empirical evidence corresponding with the observations of the literature suggests that dementia was also perceived as '*ugonjwa wa kusahau*', meaning memory loss disease/disease of forgetting (Mushi et al., 2014, p. 3). However, some participants do not have any knowledge of dementia, as observed from the literature:

> *I don't know what the problem is* (Mushi et al., 2014, p. 3).

Nevertheless, some respondents attributed dementia to lifestyle behaviour, such as tobacco smoking, marijuana, and alcohol intake (Owokuhaisa et al., 2020) and the use of other medications (Berwald et al., 2016; Owokuhaisa et al., 2020), as well as poverty:

> *When you are poor, everything fails . . . the family becomes disorganised you get problems and lack knowledge* (Owokuaisa et al., 2020, p. 5).

**Dementia identity paradigm**

Indeed, dementia as a disease is a biomedical construction, and dementia as an illness is a lay construct and holistic. Nevertheless, dementia as a sickness is based on relationships with other people. Thus, dementia sickness is a social identity (Twaddle, 1994a, p. 11). Therefore, the knowledge of dementia as a sickness amongst Black Africans could mean dementia has to do with social identity and is associated with 'older age', 'madness', or being 'crazy'. For example:

> *Had it not been that he is old we will say he is mad* (Agyeman et al., 2019, p. 909).

Nonetheless, amongst Black Africans, dementia is situated with the mind/brain and body identity theory (Farrell, 1950) or embodied identity (Myin & Zahnoun, 2018) or personhood and wellbeing (Kitwood & Bredin, 1992). Hence, the identity theory of the mind/brain and body holds that the processes of the mind are identical to the state of the brain (Farrell, 1950; Feigl, 1958; Smart, 1959). Indeed, dementia is considered 'old', 'crazy', or 'madness'. Such requires managing the interactions and relationships of those with dementia on the perceived difference with the other, such as friends, relatives, and families in the community, based on the construction of the mind/brain and body. In that case, dementia as a disability, such as 'madness' or being 'crazy' is a physical and mental sickness. Sickness is a social identity based on the interaction of the person with dementia and their relationship with others in the community. Indeed, social identity theory can be based on the perception that the dementia identity is constituted through a process of differences defined in social relationships, behaviour, or membership of a group (Tajfel &Turner, 1979), such as being a Black African living in the UK.

Nevertheless, dementia as a disability (older age, madness, or being crazy) can relate to the naturalist view of personhood that depends solely on a performance criterion of a person with dementia likened to a machine rather than a person as a moral agent (Taylor, 1985). However, people with dementia are not machines but human beings constituting a spirit, body, and soul (White, 2013). Therefore, they are transcendental (Nelson-Becker, 2017) and connected to free will and human volition (Frankfurt, 1971). They can make decisions and choose and decide on a course of action (Ossorio, 2013).

Overall, the researchers concluded that the knowledge about dementia was 'lacking'. Indeed, an assumption based on a biomedical construction. The evidence provided in the studies was not compelling and lacked context and credibility. Biomedicine is often reductionist because it focuses more on physical dimensions and classifies dementia as a disease without considering other factors such as personality, religious beliefs, age, education, gender, culture, and socioeconomic status.

Nevertheless, physicians indeed have the legitimate right and knowledge to classify the dementia phenomenon as a disease. However, the literature review shows that Black Africans in Africa have knowledge and beliefs about dementia that is socioculturally constituted and constructed. Although, the findings from the African studies show that the literature (see Tables 4 & 5) was mostly lacking in the researcher's positionality (epistemological and ontological stance). Nevertheless, the Black Africans' dementia knowledge and beliefs differ from biomedical knowledge and beliefs about dementia. Therefore:

1. What are the lay knowledge and beliefs towards dementia amongst Black African populations living in the UK?
2. What are the lay concepts of dementia, perceptions of dementia risk factors and dementia help-seeking or attitudes amongst Black Africans living in the UK?
3. What is the dementia help-seeking and caregiving or treatment of people with dementia amongst the Black African populations living in the UK?

Indeed, there is a more substantial need to explore lay knowledge and beliefs towards dementia amongst Black African people living in the UK. It is essential to explore the above research questions in the Black African community in the UK to inform dementia policy and practice.

## Summary

The systematic review (evidence synthesis) explored how dementia was constituted and constructed amongst the African population in studies conducted in the UK and Africa. Key search words were used for the search: 'dementia', 'Alzheimer's', 'culture', 'religion', 'anthropology', 'belief', 'perception', 'knowledge', 'lay', 'view', 'stigma', 'attitude', 'constructionism', 'Africa', and 'UK'. Each keyword and the phrase were initially used singly and combined using the Boolean operators 'AND' and 'OR'. A comprehensive literature search on the research topic was performed using Google Scholar to overview the research topic. Three electronic databases were searched: Scopus, Web of Science, and PubMed/Medline.

Twenty-two (n=22) qualitative studies met the eligibility criteria and were systematically appraised and included in the review. The papers were evaluated, described, and critiqued. Nine (n=9) were studies conducted in the UK, and thirteen (n=13) were research papers conducted in Africa (5 studies from South Africa, 2 studies from Tanzania, 1 study from Congo, 2 studies from Uganda, 2 studies from Nigeria and 1 study from Ghana). The included studies were analysed. The procedure for the analysis adopted a thematic approach. Four themes were developed from the research and illuminated how dementia was constituted and constructed amongst African populations, and they were discussed. The themes included: (i) dementia witchcraft paradigm, (ii) dementia older age paradigm, (iii) dementia disease and illness paradigm, and (iv) dementia identity paradigm.

However, all the UK papers (n=9) were multi-modelling of ethnicity in the studies and lacked methods, theory, and empirical evidence. Perhaps, the authors should have reported them. Hence, the researcher evaluated the qualitative studies by drawing on philosophical and evaluation discourses (Crewell, 2006; Schwandt, 2002; Scale, 1999), such as their epistemological concepts (Lather, 1986) and trustworthiness criteria (Lincoln & Guba, 1985; Lincoln et al., 2011). The data did not separate the findings of the Black Africans from the Caribbean people. Therefore, the researcher considered the results not compelling and could not make reliable conclusions about the Black African populations in the UK. Thus, the study was not dependable and lacking in credibility. Nevertheless, all the African studies also lacked positionality (see Table 4).

In addition, five (n=5) out of the nine (n=9) included UK research were studies conducted over ten years ago. Therefore, most of the UK studies' findings are outdated, unreliable and not dependable. Moreover, the UK studies were deficient in exploring lay knowledge and beliefs about dementia, particularly the lay conceptualisation of dementia amongst the Black African populations. Therefore, the study lacked philosophical concepts (Lather, 1986), thus suggesting an essential need to explore the lay knowledge and beliefs about dementia amongst Black African populations in the UK. More importantly, life expectancy in Black Africans living in the UK is increasing and is expected to rise further from an average of 65 years due to some improvement in their quality of life and better access to vital health services (Wohland et al., 2015). Therefore, it is expected that dementia will rise among Black Africans living in the UK. Nevertheless, the researchers concluded that Black Africans in the UK lack dementia knowledge. However, the current researcher does not believe Africans in the UK lack lay knowledge and beliefs about dementia but may lack biomedical knowledge of dementia.

Moreover, the review identified a need to engage researchers from Black African backgrounds in future dementia research in the UK to balance the etic and emic perspectives of the dementia phenomena. Therefore, the review led to the development of research questions exploring the lay knowledge and beliefs towards dementia amongst Black African populations living in the UK. Thus, the researcher develops a conceptual framework for the current study and collects empirical data. The current study utilises thematic data analysis informed by a grounded theory approach, and the findings separated data with age groups, gender, education, and status as identified. The next chapter presents the theoretical framework for the current study.

# Chapter 3

# Theoretical Framework

## Introduction

The theoretical framework is the structure that guides the current study. Therefore, this section discusses the lay concepts of dementia, focusing on the research questions and the overarching philosophy underpinning the study. The chapter is localised within the discipline of medical sociology and medical anthropology. It drew its strength mainly from the sociological and anthropological lay concepts of health and illness and social constructionism. The chapter describes, discusses, and explains the theoretical approaches by focusing on the lay concepts of dementia and the research questions. It argues that lay knowledge of dementia is ‘a body of knowledge’, which could be regarded as expert knowledge with an equal weight with medical expert knowledge of dementia, and both pieces of knowledge are invaluable in dementia care. Thus, it argues that biomedical knowledge should not be privileged epistemologically and ontologically over the lay knowledge of dementia. Furthermore, it explores how the current study’s theories interact and highlights the theoretical strengths and drawbacks.

## Lay concepts

The concept of ‘lay appraisal’ has been used in accessing laypersons’ knowledge and beliefs about mental illness and was first recognised in the 1950s (Hollingshead & Redlich, 1958), highlighting the role of families, individuals, friends, and relatives in identifying the signs and symptoms of dementia, and in making decisions about the appropriate course of action in diagnosis, treatment, and care. Therefore, to understand the concepts of dementia amongst Black Africans in the UK and their perceptions of dementia, the researcher first draws from Segall and Robert (1980) and Hunt and McEwen (1980). They argued the need to redress the balance between subjective knowledge and medical knowledge by considering lay and professional perspectives in health. This enables researchers to get a stronger hold on how laypeople from the Black African community in the UK currently feel and attach meanings to dementia as a medical and sociocultural problem and as a disability and human rights issue (Angus & Bowen-Osborne, 2014; Rushford & Harvey, 2016; Shakespeare et al., 2019).

Still, the path of the current study is on public health and health promotion, so drawing mainly from lay concepts of health and illness provides the theoretical framework that underpins the study. Although the previous research, Segall and Robert (1980) and Hunt and McEwen

(1980), focused on ‘doctor-patient communication’ and ‘subjective health indicator’, respectively. However, drawing from both papers on lay perspectives of health and illness enriched the conceptual framework for the current study on dementia. Even though Segall and Robert’s (1980) study in Winnipeg had several conceptual and methodological problems, as highlighted in Prior (2003) paper, they suggested some weaknesses and essential insights in their studies. For example, a good number of the respondents to the survey misunderstood the meaning of ‘malignant’ and ‘fatal’ (Prior 2003, p. 41). Nonetheless, all the papers helped researchers to understand lay concepts of health and illness (Bury, 1982; Lawton, 2003).

Indeed, the papers helped researchers to understand how laypeople can be considered ‘knowledgeable’ by informing them that laypeople can comprehend medical information and medical constructions (Arksey, 1994) and give detailed accounts of lay perspectives of dementia, including other illnesses and diseases. For example, lay knowledge of genetics (Richards & Ponder, 1996), lay knowledge and beliefs about HIV (Moseby, 2017), lay knowledge and ideas about tuberculosis (Zein et al., 2017; Gebremariam et al., 2011), lay knowledge and beliefs about Parkinson’s disease (Werner & Korczyn, 2010), and accounts of other people such as patients, friends, relatives, and families in communities in the context of lay knowledge and beliefs (Yoeli & Cattan, 2017). Hence, this provides the current research with some insightful understanding of the sociological and anthropological lay concepts of health and illness that underpin this study on dementia, suggesting that the participants and their narratives can be considered lay experts.

Moreover, patients and their families, friends, and relatives’ experiences can help the current researcher facilitate collective processes of lay knowledge production (Werner, 2005; Egher, 2019) and understand lay perceptions of risk factors (Lipworth et al., 2010; Ng’ang’a et al., 2016; Riley et al., 2019). Thus, evidence of the current study is discussed, illuminating the importance and values of lay knowledge. Indeed, based on the evidence, the Black African participants for the current research are knowledgeable, perhaps lay experts. There is limited knowledge and understanding of lay concepts of dementia and lay dementia risk factors amongst studies in the UK (e.g., Gow & Gilhooly et al., 2004; Mukadam et al., 2011; Parveen et al., 2016; Berwald et al., 2016). Thus, further study is needed to explore lay concepts of dementia, particularly amongst the Black African community in the UK.

Therefore, this study argues that considering the lay viewpoints on dementia knowledge and beliefs provides medical doctors with adequate dementia assessments of how Black Africans in the UK feel, experience, and attach meanings to dementia. Lay people often use the sociological concept of health and illness to understand their illness and associated risky behaviours. Thus, lay ideas of dementia amongst Black Africans in the UK are drawn upon to provide anthropologically informed public health and health promotion solutions to the problems identified in the literature review. The review findings suggest that Black Africans in the UK lack dementia knowledge (e.g., Berwald et al., 2016).

> *Higher number of Africans reported a lack of knowledge of dementia* (Berwald et al., 2016, p. 5).

Indeed, the findings suggest a limited understanding of biomedical concepts of dementia amongst Black Africans in the UK. Hence, drawing on the sociological lay concepts of health and illness as the theoretical framework enables the researcher to explore lay knowledge and beliefs about dementia amongst Black Africans living in the UK. Previous evidence suggested a limited lay concept research on Black African's meaning of dementia. Therefore, there is a greater need to understand lay concepts of dementia, perceptions of dementia risk factors, and how Black Africans in the UK view and give meanings to dementia and associated barriers to dementia treatment and diagnosis. Black Africans in the UK may lack biomedical knowledge of dementia but do not lack a lay understanding of dementia. Of course, everyone has access to their own type of lay knowledge (Levy, 2022).

The lay concept of dementia is holistic and contrasted with biomedical reductionism. It means that it provides knowledge that will look at the whole person, including their spiritual, emotional, and physical well-being, rather than just the dementia illness (Please refer to Figure 3 highlighting the lay conceptual model of dementia). The model illustrates that everyone has a different experience of dementia and a path to help-seeking or treatment, influenced by occupation, age, gender, religion, language, education, income, culture, and beliefs. Lay dementia knowledge and beliefs are held mainly by laypeople, such as patients, families, relatives, and friends. Nevertheless, they are considered to have expert knowledge of their dementia illness through a process of 'reflection' (Maslen & Lupton, 2019) and 'lived experience' (van Manen, 1997; Britten & Maguire, 2016).

Although, within a political context, Habermas (1987) and Beck (1992) argued against 'expert' culture, suggesting that expert knowledge is a kind of possession that privileges its possessors with power that others cannot acquire, thus leading to inequalities and injustices in a community. However, Turner (2001) argued that 'expert' culture should be popularised in any discipline, whether in medicine or other disciplinary fields. Indeed, it inferred the importance of lay expert knowledge in public health and medicine (Parsons & Atkinson, 1992; Popay et al., 1998), increasing what laypeople have to offer through knowledge of dementia. Of course, lay knowledge can be as valuable as medical knowledge. For example, Popay and Williams (1996) argued that laypeople acquire an ‘expert’ body of knowledge different from medicine but can be equal to that of professionals in the public health field.

Likewise, Armstrong (1985) argued that modern medicine should not be privileged epistemologically and ontologically above lay expert knowledge, as all forms of knowledge are equal, suggesting that a lay understanding of dementia can be as valuable as biomedical knowledge of dementia in the management of dementia in the Black community. Furthermore, ‘there is no way of judging one account of reality as better than another’ (Bury, 1986, p. 165). Therefore, judging medical knowledge as better than lay knowledge can only lead to epistemic tension (Haw et al., 2018). Similarly, Dupras and William-Jones (2012) argued the need for professionals such as doctors to accept the limits of their expertise and recognise the ability of laypeople to understand and contribute to their health and illness. Therefore, this current study considers both the knowledge (biomedical and lay knowledge) as ‘expert’ knowledge because health professionals have medical expertise (Bryson, 2014). Likewise, laypeople are experts in their professions (Madeleine & Rabeharisoa, 2012) and in their lay dementia knowledge.

Nonetheless, Maslen and Lupton (2019) considered a ‘lay expert’ as someone who can negotiate, reflect, and understand rules of engagement. However, Prior (2003) suggested that laypeople have insufficient expertise to make quality judgments or be considered ‘lay experts’. However, compared to a noble profession such as law, evidence suggests that laypeople can contribute meaningfully to decision-making and judgment. For example, laypeople are ‘lay magistrates’ (Vidmar, 2012) and ‘lay justices’ (Irvine, 2020) in a judicial decision, making of the courts with the assumptions that: (i) laypeople have knowledge that can be valuable, (ii) laypeople came from a wide range of careers bringing a variety of experience, and (iii) the process of recruiting them is cost-effective. Indeed, using laypeople in the court of law has helped reduce specialised language and made decisions fairer. Likewise, in dementia care, laypeople can contribute to dementia management in the community and can cause dementia care in the community to be more egalitarian.

Nevertheless, Prior (2003) argued that for laypeople to be considered ‘lay experts’ in dementia, they must have sufficient medical skills and training. That is true in the sense of accommodating laypeople into medical practices. However, Prior's (2003) paper got it right, but it can also be wrong. Lay concepts of dementia are informal, common-sense explanations, experiences, or meanings attached to dementia. Lay ideas of dementia are often different from the formal biomedical constructions of dementia reality. However, dementia knowledge is gained from indirect or direct face-to-face interaction rather than through representations constructed by medical doctors or biomedicine (Segall & Roberts, 1980; Hunt & McEwen, 1980; Tuckett et al., 1985; Warwick et al., 1988; Williams, 1984; Arksey, 1994).

Likewise, drawing on training and experiences within the researcher's capacity as a trained medical doctor and applied medical anthropologist suggests that medical doctors or other health professionals can hold medical expert knowledge of dementia. However, the lay concept is mainly controlled by laypeople such as patients, families, relatives, and friends (see Autobiographies – Dementia UK). Therefore, they can be 'lay experts' based on their dementia experiences (Tuckett et al., 1985; Arksey, 1994) and are considered 'knowledgeable' (Segall & Robert, 1980; Hunt & McEwen, 1980), although not in similar ways as health professionals, such as medical doctors who trained to acquire medical knowledge and assimilate the needed skills to practice medicine. Nevertheless, health professionals can accommodate the idea of 'lay experts' in dementia practices through education and training (Epstein, 1995; Prior, 2003), in that case as 'medical experts'. However, the current study is not about the practice of dementia but the lay knowledge and beliefs about dementia to inform policy and practice.

The observations from the literature review suggest that some GPs in the UK can hold 'lay expert' views about dementia. In Mukadam et al.'s (2011) study, a carer responded that her GP said 'normal ageing' was a symptom of dementia (Mukadam et al., 2011, p. 1073). Nonetheless, on second thought, it could also have been a misunderstanding. It is hard to think a GP could say this. Nevertheless, the current study argues that lay knowledge and beliefs about dementia can be 'experiential' or 'reflections' based on evidence, experience, and meanings attached to dementia, and only partially based on scientific explanations. The observation suffices that some health professionals can hold on to lay-professional views of dementia in varied capacities, as in the pathological process of dementia. As discussed above, medical doctors can draw upon lay concepts of dementia, notwithstanding holding a more decisive view on the biomedical concepts of dementia. Likewise, laypeople can also draw knowledge from the biomedical concepts of dementia despite having a firmer stance on the lay concepts of dementia. Indeed, it suggests that health professionals such as medical doctors and laypeople such as patients, friends, families, and relatives from the Black African communities in the UK have ‘expert’ knowledge to contribute to dementia management in the UK. Therefore, the current study disagrees that Africans in the UK lack dementia knowledge, as suggested in Berwald et al.’s (2016) and Parveen et al.’s (2017) studies. Instead, the current study strongly believes in redressing the balance between lay knowledge of dementia and biomedical understanding of dementia in dementia management for the Black community in the UK.

Similarly, Morton-Chang et al. (2019) suggested a ‘balance of care’ toward a community-based dementia care strategy. Thus, the ‘balance of care’ would mean a strategic adjustment of dementia care from hospital to community social care services. Therefore, a ‘balance of care’ in dementia improves the health and the quality of care of people with dementia in the Black African community in the UK while reducing the cost of dementia care.

Nonetheless, the current research is limited to nonmedical professionals or laypeople, specifically Black Africans living in London, because evidence suggests that laypeople can be experts by having experiential knowledge of their condition (Busby et al., 1997; Monaghan, 1999). However, they may hold an understanding of dementia that may be abusive or stigmatising (e.g., Jacobs et al., 2022; Nwakasi et al., 2021; Owokuhaisa et al., 2020; Kakongi et al., 2020; Kehoua et al., 2019; Mkhonto & Hanssen, 2017; Hindley et al., 2016; Mushi et al., 2014.). Thus, one can learn about dementia by living through or with the condition. In any case of stigmatising beliefs, education and training can improve the lay knowledge of dementia.

Furthermore, laypeople can be experts by having a par with scientific training (Arksey, 1994; Epstein, 1995). Therefore, as coresearchers, laypeople can have expert knowledge (Mockford et al., 2016; Di-Lorito et al., 2020; Miah et al., 2020). Likewise, laypeople can have expert knowledge by involving abstract scientific production (Dube & Lapane, 2014) and by being lay health providers but not medical professionals (Kennedy et al., 2017; Flynn et al., 2017). Therefore, laypeople are experts in lay matters of health and medicine and in the dementia phenomena. Exploring lay knowledge and beliefs about dementia and involving lay people in dementia management provides equality, equity, and justice in dementia services and can be cost-effective.

Similarly, Britten and Maguire (2016) reflected upon the changing status of lay knowledge over the last 20 years. They argued that lay knowledge should be taken more seriously due to social movement and social action and moving from ‘anecdotes’ to ‘lived experience’, the understanding of the dementia phenomenon gained by experiences and choices. For example, some observational studies illustrated how signifiers of class and gender could influence the person with dementia and their family or carers (Kontos & Martin, 2013). Moreover, ‘disruptions’ such as in everyday practices of dressing, relationships, washing, and maintaining bodily appearance could have different meanings for persons with dementia, their families, friends, and relatives (Twigg & Buse, 2013).

Likewise, Jones (2017) argued that inequalities and personal responses to dementia are understood in the context of social class structures that shape everyday meanings of dementia. Therefore, lay concepts of dementia can be valid in health and medicine, especially in dementia care or dementia diagnosis and treatment, and relating to policy and practice. This is because laypeople can have extensive knowledge about dementia and challenge dementia medical hegemony. Moreover, lay interventions are cost-effective (Raphael et al., 2013) and can add value to dementia management in the UK.

Prior (2003) reflected upon the lay understanding of health and illness and argued for limited use of lay knowledge or lay expertise in health and medicine by drawing upon three of his studies conducted amongst people living in South Wales. One of the studies drew upon dementia and argued that laypeople are not ‘experts’ and are rarely skilled. Moreover, they can often be wrong about the causes, course, and management of dementia. The study further argued that experience is insufficient to understand the complexities of dementia conditions and that experiential knowledge is limited and idiosyncratic. Nevertheless, Prior (2003) provided inadequate evidence by drawing on just three of his studies, limited in scope and locality without demographic considerations. For example, he did not consider the participant’s age, occupation, gender, ethnicity, migration, education, socioeconomic status, and sociocultural factors. His findings suggested that lay carers had no knowledge of the full range of Alzheimer’s symptoms and that a carer’s expertise was limited in many ways. Even as a qualified medical doctor and a professional, assuming to know all about the biomedical concepts of dementia and its pathogenesis is questionable, and this current study presumes so for many medical doctors. In addition, a doctor’s expertise in medicine can be limited in many ways, such as in reductionism, the reason for subspecialisation in a particular field of medicine. Therefore, medical doctors also do not know it all. Dementia knowledge is not the rule of the ‘all or none’ principle. Hence, based on evidence, medical knowledge of dementia can be considered medical expert knowledge in practice, and lay knowledge of dementia can be regarded as expert knowledge in dementia caregiving in the Black community. Education and training can also advance both expertise (Prior, 2003).

Thus, the two knowledge domains (lay expert and medical expert knowledge) require an integrated approach (Vennik et al., 2014) that can benefit dementia diagnosis, treatment, and prevention. Indeed, it highlights the importance of 'balance of care' in dementia, where the role of a layperson is essential. Moreover, according to Kenigsberg et al. (2016), prevention of dementia through managing lifestyle-related risk factors may be a more realistic goal than dementia treatment. Furthermore, public health policies are more likely to improve awareness and understanding of dementia, providing good quality early diagnosis and intervention for all ethnic groups, improving quality of care from diagnosis to end of life, using clinical and economic endpoints. Indeed, the prevention of dementia remains a goal, as a delay in the onset of dementia will effectively stand as the critical preventative strategy. A part of the possible preventive strategies for dementia will require the involvement of laypeople in the Black African community and the consideration of lay or modifiable and non-modifiable risk factors for dementia (Baumgart et al., 2015; Killin et al., 2016; Gonder et al., 2019; Anstey et al., 2019; Choi et al., 2020; Livingston et al., 2020). Also, delaying the onset of dementia for about five years will half its prevalence (Jorm et al., 1987). Even so, young onset dementia is exceptionally distressful, but the factors contributing to its onset are poorly understood (Cations et al., 2019). Therefore, exploring lay knowledge or preventative aspects of dementia, including young onset dementia, can guide efforts to delay and prevent dementia symptoms in later life (Livingston et al., 2020). Buttressing further, the economic endpoint of lay interventions is cost-effective (Raphael et al., 2013).

In addition, advancing age remains the most significant risk factor for developing dementia (Liu et al., 2019). Dementia can double every five years after 65 years, leading to a steady increase in dementia with advancing age (Jorm et al., 1987; Jorm & Jolley, 1998). Other potential risk factors for dementia includes lifestyle related risk factors, such as excessive alcohol consumption (Gutwinski et al., 2018; Peng et al., 2020), smoking (Durazzo et al., 2014; Abner et al., 2019; Deal et al., 2020), obesity (Pugazhenthi et al., 2016; Pedditzi et al., 2016; Kivipelto et al., 2018), diabetes (Meneilly, 2018; Xue et al., 2019; Umegaki, 2019), hypertension (Lulita and Girouard, 2017; Walker et al., 2017), head injury (Li et al., 2017; Mendez, 2017), depression (Kessing, 2012; Bennett & Thomas, 2014; Steffens, 2017; Rubin, 2018), environment (Fleming et al., 2017; Soilemezi et al., 2019), loneliness (Sutin et al., 2020; Sundstrom et al., 2020), lack of exercise and physical activity (Lamb et al., 2018; Gholamnezhad et al., 2020), lack of education and mental stimulation (Sharp & Gatz. 2011; Arce-Renteria et al., 2019), consumption of saturated fats (Mental Health Foundation, 2006), hypercholesterolemia (Appleton et al.,2017), antioxidants (Crichton et al., 2013; Koch et al., 2018), and genetics (Goldman & van Deerlin, 2018; Serrano-Pozo et al., 2021).

Furthermore, lay knowledge about dementia risk factors can be perceived differently from the usual biomedical expertise and understanding of the dementia risk factors, thus acting as a barrier to dementia prevention. Laypeople can have knowledge and beliefs about dementia risk factors that can be interpreted within the 'lay epidemiology' (Bury, 1994; Allmark & Tod, 2006; Lovatt et al., 2015; Pihl et al., 2017), a process through which laypeople can understand dementia health risks. Therefore, lay perceptions of dementia risk factors can influence behaviour and help-seeking, and laypeople may not want to identify with people with dementia due to stigma. Stigma can lead to a 'spoiled identity' (Goffman, 1963). For Goffman, 'stigma' describes the experience of a phenomenon or event that is deeply shameful, and he uses the term 'spoiled identity' to refer to the identity that causes a person to experience shame. Likewise, evidence in the UK shows that dementia can be associated with stigma (Mackenzie, 2006). Medical expert knowledge suggests that due to the stigmatising dementia beliefs, Black Africans in London presented late to inner London memory services (Tuerk & Sauer, 2015). Indeed, it divides Black Africans in the UK into those who are normal and those who are not, consequently diminishing the worth of an individual and stigmatizing those in the not-normal category as deviant. This acts as a barrier to dementia management, diagnosis, and treatment (Rewerska-Jusko & Rejdak, 2020; Kane et al., 2020; Fletcher, 2021). Indeed, suggesting a need for dementia-friendly services for Black Africans in the UK is based on empirical evidence (Woodward, 2019; Maki et al., 2020). Hence, in the current study, exploring lay knowledge and beliefs about dementia can go a long way to integrate evidence for better dementia management for Black Africans in the UK.

Of course, lay knowledge and beliefs about dementia are critical yet underexplored elements contributing to disparities in dementia care. Therefore, the problem of the lack of dementia knowledge amongst Africans in the UK (e.g., Berwald et al., 2016; Parveen et al., 2017) should primarily be understood as an issue of dementia health inequality and injustice. Indeed, improved or advanced dementia knowledge and beliefs can reduce risky behaviours amongst Black Africans in the UK. A greater understanding of dementia lay knowledge and beliefs are crucial for dementia care at the patient and broader population levels. Understanding the lay concepts of dementia, lay knowledge and beliefs, and associated lay dementia risk factors is a foundational key to the successful management and prevention of dementia amongst Black Africans in the UK. Indeed, the unpublished study of Gow and Gilhooly et al. (2004) suggests that the study of lay concepts of dementia in the UK is limited, and researchers have not taken it seriously. Improving people's lay knowledge can be essential for 'empowerment' (Rushford & Harvey, 2016) in dementia community care. Moreover, it can produce more egalitarian dementia management in the Black African community in the UK.

## LAY CONCEPTS OF HEALTH AND ILLNESS

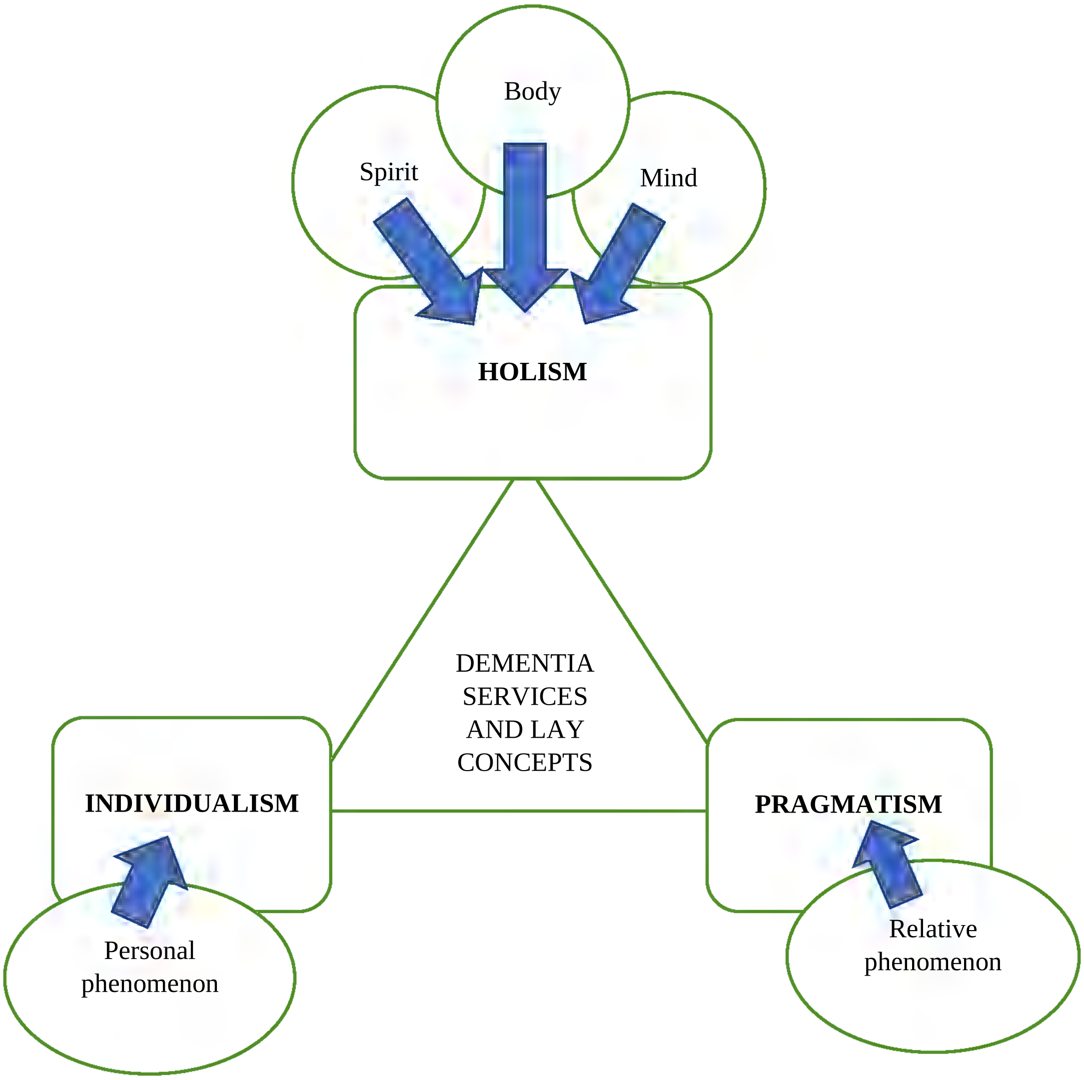


Figure 3. Lay conceptual model of dementia.

*The conceptual model is a proposed three-dimensional representation of dementia services and the lay concepts of dementia that the researcher developed inductively from the evidence. The model illustrates that everyone will have a different experience of dementia, and their characteristics and sociocultural circumstances will influence a path towards dementia help-seeking, diagnosis, and treatment. The components of the model are as follows: (i) Holism* *suggesting that the model is holistic, and everyone will have holistic responses and that the lay knowledge of dementia accommodates the whole person, including their spiritual (spirit), emotional (mind) and physical (body) well-being rather than just the dementia disease. (ii) Individualism suggests that the lay knowledge of dementia is 'anecdote' and 'live experience', meaning that the lay knowledge of dementia is a piece of personal knowledge and experience about the dementia phenomenon gained through direct or indirect interaction rather than through a representation of dementia constructed by the doctors or biomedicine. (iii) Pragmatism suggests that the lay knowledge of dementia path towards help-seeking or treatment is relative and person-centred and influenced by extrinsic factors, such as ethnicity, gender, education, income, socioeconomic status, occupation, religion, culture, knowledge, and beliefs.*

Generally, the lay concept of health and illness is a broader conceptual model underpinning lay knowledge and beliefs about an illness, which are held mainly by laypeople in communities to understand and give meanings to their health and illness and to provide explanations for dementia (Blaxter, 2004; Gow & Gilhooly et al., 2004; Helman, 2007; Nettleton, 2013). Similarly, technology is now a driving force in dementia knowledge and management (Sriram et al., 2019; Moyle, 2019; Astell et al., 2019). The same technology also promotes advancement in lay knowledge and beliefs about dementia. Therefore, the current study explores internet use in dementia lay knowledge. For example, technology such as the internet (Hopwood et al., 2018; Leng et al., 2020) and e-health (Dequanter et al., 2020; van-Rijn et al., 2020) is recalibrating the power relationship between laypeople and health professionals, such as the medical doctors in dementia management. The internet has become a significant source of online dementia health information for laypeople, facilitating networking and fostering lay expertise (Maslen & Lupton, 2019). Thus, providing resistance to dominant dementia specialist services indeed emphasises how dementia lay knowledge and beliefs via social media and online resources are experienced (Lupton & Maslen, 2019; Maslen & Lupton, 2019). However, the lay concept of dementia is understudied and not taken seriously in the UK for the Black African populations.

Understanding dementia using the lay concepts of health and illness places dementia within a broader and macroscopic spectrum, including the physical, emotional, environmental, social, and spiritual well-being, and unlike the biomedical concepts of dementia associated with reductionism. In this case, dementia is limited to organ, tissue, and cellular spectrums. How dementia affects people in day-to-day life varies from one individual to another. Therefore, researchers need to treat people with dementia as individuals with unique identities and biography. The lay concepts of dementia have theoretical underpinnings that partially arise from broader theories of health and disease. For example, the biomedical models suggest that health is the absence of disease (Scadding, 1988) and is localised within the theory of pathogenesis (Tisher & Salardini, 2019; Sivasthiaseelan et al., 2019). Indeed, a positivist epistemology thus suggests that dementia is a pathological disease and must be treated medically.

However, a disease can be considered deviant from social, cultural, or moral norms (Blaxter, 2004; Helman, 2007). The lay concepts of dementia mainly include community-developed sociocultural models (Goeman et al., 2016; Bosco et al., 2018; Bosco et al., 2019) and are social and cultural constructions. Therefore, health is a construction (Blaxter, 2004; Pratt, 2019) encompassing the body, mind, and spirit either from an interpretivist or constructivist epistemology. However, the current study is not about ethnicity, but in Western society, the body is often thought of as a machine (Gleyse, 2012; Reynolds, 2017; Marchal, 2017) and the mind as a computer (Crowther-Heyck, 1999) that can be 'tune-up', and illness is something lay people perceived as a breakdown of the machine or the computer. In this case, there is a contrast between the Western views of the body and mind from the non-Western perspectives in which the human body is a part of the supernatural and spirit world, cultural, and personal values (Maduro, 1983; Dobkin de Rios, 1984; Helman, 2007; Mark & Lyons, 2014; Laios et al., 2016). Moreover, this suggests that dementia illness can result from spiritual warfare and social, structural, and family dysfunction.

On the other hand, dementia health can be considered a balance of homeostasis or harmony and a state or status (Blaxter, 2004). Likewise, Bradley et al. (2018) argued that health is not a static state of being but a dynamic quality of living where the body, mind, and spirit are fully engaged and involved in making the most of each day. Moreover, dementia health in terms of balance is a common-sense knowledge amongst laypeople (Lerner, 2019), suggesting a need to incorporate balance in dementia care strategy (Morton-Chang et al., 2019). The balance is a balance in knowledge towards dementia that will include both lay and biomedical understanding of dementia in dementia care in the community. Hence, the two forms of balance involve moving dementia care from acute hospitals to social care services and integrating lay and biomedical knowledge into community dementia services for Black Africans in the UK.

Therefore, dementia is a holistic phenomenon. Indeed, it can interconnect dementia health and illness with all other aspects of life, such as everyday life, working life, family life, spiritual life, and community life. Likewise, health is a resource (Eckenwiler, 2020), a holistic phenomenon emphasising hope and well-being (Allen et al., 2007) and not just the absence of disease (Scadding, 1988; Blaxter, 2004), suggesting that medical doctors must consider whole life situation. Therefore, sociocultural differences in the conceptualisation of health and illness, such as dementia, can be problematic for doctors trained only in biomedical perspectives (medical models – a positivist epistemology and objectivist and realist ontology). Thus, it may lead to delayed or misdiagnosis and a decline in treatment uptake by patients and families within a community operating under interpretivism or constructivist epistemology with a subjectivist ontology. Moreover, the lay concepts about the appropriate management or treatment for diseases such as dementia may also differ from a doctor's, suggesting that 'illness is something a human has and disease is something an organ has' (Helman, 2007, p. 126).

In addition, lay concepts of health and illness for dementia depend on people as individuals. Individualism relates to dementia as a unique phenomenon promoting personhood (Dewing, 2008). It is centred on the individual as a moral agent (Moll et al., 2007), a part of the community, and a more substantial need to feel closer to family and relatives (family bonding), seemingly a fundamental issue. Moreover, dementia health values for most people are individualised, and everybody is 'unique'. Therefore, there is a need for effective dementia person-centred care (Kim & Park, 2017) because dementia is a phenomenon portrayed by personal and sociocultural factors, including income, employment, migration, housing, transport, and environment. Indeed, strategies to improve dementia must be individualised (Kitwood, 1997; Kitwood, 1990a; Kitwood, 1993a; Kitwood, 1993b). Nevertheless, some researchers may understand personhood in sociocultural rationality rather than individual terms (Davis, 2004), such as embodied identity (Myin & Zahnoun, 2018), selfhood (Kontos & Martin, 2013), and the concepts are foundational in person-centred care (Kitwood & Bredin, 1992; Kitwood & Benson, 1995). According to the naturalist epistemological tradition, personhood designates a human agent as an individual who possesses continuous consciousness over time and can frame representations about dementia, formulating care plans and acting on them (Taylor, 1985), suggesting that dementia can be equal to a loss of personhood. Therefore, this leads to the research of 'lived experiences' (van-Manen, 1997), especially in dementia. Nonetheless, personhood is an existential construct, as well as a relational construct (White, 2013). The moral sense of personhood denotes individuals as persons or human beings. Moral agents can engage in behaviours that can be evaluated as moral, and they are able to make their own choices in dementia care, unlike nonmoral agents, such as animals or a nonhuman (Nobis, 2011). However, the metaphysical personhood in dementia care is transcendental beyond the physical, with a distinct spirit capable of living after the death of the individual’s physical body (Nelson-Becker, 2017). Nevertheless, physicalists believe a person is essentially a physical body consisting of a mind/brain (Farrel, 1950; Fiegl, 1958; Smart, 1959).

Suffices to acknowledge that lay concepts of health and illness such as in dementia in non-Western society can be derived from within individual, from the natural or physical world, from the social world, from the cultural world, from the supernatural world, and from personal and social values (e.g. Mushi et al., 2014; Hindley et al., 2017; Mkhonto & Hassen, 2018; Kehoua et al., 2019; Hossain et al., 2020; Owokuhaisa et al., 2020; Kakongi et al., 2020; Nwakasi et al., 2021). Lay concepts about causation of dementia in the Western societies often encompass sociocultural models and individual factors. Within the individual context, causes of dementia may be attributed to inappropriate behaviour, such as exposure to environmental contaminants or exposure to germs (Helman, 1978), lack of exercise (Lamb, 2014; Lamb et al., 2018; Gholamnezhad et al., 2020), lack of balance (Lerner, 2019) or lack of proper diet (Petersson & Philippou, 2016; Yusufov et al., 2017; McGrattan et al., 2019), poverty or as a result of social inequalities (Jones, 2017; Peterson et al., 2019), and inequity (Giebel, 2020; Mejia-Arango et al., 2021). Therefore, the lay concepts of dementia can be considered a subjective response of an individual to those around him and his environment and how it affects his well-being, behaviour, and relationship with others in the community. Indeed, the lay concepts of dementia hover on the individuals’ ‘authentic happiness’ and ‘positive psychology’ (Allen et al., 2007). However, it can be associated with caregiver burnout and exhaustion with dementia, and the current study will further question respondents about this.

Furthermore, the lay concept of dementia is associated with pragmatism, a philosophical position (Schoneberger, 2016; Deering et al., 2021) that considers dementia knowledge practically driven and depends on individual choice of treatment. Thus, dementia is experienced and evaluated according to individual understanding and beliefs. Moreover, what they may find reasonable and practicable given their backgrounds, such as gender (Podcasy & Epperson, 2016), age, race, and ethnicity (Harwood & Ownby, 2000; Mukadam et al., 2011), income, occupation, and employment (Thomson et al., 2019), and language (Kindell et al., 2017; Krein et al., 2019). Therefore, dementia is not just the absence of disease because many people are realistic in their expectations. Thus, the lay concept of dementia is pragmatic, culturally bound, and socially related to the sociocultural models of dementia. It emphasises values, the need, and the importance of reducing inequalities in dementia health and increasing dementia equity related to health and well-being, unlike the medical models of dementia that focus on the presence and treatment of diseases.

Within the medical models, the cause of dementia is expressed and described within a biological framework (Ljubenkov & Geschwind, 2016; Arvanitakis et al., 2019), with high value placed on scientific research, pathologically driven, and the need for health services to diagnose and treat dementia. Generally, good health entails the notion of 'well-being'. It can be defined as the extent to which an individual or community can realise their aspiration and satisfy their needs on the one hand and, on the other hand, the ability to change and cope with their environment (Tannahill, 2009; Kirk et al., 2014). Thus, health is a positive concept that emphasises social, cultural, and economic resources and physical capabilities (WHO, 1984; Allen et al., 2007; Conti, 2018; Sirgy, 2019). Therefore, dementia is not just the absence of disease but also a disability (Rushford & Harvey, 2016; Wright, 2019; Shakespeare et al., 2019). However, legal personhood suggests that people with dementia and their caregivers in the Black African community in the UK can enter 'social contracts' or engage in deliberate or intentional actions that can be satisfactory to both due to reciprocal engagement (Ossorio, 2013).

Likewise, the researcher understands that dementia as a public health and health promotion goal is more concerned with promoting healthy lives and well-being (Tannahill, 2009; Potvin & Jones, 2011; Kirk et al., 2014). Rather than the simple prevention of dementia, it must concern lifestyle issues and social, cultural, economic, and environmental influences on dementia; a more positive and pragmatic approach that works at individual and structural levels for dementia management. Indeed, health is a state of complete physical, mental, and social well-being and not merely the absence of disease as earlier mentioned (WHO, 2017). This suggests that environmental factors, sociocultural factors, gender, and social determinates of health (Spruce, 2019) are crucial when considering what is required to improve dementia services, prevention of the dementia disease, and promotion of good health and well-being. This also strengthens the slogan 'health is wealth' (Feachem & Medlin, 2002); indeed, investment in dementia health is key to boosting wealth (Lancet, 2019), and health is human rights (Willen, 2019). Therefore, dementia is a human rights issue (Rushford & Harvey, 2016), inferring that the focus of public health and health promotion approach towards dementia should be holistic, preventative, promoting healthy living, and centred around a ‘balance of care’ (Morton-Chang et al., 2019). This entails striking a balance by integrating both lay and biomedical knowledge of dementia to deliver equitable and cost-effective dementia services.

Therefore, the balance of care infers that dementia lay knowledge and beliefs express dementia wholeness, and the lay concept of dementia is holistic. To know whether this is a true belief, the researcher asked respondents the questions in the current study because dementia impacts the Black Africans’ ability to function effectively in multiple aspects – physically, mentally, socially, culturally, and spiritually – within the community they live in the UK. This can also impact their coping strategies as driven by the theory of salutogenesis, where coherence serves as a key determinant of health (Antonovsky, 1978). A sense of coherence amongst Black Africans in the UK is essential in dementia management and influences dementia caregiving outcomes. A lower sense of coherence is associated with higher psychological distress and less emotional support (Goncalves-Pereira et al., 2021). Therefore, the researcher links the lay knowledge and beliefs about dementia amongst Black Africans living in the UK to their everyday lives in association with ageing, gender, religion, ethnicity, income, employment, housing, education, status, citizenship, and migration, including more complex issues such as language, family structure, and culture.

The researcher understands that it is possible to predict dementia or assess different levels of risk using diagnostic and genetic testing in medicine and institute preventative measures using biomedical concepts (Kumar & Clark, 2021). Despite its chaos, it may be worth coping with dementia because meaning may be attached to the dementia illness amongst Black Africans living in London. Therefore, the researcher argued that medical doctors’ emphasis on diagnosing and treating dementia within the confines of traditional biomedical concepts is insufficient. There is a more potent need for medical doctors to look beyond biomedical concepts of dementia and the traditional dementia specialist services (Midtbust et al., 2018; Lian et al., 2017) if medical professionals wish to manage and prevent dementia amongst Black Africans in the UK more effectively within the community. Indeed, the quality of life of people with dementia and their families can be strongly influenced by material resources and interpersonal issues (Landeiro et al., 2018; Zauszniewski et al., 2019; Yen & Lin, 2019), including psychological burden, resilience, stress, coping strength, and a sense of coherence (Stansfeld et al., 2019; Childers, 2019; Turro-Garriga et al., 2020). Inference from these studies suggests that salutogenesis is fundamental and valuable in public health and health promotion research (Bauer et al., 2020). Nevertheless, a more critical way of understanding dementia and the meaning of dementia is to explore the lay knowledge and beliefs about dementia amongst Black Africans living in the UK, using sociological and anthropological lay concepts of health and illness as a part of the theoretical framework.

### Social constructionism

In addition, the current study is underpinned by social constructionism (Bury, 1986; Berger & Luckmann, 1991; Burr, 2015; Burr & Dick, 2017). Therefore, the researcher interviewed respondents in the current study (see Chapter 4) to collect and analyse the data using a constructionist and reflexive thematic data analysis (Braun & Clarke, 2019), informed by a grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1994). The social constructionism aspect of this study rests on the philosophical assumptions that multiple versions of the dementia phenomena are legitimate and valid (Haapala et al., 2018; Bosco et al., 2019; Birt et al., 2020). Although, the standard for dementia reality is defined in relationship to professionally based biomedical knowledge of dementia as a disease (Ferencz & Gerritsen, 2015; Geschwind, 2016). Medical doctors hold strong jurisdiction over what counts as dementia scientific facts and the actual knowledge of what constitutes dementia. Lay constructs of dementia reality are considered untrue or dementia myths and legends (e.g., Roman, 2004; Neitch et al., 2016; Hossain & Khan, 2019; Ranscombe, 2020). However, lay knowledge of dementia and medical understanding of dementia is worthy of equal weight. In line with other 'social constructionists', the researcher argued, 'there is no way of judging one account of reality as better than another' (Bury, 1986, p. 165). Although, some researchers can test dementia hypotheses and judge dementia knowledge against others. Nevertheless, the fact is that researchers are a part of the research instrument or process (Rew et al., 1993; Pezalla et al., 2012) and are riddled with bias in many ways (Katz, 2019; Andersen et al., 2019), including the researcher's cultural, religious, and political stance or views, as well as bias from research funding (Lexchin, 2012; Murray et al., 2016; Knottnerus & Tugwell, 2018).

Thus, the current researcher's position is simple and based on evidence: social constructionism delineates a viable space in which dementia knowledge can occupy safely and comfortably, addressing how the lay and biomedical ideas or meanings of dementia are shaped, constituted, and constructed. Most of the dementia facts (e.g., Alzheimer's Association, 2021) we consider objective dementia realities are social and cultural constructs that change with time and process. Therefore, social constructionism is the theory that suggests that people develop knowledge of dementia in a sociocultural context, and that what people perceive as dementia reality depends on shared assumptions. Hence, the lay constructs of dementia reality and biomedical constructs of dementia reality are shared assumptions or beliefs.

In addition, drawing from Burr and Dick (2017, p. 59), social constructionism suggests that how people understand and perceive dementia is a product of how the dementia phenomenon is constituted, constructed, and produced through language and culture. It further highlighted that people's knowledge and understanding of dementia are therefore not absolute or final but rather framed by 'discourses', which often reflect the ideas of powerful groups in society acting to disadvantage or overpower the less powerful groups or individuals. Therefore, medical doctors have power over laypeople and can make legitimate claims about dementia as a disease. They can also lobby other authorities, such as governments and educational institutions, which will only see the doctors' views of dementia as valid knowledge and critical to dementia management than the lay constructs of dementia reality, such as an impairment or a disability (Rushford & Harvey, 2016; Shakespeare et al., 2019).

Thus, the current study's social constructionism concerns how dementia reality is constituted, constructed, and understood amongst Black Africans in the UK. It has both epistemological and ontological perspectives. The epistemological view of the study is rooted in constructivism and positivism, with the constructivist stance opposing positivism. Constructivist epistemology is an epistemological perspective that assumes that the lay knowledge of dementia is constructed by the researcher and not discovered. However, positivism assumes that the lay knowledge of dementia is revealed by observation, meaning that what exists is what the researcher perceives or observes to be the actual knowledge about lay dementia reality. Nevertheless, the ontological perspective of the current study assumes that the lay knowledge of dementia is subjective and rooted in an experience without objective truth, thus opposing objectivism that assumes that the lay knowledge of dementia is an objective, measurable dementia truth. Therefore, positivists and objectivists are not concerned with constructing lay dementia knowledge, meanings, or how the dementia construction makes meanings to laypeople because they cannot be measured scientifically or objectively (Corry et al., 2019; Park et al., 2020).

However, one key aspect of social constructionism is that it encourages scepticism about 'facts' and 'reality', or 'scientism' (Stein & Illes, 2015). Therefore, social constructionism cautions researchers from being suspicious of their dementia assumptions. The theory focuses on the notion that humans rationalise their experiences by creating models of the social world, sharing, and reifying these models through language (Burr, 2015). Indeed, implying that how laypeople perceive or give meaning to dementia results from historical, sociocultural, and political processes rather than an inevitable result of doctors' more excellent knowledge and understanding of dementia 'reality'. For example, Assal (2018) highlighted that dementia was framed from the Latin word '*demens*'. The term dementia was acknowledged since the 13th century and gained recognition in medical institutions in the 18th century. However, the concept was restricted to senile dementia, and it was not known as a disease but as a neurological condition leading to psychosocial disorder. In the 19th century, individuals with dementia were recognised as patients for the first time, and senile dementia became a disease, making it a biomedical construct.

Similarly, Foucault's (1973) paper 'The Birth of the Clinic' offered doctors a philosophical account of space and time, questioning the relationship between biomedical constructs and medical and institutional space. It suggests a complex interplay of politics, economic, and social power emanating from medical institutions and knowledge production, and how the concepts of disease such as dementia have changed alongside societal changes from the late 18th century to the early 19th century. The 'medical gaze' is more exciting and perceived as a positivist philosophy that identifies relationships based on power with the doctor and laypeople. The doctor treats the patients' bodies as objects separate from their social identities, such as age and gender. Nevertheless, age, gender, body, and mind are relative and subjective and perceived differently within societies in relation to dementia (Armstrong et al., 2022; Jacobs et al., 2022). In some cultures, some people can view the body, spirit, and mind differently with dementia (Owokuhaisa et al., 2020; Kakongi et al., 2020; Nwakasi et al., 2021).

Therefore, the researcher sees Foucault's medical gaze as a medical separation of a patient's body from his social identity. Indeed, the 'medical gaze' is the lens through which doctors produce dementia knowledge. The doctors can penetrate the patient's body intrusively, diagnose dementia, and prescribe treatment for dementia disease. Again, it suggests that dementia, which was previously concealed, was brought to the forefront through the enlightening influence of the medical gaze. Consequently, it became regarded as an objective phenomenon, free from the association and distortion of dementia with the body, spirit, and mind. This medical gaze brought unbiased truth about dementia onto the light. However, as a trained medical doctor, the researcher argues that the medical gaze is limited. Evidence suggests that the perceptions of dementia and its association with the body differ in different societies and cultures (Cipriani & Borin, 2015). For example, unlike in the West, older age is perceived with negative connotations such as ‘tragedy’ (Sweeting & Gilhooly, 1997, p. 98; McParland et al., 2017, p. 261). Nonetheless, older people are held in Africa as belonging to a religious age group to be treated with reference and respect and considered guardians of the clan’s tradition and history (Ndamba-Bandzouzi et al., 2014).

In addition, with the medical gaze, the ‘older age’ beliefs in Western societies can lead lay people to extend their ‘youthful look’ or uphold their social functions in various ways that may be detrimental to their well-being. Such behaviours may induce the use of biomedical concepts such as ‘anti-ageing’, ‘implants’, or ‘life enhancement’ as a form of ‘elixir of youth’ (Helman, 2007, p. 11) or in more positive ways such as exercise (Lamb, 2014; Lamb et al., 2015; Lamb et al., 2018; Gholamnezhad et al., 2020) to escape the vulnerability of older age and in the prevention of dementia (Lamb et al., 2018; Alty et al., 2020). However, outside of the medical gaze, lay people can also engage in religious activities such as prayers or faith (Heese, 2015; Hindley et al., 2016). Prayers, spirituality, and religiosity can be a great source of comfort and strength in dementia and suffering and can give meaning to dementia and despair (Connell & Gibson, 1997). Therefore, they can be seen as a form of therapy for dementia.

Nevertheless, lay people’s feelings about religious activities, such as in dementia care, can be complicated (Daly et al., 2014). So, culture informs the lay constructs of dementia and can influence perspectives on the interpretations or meanings given to dementia relating to the body, spirit, and mind. For example, different societies can perceive dementia and ageing from different frames of reference beyond biomedical constructs (Heese, 2015). In fact, excluding culture, the knowledge and relationship between dementia and older age may be an ‘empty variable’ (Perkinson & Solimeo, 2013, p. 102), suggesting that the dementia reality is a construct varying in meanings between laypeople and medical doctors. Thus, they are propositions made as a basis of reasoning without any assumptions of the truth about the dementia phenomenon.

Hence, if Western philosophical thoughts dominate the dementia services in the UK, positivism can be privileged over interpretivism/constructionism (Dalmer, 2020). The dementia phenomenon amongst Black Africans in the UK can be relative and associated with pluralism (Kusch, 2017), leading to inequity in dementia services for the Black African communities in the UK. The researcher argues that lay expert knowledge of dementia is ‘a body of dementia knowledge’ or ‘general cultural stock of dementia knowledge’, which can be regarded as expert knowledge with an equal weight with medical expert knowledge of dementia. Even so, Popay and Williams (1996) suggests that lay knowledge about health and illness, such as dementia, can be extensive and not limited to the conventional distinctions between ‘nonscience’ or ‘scientific’ concepts. Instead, it is based on a robust and holistic understanding of the dementia phenomenon in which individuals construct meaning for ‘common sense’ experience of dementia, thus intersecting biomedical constructs and lay constructions about dementia and its management in the Black African community.

Furthermore, applying the Foucauldian approach (Foucault, 1973) to understanding power-knowledge relationships in dementia reality transcends how the dementia phenomenon is constructed and experienced. Therefore, challenging the medical constructs of dementia is not a matter of seeking the truth about dementia but of detaching power from medical hegemony. The medical construct of dementia is imbued with power, whilst the lay construct of dementia is at the lesser end of the continuum. Therefore, power is an agent of coercion embodied in producing the knowledge and the ‘truth’ about dementia. Thus, power is based on knowledge, and power uses knowledge (Foucault, 1973). In such cases, power reproduces dementia knowledge by opening new ways of thinking about dementia, but power can also limit dementia knowledge by being restrictive in many ways. For example, in ‘Discipline and Punish’, Foucault (1977) argues that modern society is a ‘disciplinary society’, suggesting that power is everywhere in society and essentially exercised in many ways in a variety of institutions, such as educational institutions and hospitals. Thus, it produces dementia knowledge and behaviour that defines the acceptable truth about dementia, its perceived risks, and the acceptable help-seeking for dementia. Consequently, the internalised stigma becomes a mode of power for medical and social control and regulations (e.g., Andersen et al., 2022; Jacobs et al., 2022).

Indeed, Foucault (1973) argued that modern clinics were a part of the socioeconomic interest of power where other authorities, such as educational institutions and governments, see the views of medical doctors as critical to their survival and prosperity. Therefore, when laypeople enter the clinics, they also enter the field of power where the layperson can be manipulated by medical doctors (Burr, 2015; Burr & Dick, 2017). Therefore, in this study, the researcher ensures that no power relationship exists between the lay respondents from the Black African community in London and himself as perceived by the researcher as he did all he could to mitigate the power difference. The data collection and analysis are driven by the participants’ words and narratives, not by the researcher’s medical ideas or constructions. Hence, the researcher is persistently reflexive in his medical stance to avoid power relations between the participants and himself (see Chapter 4).

Of course, in most biomedical dementia studies, medical hegemony superseded the lay constructs of the dementia phenomenon. Indeed, it overshadows the lay knowledge of dementia. Some of the medical constructs of dementia are medical 'jargon', sometimes very difficult to pronounce and made no tangible meaning to laypeople but the clinicians (Sevinc et al., 2005; LeBlanc et al., 2014; Pitt & Hendrickson, 2020). However, it does assume superiority over the lay constructs of dementia, occupying positivist and objectivist epistemological positions with a realist ontological stance. Nonetheless, most of the medical 'jargon' is subjective medical constructs that may change in time and with a process, such as in the use of exercise (Lamb et al., 2018), successful ageing (Rowe & Kahn, 1997), or pharmacological drugs in the treatment of dementia (Davison, 2014; Kumar & Clark, 2021). Therefore, judging medical constructs of dementia as better than lay constructs of dementia can only lead to epistemic tension. Both medical and lay constructs of dementia are invaluable.

Moreover, the researcher argued that the constructionist approach is the opposite end of a continuum to the positivists in terms of assumptions about the dementia reality. The positivist view assumes that dementia reality is entirely separate from human perceptions and unchanging (Kumar & Clark, 2021), whilst the constructionists thinks that dementia reality is an outcome of power, human and societal processes and that it is impossible to separate the dementia constructs from the culture and methods in which it is constituted or framed. Therefore, echoing Burr (2015) and Burr and Dick (2017), social constructionists' position accepts one or more of the following key assumptions: (i) a critical stance toward taken-for-granted ways of understanding dementia. It challenges the view that traditional knowledge is based upon objective, unbiased observations of the dementia phenomenon, thus opposing positivism, objectivism, and realism; (ii) how we commonly understand the dementia phenomenon, the methods, and concepts we use are historically and culturally bound; (iii) our knowledge of the dementia phenomenon and our typical ways of understanding the dementia phenomenon is sustained by sociocultural process; and (iv) our dementia knowledge and social action go together, hence our constructions of dementia is bound up with power relationships.

Considering the assumptions, biomedical dementia knowledge can be viewed as a construct, knowledge embodied within medical language and constructions (Lian & Bondevik, 2015) that emphasise positivism and objectivism. Furthermore, lay dementia knowledge is considered a construct and knowledge that highlights interpretivism/constructivism and subjectivism (Green & Thorogood, 2018). Variations in both perspectives may lead to situations where dementia can be perceived as a disease in one community but not in the other, leading to differences in dementia behaviours and help-seeking. For example, in some Western societies, dementia may be perceived as a disease (Birt et al., 2017; McParland, 2017) that must be treated with pharmacological drugs. Some non-Western societies, such as African communities, can perceive dementia as an illness or a normal ageing process (Hassen, 2013; Ciprani & Borin, 2015). Social constructionism draws its influence from several disciplines, including sociology, psychology, anthropology, religion, economics, and education.

Nonetheless, this study has focused on public health and health promotion. However, new public health and health promotion have emerged alongside the traditional public health and preventative medicine discipline. Health promotion is a unique discipline (Davies, 2013) that relates closely to public health yet differs by strongly emphasising personal and community autonomy, participation, and empowerment amongst individuals and their communities (Davies, 2013). Thus, public health and health promotion are unique disciplines. Its concepts are borrowed from major contributory fields of religion, medical sociology, medical anthropology, medical psychology and education, and public health and medicine.

Again, the current study is not about discovering the dementia reality or the truth about dementia but how dementia is constituted and constructed amongst the Black Africans living in London. Dementia can be constructed in coordination with others and separately within individuals (Whitman, 1993). Indeed, constructs exist and are constructed by the community, groups, or individuals. Two kinds of constructs will drive the study: (i) cultural and (ii) social constructs of dementia (e.g., Henderson and Henderson, 2002; Poveda, 2003; Henderson & Traphagan, 2005; Zeiling, 2012; Lian & Bondevik, 2015; Hamad et al., 2017; Bosco et al., 2019). The social and cultural constructs of dementia are encapsulated in dementia sociocultural and medical models and drawn from lay and biomedical concepts, respectively. The researcher explains both models later in this chapter. However, they differ between Africa and the UK, laypeople and doctors, and lay experts and medical experts, depending on the events surrounding the time and are subject to change. Therefore, a vital contribution of this thesis is that dementia knowledge is not static.

Hence, drawing on the current study, the researcher assumes the phenomenology of dementia over the centuries has been causally associated with witchcraft, among other factors, and has continued to change (Zeiling, 2012). On a conceptual level, dementia is open to various interpretations and subject to historical, political, and cultural mores, invoking emotional responses, stories, and languages as metaphors persistently used in explaining the dementia phenomenon. For example, in the UK, and drawing from Zeiling (2012), dementia has been described as a ‘millennium demon’, ‘silent tsunami’, ‘wave of dementia’, ‘silent epidemic’, and with biblical allusions such as the need for a ‘crusade to overcome it’, and images of ‘light’ and ‘darkness’. The light is often contrasted with darkness, which may symbolise possible medical advancements in treating dementia, whilst the darkness may symbolise tragedy. Thus, lay knowledge of dementia and medical understanding of dementia is, in a way, juxtaposed (Zeiling, 2012, p. 260). Therefore, to consider the powerful sway of the broader historical and sociocultural constructions of dementia, the researcher draws on some global studies. More so, to inform the current research on the association between dementia, older age, and memory, even though the current research is not about ageing and memory but dementia. However, they are seemingly interconnected.

Thus, the researcher considers the sociocultural model and medical constructs of ageing associated with memory and dementia, differing between Western and non-Western societies, and have continued to change over time. (Helman, 2007; Lamb, 2014; Jaconelli et al., 2017; Urtamo et al., 2019). Indeed, relating it to the respondents from the Black African community in London and acknowledging that Africa is a non-Western society whilst the UK is a Western society. Usually, memory difficulty is one of the most common complaints in dementia, ageing or older age. Thus, practical and theoretical underpinnings motivate studying ageing-related dementia and memory function changes. The theoretical approaches to memory loss in ageing are: (i) a decline in processing speed, (ii) reduced processing resources, (iii) ageing-related inhibitory deficits, and (iv) decreased cognitive control (Baddeley et al., 2002, p. 543). The idea is that decreased mental processing speed underlies all age-related cognitive deficits directly or indirectly by disrupting the time of a complex sequence of mental operations. Hence, within this framework, ageing-related deficits in memory are not attributable to impaired memory processes but to a generalised age difference in processing speed, unlike in dementia, where it is perceived as an impaired memory process and a medical disease condition.

The phenomenology of memory can be described as information stored in the mind/brain and the processes of consolidating and retrieving such information (Robertson, 2002; Brewin, 2018). It is arguably the most basic and essential operation of the mind/brain. Memory impairment can lead to dependency on others, such as dementia and older age. However, some people with dementia and older people can maintain their independence for many years before death (Alzheimer's Society, 2017, p. 36). Nonetheless, most studies contextualise the Western experience of living with dementia (Birt et al., 2017; McParland et al., 2017; Pritchard-Jones, 2020). Presumably, the decisions and scientific methods employed in investigating these issues and providing solutions are ethnocentric, lacking complete adaptation to lay constructs of dementia. Biomedical constructs of dementia mainly focus on the brain, and how cultural contexts and social relationships shape dementia amongst laypeople are ignored. Moreover, linking it to the work of Hassen (2013, p. 231), culture is shared meaning, symbols, and beliefs that provide support and a sense of security and social identity.

### Social identity theory

'Black African' is on the list of ethnic identities in the UK (ONS, 2019). This signifies an individual's affiliation with specific ethnic groups within the UK and establishes a social identity. Social identity is theoretically underpinned by social identity theory (Tajfel & Turner, 1979). Thus, Tajfel and Turner (1979) proposed that groups (e.g., ethnicity, race, religion, occupation, social class, and family) were an essential source of social identity. Hence, a particular group will give people or individuals their social identity and a sense of pride and self-esteem, that is, a sense of belonging to a social world. Thus, the ways the Black Africans living in London may perceive dementia can be central to something they discuss together and understand in a certain way and in a relationship to the others, which may provide similarities or a shared reality of the dementia phenomenon amongst the participants as a group. Indeed, it confers a social identity.

Interestingly, Tajfel and Turner's (1979) social identity theory (SIT) has now broadened to encompass a wide range of phenomena both as a theory of intergroup relationships and as a theory of self-identity (Brown, 2020). Therefore, affiliation with a group will typically confer self-identity, self-esteem, and self-pride. Indeed, it is an assumption, but it assists the participants in the current study in sustaining their social identity as a particular group in relation to others. Thence, people within the group can be perceived as in-groups, and people outside the group can be perceived as out-groups (Tajfel & Turner, 1979), which means that in-groups and out-groups are centred on perceived differences and similarities towards dementia. Moreover, the group members of an in-group may seek to find the negative aspects of an out-group (Tajfel & Turner, 1979), thus enhancing their self-identity, self-esteem, and self-pride. In this case, it may lead to prejudice (McLeod, 2019).

On the other hand, some multicultural studies using multicultural theory proposed cultural diversity amongst groups. Affirmation towards the groups, particularly concerning ethnicity, corresponded with a higher acceptance towards out-groups (Negy et al., 2003). Indeed, cultural diversity can be perceived as a strength and having different cultures or groups respect each other’s differences and similarities about dementia. As noted, the current study is not an ethnicity study. Ethnic diversity in a health study can be complicated and complex. However, getting people from different groups and cultural backgrounds to work cooperatively on dementia care or dementia management within a neighbourhood or community in the UK can reduce prejudice (Shirayama et al., 2019).

Therefore, in this study, social group-defining norms serve as the basis for the social identity that influences participants’ attitudes and feelings regarding their in-groups and out-groups. Indeed, Tajfel and Turner (1979) proposed that evaluating others is both a cognitive and an intuitive process that involves (i) categorisation, (ii) social identification, and (iii) social comparison. Nonetheless, social identity theory elaborates that assigning a person to a group or membership is not something foreign or artificial to that person but a natural and vital part of the person or the people assigned to the group (McLeod, 2019). In this case, the current study is linked to the participants’ originality as Africans. Thus, this provided the social identification processes of the group as Black African populations living in London. They were first-generation migrants from West Africa and were marginalised churchgoers. Therefore, all the participants had a common background that was true and real towards the dementia phenomena.

### Power-relationship

Indeed, the researcher understands dementia ideas as an unequal power relationship in the community or clinics (Foucault, 1973, 1977), and as such as between laypeople (e.g., patients, families, friends, and relatives) and professionals (e.g., doctors) and between the ideologies of Western and non-Western societies (e.g., Lamb, 2014). Foucault’s conceptualisation of power suggests that power is ‘relational’ and ‘productive’ (Foucault, 1973). Relational and productive in context because power is permeated in doctor-layperson relationships or interactions in dementia care and can produce ways of being which might be unfitting to laypeople in the community (Foucault, 1973; Foucault, 1977). For example, doctors use medical ‘jargon’ in community clinics and their surgeries (Links et al., 2019).

Moreover, it makes meaning to the doctors and their colleagues but makes no meaning to laypeople either as patients, friends, families, or relatives, but rather perceived as a form of dominance and superiority of the doctors in dementia diagnosis and treatment. In addition, doctor-layperson interactions often produce a form of dementia knowledge via history taking and the conducting of laboratory investigations. Still, doctors tend to belittle laypeople in most interactions and perceive them as objects or subjects. Indeed, it represents a form of systemic control over laypeople rather than as co-constructors of dementia knowledge or in the coproduction of the dementia guidelines and the clinical management of dementia.

Hence, underpinning social and cultural constructs are the essential connections between power and knowledge; no power relationships exist without the associative constitution of a particular field of expertise. Therefore, all knowledge is constructed simultaneously with power relationships (Foucault, 1973; Foucault, 1977). Hence, knowledge includes what people perceive as subjects and what they know as objects of knowledge (Scales et al., 2017). Hence, dementia cultural constructs embody people and their culture, and culture is a complex whole that includes learning and beliefs acquired as members of a community. It comprises a system of shared ideas and concepts; therefore, culture can be considered a set of behaviour or guidelines (Helman, 2007), or a system that guides medical doctors and laypeople in transmitting the dementia behaviour or dementia guidelines to the next generations, such as medical students or families respectively. Thus, it is a process considered as ‘enculturation’ (Smith et al., 2017; Bosco et al., 2019).

The ways of conceptualising dementia have influenced the medical and lay representations of the condition (Smith et al., 2017; Bosco et al., 2019; Vatanabe et al., 2020), suggesting that past defining characteristics of dementia have influenced medical and lay constructs of the dementia phenomenon. These views are interpreted, assimilated, or rejected by individuals or transmitted within and across cultures through enculturation. More importantly, enculturation teaches medical doctors to accept the norms and values of dementia medical knowledge as members of a clinical profession and fulfil the needed dementia functions and roles of a medical doctor. Likewise, enculturation would also suggest that Black Africans living in London should accept the norms and values of the British people and the Western contextualised dementia management. However, some Black African people in the UK may not integrate fully into the community due to personal circumstances and poor social capacity.

Therefore, a community is a 'school' of enculturation for community members, as medical schools are a form of enculturation for medical students. Hence, the Black community in the UK is a 'school' for Black African people. Similarly, becoming a medical doctor is a form of enculturation. Nonetheless, evidence shows that social class affects the circumstances and how people will value one another (Sayer, 2002, 2005). Indeed, medical doctors have acquired higher power and social status by training, have the right to classify dementia disease conditions, and are empowered with the concepts of 'medicalisation' (Helman, 2007; Conrad, 2007; Nettleton, 2013).

Nevertheless, expanding the biomedical concepts over the lay concepts can also present undesirable effects such as unbalance in dementia management. Medicalisation is how the jurisdiction of modern medicine has expanded in recent years and now encompasses many problems that formerly were not defined as medical entities, such as dementia (Helman, 2007, p. 163). It examines how medical doctors develop and apply medical categories. To a lesser extent, it focuses on how laypeople internalised medical and pharmaceutical perspectives as a taken-for-granted subjectivity (Conrad, 2007, p. 14). Therefore, a better understanding of the social and cultural constructions of dementia amongst laypeople can improve public health and health promotion approaches in dementia care in the UK. Moreover, they are shifting from care to 'empowerment' (Rushford & Harvey, 2016) and a more effective community-based dementia care strategy (Morton-chang et al., 2019).

Nonetheless, drawing on the literature review (evidence synthesis), the researchers suggested that Africans in the UK lack knowledge of dementia. However, observation of the empirical evidence from the literature review indicated a discrepancy and inequality in the UK dementia services and dementia knowledge. The disparity was evident in power relationships between the doctors (professional dementia service providers) and laypeople (lay dementia service providers) and a dichotomy between Western and non-Western ideologies in the knowledge of dementia. Whilst the researchers may conclude that Africans in the UK lack the knowledge of dementia, many participants in the studies believed that their GPs lack the knowledge of dementia as observed, thus creating tension between lay and medical knowledge of dementia:

> *Many perceived that their GPs lacked dementia knowledge . . . Some had experience negative interactions with their GPs* (Parveen et al., 2017, p. 738).

On the other hand, it shows how their dementia gaze constitutes their subjectivity. Indeed, the doctors, researchers, and respondents become self-scrutinising, self-diagnosing and self-analysing subjects, and objects (Conrad, 1979) and with the power to judge others objectively or subjectively. Hence, the dementia gaze operates as a socialising force on viewers and those viewed as objects or subjects.

### Sociocultural model

The sociocultural model can be considered a way of thinking and interpreting dementia and the dementia community care for Black Africans in the UK. It can be viewed as a part of the thesis dementia conceptual framework but significantly different in some ways because it emerged from the data. It is pragmatic and represents a set of prescriptions for medical doctors, health providers, and community leaders to interpret the dementia constructs and provide needed community dementia care and support for Black Africans in the UK.

Therefore, the sociocultural model of dementia seeks to understand and interpret dementia and the emotions and behaviour of the Black African people within the community by placing dementia lay knowledge and beliefs within the context of the circumstances and biography of the individuals, such as age. The researcher developed the sociocultural model inductively as informed by the empirical data (see Chapters 5, 6, 7 and 8). It is holistic, encompassing the medical constructs of dementia as a disease and the lay concept of dementia illness, social world concepts such as social and cultural constructs, and supernatural world concepts such as spirituality, religion, and the individual biography/identity.

Thus, the sociocultural model is pragmatic. The model is associated with learning and understanding the individuals in the Black African community as a person with a history and background (Kitwood, 1997). Therefore, dementia care and support can be designed and tailored more appropriately to individual needs (Kitwood, 1993b; Kitwood & Bredin, 1992). Hence, the sociocultural model helps understand inequalities associated with dementia, influenced by sociocultural factors such as the individual biography and history, culture, environment, ethnic identity, education, status, and language (see Chapters 5, 6, 7 and 8), and it addresses the concerns for dementia equity in the Black community. Therefore, these factors must be considered when planning dementia care and support in the Black African community in the UK.

Moreover, a ‘sociocultural blindness’ that overlooks social and cultural constructs of dementia will account for injustices and inequalities in the uptake and access to dementia care services. The sociocultural model of dementia can suggest the extent to which dementia is a diachronic phenomenon, and it shows how the biomedical concepts and lay concepts of dementia are a false dichotomy. They intersect and are interconnected. One essential point this thesis makes is that dementia knowledge and the management of dementia are not static and must be driven by equity. As such, it is shifting the focus of public health and health promotion to ‘enablement’ and ‘empowerment’ (Rushford & Harvey, 2016) and the need for a ‘balance of care’ in dementia (Morton-Chang et al., 2019).

Furthermore, dementia as a disability is not an individual’s intrinsic characteristic but an outcome produced by social processes. Disability is not an illness or a disease that exists purely at the intrinsic level of the individual as a pathology. However, it is a condition created by a combination of social, cultural, biological, environmental, and material factors (Liden, 2017). Thus, the sociocultural model intersects dementia disease and illness amongst the Black African population in the UK.

## Medical model

The medical model was defined by Laing (1971) as the ‘set of procedures in which medical doctors are trained’. Thus, the medical model of dementia is a way of thinking of dementia as a disease whereby medication is often used in treating dementia as a medical intervention. In the UK, the model comprises organised, legally sanctioned medical doctors, including doctors of various specialities such as the GP and psychiatry. It also accommodates nurses, pharmacists, and paramedics (Helman, 2007). The term is often used in general medical practice and psychiatry, suggesting that it is a scientific process involving a systematic process of observation, description, and differentiation (Laing, 1971), thus moving from the diagnosis and treating symptoms of dementia to identifying the disease aetiologies, risk factors, and developing specific treatments for dementia (Davison, 2022; Kumar & Clark, 2021), based on some epistemological and ontological assumptions, including positivism, realism, naturalism, reductionism, and essentialism (Green &Thorogood, 2018).

Within the medical model, dementia is defined as a syndrome rather than a particular disease describing a group of symptoms that can include progressive memory loss, difficulty in thinking and problem-solving, language difficulty, and changes in mood, perception, or behaviour (Raz et al., 2016; Gale et al., 2018; Garre-Olmo, 2018). The medical model of dementia is based on the assumed rationality and positivism of ‘Western medicine’ (Gaines, 2016). It teaches the superiority of medicine over other ‘ethnomedicine’ (Gaines, 2016) and suggests that as dementia progresses, the brain’s structure and chemistry change, causing damage to nerve cells (Davison, 2022; Kumar & Clark, 2021). This view is reductionist and determinist as it suggests that chemical imbalance can cause dementia. Drawing on Laing (1971), it is a set of knowledge in which all doctors are trained and do not consider other sociocultural factors that cause dementia. As such, the current researcher is a trained medical doctor and reflected on his medical training and medical model of dementia (see Chapter 1). It is a reductionist approach and considers only abnormal bodily functions. Unlike the other concepts, it mainly provides dementia diagnosis and treatment with drugs. The drug therapy targets receptors to act on the neurotransmitters in the synapses (Davison, 2022; Kumar & Clark, 2021). Therefore, the medical model allows doctors to ascertain what is physically or biologically dysfunctional with the person with dementia instead of what the person needs to live independently and fully. It cannot educate individuals and their families about the dementia phenomenon. Thus, the person with dementia is excluded from the therapy as the focus is on brain chemicals rather than quality of life and independence. Indeed, medicalising dementia (Sedler, 2016).

The main explanations of dementia within the medical model are based on biomedical ideas, brain abnormality and genetic factors (Davison, 2022; Kumar & Clark, 2021), thus pathologising people with dementia. The doctor considers the diagnosis and prognosis and prescribes treatment of dementia with medicines. However, it creates low expectations among people with dementia, leading to a loss of independence, choice, and control in their everyday lives. The medical model often takes a nature instead of nurture approach to dementia. Thus, there is a need to consider the broader sociocultural context, including the religion and spirituality of the person with dementia and their health and well-being, as argued in this thesis, which would contribute to a broader holistic approach tailored to the biography of the individuals with dementia and their personalised needs.

Even so, some doctors have noted the challenges in using the medical model, which led to conceptualising the ‘biopsychosocial model’, and can be considered a medical model. The model was first conceptualised by George Engel in 1977. Drawing on Engel (1977), the principle of the biopsychosocial model includes biological, psychological, and social dimensions of the person with dementia with the understanding that the person with dementia is a whole person, not an isolated brain. Therefore, doctors using the model in dementia would utilise a holistic approach considering the individual’s personality, religion and spirituality, environment, culture, and biological factors. Thus, the biopsychosocial model in dementia care provides philosophical and practical clinical guidance (Papadimitriou, 2017) in the Black African community and dementia services.

### Spiritual model

Unlike the medical model, the spiritual model of dementia is a way of thinking about dementia spiritual care. Exploring the spiritual model of dementia and spiritual care is not within the scope of the current study. However, spiritual concerns are significant to many patients with dementia, particularly at the end of life (Kaufman, 2002; Sulmasy, 2002). It intersects with the biopsychosocial model of dementia, as highlighted in the medical model. It consists of healers that are not part of the medical system but occupy the intermediate position between the sociocultural and medical models of dementia, and in Africa, it may include spiritual healers, faith healers, herbalists, or traditional healers (e.g., Owokuhaisa et al., 2020; Kakongi et al., 2020; Hindley et al., 2016; Mushi et al., 2014). A spiritual model of dementia care is rare in the UK's dementia services. However, it is not uncommon. The current research identifies that exploring spiritual beliefs in dementia care is essential but complex (Nelson-Becker, 2017; Daly et al., 2014). Indeed, the spiritual model of dementia care is poorly understood by most physicians (Damianakis et al., 2016).

McKee and Chappel (1992) suggested involving spiritual issues and concerns in medical education. They recommended in their studies that the medical model be expanded to a biopsychosocial-spiritual model as a guideline for practising physicians, including those involved in dementia services. The biopsychosocial-spiritual model can shape how medical doctors are trained to provide contextualised and holistic care for people with dementia (Vermette & Doolittle, 2022). Thus, holistic dementia care must address the individual's relational existence – physical, psychological, social, and spiritual. The domains for accessing spirituality in dementia services must include religiosity, religion, religious coping and support, spiritual well-being and needs (Odbehr et al., 2017). It is complex but based essentially on love, faith, and connectedness.

Indeed, Odbehr et al. (2017) explored a spiritual model of dementia, the meanings of spiritual care and the understanding of religious needs in persons with dementia. They provided a construction that described the spiritual model of care for the person with dementia as a process of performing religious rituals that provide a sense of comfort, a process of knowing the person with dementia, which provides opportunities to understand the person's meaning and purpose, and a process of attending to basic needs of the individual with dementia provides an opportunity to appreciate others' vulnerability and humanness. The authors concluded that spiritual care intends to help persons with dementia express their faith, love and religious beliefs and support persons with dementia to experience meaning in life through to the end of life, connectedness to self, God or deity and other persons. Some researchers have referred to spirituality in dementia care as individual relationships with the sacred, meaningful entities beyond oneself or transcendent (Nelson-Becker, 2017). In the current study, prayer served as a dementia therapy. The group believed in God as their source of protection, hope, courage, and a means to cope with dementia and the complexities of life.

The current study focuses on the lay knowledge and beliefs about dementia amongst Black Africans, first-generation migrants and churchgoers from West Africa living in the UK, who identified as laypeople. Nonetheless, the researcher identified them as lay experts. Lay expertise in this study is essentially the 'general cultural stock of knowledge' (Wilcox, 2010, p. 45) or a 'body of knowledge' (Grundmann, 2017) about dementia held by the Black African respondents in their communities in the UK. It is an integral part of faith, mainly through prayer, which serves as therapy for dementia in dementia care. It promotes the dementia services of the Black Africans in the community and advocates for equitable access to holistic dementia care as a human rights. Even so, previous evidence suggests that religious and spiritual people tend to have higher self-esteem and positive dementia beliefs (Weiseman de mamani et al., 2017). Robert and Maxfield (2018) suggested that internalising a dementia belief and developing and building a social network within a religious community can provide a psychological buffer against dementia worry. Doctors encouraging and tapping into individuals' spiritual beliefs help them cope and enhance their quality of life (Best et al., 2016; Soto-Espinosa & Koss-Chirino, 2017).

Of course, the spiritual model of dementia intersects with the biopsychosocial, medical, and sociocultural models of dementia. They are not mutually exclusive and are not independent of each other. Thus, Churches in the UK can influence dementia behaviours, and involving churches in dementia services incorporating spiritual contextualisation for Black Africans can be adequate (Campbell et al., 2007). However, exploring the spiritual model of dementia is beyond the scope of the current study. Nevertheless, it intersects with the biopsychosocial-spiritual model of dementia. All the models in the current study are interconnected and are not mutually exclusive. Applying the biopsychosocial-spiritual concept in dementia care in the UK can lead to a profound change in dementia services.

## Theoretical strengths and drawbacks

The lay concepts of dementia are a broader conceptual model of health and illness that can explain how people maintain their health and body and provide lay explanations for the dementia phenomena. Understanding dementia using the lay concepts of health and illness places dementia within a border and macroscopic spectrum, including the body, spirit and mind, and sociocultural contexts (see Figure 3), unlike the biomedical concepts of health and disease. The biomedical idea of disease is associated with reductionism and is limited to organ, tissue, and cellular spectrums (e.g., Davison, 2014; Kumar & Clark, 2021).

The lay concepts of health and illness suggest that laypeople are ‘knowledgeable’ (Segall & Robert, 1980; Hunt & McEwen, 1980) and laypeople are ‘lay experts’ (Parsons & Atkinson, 1992; Popay et al., 1998; Tuner, 2001; Wilson, 2007). Likewise, lay knowledge can be lay expert knowledge, which is as valuable as medical expert knowledge (Popay & Williams, 1996; Turner, 2001). Therefore, improved, or advanced lay expert knowledge of dementia, can be crucial in dementia community care (Oborn et al., 2019). Hence, the researcher did not privilege medicine in epistemological and ontological positions over the lay knowledge of dementia by applying the philosophical concept of ‘bracketing’ (Gearing, 2004, p. 1433). Indeed, the researcher understands his orientation standpoint and epistemological and ontological perspectives and the theoretical framework guiding the study. Therefore, the foundational focus in ‘bracketing’ holds in abeyance presupposition of his biomedical understanding of dementia (Gearing, 2004, p. 1433) to illuminate the lay concepts of dementia in the study. Of course, the researcher bracketed his biomedical knowledge about dementia; he is a medical doctor, but he believes all forms of knowledge can be equal (Armstrong, 1985; Bury, 1986; Monaghan, 1999).

Even so, the process through which ‘bracketing’ occurs in research is shifting, debatable, and needs more consensus on how it should be conducted (Tufford & Newman, 2012). Drawing on Husserl (1931), looking beyond biomedical preconceptions and assumptions of dementia in the current research is possible and desirable. However, Heidegger argued that bracketing out preconceptions and assumptions is not entirely possible (Heidegger, 1962). Instead, the researcher could adopt a contextual interpretation and meaning of the dementia phenomenon based on engagement as a means of knowing (Heidegger, 1962). Indeed, the researcher ensured prolonged engagement with the data and the participants in the field.

Nevertheless, the present researcher argues, like Ashworth (1999), that he ‘bracketed’ his medical preconceptions and assumptions of dementia to reveal the ‘lived experiences’ of the dementia phenomenon as ‘witchcraft’ amongst the Black Africans living in London in the entire research lifecycle through a process of reflexivity, reflection, rigour, and transparency (Heidegger, 1962; Husserl, 1931; Dorfler & Stierand, 2019). Of course, some respondents were aware of the researcher’s medical background, and he chose to be transparent about it. Regardless, some participants called him a ‘brother’ and ‘son’ rather than a doctor. Thus, it acknowledges the importance of the researcher’s subjectivity given his similar ethnicity and relationship with the participants, who were churchgoers and functioned as co-decision makers in the research process and the creation of dementia knowledge. Therefore, it was essential for the researcher to be honest, open, and vigilant about his medical background and preexisting biomedical thoughts and knowledge and engage in the self-reflective process of ‘bracketing’, whereby he recognised and set aside but did not abandon his biomedical knowledge of dementia and assumptions to attend to the respondents’ account of dementia with an open mind (Starks & Trinidad, 2007, p. 1376).

Thus, in this study, ‘bracketing’ the researcher’s biomedical assumptions and preconceptions to reveal the dementia phenomenon as witchcraft and as driven by the participants’ own words was a strength and added scientific rigour and validity to the qualitative research (Sorsa, 2015). Nevertheless, it was challenging, and the need for more consensus over what needs to be held in abeyance continues as an ongoing debate in qualitative studies (Gearing, 2004).

Regardless, this study reinforces that lay knowledge of dementia can be as valuable as medical knowledge of dementia. Moreover, ‘there is no way of judging one account of reality as better than another’ (Bury, 1986, p. 165). Therefore, judging biomedical knowledge of dementia as better than lay knowledge of dementia can lead to epistemic tension (Busby et al., 1997; Haw et al., 2018). Nevertheless, the researcher understands that there is a hierarchy in dementia knowledge and is influenced by aspects of power and identity, such as education, gender, ethnicity, and professional status, such as being a medical doctor. Nonetheless, the current research argues that medical doctors should take lay knowledge about dementia more seriously due to ‘lived experience’ (van Manen, 1997). Laypeople gain personal experiences of dementia through direct and indirect everyday experiences rather than dementia knowledge constructed by medical doctors because laypeople can learn about dementia by living through it.

Nevertheless, some of the sociocultural constructs of dementia may prompt inferences about dementia that ultimately have negative consequences and might lead to incorrect views about dementia and ineffective strategies for prevention (Prior, 2003; Hirji, 2004). These may include beliefs in witchcraft as a cause of dementia (e.g., Ndamba-Bandzouzi et al., 2014; MKhonto & Hassen, 2017; Zeiling, 2012) and associated dementia stigma and taboo (e.g., Jacobs et al., 2022; Owokuhaisa et al., 2020; Kehoua et al., 2019; Mkhonto & Hanssen, 2017; Hindley et al., 2016; Adebiyi et al., 2016; Mushi et al., 2014), and inappropriate language and metaphors (Zeiling, 2012).

Moreover, Prior (2003) suggested that laypeople have insufficient expertise to make quality judgments or be considered lay experts. They inferred that laypeople might need some training and education to be active in dementia management. Indeed, Prior (2003) argued that for laypeople to be considered knowledgeable and lay experts in dementia, they must have sufficient medical skills and training. Therefore, medical doctors need to be aware of dementia lay constructions and their inferences to avoid the avoidable and avoid making costly mistakes that would jeopardise their patients' lives. Nevertheless, the sociocultural model illuminates the lay knowledge and beliefs about dementia amongst the Black Africans living in London. The model suggests that laypeople from the Black African community in London are lay experts. The sociocultural model is informed by sociocultural factors (see Chapters 5, 6, 7 and 8), and the model can effectively be used to manage dementia in the Black African population in the UK. Of course, 'lay expertise is a general stock of knowledge' (Wilcox, 2010, p. 45) or the 'body of knowledge' (Grundmann, 2017).

The public health and health promotion strategy fails to use the lay concepts of health and illness to address the consequences of inequalities, inequity, and poverty in dementia care in the community. Indeed, it limits community health 'enablement' and 'empowerment' (Rushford & Harvey, 2016; Morton-Chang et al., 2019). Although, the use of lay concepts of health and illness in understanding the meanings of dementia may lead to the manipulation of choices in dementia care in the community, which may play a meaningful role in the deterioration of public trust in medical doctors and the dementia community services. Nonetheless, social constructionism may ignore the contributions made by biomedical concepts to dementia even though the scientific consensus is that dementia is a complex outcome of both biological and sociocultural influences (Kumar & Clark, 2021; Kenigsberg et al., 2016; Alzheimer's Society, 2017). In addition, social identity theory can lead to prejudice (McLeod, 2019).

Interestingly, the dementia sociocultural model of community care suggests that dementia is a disability, unlike the medical model, and that disability is not an intrinsic characteristic of an individual, but an outcome produced by social processes (Angus & Bowen-Osborne, 2014; Rushford & Harvey, 2016; Shakespeare, 2019). Thus, dementia as a disability does not exist purely in the individual's brain pathology. Instead, it is a condition created by a combination of social and personal factors (Liden, 2017), including income, employment, age, language, education, transport, environment, housing, migration, and citizenship (Kelly & Innes, 2013; Brannelly, 2016). Therefore, dementia is a human rights and medical and social problem (Rushford & Harvey, 2016).

Moreover, the concepts of successful ageing in imbued in biomedicine. Thus, it could be vague and unclear (Martin et al., 2014; Carver & Buchanan, 2016; Urtamo et al., 2019) for laypeople and equally for the Black Africans living in London. Despite its inspirational elements, the visions offered by the concepts of successful ageing might be counterproductive (e.g., Lamb, 2014) for the Black Africans living in London because it can be perceived as discrimination against older age. Separating older age and the concept of successful ageing from the culture of the Black African populations in the UK is challenging. As such, the researcher did not apply the concepts of successful ageing in the current study. Nevertheless, interconnected with healthy ageing (WHO, 2020).

Finally, the conceptualisation of power-relationship suggested that power was 'relational' and 'productive' (Foucault, 1973, 1977). Consequently, it becomes a driving force in asserting dominance in dementia management in the Black African community in the UK. This underscores the need for equity and equality in dementia caregiving in the Black community in the UK. Again, to remind us, the current research questions are highlighted.

**Research questions**

1. What are the lay knowledge and beliefs towards dementia amongst Black African populations living in the UK?
2. What are the lay concepts of dementia, perceptions of dementia risk factors, and dementia help-seeking or attitudes amongst Black Africans living in the UK?
3. What is the dementia help-seeking and caregiving or treatment of people with dementia amongst the Black African populations living in the UK?

## Summary

This study localised the framework chapter within the discipline of medical sociology and medical anthropology within the path of public health and health promotion research. It drew its strength mainly from the sociological and anthropological lay concepts of health and illness and social constructionism. The chapter described, discussed, and explained the components of lay concepts of health and illness and social constructionism, focusing on lay concepts of dementia and the research questions. It explored how the theories are related and how they interact. Conceptualising the 'biopsychosocial-spiritual model' (Sulmasy, 2002), a medical and spiritual model. The principle of the biopsychosocial-spiritual model includes biological, psychological, spiritual, and social dimensions of the person with dementia with the understanding that the person with dementia is a whole person, not an isolated brain (Engel, 1977; McKee & Chappel, 1992; Vermette & Doolittle, 2022). The researcher reflected on the current study and saw the participants' narratives as knowledgeable and lay experts. He also noted that public health and health promotion are unique disciplines (Davis, 2013) because the new public health and health promotion have emerged alongside the traditional public health and preventative medicine disciplines. Health promotion relates closely to public health yet differs by strongly emphasising community and participants' autonomy in participating and empowering individuals and their communities (Davis, 2013). Therefore, public health and health promotion have concepts borrowed from major contributory disciplines of medical sociology, medical anthropology, medical psychology and medical education, and traditional public health and medicine.

In addition, the researcher argued that the use of the lay concepts of health and illness, based on evidence, suggested that laypeople are 'knowledgeable' (Segall & Robert, 1980; Hunt & McEwen, 1980) and laypeople can be 'lay experts' (Parsons & Atkinson, 1992; Popay et al., 1998; Tuner, 2001; Wilson, 2007) when they are provided with education and training. Thus, lay dementia knowledge can be expert knowledge (Britten & Maguire, 2015; Maslen & Lupton, 2019), and it is as valuable as medical expert knowledge (Popay & Williams, 1996; Turner, 2001). Indeed, Armstrong (1985) argued that modern medicine should not be privileged in epistemological and ontological positions above lay expert knowledge, as all forms of knowledge can be equal. Thus, the researchers suggested that lay expert knowledge of dementia can be as valuable as professional and biomedical knowledge of dementia in the management of dementia in the Black African community in the UK (Oborn et al., 2019). Indeed, 'there is no way of judging one account of reality as better than another' (Bury, 1986, p. 165). Therefore, this study argued that judging medical knowledge of dementia as better than lay knowledge of dementia could only lead to epistemic tension (Busby et al., 1997; Haw et al., 2018). Of course, Dupras and William-Jones (2012) argued the need for professionals such as doctors to accept the limits of their expertise and recognise the ability of laypeople to understand and contribute to their health and illness, such as in dementia management. *Lay expertise* is defined as a general stock of dementia knowledge or the body of dementia knowledge (Wilcox, 2010; Grundmann, 2017).

Furthermore, the chapter highlighted the strengths and drawbacks of using the lay concepts of health and illness and social constructionism. Still, the researcher argued for a balance in dementia care in the community by suggesting the need to balance lay expert knowledge of dementia and medical understanding of dementia. Both performances are considered necessary for dementia management in the Black African community in the UK. Moreover, the dementia sociocultural model of care suggests that dementia is a disability and brain impairment (Angus & Bowen-Osborne, 2014; Rushford & Harvey, 2016; Shakespeare, 2019). Therefore, the researcher argued that disability is not an intrinsic characteristic of an individual, but an outcome produced by social processes (Liden, 2017). Thus, dementia as a disability is not something that exists wholly at the level of the individual pathology, but a condition created by a combination of social and cultural factors, including age, gender, language, education, income, employment, transport, environment, housing, migration, status, and citizenship (Kelly & Innes, 2013; Brannelly, 2016). Therefore, this study added the sociocultural model for dementia management for the Black African community in the UK to the dementia services. The next chapter presents the methodology for the current study.

# Chapter 4

# Methodology

## Introduction

This chapter shows how the researcher collected the data and heard the voices of the laypeople from the Black African community in London. Therefore, this chapter sets out the research methodological approaches, including the research design, data collection methods, and analysis. The research design is the overall structure and plans that guide answering the research questions and identifying the data collection methods (Braun & Clarke, 2013; Barbour, 2014; Green & Thorogood, 2018; Mason, 2018). Research methods are the practices and techniques used to collect, process, and analyse the data (Gibbs, 2007; Braun &; Miles et al., 2014; Mason, 2018; Clarke, 2019). Therefore, in this chapter, the researcher considers the research methodology as the whole activity and the plans the study followed throughout the research process (Braun & Clarke, 2013; Barbour, 2014; Mason, 2018). Moreover, this chapter highlights the philosophical underpinning. It illuminates the research design, study site, recruitment process, sampling, data collection, ethical issues with considerations, data analysis, and the pilot study, and the researcher reflected on the study. First and foremost, the research aims and objectives are highlighted.

### Research aims:

- To explore lay knowledge and beliefs towards dementia amongst Black African populations living in the UK.

### Research objectives:

1. To use qualitative research methods to explore lay knowledge and beliefs towards dementia amongst Black African populations living in London.
2. To understand the lay concepts of dementia, perceptions of dementia risk factors, and dementia help-seeking or attitudes amongst Black Africans living in London.
3. To understand the dementia help-seeking and caregiving or treatment of people with dementia amongst the Black African populations living in London.

## Philosophical underpinning

The current research levels of theory were related to social constructionism and sociological and anthropological lay concepts of health and illness (see Chapter 3). The research theories were not about discovering the dementia reality or truth about dementia but how the ideas, views, and meanings of dementia were shaped. It showed how dementia was understood amongst the laypeople from the Black African community in London through their experiences, views, and ideas. It sheds light on how the laypeople from the Black African populations living in London perceive and assign significance to dementia, and how their knowledge and beliefs about dementia were constituted and constructed, which are notably influenced by their culture and affected their help-seeking behaviours. Therefore, the study's social constructionism theory was based on the philosophical notion that lay dementia knowledge and beliefs amongst Black Africans were socially constructed. That is, the idea that the dementia reality was created and shaped through social interactions, relationships, and experiences (Berger & Luckman, 1966; Gergen, 1996; Bosco et al., 2019; Rewerska-Jusko & Rejdak, 2020). Therefore, since the dementia reality was constructed, the lay dementia knowledge and meanings were derived and shaped from social interactions, culture, and understanding. Therefore, the Black Africans living in London could be seen constantly 'negotiating meaning' (Gergen, 1996, p. 119) about dementia. Hence their lay dementia knowledge and beliefs were not static but influenced by sociocultural factors.

The current study explored the lay knowledge and beliefs towards dementia amongst the Black African populations living in London. Therefore, the philosophical approaches to the current research were based on fundamental principles concerning epistemology and ontology, including the basic assumptions that constituted the philosophical underpinnings of the lay dementia knowledge centred on the current research questions. Hence, epistemology and ontology led to functional philosophical methodologies and constrained the appropriate methods for the current research (Braun & Clarke, 2013, 2019; Mason, 2018).

Indeed, epistemology in this research was based on the process of knowing dementia and how the participants knew what they knew about dementia (Guba & Lincoln, 2008). Therefore, epistemology informed the current study's ground of knowledge, which was about lay knowledge and beliefs towards dementia. It addressed the question of what was possible to know about the lay knowledge of dementia amongst Black Africans in the UK. From this point of view, the development of lay knowledge about dementia for the current research was characteristic of the current study's epistemological interpretivism/constructivism. Indeed, interpretivism/constructivism was associated with the philosophical positions of epistemological subjectivism and idealism, which included social constructionism. These approaches rejected the objectivist (objectivism) view that the meaning of dementia amongst Black Africans resided within the mind independently of human perception or consciousness. Thus, the epistemological idealism described and illuminated the metaphysical perspectives and suggested that the dementia reality amongst the participants was a mental construct and transcendental, closely connected to ideas such as holism involving spirituality and religion. Indeed, holism constituted spirit, body, and mind. This suggested that the lay dementia knowledge was intuitive and involved a cognitive process.

In this case, underpinned by social constructionism, the current study considered how the researcher gained and interpreted the lay knowledge about dementia that existed and was in a relationship with the respondents who identified as laypeople from the Black African community in London and were recruited from multiple church sites. On this hand, the lay knowledge about dementia was socially constructed by the participants without any power relationships but a mutual influence on one another and with the researcher. Thus, this study viewed the dynamic relationships between the respondents and the researcher as central to capturing the participants' inherent contextualised dementia ideas and experiences (Mason, 2018; Green & Thorogood, 2018; Braun & Clarke, 2019). Compared to the previous studies, relationships between the researchers and their participants were not adequately considered (see Table 4). Indeed, the participants' narratives and views drove the data for the current research. The researcher became immersed in the participants' experiences to credibly represent and interpret their lay knowledge and beliefs about the dementia phenomena. The researcher conducted the data analysis reflexively using thematic analysis (Braun & Clarke, 2013, 2019) utilising a grounded approach (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to ensure the participant voice and their ideas and meanings of dementia were foregrounded in the theoretical outcome. Therefore, this study's critical realism (idealism) showed that dementia knowledge was a social product, not independent of the participant's thoughts and intuitions. (Green & Thorogood, 2018).

On the other hand, ontology in the study was the philosophical position of the nature of dementia reality. Therefore, within the context of this qualitative research, the ontology was discussed in terms of beliefs about lay dementia reality. Also, within this context, there exists a lay dementia reality that was objective (objectivism) among Black Africans in the UK, one that was seemingly universal and consistent with their understanding of dementia in their countries of origin in West Africa. At the same time, the lay dementia reality was subjective (subjectivism) and real (realism) or contextual (contextualism). Therefore, the lay dementia knowledge and beliefs were understood within the contexts within which they were embedded (Hay & Singh, 2012), such as in the UK or Africa.

Moreover, the dementia viewpoints were represented in terms of emic and etic in understanding the dementia culture (Geertz, 1983). Furthermore, the ontological subjectivism in this study was the doctrine that the lay dementia reality was fluid and that there was no absolute or objective truth about dementia. Thus, the dementia phenomena were created from the perceptions and consequent actions of the participants as social actors concerned with their existence. Moreover, ontological subjectivism helped the researcher to understand the subjective dementia reality of the participants. Hence, the researcher understands their perspectives, views, and narratives truthfully (realism) and meaningfully (Braun & Clarke, 2019). Therefore, this study was broadened epistemologically and ontologically.

Functional epistemological and ontological approaches also encouraged different kinds of reflexivity (Braun & Clarke, 2013, 2019). Reflexivity was also a concept that the researcher used to explore and deal with the relationship between the participants and himself (Braun & Clarke, 2019). Reflection meant thinking about the conditions for what the researcher was doing and investigating how his intellectual background as a medical doctor and applied medical anthropologist and his cultural background as a Black African living in Southeast London affected his interactions with the respondents and the dementia research (Braun & Clarke, 2013, 2019).

## Research design

The study is qualitatively designed to obtain empirical data by interviewing the respondents to answer the research question. Thus, the research design can be defined as the methodological procedure or plan that the researcher used in answering the established research questions through data collection, analysis, interpretation, and discussion (Barbour, 2007; Boeije, 2010; Braun & Clarke, 2013; Grbich, 2013; Barbour, 2014; Miles et al., 2014; Mason, 2018). The methodology was the plan for how the research combined methods and theory informed by the researcher's philosophical beliefs guiding the qualitative research design (Denzin & Lincoln, 2018).

Therefore, qualitative design was primarily used to collect the empirical data, describe, interpret, contextualise, and gain in-depth insights into the dementia phenomenon amongst Black Africans in the UK. Generally, a qualitative approach explores subjective experiences, beliefs, and concepts and could be used to gain in-depth knowledge of context or culture and generate new ideas (Braun & Clarke, 2013, 2019; Barbour, 2014; Mason, 2018). Indeed, the qualitative design used in the current research offered rich and compelling insights into the dementia ideas, narratives, views, experiences, and culture and provided context and the perspectives of families, relatives, and friends of those affected with dementia in the Black community in London.

Usually, qualitative designs are more flexible and inductive (Braun & Clarke, 2013, 2019, 2014; Mason, 2018). Nevertheless, the designs of studies would depend on the epistemological and ontological positions of the researcher, usually shaped by the disciplinary area of the researcher (Wright et al., 2016; Tobi et al., 2018). From this standpoint, social constructionism and sociological and anthropological lay concepts of health and illness underpin the current study (see Chapter 3). However, this study is situated in the discipline of public health and health promotion and is unique (Davies, 2013). The epistemological and ontological concepts in the current study are borrowed from significant disciplines. Therefore, the qualitative research design for the current study can be considered the methodological framework the researcher created to answer the research question based on his beliefs and the functional epistemological and ontological stance (Braun & Clarke, 2013, 2019), which defines the methods of the data collection and analysis, from the semi-structured interviews through to transcribing, data coding, interpretation of findings, and discussion.

The qualitative methodology was appropriate and was accurately used to produce the lay knowledge and beliefs about dementia amongst the Black African populations living in the UK. The qualitative research in the current study was centred on delving into the ideas and meanings associated with dementia. Consequently, it focused on the realm of lived experiences, as this is where the collective and individual dementia beliefs and behaviours intersected with culture (Denzin & Lincoln, 2018). Therefore, the qualitative research consisted of a set of material practices; for example, the interpretative and constructionist methods made the lay knowledge and beliefs about dementia visible. Thus, the researcher better understands the lay representations and complexities of the dementia phenomenon.

Furthermore, the qualitative methods positioned the researcher in the study and situated his research activities as a part of the research instrument (Braun & Clarke, 2013, 2019; Glaser & Strauss, 1967; Strauss & Corbin, 1994). Indeed, the researcher was a part of the current study's research instruments. The qualitative research methodological bricoleur was adept and enabled the researcher to perform several tasks between and within competing, overlapping perspectives and paradigms ranging from data collection to analysis, coding, and interpretation. The methodological procedure showcased rigour and provided the qualitative evaluation criterion: credibility, transferability, dependability, confirmability, and trustworthiness (Lincoln & Guba, 1985; Lincoln et al., 2011), and intensive self-reflection and introspection (Weinstein & Weinstein, 1991; Nelson et al., 1992; Seale et al., 2004). Thus, the researcher discovered that the lay dementia knowledge and beliefs were a sequence of representations connecting the parts of dementia to the physical, metaphysical, and community. Thus, the qualitative design was holistic and met the rationale for its use in the current study.

### The rationale for qualitative research

The researcher chose qualitative research based on the assumptions that qualitative research focuses on making sense of dementia 'lived' experiences, an observable phenomenon in a specific context with specifically selected individuals, rather than attempting to generalise from the sample to the population (Braun & Clarke, 2013, 2019; Barbour, 2014; Mason, 2018). Thus, the researcher ideally subscribes to a reflexive, relational, dialogic, embodied, and collaborative research process grounded in interpretative social science (Denzin & Lincoln, 2018; Leavy, 2020).

Indeed, qualitative research has a wide range of approaches, tools, and values that guide the qualitative study. It is a rich, evolving tradition with innumerable knowledge-building and sharing possibilities (Denzin & Lincoln, 2018; Braun & Clarke, 2019; Leavy, 2020). Thus, the researcher uses qualitative research to constitute and construct lay knowledge and beliefs amongst Black Africans. Indeed, the researcher considered qualitative research a bricolage or craft (Denzin & Lincoln, 2018; Braun & Clarke, 2019; Leavy, 2020).

Therefore, qualitative research helps the researcher to build a meaningful relationship between the laypeople from the Black African community in London and himself, facilitating a better understanding of their lay knowledge and beliefs about dementia as an inquiry (Denzin & Lincoln, 2018). The researcher spent a long time in the field collecting rich data.

Moreover, the primary driver for selecting the qualitative rather than quantitative research design was its methodological reliability and theoretical disposition on the topic of study (Mason, 2018). Of course, qualitative methods are highly flexible, malleable, and versatile and require a smaller sample size and nonmeasurable data, unlike quantitative research on the study. Indeed, the researcher perceived the malleability of the qualitative approach as a strength in knowledge production (Green & Thorogood, 2018).

More so, participants, as coresearchers, were allowed to express their views freely (Braun & Clarke, 2019) rather than tick a box. Indeed, the current study involves the emotionality and subjectivity of the participants and the researcher (Braun & Clarke, 2014). Nevertheless, a quantitative design would primarily deal with more extensive numerical data, a larger sample size, and the relationships between attributes rather than respondents' subjectivity (Curtis & Drennan, 2013), perhaps to establish facts rather than subjective ideas or feelings. Thus, quantitative research is primarily used to test hypotheses regarding relationships between different variables and usually starts with a theory. Moreover, quantitative research adopts positivist and objectivist paradigms and involves collecting and analysing highly structured data. It is usually based on rules and logic, requiring more significant numbers to deliver measurable facts that could be analysed statistically and provide generalisation (Curtis & Drennan, 2013), which is optional for qualitative research. Hence, quantitative research is most appropriate in situations with preexisting knowledge, permitting the use of standardised data collection methods, such as surveys, questionnaires, experiments, and deductive reasoning (Creswell, 2009, 2013). However, it is not primarily used to explore dementia meanings, ideas, experiences, and feelings. Thus, its approaches are not appropriate for the current study.

Therefore, qualitative research is the best fit for the current study on the dementia phenomenon, which is required to explore the lay knowledge and beliefs towards dementia amongst the Black African populations in the UK. The qualitative research methodology is in line with the research's epistemological position. Therefore, as adopted, qualitative research can be defined as a process of understanding the interactions of the dementia phenomenon in its context. Qualitative research considers context and is a method of naturalistic inquiry that is usually less obstructive and does not manipulate a research setting (Bryman, 2012). Thus, the current study aimed to study the Black Africans in their natural social settings in London and to collect naturally occurring data. Indeed, it aims to understand the individual's viewpoints without making value judgments during data collection nor allowing the researcher's voice to dominate the voice of the participants (Bowling, 2018). Hence, the researcher's reflexivity supported his functional and philosophical perspectives, a way of doing or acting within the context of research from start to finish (Glaser & Strauss, 1967; Strauss & Corbin, 1994; Braun & Clarke, 2019).

Using qualitative research methodology provided a more general understanding through the analysis of the interviews, which illuminated the Black Africans' ideas, experiences, views, and perceptions of the dementia phenomenon in their own words (Braun & Clarke, 2013, 2019). Therefore, this qualitative research adopted a contextual approach with an inductive orientation, aligned with the interpretative paradigm. Indeed, the qualitative research favoured interactions, feelings, and experiences of the Black African people through open-ended and subjective questions, enabling the researcher to acquire a large amount of information on the dementia phenomenon from the 31 Black African respondents living in London whom the researcher interviewed. Moreover, the qualitative design allowed the researcher to engage in several processes to ensure that the qualitative research was conducted rigorously, which included being honest about his theoretical perspective and values from the outset and that the methodological possibilities were rich (Leavy, 2020).

Furthermore, the review of the UK qualitative studies (n=9) showed that the previous qualitative studies were multi-modelling of ethnicity in the research, and using the platform for evaluating qualitative research (EQR) shows that the studies were lacking in philosophical and methodological validity (Crewell, 2013; Schwandt, 2002; Seale, 1999; Lather, 1986; Lincoln & Guba, 1985). For example, in epistemological concepts (Lather, 1986), perhaps, the authors did not report them. The previous data did not separate the findings of the Black Africans from the Caribbean people. Hence, the results were not compelling, and the researcher could not make reliable conclusions about the Black Africans' lay knowledge and beliefs about dementia; therefore, the studies lacked credibility. Furthermore, the study's findings need to be updated and more dependable. Moreover, the previous studies should have highlighted the researcher's positionality with their participants and the study (see Table 4). Hence, the researcher judged the previous studies as lacking in trustworthiness by using Lincoln & Guba's (1985) discourse on trustworthiness and concluded on a need for further study in the UK using a qualitative research paradigm.

### Quality indicators for qualitative research

The indicators of rigour and quality suggested best practices for qualitative research design as they related to the steps of designing, conducting, and reporting qualitative research (Johnson et al., 2020) and were essential in the current dementia study. Indeed, the researcher used Lincoln & Guba's (1985) discourse on trustworthiness criteria as the guideline for quality indicators in the current qualitative research. The criterion has been generally accepted as the platform for evaluating qualitative research (EOR) and assisted the researcher in judging the quality of the current research. It offered sufficient flexibility to accommodate the diverse approaches and multiple interpretive best practice methods for achieving the study's quality, rigour, and trustworthiness within the qualitative paradigm (Lincoln & Guba, 1985; Lincoln & Guba, 1994; Lincoln et al., 2011). They continue to advocate for five key concepts that can be used to assess the quality of qualitative research:

1. Credibility
2. Transferability
3. Dependability
4. Confirmability
5. Authenticity

To achieve quality and rigour through credibility and authenticity, the researcher ensured that all the elements that allowed others to recognise the ideas, views, experiences, and meanings of dementia were contained within this study through the researcher's interpretation of the data and by showcasing the participants' narratives and views in their own words. Thus, to achieve authenticity in the study, the researcher had to pounder on the following questions:

- Does the study represent a fair range of differing viewpoints on dementia amongst the Black African population in the UK?
- Do the findings have a transformative potential in dementia practice in the UK?
- Is there a community consensus amongst the Black African population and medical doctors that the findings are 'useful and have meaning for action and further steps' that could be applied in dementia services in the UK (Lincoln et al., 2011, p. 116)?

Therefore, member checking (Brit et al., 2016) was used to inquire about apparent authenticity amongst the Black African population in the UK (Lincoln & Guba, 1994; Lincoln et al., 2011). Indeed, the researcher ensured that members checked the transcripts for accuracy and were represented by the data. The member checking involved returning the transcripts to the participants to ensure that the interpretations of the data accurately represented their views and ideas about the dementia phenomenon. As such, the process further ensured the researcher prolonged engagement with the data and the participants in the field.

Furthermore, the researcher's supervisory team checked the data, and their advice added value, rigour, and quality to the data analysis. It further ensured that the findings were relevant and met the study's aim because it was essential to ensure that other members of the community, 'the end-user' (Lincoln et al., 2011, p. 116), such as medical doctors, can use the study's findings to change their dementia practice. Therefore, the researcher shared the results with Public Health Registrars in London during his mentorship programme with the UK's Faculty of Public Health. Regardless, the researcher excluded doctors and health practitioners from the study, but they were helpful as the end-user.

More so, the researcher used a 'rich' and 'thick' description to provide detailed contextual information, which could judge the ability to transfer the study's findings from one group to another. Therefore, this study provided rich data and context to ensure possible transferability. Indeed, the transfer of lay dementia knowledge and beliefs can occur if both contexts are similar. In addition, the researcher ensured that the data was dependable and transparent by describing the research process in sufficient detail to allow for any study replication. As such, the supervisory team provided good advice on the data analysis process, which added rigour and quality to the study, ensuring that the decision trail in the analysis process was dependable and could be replicated by others. Nevertheless, the researcher was more interested in transparency and less in replicability in qualitative research (Aguinis & Solarino, 2019).

In addition, the researcher ensured confirmability by being self-critical and reflexive about how his own background and preconceptions affecting the research. He ensured that the results were based on and reflective of the information gathered from the participant and not his own interpretations (Johnson et al., 2020). Indeed, he employed confessional and realist tales in his writings and memos (Van Maanen, 1988). Moreover, the researcher conducted a pilot study to ensure he was better prepared, informed, and prepared to face any difficulties that could arise in the study. Indeed, it added quality and rigour to the current study. The salience of the methods and qualitative quality indicator adopted from Lincoln & Guba's (1985) discourse on trustworthiness criteria as the guideline for the evaluation in this study is further discussed (see Chapter 9).

Nevertheless, each qualitative research tradition has its own rationale for quality consideration (Creswell, 2006). For example, others have criticised the trustworthiness criteria (Schwandt, 2002; Seale, 1999). Some have used validity as a broad epistemological concept to justify qualitative inquiry (Lather, 1986) and can also include the provision of a clear rationale for sampling, determination of data saturation, and ethics in research design. Indeed, the researcher's conceptual framework (see Chapter 3), the literature review (see Chapter 2), and ethical conduct referred to his moral principles and values. They were part of the current research process and helped the researcher to guide and justify his methodological decisions, which was critical to achieving rigour and quality in the research.

Nevertheless, other researchers have suggested best practice guidelines for evaluating qualitative research (Anderson, 2010). Some have advocated for a checklist or strict criteria (Wu et al., 2016). EQR is evolving because choosing a set of evaluative criteria is socially constructed and politically driven (Leavy, 2020). Nonetheless, as the researcher has used in the current study, most qualitative research attempts to adopt trustworthiness discourse as validity or trustworthiness (Lincoln & Guba, 1985; Lincoln & Guba, 1994; Lincoln et al., 2011). Although, recently, some qualitative researchers have provided a categorical format of EQR (Leavy, 2020).

Moreover, the researcher ensured a 'thick' and 'rich' data description. He provided comparative and reflexive analysis to achieve data saturation in the current study, a common standard for rigour and quality in data collection in qualitative research (Braun & Clarke, 2013, 2019; Glaser & Strauss, 1967; Strauss & Corbin, 1994).

### Research refining process

The research questions and interview protocols, such as the interview guide and vignette, were modified and refined based on the review process, concurrent data collection, and analysis. Indeed, the research questions were generated from the literature review and theoretical framework chapters. The development of the interview guide is discussed in the pilot study. The researcher used the refining process to refine and focus the research questions, aims, and objectives, as well as the protocol, the interview guide, and the vignette through a continuing inquiry process. The vignette was adopted and modified to fit the research questions, aims, and objectives. In addition, his supervisory team reviewed and provided advice on the protocol and how the vignette could add quality to the research. For example, they advised adding a question about the vignette as the first question on the interview guide (see Appendix 1) since the participants' thoughts would enrich the inquiry:

> *Question I: What are your thoughts about the vignette?*

The supervisory team continued to critique the study methods, including the interview guide and the pilot study, to improve the study's rigour and quality. As a result, a few questions were modified to improve the protocol; for example, the question on theme six exploring dementia treatment and caregiving was slightly modified from 'elderly' to 'older person':

> *Question 6: Who is the main person likely to take care of the* ***elderly*** *in the family?*
> *Question 6 (modified): Who is the main person likely to take care of* ***older person*** *or the person with dementia in the family?*

Furthermore, the section on the pilot study discussed the development of the study's interview guide. The development of the qualitative semi-structured interview guide contributed to the research's objectivity and trustworthiness, making the study's result more plausible (Kallio et al., 2016). Nonetheless, some examples of the question in the protocol are included (see appendix 1):

> *Question: What do you know about dementia?*
> *Question: What are your beliefs towards dementia?*
> *Question: Tell me about your experience with dementia.*

In addition, the supervisory team thoroughly validated the codes and coding audit trail, emerging themes, and the study conclusion to check on the current research bias by actively seeking out and scrutinising data that did not fit nor support the researcher's interpretations of the data. This is a part of the debriefing process in this study. In addition, the supervisory team reviewed the chapters and provided feedback on the conclusions generated from the study's results (Chapters 5, 6, 7 and 8). The team's feedback enhanced the current research and the study's conceptual framework. Furthermore, the present study added witchcraft and sociocultural model to the literature (see discussion Chapter 9). Indeed, the refining process added value, rigour, and quality to the current study.

### Study site: Church

This study was conducted in churches in London but primarily used online platforms due to the increased spread of coronavirus in England. Therefore, the researcher avoided face-to-face contact with participants to achieve a secure COVID-19 environment. Thus, the online platforms complied with the government's legal restrictions and legislation on social distancing in England during the COVID-19 pandemic. The researcher collected data from 6 March 2021 to 3 October 2021 and selected participants from multiple church sites in the Black community in London.

## Recruitment

The current study recruited participants from two church sites in London by contacting the gatekeepers who were the leading pastors of the churches to seek consent, request access, and obtain letters to access members of the churches. The researcher invited potential participants using a research poster (see Appendix 4). The pastors advertised and circulated the research poster to members so they could contact the researcher voluntarily for further information. The researcher sent an electronic copy of the invitation letter and participant information sheet (PIS) to each potential participant who got him. Those interested contacted the researcher, and those not interested in the research did not bother to contact him.

However, most participants made contact by telephone, and all the participants that made contact and met the inclusion criteria were enrolled and interviewed. The researcher asked those that contacted him to enrol in the study if they wished and informed the potential participants that the research was voluntary and independent of their churches. Refusal or withdrawal from the research will not involve a penalty or affect their attendance at church services or worships, now or in the future. The study was independent of the churches. The researcher informed the participants that they could withdraw from the study before the start of data analysis without any reason or consequences. He also told all the participants that the interviews were online and gained their consent to participate in the study via their online platforms (the online platform each person chose).

The enrolled participants verbally signed a consent form (see Appendix 5) and were recorded at the interviews. The church's estimated population was about 350 members. Therefore, the researcher asked the enrolled participants to tell others about the study if they wished. Referred participants interested in the study contacted the researcher directly for further information. The researcher sent the electronic copy of the invitation letter (see Appendix 7) and participant information sheet (see Appendix 6) to each referred participant who made contact. He asked them to enrol in the study if they wished. A total of 31 respondents contacted him, all participated in the study, and none withdrew from the research. The researcher did not request participants' contact details except those who asked for a summary of the findings.

## Sampling

The current research targeted Black African populations in London, men and women, and adults aged 20 to 85. Indeed, 31 men and women participants participated in the study, including 14 women and 17 men, adults aged 20 to 79 years. Many participants were aged 30 to 59, but most were aged 40 to 59, and a few were aged 60 to 79. The aged 70 and above are a lesser number of the participants. None of the participants was above age 79 or below age 20. The median of each age range was used in the analysis (see Appendix 10B). Thus, the study utilised constant comparative analysis to ensure a relatively consistent sample size for both males and females and data saturation. The participants' names were anonymised, as shown in the table (see Appendix 10B). All participants are first-generation immigrants from West Africa and identified as laypersons from the Black African community in London and were churchgoers (see Chapter 5).

The researcher interviewed all the participants, comprising 31 laypeople from the Black African community in London. They were from different social classes, including various occupations (see Appendix 10B). This helped to ensure adequate data from the study to establish a robust and valid understanding of dementia and achieve saturation in themes (Braun & Clarke, 2013; Mason, 2018). Nevertheless, this study excluded people within the field of medicine, such as doctors, nurses, pharmacists, and paramedics, from the interviews. Regardless, no medical doctors came forward for the interview because the researcher indicated in the participant information sheet (PIS) that health professionals were not expected to participate in the research (see Appendix 6). The participants were not people with dementia (PWD). However, most respondents had experiences with persons with dementia; for example, most of the participants were carers (see Chapter 5 and Appendix 10B).

Thus, the study adopted purposive sampling methods (Braun & Clarke, 2013; Mason, 2018). A purposive sample is considered a non-probability sample that is selected based on the characteristics of the population (Braun & Clarke, 2013). The use of purposive sampling ensured that the current study achieved the research objectives and answered the research questions. Thus, the purposive sampling employed in the study provided heterogeneous and homogenous purposive samples. Heterogeneity samplings in age, sex, levels of education, and occupation of the participants helped the researcher to interview as many kinds of Black Africans as possible. The homogeneity sample was created based on religion, race and ethnicity, and the participants were only Black African populations living in London.

Therefore, employing heterogeneous and homogenous samples helped the researcher construct robust and valid views about dementia from the participants' perspectives. Indeed, the researcher provided 'thick' and 'rich' descriptions of the enrolled participants (see Chapter 5 and Appendix 10B) and included inclusion and exclusion criteria for the study.

### Data collection

Using a grounded theory approach, the researcher employed a critical principal data collection method (Braun & Clarke, 2013, 2019). The data collection and analysis were ongoing and simultaneous (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Therefore, the data collection was iterative (Miles et al., 2014; Braun & Clarke, 2019; Mason, 2018), and the researcher used a vignette and semi-structured interviews to collect the 'rich' data. Indeed, the researcher conducted the first interview, followed by subsequent interviews. The data analysis collected from the interviews proceeded alongside subsequent reflections and discussions, which subsequently informed the following consultations on the data collection (please refer to Figure 2). Therefore, the data collection and analysis were simultaneous and comparative (Braun & Clarke, 2013, 2019). The researcher employed a cyclical process in refining and tweaking subsequent interviews for data saturation.

Alternatively, the researcher considered the use of a focus group for data collection, which was a standard methodology for qualitative design (Braun & Clark, 2013) and would have been a faster and more effective way to elicit dementia knowledge and beliefs from the perspectives of a variety of Black African populations in the UK simultaneously (Miles et al., 2014; Braun & Clarke, 2019; Mason, 2018). It would have offered an in-depth understanding of the participant's knowledge and beliefs about the dementia phenomenon. The researcher would have more effectively observed their group dynamics and human interaction, such as body language (Miles et al., 2014; Braun & Clarke, 2019; Mason, 2018). However, in comparison with the individual interviews, there was a possibility that members may not express their honest and personal opinions about the dementia phenomenon because some of their dementia beliefs may oppose the views of another participant, or some participants may be shy to speak up (Miles et al., 2014; Braun & Clarke, 2019; Mason, 2018). Moreover, as the moderator, the researcher could significantly impact the outcome of the focus group discussion, which could be intentional or inadvertent (Miles et al., 2014; Braun & Clarke, 2019; Mason, 2018). Moreover, focus groups are much more expensive, and engaging a large group online would have been challenging. In addition, the data analysis would have been time-consuming for the current study (Miles et al., 2014; Braun & Clarke, 2019; Mason, 2018).

**Topic sensitivity**

The researcher found dementia a sensitive topic for discussion for himself and others, particularly for those respondents who have experienced the illness or knew someone with dementia. The dementia study was a sensitive topic that the researcher considered carefully, factored a few extra things into planning the research protocol, and emotionally protected himself and the participants. The ethical and moral responsibility was to protect the participants and the researcher from unwanted emotions; ethics and morality played a central role in the process. Firstly, the researcher started by ensuring he was in the right frame of mind for the study. The researcher ensured that he was not exhausted and overwhelmed by the dementia topic, as it would have made it harder for the participants to concentrate and talk freely and openly. Thus, the researcher ensured he was comfortable and settled within himself, which enabled the researcher to build rapport with the participant and subsequently made them equally calm, relaxed, and able to talk openly and freely.

Secondly, the researcher considered what might occur before, during and after the interviews, as dementia was a sensitive and distressful topic for discussion in which respondents could become upset or angry. Therefore, the researcher was conscientious throughout the research process by ensuring he did less than four interviews in a row. The researcher also left a few days between research interviews to reflect on what he had heard and ensure he could take the next rounds of interviews.

The next stage was moving the focus away from himself to the participants by being attentive and sensitive to their needs during and after the interviews. Indeed, the qualitative research design allowed for flexibility in the process. It allowed for exploratory and explanatory perspectives (Braun & Clarke, 2019; Mason, 2018; Bryman, 2012) that put the respondents in charge of their views and narrative without being pressured to say anything they did not want to. Thus, the design facilitated the process of acceptance and trust. For example, the respondent consented to participate in the study before the start of the interviews. The researcher’s communication with the participants was culturally sensitive. He used the vignette to favour a gradual entry that allowed the respondent’s feeling of intrusion to be managed socioculturally, thus generating a relationship of trust between the participants and himself. The researcher ensured he consciously and carefully constructed the vignette and adapted it from the literature

(Uppal et al. 2014, p. 404). It was used to mitigate the power dynamic in the study between the researcher and the participants in the discussion, and it shows that they were both involved in the co-construction of dementia knowledge or knowledge creation. The vignette was ethically robust and explicit and was reviewed by the supervisory team.

In addition, the researcher used the participant information sheet (PIS) to inform the participants that the discussion of dementia may potentially cause distress during the interviews (see Appendix 6), so the researcher encouraged the respondents to speak to their GP for advice before any of the discussions. He also offered the participants the possibility of withdrawing from the research if they considered it upsetting, and the researcher provided a list of local counselling resources for helpful advice. Hence, the approach guaranteed informed consent and encouraged the active participation of the respondents in the study. All the participants were emotionally stable except for one of the respondents that became a bit emotional. Still, the researcher offered to stop the interview, but the participant wanted to continue, and he spoke freely for the rest of the interviews without any intervention. At the end of the interview, the researcher asked the respondent how the interview made him feel as a way of debriefing, and he responded that he felt good and was fine.

However, the researcher did not create a debriefing protocol for the research interviews. Nonetheless, at the end of each interview, the researcher turned off the recorder and inquired about the participant's well-being and if there were any issues they wanted to discuss. All participants reported feeling well and exchanged pleasantries by saying goodbye. After the interview, the researcher sent a WhatsApp attachment to each participant, providing a list of local counselling resources that may be helpful for advice and support if needed. The researcher ensured the well-being of the interviewees by conducting a follow-up telephone call. All participants reported positive emotions. However, future studies require an ethics committee-approved debriefing protocol due to the emotional nature of discussing dementia.

### Interviews

Individual semi-structured interviews were conducted remotely via Zoom, WhatsApp, Facebook, Skype, and telephone, depending on the participant's preference. The researcher informed all the participants that the interviews were online and gained their consent to take part in the study (Mason, 2018) via the online platform that was convenient for them. Before any interview meetings, participants were provided with an electronic copy of the participant information sheet (PIS) and must sign a consent form during the interviews. The researcher interviewed male and female adults and used comparative methods until the study achieved data saturation. For example, the researcher interviewed people from various occupations and adults of different ages to ensure the current study developed adequate data to establish a robust and valid understanding of dementia and achieve data saturation. Thus, the researcher conducted 31 interviews. Each interview lasted for about 35 minutes to an hour maximum. The researcher introduced the research topic and read the vignette (see Appendix 2) at the start of the discussions. The interviewees had no access to the vignette in advance (the researcher only read the vignette at the beginning of each interview). The study discussed earlier the development and refining of the interview guide and vignette, and using the vignette provided an equal standard for all the participants during the discussions. Indeed, the researcher would use it repeatedly if he had to co-construct knowledge about dementia with the community and mitigate the power dynamic between the researcher and participants (Charmaz, 2006). More importantly, it was culturally sensitive, and all the respondents understood the vignette and responded accordingly. The researcher used the interview guide (see Appendix 1) to guide the discussions. The interviews were recorded and transcribed verbatim. The transcripts were checked with members (Birt et al., 2016) for interpretative accuracy and to explore the credibility of the findings (Lincoln & Guba, 1994; Lincoln et al., 2011). Meanwhile, the inclusion and exclusion criteria for the study are highlighted.

**Inclusion criteria:**

- Black Africans
- Christians/Churchgoers
- Aged 20 to 85 years old
- Male and female
- Able to speak English
- No hearing impairment (in order to participate in the interview without difficulty)
- Capacity to make a valid decision
- Compliance with online ‘terms of use’

**Exclusion criteria:**

- Non-Black Africans
- Non-Christians/Non-Churchgoers
- Aged less than 20 and aged above 85 years

- Limited capacity with English
- Significant hearing impairment
- Lack of capacity to make a valid decision
- Registered health professionals in the UK (e.g., doctors, nurses, pharmacists, and paramedics)
- Non-compliance with online ‘terms of use.’

### Ethical considerations

The study sought ethical approval from the College of Health, Medicine and Life Sciences Research Ethics Committee, Brunel University London. The Ethics committee authorised the research to proceed (see Appendix 8). Approval was granted for the study to be carried out between 1 December 2020 and 1 September 2022 with the reference number: 25440-MHR-Dec/2020-28887-2. Ethical issues bridged the current research philosophical and praxis aspects (Leavy, 2020). It is also linked to the current research ontological, epistemological, and functional imperatives. Thus, the researcher considered the study’s methodological issues and critical ethical questions: What are the possible benefits to subjects, society, and the research community? Would others manipulate the research to the detriment of the subjects and their community? What might be the psychological effect on the participants? Would the research findings be fed back to the community?

In the UK, the role of ethics is primarily to consider the interests of the research participants and ensure that the relevant codes of practice are upheld. The general ethical principle governing research is that participants must not be harmed due to their participation in the research and must give informed consent to participate. Therefore, the current study was governed by the foundational norms of research ethics: beneficence, respect for persons, and justice (BSA, 2017), which involved informed consent, assessment of risks and benefits, and selection of subjects. However, the research design did not anticipate any safeguarding concerns and did not stipulate measures to manage them (see Reflexivity).

Nevertheless, the researcher informed the participants that he would disseminate the positive and negative evidence through conferences and journal publications. The researcher anonymised all names; the participants’ actual names would not appear in the thesis or publications. The researcher would store the data for ten years post-research publication and protect it under the UK Data Protection Act 2018. The Data Protection Act 2018 is the UK’s

General Data Protection Regulation (GDPR) implementation. Confidentiality also allowed each participant to be identified by pseudonyms rather than real names. The researcher also removed all the information that could identify the participants (Barbour, 2007; Braun & Clarke, 2013; Barbour, 2014; Mason, 2018). The researcher developed a rapport with the participants, nurtured and monitored relationships with participants and altered patterns of interaction as deemed necessary to ensure the highest level of mutual respect and dignity (Adams et al., 2015).

### Ethical consideration of incentives as payment for time

The researcher acted ethically within a value system to compensate respondents for their time. The researcher offered a £10 Amazon voucher to each participant that participated in the study as a reimbursement for their time. The researcher considered key ethical questions concerning the incentives and concluded that the motivation was reasonable, not coercive, and did not undermine respondents' voluntary consent. However, a few participants rejected the offer. Still, they participated in the study.

### Ethical checklist for the online interviews

The researcher believes in 'relational ethics' (Ellis, 2007). Thus, he adapted Gelinas et al.'s (2017) ethical checklist on issues and recommendations for the online interviews to ensure effective rapport and ethical relationships with the participants during the discussions. The adapted checklist primarily deals with privacy, confidentiality, transparency, anonymity, risk, and harm. Hence, the researcher guarantee the following:

1. Privacy: The researcher must handle personal information responsibly, even if it has been made widely available online by minimising individuals suffering embarrassment, loss of dignity, or other harm.
2. Confidentiality: The researcher must not disclose sensitive information to others without the participant's explicit permission or engage in online communication that will allow others to infer sensitive information about participants or potential participants, even if that information has already been made public in a different context.
3. Harm and risk: The researcher must be mindful of the values and potential vulnerabilities of those approached online and ensure online communication are not offensive or insufficiently sensitive to their condition.

4. Transparency: The researcher must be truthful and honest when interacting with research participants to promote trust
5. Truth and honesty: The researcher must be truthful in recruitment activity and honest when describing the study aims, details, risks, and benefits. Therefore, the researcher ensured to use of a user-friendly PIS.
6. Access: The researcher must ask explicit permission from the gatekeepers and will not fabricate a false identity.
7. Informed consent: The researcher must seek to obtain informed consent using a consent form.
8. Anonymity: The researcher must ensure all data is anonymised and remove all identifying data before publication.
9. The researcher must actively consider other ethical issues associated with the online policies and ‘terms of use’, such as email, WhatsApp, Facebook, and Zoom terms of services.
10. The researcher must not recruit from the networks of participants without permission and informed consent.
11. The researcher must manage online communications from and between participants in a way not to cause risk and harm to others.
12. Participants must have the capacity to make a valid decision to participate in the study.

### Data analysis

The procedure for the study adopted thematic analysis (Braun & Clarke, 2013, 2014) informed by a grounded theory approach (Glaser & Strauss, 1967; Strauss & Corbin, 1998), which was drawn upon in the coding and analysis of the data thematically. Coding in qualitative research could be confusing with themes. Grbich (2013) identified coding as a process of grouping and labelling data to make it more manageable for a display and to provide answers to the research questions (Grbich, 2013, p. 259). Functionally, Braun and Clarke (2013) considered coding to identify aspects of the data relating to the research questions (Braun & Clarke, 2013, p. 206). However, Saldana (2013) thought of coding as a thematic analysis. Therefore, coding and thematic analysis have inclined to be represented separately, sequentially, or with coding preceding thematic analysis (Grbich, 2013, p. 260).

Nonetheless, Mason (2018) considered codes as thematic, descriptive, conceptual, axial, interpretive, and analytic, which could be hierarchical, loose, rough, or open (Mason, 2018, p.

194). Similarly, Miles et al. (2014) considered codes as labels that assign symbolic meaning to the descriptive or inferential information compiled during a study (Miles et al., 2014, p. 72). However, Boeije (2010) considered coding a tool to create order (Boeije, 2010, p. 94). Therefore, coding means categorising data segments with a short name that simultaneously summarises and provides accounts for each piece of data. Hence, codes are primarily, but not exclusively, used to retrieve and categorise similar data chunks so that the researcher can quickly find or pull out the segments relating to the research question (Mile et al., 2014, p. 72).

By and large, thematic analysis is a process for identifying themes and patterns or meanings across the dataset concerning the research questions (Braun & Clarke, 2013, p. 175). The thematic analysis could be flexible; however, it does not prescribe methods for data collection, theoretical positions, or epistemological and ontological frameworks (Braun & Clarke, 2013, p. 198). Regardless, the current study used thematic analysis to develop a detailed descriptive account of the dementia phenomenon, as well as a constructionist analysis which identified the concepts and ideas that underpin the explicit data contents or the assumptions, beliefs, or meanings of dementia in the data set (Braun & Clarke, 2013, 2014). These analytical approaches were employed, with all due respect to the terminological confusion regarding thematic analysis, whether it is considered as coding or as a combination of thematic analysis and coding. In the current study, the researcher comprehensively considered thematic analysis as a data reduction process (Glaser & Strauss, 1967; Strauss & Corbin, 1994) (Please refer to Figure 1). Indeed, it is one of the leading data analytical options in qualitative research (Grbich, 2013, p. 61), which involves (i) open coding, (ii) focus coding, (iii) categorising, and (iv) thematic coding.

Hence, the researcher started the coding by familiarising himself with the qualitative data (interviews) collected. That is, familiarising himself with the interview transcripts. The process involved literal, interpretative, and reflexive readings of the data generated (Barbour, 2007; Boeije, 2010; Braun & Clarke, 2013; Grbich, 2013; Barbour, 2014; Miles et al., 2014; Mason, 2018). The interview transcripts were verbatim transcriptions. The researcher was interested in the words and language used, what the data means or is inferred, and his interaction with the participants as a part of the data generated. Indeed, an essential part of the data collection was to capture how the participants expressed themselves verbally and nonverbally (Barbour, 2007; Braun & Clarke, 2013; Barbour, 2014; Mason, 2018). More importantly, the data coding and analysis were driven by the participant’s views and narratives. Notwithstanding, as a social researcher, the researcher sees himself inextricably implicated in data generation and interpretation.

Indeed, after conducting the interviews, the researcher transcribed each of the interviews manually by transcribing them himself, which allowed the researcher to make sense of the rich data and familiarise himself with the data in both the context and content of the interviews. Member checking (Brit et al., 2016) was used to inquire about the data's apparent authenticity and interpretative accuracy with the participants to enhance trustworthiness (Lincoln & Guba, 1985; Lincoln & Guba, 1994; Lincoln et al., 2011). Again, data confidentiality was crucial (Kaiser, 2009); hence, the researcher remained compliant with all relevant data protection regulations, particularly with the Data Protection Act 2018 and Electronic Communications Regulation 2013, which regulate communications by telephone, email, and text.

The researcher started doing complete rather than selective coding (Braun & Clarke, 2013). By completing coding, the researcher aimed to identify all things of interest and relevance in answering the research questions (Grbich, 2013; Barbour, 2014; Miles et al., 2014; Braun & Clarke, 2013; Mason, 2018). Therefore, the interview transcripts were coded in many ways to fit the aims and objectives of the current study, and the codes were highlighted in colours, thus enabling the researcher to generate the codes inductively from the data (see Appendix 11). The codes were generated inductively from the data, particularly by summarising the participants' own words or excerpts from the interview transcripts. Firstly, the researcher noted that in doing so, coding the quotes (the participants' own words) would enrich the value of the data, thus expanding the value of the data rather than reducing it (Gibbs, 2007, p. 3). However, the coding was done line-by-line and in-between as needed and deemed necessary in answering the research question (Braun & Clarke, 2013; Saldana, 2013; Mason, 2018).

Indeed, the coding was done systematically to categorise the participants' own words in the data to find themes and patterns for analysis (Braun & Clarke, 2013; Grbich, 2013; Barbour, 2014; Mason, 2018). Therefore, the coding provided transparency and reflexivity to the research questions and the participants' understanding and beliefs about dementia. Hence, the themes provided insights, contexts, and an accurate representation of the data set, participants' narratives and views about dementia, and events or stories behind the data collected (Braun & Clarke, 2013; Manson, 2018). Likewise, the grounded theory approach and the iterative inquiry (Glaser & Strauss, 1967; Strauss & Corbin, 1998), the epistemological perspectives, and the researcher's intellectual puzzles supported the idea that the dementia phenomena could be coded across the data set and themes.

Themes are repetitions across more than 2 or 3 of the interview transcripts (Braun & Clarke, 2013; Mason, 2018). Perhaps repetition is one of the easiest ways to identify themes (Gery & Bernard, 2003) and can be likened to the 'walls and roofs of a house', and the codes likened to the 'individual bricks and tiles of the house' (Braun & Clarke, 2013, p. 207). The metaphor was a good analogy for better understanding the differences between codes and themes. In this case, it provided a lucid moment, a straightforward process characterised by a clear understanding of the categories and themes for the current study (please see Figure 1).

Thus, in so doing, the researcher utilised a combination of inductive and deductive approaches to qualitative coding. Inductively, the researcher developed and derived the codes as he read and highlighted what he saw in the data without a preconceived idea of what the codes should be and instead used a grounded-up approach (Miles et al., 2014; Braun & Clarke, 2013) in deriving codes from the data. However, the codes were driven by the participant's own words, as mentioned earlier. Therefore, it was like inductively allowing the codes to emerge from the raw data. Notwithstanding, the embedded theories within the data were also identified using a deductive approach. Thus, through deductive reasoning, the researcher assigned a theory to the excerpts (Braun & Clarke, 2013; Miles et al., 2014). For example, the researcher read through the dataset using a top-down approach and developed a set of theoretical codes from an existing theoretical framework (please refer to Chapter 4). The researcher then assigned the excerpts (participants' own words) to theoretical codes. Deductive reasoning relies on making a logical premise and basing a conclusion around the belief, meaning that if a belief is true, the conclusion must be true (Leavy, 2020). For example, dementia is a brain disease, and all diseases are biomedical concepts. Therefore, dementia is a biomedical construct.

Another example could be that witches cause dementia. Witchcraft is a metaphor, and therefore, dementia is a metaphor. However, the current study is not about developing a theory but understanding lay knowledge and beliefs about dementia. According to Braun and Clarke (2013), the theoretical codes go beyond the explicit content of the data. They are latent codes that invoke the researcher's conceptual and theoretical framework in identifying the assumptions and frameworks that underpin what is said in the data or what the researcher understands as the implicit meanings identified within the data (Braun & Clarke, 2013, p. 207). Indeed, the theoretical framework allowed the researcher to see and identify things in the data and interpret and code them in ways that might differ from other researchers because no researcher intends to code the same way (Mason, 2018; Braun & Clarke, 2019). However, the coding procedures were pragmatic, similar, and standard practice (Braun & Clarke, 2013; Barbour, 2014; Mason, 2018).

Indeed, the researcher searched for codes across the dataset to ensure that the excerpts provided the same underlying ideas and meanings. Then, he unified the codes across the dataset and turned the codes into categories and finally into themes (Braun & Clarke, 2013; Miles et al., 2014; Barbour, 2007; Mason, 2018), thus providing specific structures with the intent of a continuous analysis within the structures. Indeed, the researcher utilised the standard coding process for qualitative data that most qualitative researchers would generally follow. It involved reading through the data for familiarity, applying codes to participants' words or the excerpts, conducting rounds of coding, grouping codes in line with themes, and finally, making interpretations and explaining the research findings. Below highlights a summary of the step-by-step guide on the data coding process and thematic analysis using a grounded approach (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Thus, the audit trail features the various steps the researcher took to ensure that the data coding and analysis were appropriate to answer the research questions (Barbour, 2007; Boeije, 2010; Saldana, 2013; Braun & Clarke, 2013; Grbich, 2013; Miles et al., 2014; Manson, 2018).

### Step A: Open coding

Open coding: One of the key features of using a grounded approach or in the 'constant comparative' analytical process of coding allowed the researcher to constantly move back and forth and ensure that the complexity of the data was represented in the analysis. The step was fast and loose (Saldana, 2013; Braun & Clarke, 2013; Mason, 2018). For example, using the excerpt (participant's own words):

Participant's words: [I think it is just about a Nigerian woman living in London that is finding it difficult to cope with her life due to her illness].

1a. Open coding: [Having an illness]

1b. Open coding: [Nigerian woman living in London]

### Step B: Theoretical coding

Theoretical coding: A feature in which the codes go beyond the explicit content of the data. They were latent codes that invoked a conceptual and theoretical framework to identify the assumptions that underpin what was said in the data or the implicit meanings identified within the data (Saldana, 2013; Braun & Clarke, 2013; Mason, 2018). The theoretical codes were derived deductively from the theoretical framework (please refer to Chapter 4). It allowed the researcher to see and identify things in the data as driven by the participants and interpret and code them in a particular way he comprehended, visualised, and co-construct the data (Glaser, 2005; Charmaz, 2013). However, this is driven by the participants' own words. For example, using the excerpt (participant's own words):

Participant's words: [I think it is just about a Nigerian woman living in London that is finding it difficult to cope with her life due to her illness].

1a. Theoretical underpinning: [Lay concept]

1b. Theoretical underpinning: [sociocultural concept]

### Step C: Focus coding

Focus coding: The second round of coding provided an interpretative lens to the participants' own words or excerpts (Saldana, 2013; Braun & Clarke, 2013; Mason, 2018). The second coding round was about finding patterns, renaming the codes and getting the codes closer to forming a category. For example, using the excerpt (participant's own words):

Participant's own words: [I think it is just about a Nigerian woman living in London that is finding it difficult to cope with her life due to her illness].

1a. Focus coding: [Dementia is an illness]

1b. Focus coding: [Black African]

### Step D: Category

Category: A feature in which the researcher turned the focus code into a category. The categorised codes of the participants' own words provided a specific structure (structural coding) to allow a continued analysis across the dataset within the structure. Furthermore, this is based on the research questions, aims, and objectives, and grouping together codes that are similar (Barbour, 2007; Boeije, 2010; Saldana, 2013; Braun & Clarke, 2013; Grbich, 2013; Miles et al., 2014; Manson, 2018). For example, using the excerpt (participant's own words):

Participant's words: [I think it is just about a Nigerian woman living in London that is finding it difficult to cope with her life due to her illness].

1a. Category: [Lay knowledge]

1b. Category: [Ethnicity]

### Step E: Thematic coding

Thematic coding: A feature in which the researcher searched for themes and patterns across the dataset (unifying codes) and ensured that the participants' words or excerpts pointed to the same underlying idea or meaning. Thus, it provides an explanation and a specific structure with the intent of a continuous analysis within the structure (Barbour, 2007; Boeije, 2010; Saldana, 2013; Braun & Clarke, 2013; Grbich, 2013; Miles et al., 2014; Manson, 2018). For example, using the excerpt (participant's own words):

Participant's words: [I think it is just about a Nigerian woman living in London that is finding it difficult to cope with her life due to her illness].

1a. Theme: [Illness and disease]

1b. Theme: [Social identity]

### Step F: Managing the data

Managing the data: The dataset was organised using Excel (see Appendix 9). Usually, organising data is a practical challenge for any researcher and epistemological in a sense, with an implication on how the researcher will interpret the data and the kind of argument the researcher wants to make based on the study (Mason, 2018, p. 187). Thus, the researcher chose to use Excel rather than Nvivo 12, and there was no need for SPSS because SPSS is used mainly or fundamentally for quantitative rather than qualitative data.

### Pilot study

Drawing on Wray et al. (2017), the researcher conducted a pilot study to understand and test the technicality of the online platform (Zoom, Telephone, WhatsApp, and Facebook) to test and finalise the interview guide and vignette, and to check and establish what worked or did not work. The researcher had some concerns with conducting the research online. He foresaw some potential pitfalls and challenges, such as whether the participants have access to appropriate equipment, such as phones or computers. Do the participants have sufficient digital skills or have the technical know-how or the right technical skills? Does everyone have access to the internet? Will the online method include or exclude any groups? Do the participants and the researcher have access to a private space to sit while connecting online or conducting a telephone interview? How would the researcher record or capture the interviews remotely? How is the researcher sure of the person's identity he would be speaking with online or on the phone? Would the remote interview place more power in the researcher's or the participant's hands? Whilst these concerns might only partially prevent the researcher from conducting the study remotely, he needed to ensure the investigation was workable, determine the research feasibility, and carefully consider his relationships with participants.

Therefore, the researcher conducted a pilot study with three individuals recruited from the churches, mirroring Van Teijlingen and Hundley's (2001) suggestions for a smaller version of the study sample for a feasibility study. The three individuals did not participate in the main interviews. However, the data from the pilot study were coded, analysed, and added to the primary research because the researcher needed not to make significant changes to the pilot. The main reason for the pilot study was to test the online platforms' feasibility, the interview guide and the vignette, and the feasibility of utilising a thematic analysis using a grounded theory approach to ascertain if any changes would be required with the methods, including the use of the interview guide and vignette.

The researcher followed through with the pilot process carefully but needed to check with the members (Brit et al., 2016) to seek their views on what worked and did not work in the process to identify any change that may be required from their standpoint. The process would have added more rigour to the study. Nevertheless, the transcripts and findings were discussed with them individually to gain feedback and reach a consensus that the result was valuable and meaningful to the Black community in the UK (Lincoln et al., 2011). Thus, the primary study followed the exact process in the pilot.

If changes were needed, the researcher would have sought amendment with the ethics committee of the College of Health, Medicine and Life Sciences Research Ethics Committee, Brunel University London. Therefore, the researcher conducted the pilot study using the same methodological approaches to test the methods and the technicality of the interview guide, the vignette (research instruments), and the thematic analysis for data analysis. Hence, the pilot study was to answer the central question: ‘Can the full-scale study be conducted the way it has been planned, or should some components be altered or changed?’

The researcher drew on Kallio et al.’s (2016) five phases of developing a framework for a qualitative semi-structured guide. Firstly, the researcher identified the qualitative research prerequisite for using a semi-structured interview to explore lay knowledge and beliefs towards dementia. Secondly, the researcher developed the interview guide by drawing questions from the literature review and the theoretical framework to inform the empirical research and retrieve and use previous dementia knowledge to inform the current study. These were simple questions that the researcher needed to explore further. Indeed, the questions were simple but needed to elicit longer answers from the participants. They were developed to fit the Black African community in London and explore their lay knowledge and beliefs towards dementia. The researcher’s goal was to tap into their experiences, the meaning of dementia, and their expertise. Thirdly, the researcher formulated the structure for the semi-structured interviews by developing the questions asking ‘how’, ‘what’, and ‘tell’ rather than ‘why’ on dementia to elicit lay concepts and stories of the process rather than the accepted ‘biomedical account’ of dementia. The researcher also elicited further and for clarity or as a follow-up question by using prompts rather than asking direct questions. Some examples of the query included (please refer to Appendix 1) the following:

> *Question: How would you know you or someone has dementia in your community?*
> *Question: How do people in your community recognise dementia?*
> *Question: Tell me about any experience with dementia signs and symptoms*
> *Question: What do you know about dementia?*
> *Question: What are your beliefs towards dementia?*
> *Question: Tell me about your experience with dementia.*
> *Question: What are the causes of dementia in your community?*
> *Question: What is your belief about these causes of dementia in your community?*
> *Question: Tell me about these causes of dementia in your community.*
> *Prompt: Tell me a bit more.*

The researcher ensured he achieved a logical flow during the interview by considering what should come first and what follows more naturally. Thus, the questions were structurally divided into six themes, and there were a few adjustments in language and questions after several interviews. The researcher asked the difficult questions towards the end of the interview when he had established rapport with the respondents. The researcher’s last question provided closure for the interview, which made the respondents empowered, listen to, and acknowledge. The researcher did not develop an interview debriefing protocol, but the last questions aimed at empowering and debriefing the respondents. For example:

> *Question: What insights and lessons from your experience would you wish to share with others?*
> *Question: Is there anything we should have talked about but did not?*
> *Question: Do you want to ask me any questions?*

Fourthly, the researcher piloted the guide. Of course, he conducted the pilot study to evaluate the feasibility (Van Teijlingen & Hundley, 2001) of the critical steps in the main study. That included ascertaining the recruitment rate of participants and the eligibility criteria, estimating the time and resources needed for the study, determining data management, and the protocol’s effectiveness, such as the drafted interview guide, the dementia vignette, and data collection and thematic analysis. Thus, by conducting the pilot study, the researcher was better prepared, informed, and prepared to face any difficulties that were most likely to arise in the main study. The researcher became more confident with the research instruments for data collection and analysis.

The pilot study potentially increased the rigour and quality of the current study as findings from the research informed subsequent parts of the study process. Echoing Van Teijlingen and Hundley (2001), the two main types of pilot studies used in health and social science are primarily for (i) smaller versions of the studies, feasibility studies, and (ii) the pre-testing or trial of a particular research instrument. Lastly, the researcher presented the completed research instruments and the findings to the supervisory team for scrutiny.

### Results of the pilot study

The findings from the pilot study indicated that the primary research was feasible without changes to the protocol. The data were coded, and the researcher developed themes and subthemes from the study. Furthermore, the supervisory team advised that the pilot study should be added to the main primary investigation to ensure that essential data are presented. In addition, the team advised that the researcher add a question to the interview guide to explore ‘forgetfulness’. For example, the researcher added a question about forgetfulness in the interview guide (see Appendix 1).

## DATA ANALYSIS

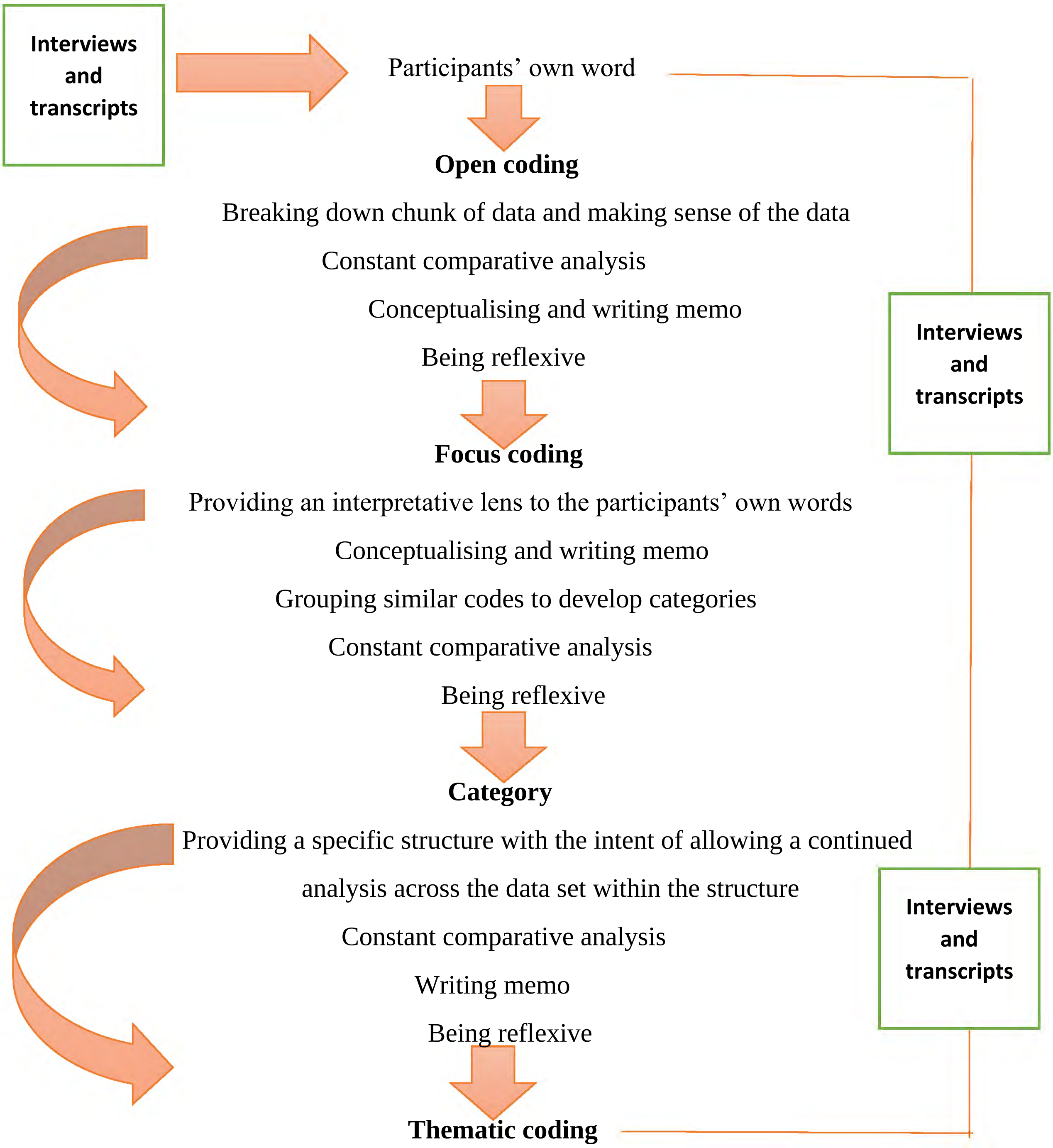


Figure 2: Thematic data analysis informed by a grounded theory approach.

*The schematic approach the researcher developed for standard data coding and analysis for the current study. It shows the iterative flow and explains how the qualitative data were coded and thematically analysed by highlighting the following key steps: open coding, focused coding, category, and thematic coding of the data (Glaser & Strauss, 1967; Strauss & Corbin, 1994).*

## Reflexivity

This section adopted both confessional and realist tales (Van Maanen, 1988); writing memos throughout the data collection and analysis was essential to the thematic grounded approach. The memos helped the researcher document insights, thoughts, and sentiments about the data collection and analysis. Therefore, a grounded theory approach recognised the researcher as an essential part of the research process. Indeed, a part of the research instrument. The researcher is a community physician (trained in Nigeria) and an applied medical anthropologist (trained in the UK). For sure, dementia is a medical terminology and concept. However, in public health and health promotion, the researcher believes proper education is fundamental in promoting good values, cultural norms, and social progress, such as equality and equity towards dementia. Therefore, in the application of cultural relativism in the current research, it is utilised not as a comprehensive concept but as a tradition that provided an interpretative outlook to correct ethnocentrism. This suggests that a group's dementia knowledge and beliefs should be understood, judged, evaluated, and grounded on that particular group's own culture, and that the norms and values of the group's culture should not be evaluated or judged by using the norms and values of another group's culture (Brown, 2008). The process helped the researcher to limit ethnocentric biases (Brown, 2008).

Notwithstanding, the researcher is a social researcher with clinical and applied medical anthropological backgrounds and a Black African living in South East London. Like those he was researching, he also goes to church. Thus, the researcher thought he was caught up between cultures and the 'emic' and 'etic' perspectives on dementia. Emic and etic are often used in anthropology to capture the distinction between knowledge and beliefs of the dementia culture and experience, that is, what an insider within a local context would recognise and resonate with, and a more distant experience of the dementia conceptualisation (Geertz, 1983). Moreover, the researcher distinguished etic as the biomedical knowledge of dementia that is generalisable and can be universally true, characterised by objectivity, and the emic perspective, which encompasses context-specific lay knowledge of dementia that is situated and not easily generalisable, reflecting a native's point of view (Pool & Geissler, 2007).

Therefore, the researcher was critically self-reflective about his clinical and medical stance on dementia. However, some of the participants in the study were perceptive or apprehensive of the researcher's medical and clinical backgrounds and continued to refer to them. Nevertheless, research ethics and integrity helped keep the researcher's relationships with the participants limited to the research and away from personal issues. Nonetheless, the researcher was committed to reducing power differences in the research by encouraging disclosure and authenticity between him and the participants (Karnieli-Miller et al., 2009). Thus, the researcher was not the ultimate source of authority, even though he is a medical doctor with medical expert knowledge about dementia. Instead, he promoted the participant's equal participation in the research process and dementia knowledge.

However, the researcher's positionality was ethically and methodologically challenging. He was not a member of the two churches, and although he is a churchgoer, he had no face-to-face contact with the participants. Nonetheless, the researcher positioned himself as both an insider and an outsider (Merton, 1972) and illuminated his ontological perspectives (Holmes, 2020). Each position has advantages and disadvantages (see Chapter 9) but depends on the purpose of the research (Hammersley, 1993). Ontologically, the insider perspective highlighted the emic account of the dementia phenomenon as lay knowledge and beliefs, which was situated within a cultural relativist position. It also recognised dementia knowledge as being relative to the Black African culture of which the researcher is a member of the community and the context in which the dementia knowledge and beliefs were both rational and meaningful within the culture (Pool & Geissler, 2007). Meanwhile, the outsider perspective is the etic account of the dementia phenomenon situated within a realist perspective and attempts to highlight the difference in culture in terms of an external standard and from an ontological position that assumes a predefined biomedical dementia reality (Davison, 2022). This context referred to the medical culture, of which the researcher was also a member. The etic accounts on dementia aimed to be culturally neutral and operated from the assumptions that the researcher's positionality (Holmes, 2020) relied on his ability to detach himself from the prejudices of the Black African's knowledge and beliefs towards dementia as witchcraft.

Nevertheless, initially before the fieldwork, the researcher believed biomedical and lay knowledge should be considered equally (Bury, 1986; Monaghan, 1999). Nonetheless, after his fieldwork, he understood that a hierarchy of dementia knowledge that existed was influenced by power, education, and professional status and could determine the research outcome (Smith, 1999). Thus, the researcher was determined to present his findings accurately and truthfully as driven by the respondents' own words and not based on his own subjective or objective views.

Regardless, the researcher anticipated some challenges associated with online research interviews, such as personal connectedness and the need to establish trust and rapport between the participants via online platforms and himself. Developing a relationship with the participants was crucial, and it allowed the participants to talk freely about the topic of discussion and led to more insightful research via online platforms. Unlike online research, the researcher can observe interesting information via nonverbal cues and body language in face-to-face interviews. However, the researcher could use online platforms. He used the participant's tone to ascertain the participant's level of confidence in talking about dementia. Nevertheless, the researcher could only partially assess the participants' confidence level since it was mostly telephone interviews. Thus, he could not evaluate their body language, expressions, or postures, such as facial expressions and eye contact.

Although the data analysis indicated a subtle difference between the men and women in the group, most women in the current study were excited to talk about dementia. They spoke at length about dementia, whilst most men just wanted to move on quickly to talk about something else without saying more than what they had to say, which may suggest that women are more intuitive than men, whilst men are more logical than women. However, both men and women were confident in talking about dementia. Nevertheless, before the pilot study, the researcher envisaged that there might be poor internet connections and computer malfunction, and faulty equipment could interrupt online sessions, especially during the COVID-19 pandemic. Technology kept us connected during the pandemic, and there was a possibility that not all church members had access to technology. Hence, the researcher thought some participants might unintentionally be excluded. However, most participants made contact by telephone, and all the participants that made contact and met the inclusion criteria were enrolled and interviewed.

Moreover, to achieve quality and rigour, the researcher was still determining the identity of the people he would interview remotely and how he would record the interviews. Thus, there might be a challenge in recording or capturing the online discussions and ensuring the privacy and confidentiality of participants. The option for the researcher to tackle these challenges was to conduct a pilot study before the primary research, as previously mentioned, to ascertain the feasibility of a pre-testing of the research instruments, which included the interview guide and vignette. A vignette can be used in dementia research to mitigate the power dynamic between the researcher and the participants in the knowledge production and to tailor anti-stigma intervention (Wusten &Lincoln, 2022). Thus, the researcher conducted a pilot study to test the vignette.

He found the vignette helpful in the research as it projected the same level of the same knowledge on dementia and enabled the researcher to contribute to the dementia knowledge. Indeed, the researcher was a co-constructor (Charmaz, 2006). Still, participants gave a more diverse account of their expertise on dementia cross-culturally. Therefore, the vast contribution of the researcher and participants to the research makes them both inseparable parts of the final creation (Karnieli-Miller et al., 2009) but mainly maintain the presence of the participants throughout the research (Charmaz, 2006).

Furthermore, the individual members checked all the transcripts for interpretative accuracy (Birt et al., 2016) and dependability (Lincoln & Guba, 1985). The researcher returned the transcripts to each respondent via WhatsApp as an attachment. Still, the attachment was sent to those participants who provided their email, and the researcher had none of the respondents' addresses. The study indeed achieved quality and rigour in the research process.

In addition, conducting the study online provided opportunities for flexibility and creativity in the research process, and at the same time, the researcher ensured clarity and maintained good research integrity. He understood the need for proper documentation and kept field notes and theoretical memos (see Appendix 14), which allowed data to evolve to a higher interpretative and constructionist level (see Figure 2). Therefore, the researcher engaged with appropriate documentation and transparency of procedure and adapted a checklist to mitigate ethical issues associated with the online study. Regardless, the online research may have been less costly than face-to-face interviews because there was no need to pay for a venue that could have been expensive. Nonetheless, the online study was compelling.

Furthermore, as noted, most of the participants were carers. Some of the carers were caring for a person with dementia. They had disclosed belief in witchcraft and, as such, potentially raised concerns for safeguarding the people with dementia in the Black African community in the UK. However, the research design did not anticipate such and had no plan to manage it. Nevertheless, the belief about dementia as witchcraft was not static. Several sociocultural factors influenced it, and the participants drew on different knowledge and ideas in making sense of dementia beliefs in various social and cultural contexts.

Nonetheless, the researcher understands safeguarding in the research is to protect people with dementia from abuse and neglect and forms a key responsibility of healthcare professionals, including medical doctors and the researcher (Richardson, 2014, p. 118). As such, it included reporting any suspected abuse appropriately during this study's fieldwork and analysis stages. Also, it included documenting discussions and any action taken accordingly, which includes following the research ethics and policies as required. In addition, the researcher understands that the ethical process adopts a hierarchical approach to safeguarding issues, with the principal supervisor responsible for reporting and following up on concerns.

Nonetheless, the current research did not incorporate any safeguarding issues in the study design. However, it is essential to note that believing in witchcraft does not necessarily amount to a safeguarding concern in the research. Instead, a 'sociocultural blindness' to the Black African's dementia belief as witchcraft by doctors or health practitioners can lead to abuse and stigmatisation of people with dementia in the Black community in the UK. Indeed, a 'sociocultural blindness' that overlooks social and cultural constructs of dementia in the Black African community in the UK will account for injustices and inequalities in the uptake and access to dementia care services. Thus, the researcher developed a sociocultural model for dementia empowerment inductively from the empirical data. The sociocultural model for dementia is considered a way of thinking and interpreting the dementia phenomenon amongst Black Africans in the UK. It is pragmatic and represents a set of prescriptions for medical doctors and health practitioners to analyse the dementia constructs and provide needed community dementia treatment and support for people with dementia and their family.

### Summary

The chapter set out the study methodological approaches that demonstrated the research design, theory, and study methods. It provided the pilot study and primary investigation. The pilot study results indicated that the primary research was feasible without protocol changes. The researcher added the data and findings of the pilot study to the primary research to ensure the study had all the essential data. The researcher also interviewed men and women online, used comparative analysis until the study achieved data saturation, and interviewed people with various sociocultural backgrounds and occupations, excluding medical doctors, nurses, pharmacists, and paramedics, but adults of different ages (aged 20 to 85 years) to ensure the study developed adequate data to establish a robust and valid understanding of dementia and achieve data saturation. Thus, the researcher conducted 31 semi-structured interviews with 31 Black Africans living in London who considered themselves laypeople from the Black community in London and were churchgoers. Each interview lasted for about 35 minutes to an hour maximum. The interviews were recorded and transcribed verbatim. The chapter provided the data analysis process of the study; the data were thematically analysed using a grounded theory approach, and the researcher reflected on the study. The next chapter presents the findings.

# Chapter 5

# Social Identity

## Introduction

This results chapter presents a ‘thick’ and ‘rich’ description of the sample and the thematic analysis of the interviews. The analysis is driven by the participants’ narratives and views about dementia, and it shows how each participant’s knowledge and beliefs about dementia are similar and varied amongst the respondents. The thematic analysis (Braun & Clarke, 2013, 2019) is flexible and was used to develop a detailed analysis and descriptive account of the dementia phenomena and answer the research question. Furthermore, it was used to establish the interpretations of the social constructionist analysis, which identifies the concepts and ideas that underpin the explicit data contents and the views and meanings in the data (Braun & Clarke, 2013, 2014, 2019).

Therefore, the analysis provides a robust descriptive and systematic framework for coding the qualitative data and using the coding to identify patterns across the dataset concerning the research questions (Braun & Clarke, 2019). The thematic analysis is presented as four interconnected themes: social identity/sociocultural model, illness and disease, help-seeking, and caregiving. The participants evaluated dementia according to what they considered reasonable or logical given their age, gender, education, occupation, religious beliefs and spirituality, ethnicity and race, socioeconomic status, social class, and other sociocultural factors that influenced their understanding of dementia. Firstly, drawing on the sample, this chapter begins by presenting the demographic characteristics and background of the participants. Secondly, the chapter illuminates the themes.

## The sample

The table (see Appendix 10A & 10B) presents the demographics and sample of the study population. It included qualities such as age, gender, educational level, occupation, country of migration, and the participant’s length of stay in the UK. The demographic characteristics provided the sociocultural trends of the study populations within a space and time. The researcher used them to draw some explanations and descriptions of the participant’s lay knowledge and beliefs about dementia. A total of 31 men and women participants participated in the study. The study included almost an equal number of men and women participants (e.g., 14 women and 17 men). Although, the study utilised constant comparative analysis to ensure a relatively consistent sample size for both males and females and data saturation.

The participants' names were anonymised, as shown in the table (Appendix 10A & 10B). The sample included adults aged 20 – 79 years. More participants were within the age range of 30 – 59 years, but most were aged 40 – 59, and a few were aged 60 -79. None of the participants was above age 79 or below age 20. All the participants were adults. Although, the study utilised constant comparative analysis to ensure a relatively consistent sample for data saturation. Nevertheless, the data suggest fewer participants in the age range of 70 and above. Finally, the median of each age range is used in the analysis (see Appendix 10B).

An important consideration concerning the sample Is that all the participants are Black people from Africa living in London. So, none of them was born in the UK, which suggests that all the participants were first-generation immigrants. Therefore, all the participants were foreign-born, and the sample included naturalised citizens, permanent residents, and temporary residents, such as students living in London. Thus, the study is limited to foreign-born or first-generation immigrants. However, the study's findings might be transferable to second-generation immigrants of similar Black African backgrounds living in London, given by parental bonds or associations. Transfer of understanding can occur if both contexts are similar, for example, by drawing on the trustworthiness discourse (Lincoln & Guba, 1985). Nevertheless, qualitative research does not aim to generalise findings (Denzin & Lincoln, 2018).

Moreover, all the participants were recruited from churches. Therefore, all the participants were churchgoers and self-identified as Laypeople. Generally, churchgoers may be considered Christians and can believe in Jesus Christ as the son of God or the almighty God, and prayer can be how Christians or churchgoers communicate or connect with their God (Rossiter-Thornton, 2002; Hamilton et al., 2020). In addition, the Bible is the holy scripture of the Christian religion, and churchgoers can use it, suggesting that participants can refer to the Bible to justify their knowledge and beliefs (Aliotta et al., 2016; Dafni & Bock, 2019). Nonetheless, religion can be a source of social and spiritual support for people with dementia and their families in the Black community in the UK, perhaps as a coping strategy. It may be challenging to transfer the findings of this study to other religious groups; however, it depends on the context of the results.

Furthermore, all the participants were immigrants from West Africa, mainly from Nigeria and a few from Ghana, Cameroon, Sierra Leone, and Liberia. Therefore, all the participants are Black Africans from West Africa and live in London. So, all the participants are first-generation immigrants from West Africa. However, more Nigerians were in the study than any other immigrants from West Africa, suggesting that the study area was densely populated with Nigerians or that more Nigerians were living in London than any other Black African population from West Africa. Perhaps it could represent an artefact of those who attended the churches from which the participants were recruited. For example, the churches included Pentecostalism. Nonetheless, the study cannot be generalised (transferability) to all Black Africans living in London but may be limited to Christians/churchgoers in context, depending on the findings.

In addition, most participants have lived in the UK for 15 years or more, and the full year a participant had lived in the UK was 40 years. None of the participants lived for less than three years in the UK. Thus, the data suggests that people who have lived in the UK for 15 years and above participated more in the study, and they were half of the sample size. More importantly, people from various work or occupations participated in the study, thus ensuring adequate data to develop a robust and valid understanding of dementia and achieve data saturation. However, the study excluded people in medicine or health professionals, such as doctors, paramedics, and nurses, but more participants were carers. The strength of this study is evident in the fact that people from all walks of life were involved. Hence, the analysis can represent the non-health professionals (e.g., laypeople from the Black African community as they self-identify). Even though the study did not include people from other walks of life, the findings can be dependable and transferable to broader settings with the same backgrounds, as the study has provided a ‘thick’ description with detailed contextual information.

Nonetheless, most participants attended University education, and some with secondary education also had vocational qualifications. Although, the study utilised constant comparative analysis to ensure a relatively consistent sample for saturation. None of the participants was illiterate; all the participants had formal education. Furthermore, most of the participants had a university degree. Therefore, a setting where the participants have no formal education can limit the degree of dependability and transferability of the findings. Next, the data is presented thematically.

## Social Identity

Social identity in this study appears relevant when individuals consider their associations. Black African or church membership is central to the participant's self-identity and shared dementia knowledge and beliefs. They identified themselves as laypeople from the Black African community in the UK. Therefore, social identity is part of the self-defined by the individual's group membership (Hogg & Rinella, 2018). So, in the current study, respondents identified socially as laypeople from the Black community. Indeed, the thematic analysis of the social identity in the current research provided information about the shared dementia knowledge and beliefs amongst the Black African populations living in London in relationships with others. Participants shared their dementia lay knowledge and beliefs and their relationship with others to validate their dementia meanings and experiences.

Heiphetz (2018) argued that religion or shared beliefs play a role in social identity. People may positively evaluate those who share their religious beliefs more than religious out-group members. Therefore, social identity is cognitive and reflexive because people will consider others based on their social identity or knowledge or the group-defining norms or beliefs that serve as their social identity, which becomes more important than the individual's self-identity (Tajfel & Turner, 1979). It became more apparent that the researcher was researching a group whose norms and beliefs were defined by their religion and ethnic background. For example, the participants were churchgoers and were originally from West Africa. However, the researcher was also aware of his stance as a social researcher with medical knowledge and anthropological experiences.

By and large, seven subthemes emerged underneath the umbrella of the social identity/ sociocultural model theme: (i) Lay beliefs, (ii) Lay knowledge, (iii) Lay expertise, (iv) Ethnicity, (v) Gender, (vi) Older age and (vii) Disability/Ability. Indeed, the constructionist analysis illuminates the lay knowledge and beliefs of dementia. However, it should not be privileged over the biomedical knowledge of dementia as all forms of dementia knowledge may be considered equal (Armstrong, 1985; Monaghan, 1999). Of course, suggesting that laypeople's knowledge and beliefs about dementia can be as valuable as the biomedical knowledge of dementia because there is no way of judging the participant's lay knowledge of dementia as lesser than the biomedical knowledge of dementia (Bury, 1986). Therefore, assuming biomedical knowledge of dementia is better than lay knowledge of dementia can lead to epistemic tension (Haw et al., 2018). Indeed, the current study analysis drew on an epistemological concept to justify an ideal of lay knowledge and beliefs inquiry that differed from medical knowledge. Thus, the empirical evidence from the current study shows that the participants identified themselves as a layperson as illuminated:

> *From my layman's perspective… my belief as a layman* (Kofi).

Similarly, drawing on Zubby identifies him as a layperson from the Black African community in the UK.

> *That is what I think. I am talking as a layman. I am talking as a layman* (Zubby).

Hence, the social constructionist analysis illuminates the participants' dementia knowledge and beliefs as lay knowledge that developed from the study. So, this chapter presented two subthemes: (i) Lay beliefs and (ii) Lay knowledge, and showcased the empirical evidence, as well as provided in-depth explanations and interpretations of the data that emerged from the interviews and was driven by the participant's narratives and views. Where quotations are used in this chapter, the participant's name is anonymised (Pseudonyms) and provided at the end of each quote.

### Lay beliefs

The lay beliefs discussed in this subsection are religion, spirituality, and prayer, which developed from the group's social identity, the key theme. The participants were laypeople from the Black African community in London and were churchgoers. Religion and spirituality are rooted in an established tradition that arises from a group of people with common lay beliefs concerning a sacred or God. For example, the interview with Ben appraises the church as a place of worship whilst discussing prayer as a part of his religion and spiritual beliefs regarding dementia. It shows how much he valued his religious beliefs in line with his understanding of dementia. Thus, the findings from the current study illuminated that the Black African group living in London were churchgoers:

> *The church is a place of worship. People with dementia can go to church and worship their God if they feel like it…. It is possible they could receive healing in the church. God is a healer and can heal anybody or any illness…There is nothing God cannot do, and praying for people with dementia is good and maybe comforting* (Ben).

For Ben, religion and spirituality may be a source of comfort and may provide healing for those who have dementia, as narrated. He believes God is a healer and can heal anybody with a dementia illness. Ben, aged 55, a builder from Nigeria, has lived in the UK for 19 years. He believes God is the beginning and the end, omnipotent and omnipresent, reflecting his spirituality. Thus, he believes that God is a deity with unlimited power, presence, and a significant influence on dementia. He perceived that the church was a place of worship, and people with dementia could go to the church, worship God, and be offered a prayer.

Similarly, Marie, a female hairstylist aged 55 and originally from Cameroon, shared a similar view about the dementia phenomenon. However, she acknowledged that she went to church and connected with God in prayer. The prayer was comforting and encouraging. Although, the prayer provided no healing for the person with a dementia illness. Marie has lived in the UK for 21 years, and her experience was that she expected a miracle and healing from God for her mother, who was suffering from dementia.

Moreover, she subsequently lost her mother to dementia, notwithstanding being observed in prayers. However, for Marie going to church took away her fears, loneliness, and stress. As narrated, positive religious beliefs can promote good health and personal well-being. Thus, the findings of the current study illuminated the support available to members of the Black Africans in their community and mainly included prayer, closeness to God and socialising:

> *There are many supports available in the church, such as being encouraged and being prayed for. The prayer was very comforting and encouraging. The prayer was soothing, and we expected miracles and healing to happen. Although it did not happen, but going to the church also took away fear and stress. There is nothing as good as being close to God in difficult times. This country can be lonely, so going to church helped us meet people, talk with people, and make friends* (Marie).

Drawing on her narratives which relate to holistic health overall, it appears that with religion and spirituality, Marie's negative experience of dementia turned around positively into a psychological and social resource for coping with stress and loneliness, leading her to build better relationships. Likewise, Nonye, a retired 75-year-old teacher who has lived in the UK for 40 years, whose narratives illustrated that being close to God was the best thing her parents gave her as a child, which expanded positively through to her adulthood. Nonye believes that the church is a place of comfort and hope and that she enjoys going to the church with her family, studying God's words, and enjoying God's presence, which suggest social and spiritual support.

Therefore, miracles and healing from dementia through prayer may not necessarily have been the only motivation for her going to the church despite seeking prayer for dementia healing for her husband. It appears that going to the church was also value-driven for many of the participants, including Nonye. Some of her views suggest that people should ally themselves with God and take for granted or believe that God knows what is best for any individual. Thus, the findings of the current study illuminated that the participants perceived God as their source of protection, hope, and courage for any member of the Black African community in London that have dementia:

> *The church is a place of comfort for me and my family, a place of hope and for digging deep into the words of the almighty God…God will always be God irrespective of what comes our way, good or bad.* (Nonye).

So, Nonye is saying that dementia is a 'bad' thing that can happen to anybody, but religion can offer comfort to those with dementia and their families. Furthermore, drawing on Nonye's narratives could suggest that people are agents and can choose or make choices for themselves:

> *We all want to live a long and fulfilled life, but we don't want to have dementia as we are ageing.* (Nonye).

Consequentially, attending church for some participants, including Ben, Nonye and Ngozi, had a more profound value focused on spirituality and worship of God rather than seeking healing for the dementia illness through prayer. Although the prayer was seemingly crucial for many and was the main gate to connecting with God, some participants acknowledged that they went to the church for prayer and dementia healing. However, for Ngozi, healing was entirely a decision of God and was independent of the individuals. Unlike the narratives of Marie, whose primary focus was for God to heal her mother, Marie's mother had dementia. Although, she found something more extensive, likened to peace or a life free of stress. Again, for Ngozi, she believed that any healing for individuals with dementia was entirely dependent on God rather than the individual's desire as viewed:

> *But people with dementia can go to church to be prayed for. There is nothing bad in praying for them. If God likes them, He can heal them* (Ngozi).

Therefore, the current study findings illuminated that religion, prayer and spirituality can represent a powerful resource of comfort, peace, hope, meaning, and life purpose but may also be intricately entangled with neurotic or psychotic disorders. For example, the views and narratives of Nonye and Ngozi, as above and Tunde's narratives, as highlighted below, may suggest that the sacred or God is entirely in control of their lives. They had little or no control over whatever was happening in their daily lives because God had a 'plan' for everyone through connectedness. Thus, the data shows that for many of the Black Africans, it could be a connection to their life purpose, but for Tunde, it may be a connectedness to a river:

> *In my village at Osun in Nigeria [interjection], they don't understand dementia, so people can also go to the river to have a wash for cleansing and spiritual purity [interjection]* (Tunde).

However, prayer can be understood as an expression of spirituality through dimensions of connectedness either transpersonally to God, intrapersonally to one's inner self, or interpersonally to others (Dafni & Bock, 2019). Evidence from the current study may further suggest that prayer is a form of communication and connectedness to God, self and others. Therefore, the narratives of most of the participants illuminated that prayer is a ritual that can interconnect religion or spirituality with the possibility of a cure for dementia as viewed:

> *I don't have any spiritual beliefs about dementia…but we can pray to God for help and healing* (Obiora).

In addition, the data suggest that through prayer, the participants may request strength from God to endure dementia, prayer may provide healing for the dementia illness, and prayer could also be used to express gratitude to God through worship. Hence, for some participants, healing from the dementia illness that can be conventional through prayer may become a significant focus. Furthermore, some participants perceived the church as equivalent to a hospital and saw Jesus Christ or God as the unseen physician who was always present in the church. Particularly for Seyi and Tunde, their views and narratives illuminated that the church could equally be considered as a hospital where those with dementia illness can obtain healing and deviant behaviours can as well be resolved:

> *Churches are a place of worship and reverence unto God. However, in some cases, as in Nigeria, churches may also be considered a 'hospital' where sins, evils, and deviance could be dealt with in health and well-being* (Seyi).

Likewise, drawing on Tunde illuminates some of the spiritual supports or activities in churches and considers the church as a ‘hospital’:

> *Here in London, I think the support that is available in churches is only prayers and preaching to them to feed their spirit. In the church they can use anointing oils to pray for them and anoint their forehead. But in Nigeria [interjection] there are churches in Nigeria where you can go and sleep in, they will wash you in the church, feed you, and pray for you with candles and olive oil. They may ask you to fast without food for a day or two. In Nigeria people believe that church is a kind of ‘hospital’ for a healing purpose and where miracles can happen* (Tunde).

However, drawing on Tunde’s narratives emphasised the differences in religiosity and spiritual support for dementia that may be available to church members in the UK. He compared it to that which may be practically available to the other members in Nigeria. For example, the support available for church members in London is prayer, but members are not allowed to sleep or live in the church. So, churches are not considered a hospital in the UK, but in Nigeria, church members can reside or live in the church.

Nonetheless, admitting Seyi’s views as above provided further clarity towards Tunde’s narratives. It informed this study that the dementia beliefs and the available practical supports were by any means possibly determined by other factors, which included the individual’s occupation and whatever may be considered practicable within Nigeria. Likewise, Kofi’s views further illuminated the dementia beliefs outside of the UK that were practically available to the members that are primarily based in Ghana:

> *The church also plays a huge role, especially in the African community. Back home in Ghana, we have prayer camps and church homes that could help people deal with dementia, and families take their loved ones or the elderly to these camps to be taken care of* (Kofi).

Thus, the data shows that the Black Africans living in the UK were comparing themselves with the others in their original countries and drawing inferences. According to Kofi’s narratives, the prayer camp practices in Ghana were geared toward spirituality involving the use of prayers and incense:

> *…they tend to gear more towards spirituality. Hence, they use prayers, incense, and spiritual solutions* (Kofi).

Furthermore, drawing on Edward's (2014) reports can suggest that in the prayer camps, people with dementia in Ghana may be chained, beaten, starved, and subjected to inhumane conditions, including human rights violation activities. The treatment for dementia may include Bible reading, prayer, and voluntary fasting for 36 hours, with some chants and dances, and people may fall into a trance. The prayer camp may consist of one pastor and some followers or a hierarchical pastoral structure with hundreds of people in residence. The prayer camp is not accessible, and families and people with dementia may be required to pay some money for food and lodging. Therefore, the evidence suggests differences in beliefs and practices towards dementia in Africa compared with the UK's beliefs and practices.

Nonetheless, Obiora is a 55-year-old Pastor and a community leader in a church in London and has lived in the UK for 24 years. He wants to do something different from the prayer camp in the UK. Although he believes in his Christian religion and God's healing powers, he also believes in prayer. However, he wants to collaborate with health practitioners in disseminating dementia information in the community, as narrated:

> *Personally, I am currently trying to organise a program to bring in different professionals to speak on health issues such as dementia and other worrying issues. I hope to organise the program in my church to sensitise members, create awareness, and keep them informed about health issues like dementia.* (Obiora).

Therefore, the current data show that the Black Africans in the community are willing to collaborate with health professionals in dementia services in the UK. Nevertheless, let us keep in mind that people affected with dementia may tend to practice their religion and spirituality as well as the use of prayer based on a variety of different motivations such as personal experiences and values, as a family habit, as illuminated in the data:

> *I enjoy being at the church and just feeling the presence of God in my life. I started as a child with my parents going to a catholic church in a neighbourhood in Nigeria before moving on to an Anglican church but now immersed in a Pentecostal church* (Nonye).

However, medical doctors may reject religiosity or prayer in dementia and mental health practices (Rossiter-Thornton, 2002). However, as the current study data shows, in a dementia practice, religiosity and prayer can provide a shared identity for the group members. They can improve an individual's self-esteem, confidence, self-pride, a sense of purpose and the need to cope with the challenges of dementia:

> *We go to church for worship and fellowship…and it gives me a greater sense of purpose and the ability to cope with the struggles of my life* (Nonye).

Furthermore, in dementia practice, religiosity can inform doctors about an individual's moral expectations and values. This study presumes that most participants will not use prayer towards their dementia unless they are convinced that the prayer is beneficial. However, medical doctors can direct more resources towards the care of the physical body than the mind and spirit. Therefore, based on the empirical evidence from the current study, religion, and spirituality, as well as prayer and music, can fill the gap or limitations of medicine in providing meaning, hope, comfort, and peace of mind for the Black African populations suffering from dementia in the UK:

> *I think Pastors could also study the word of God with them, that is, studying the Bible and fellowshipping together. Singing Gospel songs can be good; it could help to improve their memory and thinking. Maybe they may receive their memory back from God. You never can tell what God can do. Anything and everything are possible with God. All we need is faith. I pray God will help us to continue to keep to our faith and prayers* (Ben).

Thus, this study's empirical evidence suggests that collaboration and mutual learning can benefit people with dementia, their families, relatives, and doctors. Therefore, a need for open-mindedness in the acceptance, incorporation and integration of religion and spirituality. Moreover, to avoid the subtle conflicts in the use of prayer towards dementia management for Black African populations in the UK because prayer is an intersection between religion and spirituality. Many doctors who reject religion and spirituality in care will also reject prayer (Rossiter-Thornton, 2002). Recent studies have shown that GPs are encouraged to deliver spiritual care (Appleby et al., 2018). Indeed, the empirical data from the current illuminates that it is crucial for medical doctors to consider their own beliefs and to understand that their patient's faith or beliefs are equally as essential:

> *When people are diagnosed with dementia, their faith can also positively help them cope with dementia. I think the individual's faith can slow down the rate at which dementia becomes full-blown. So, faith can. This help in the person's ability to manage dementia, and what could be done so that dementia does not get to the next stage in which dementia cannot be managed [interjection], that is, when the person*

> *has completely lost his or her memory and brain abilities. So [interjection] I think faith can help build resilience for people with dementia and their family* (Obiora).

Therefore, religion, spirituality and prayer were viewed and narrated as a strength for most of the participants in this study and informed the sociocultural model for dementia. It provided comfort, hope, and healing in times of need. Notwithstanding, prayers rooted within established religious traditions were consistently associated with better health and wellbeing (Rossiter-Thornton, 2002). Indeed, the current study findings suggest that religion and spirituality, including prayer and music, inform the basic principle of holistic medicine and can serve as an adjunct in dementia health care services for Black Africans living in London. It provided comfort, hope, and resilience for families and those affected by dementia.

### Lay knowledge

As earlier mentioned, participants identified themselves as laypeople. Moreso, witchcraft, curses, craziness, madness, and insanity emerged as lay dementia knowledge in the current data analysis, which serves as a shared dementia knowledge amongst the Black African respondents in this study. For example:

> *In my village, it is called 'Ara', meaning madness or 'Isi mkpaka', meaning sour head. It was never called dementia in my village in Nigeria* (Ben).

Ben is originally from an Igbo tribe in Nigeria. He perceived dementia as 'Ara' and 'Isi mkpaka', meaning madness and sour head, respectively, thus suggesting that 'Ara' and 'Isi mkpaka' are cultural constructs and recognised as the lay knowledge for dementia amongst his tribal men in Nigeria. He further acknowledged that the phenomenon was not known as 'dementia'. Similarly, Obiora also admitted that the phenomenon was not known as dementia and that anyone with the illness was considered a witch and was mistreated. More interesting is the framing of dementia as 'behaving like a child' drawn from his experience as narrated:

> *My personal experience was in Africa; we did not understand what dementia meant. In the village, a woman that I used to know all of a sudden started behaving like a child. And she became forgetful, and she forgot who she was, she forgot her name and her family members. And then, ...because we did not understand what dementia was, people treated her badly, and people started calling her a witch and subjected her to a humiliating life* (Obiora).

However, Nwanne's narrative suggests that the people in Nigeria did not understand the phenomenon as a dementia illness, and for them, not recognising the phenomenon as dementia was problematic as many considered the condition a family curse, including it being likened to madness and witchcraft as narrated:

> *But the problem is that dementia is not well understood among our people in Nigeria. Many would think it is madness, and some people would [interjection] even think it is a family curse. Some people may say it is witchcraft [interjection] that witches are responsible for the illness* (Nwanne).

Nwanne's view of her people in Nigeria not understanding the illness as dementia was problematic, probably due to her higher educational level. Of course, Nwanne has achieved higher western education, and Nwanne is 35 years old and a master's degree student studying at one of the prestigious Universities in the UK. So, she has been exposed to western ways of thinking and ideologies. Similarly, Kelechi is 35 years old and studying for her master's degree in London. However, Kelechi did not see any problem with the dementia illness being considered witchcraft, a family curse, craziness, or madness by others but instead sees it as a way of understanding and framing the condition locally amongst the people in Nigeria as viewed:

> *Dementia in my community is stigmatised because people associate dementia with madness and insanity or being crazy. To be honest, people associate dementia with a family curse or ancestral curse [interjection], and it is just their way of understanding it locally. They could sometimes even link it up with witchcraft* (Kelechi).

Therefore, the subtle difference in the perception between Nwanne and Kelechi may be related to their field of study. Interestingly, Nwanne is in a science-oriented and related field of study, while Kelechi is in the art studies department. So, the terms witchcraft, curses and madness, craziness or insanity may be considered the everyday use of language or a metaphorical analogy of which the 'unfamiliar was made familiar' amongst the indigenous people in Nigeria. So, the terms can be considered a cultural metaphor (Zeilig, 2014) or a frame (Goffman, 1974) used to understand dementia. 'Frames' can help people understand their social worlds (Goffman, 1974). Thus, witchcraft and madness, craziness166nsanityty are practical lay knowledge or the beliefs for dementia. However, Edmund Gettier (1963) pointed out that there are situations in which a person may have a justified and true belief. Still, they would probably not be considered to have any knowledge.

Nevertheless, Kofi is 35 years old and a master's degree student from Ghana. He also did not see any problem with dementia being considered or framed as witchcraft or madness. According to his narrative, it was just the way the people in Ghana perceived dementia, and he confirmed that they did not see it as a purely medical condition but instead attached beliefs or spiritual meanings to the illness as narrated:

> *I wouldn't say there is no word for dementia per se in my community. In Ghana [Interjection] but in Ghana, where I came from, certain tribes, ethnic groups that you know, do not see dementia as a purely medical condition. They kind of attach all forms of spiritual connotation to it. [Interjection] You know [Interjection] somebody can say [Interjection] they can even say a woman suffering from dementia is a witch or suffering from witchcraft* (Kofi).

So, witchcraft, a family curse, craziness, insanity, or madness is a frame (Goffman, 1974) through which African people may perceive and understand the dementia phenomena. Perhaps embodied within their belief systems and everyday use of language for the illness, but that does not mean they lack knowledge of dementia. The indigenous people in Ghana did not perceive dementia as a medical condition but as witchcraft. Therefore, the term 'dementia' can be considered medical terminology rather than the lay use of language for the illness in Ghana. Similarly, Zubby, a 55-year-old engineer originally from Nigeria who has lived in the UK for 19 years, also framed dementia as witchcraft and linked the dementia phenomenon to metaphysical beings and forces as viewed:

> *I just told you about how it is framed in my community in Africa. When people are going through dementia, they don't see it as a sickness. They see it as karma has come upon the person and that the person has done evil, has done witchcraft against the other and that the karma is coming back on him or the person, and that is why the person is going through such a situation* (Zubby).

Therefore, laypeople and medical professionals may differ in judgement about what constitutes dementia knowledge. However, Plato argued that there was a difference between knowledge and belief in the 'Theaetetus'. Nevertheless, there may be a connection between witchcraft, curses, craziness, insanity, and madness, and it may have informed the people's lay knowledge of dementia. Indeed, knowledge can be represented as familiarity, experience, awareness, judgemental or propositional (Starmans, 2021), which means that knowledge can be based on belief, logic and even basic (Gordon, 2021).

Nonetheless, Ejiro, a 45-year-old shop owner, appears to have lived in London for 16 years. Furthermore, in similar ways to Nwanne, the previously noted master's degree student was also reasoning that dementia perceived as witchcraft and madness linked to the spiritual word was problematic and may not represent a dementia belief. He considered it a lack of knowledge and understanding amongst the indigenous people in Nigeria. So, the actual knowledge (Phillips et al., 2021) of dementia may differ from a dementia belief. However, Ejiro, currently living in London, is probably comparing the dementia beliefs with his newfound knowledge of dementia as informed in London:

> *But when I was in Nigeria, they saw dementia as a curse in my village because they didn't know it. They believe it is caused by an evil spirit or witchcraft…I don't think there is any problem here in London trying to seek help for dementia. But in Nigeria, there is a problem. And the problem is a lack of understanding of dementia [interjection]. They think it is madness* (Ejiro).

Similarly, to Ejiro, Yetunde, in her narrative, was also highlighting the change in her dementia knowledge whilst living in London. Thus, interconnecting different dementia knowledge that changes over time within a socio-cultural context as narrated:

> *We don't understand it as dementia because we don't know the name, but it is like madness. So, some people will say that dementia is madness. Because the people suffering from dementia will start talking and murmuring to themselves like they are mad [interjection], so I can say in my community dementia is like being mad [interjection] if you have dementia, they will say that you are suffering from madness.* (Yetunde).

Indeed, the current empirical data illuminated that for most participants now living in London, the way they now understand, perceive or view dementia has changed compared to whilst in Africa. Undoubtedly, all the participants emigrated from Africa and now live in London, which changed their knowledge of dementia. It could have been due to exposure and interest in learning new things. For example, Tunde is 45 years old and originally from Nigeria. He was previously a carer but later moved on to become a barber. He has his barbershop, and he is looking forward to further studying and becoming a business tycoon in the future. Therefore, a change in his knowledge of dementia could have been due to his 'exposure' and interest in learning, as narrated:

> *I did not know what dementia was until I came to the UK, so travelling to other countries is good. It is good exposure and opportunity for people to learn* (Tunde).

So, Tunde is implying that he learned about dementia in London. Similarly, for Eze, the change in his knowledge of dementia may be attributed to his exposure in the UK and interest in learning as narrated:

> *Growing up, we don't know much about it in Africa. But when I came to the UK, I started moving around and interacting with people, but we don't use the word dementia. When I started interacting with people and coming to the UK and interacting with children and adults with needs, I came to understand that there is something called dementia that existed even while I was in Africa…We did not know the name, but due to advancement in knowledge and exposure [in the UK], I now know that most of them back home were suffering from dementia.* (Eze).

Drawing on Eze's narrative may also suggest that he was given the word 'dementia' for the behaviour he was familiar with. Likewise, for Kaku, who is a 55-year-old security manager originally from Ghana and has lived in the UK for 21 years, a change in knowledge towards dementia may have been due to the dementia phenomenon being reframed due to his 'experience' in the UK as narrated:

> *My experience here in the UK is that the way they see dementia is not the way we see dementia in Africa.* (Kaku).

Nevertheless, for Bimbo, her change in knowledge about dementia may probably have been due to her occupation. Bimbo is a 45-year-old carer originally from Nigeria and has lived in the UK for 11 years:

> *I don't know any other word apart from it being called dementia here in London; it is just called dementia* (Bimbo).

Interestingly, for most participants, the change in their knowledge of dementia was brought about via technology, the use of the internet, awareness, and education. For example, Ejiro confirmed that he heard about dementia from the media as narrated:

> *That is what I want to share [interjection] before I personally did not know about dementia until I came to London and started to hear about dementia on TV and radio*…(Ejiro).

Similarly, Merida also confirmed that she heard and read about dementia from the media as narrated:

> *People don't know much about it. Yeah, people don't know much about dementia. There is not much awareness about dementia within the community [interjection], but you can read about it on the internet, though sometimes you see it on adverts and TV* (Merida).

Moreover, Yemi's narrative suggests that she had also looked up information about dementia on the internet as narrated:

> *Normally the first thing is to [interjection] thank God for Google, and people Google up a lot of information* (Yemi).

However, Kunle has not mainly read about dementia from the media but presumably may have had first-hand contact with health 'commissioners' in dementia care as narrated:

> *Obviously, not that I have actually or particularly sat down to read about dementia. But in this part of the world that we are, information is flying everything about how commissioners deal with it, and I can say that I understand what dementia is* (Kunle).

Furthermore, Nkem confirmed that Black Africans in London now have access to education and are becoming aware of dementia as viewed:

> *Generally [interjection] Africans are becoming aware of dementia; they now have access to education, information and the internet* (Nkem).

Thus, the data suggests a significant change in knowledge of dementia amongst the Black Africans living in London. However, the narratives of Fatou, a 45-year-old care manager. Originally from Sierra Leone and has lived in the UK for 19 years, she was talking from a more medical discourse whilst suggesting that some changes have occurred in the knowledge of dementia amongst the Black Africans living in London. Although, she insisted that more work is needed towards dementia knowledge amongst the group, as narrated:

> *I don't think dementia is well understood in Sierra Leone, and neither do I believe so within the Black community in the UK. But here in London, I think the Black community is starting to embrace the disease [glitches]. They are beginning to have a better understanding of the disease. But more work needs to be done within the Black community to create further awareness and knowledge about dementia…* (Fatou).

Thus, Fatou's narratives may further highlight a sense of social responsibility for the Black community in London. Nonetheless, Obiora is a 55-year-old pastor who has lived in the UK for 24 years. He sounds optimistic and enthusiastic about what he can offer as the church leader to make a difference and impact positive change. Particularly by 'talking openly' about dementia, providing education on dementia, and as well as in seeking to collaborate with medical professionals in disseminating dementia information to members of his church:

> *I know it can be difficult for people in the church community to accept dementia. So, I am thinking if there is a way, we can work together to pass the message across to the church community because the earlier the dementia signs are identified, the better for the person. And when you understand the reasons behind a problem, you can find solutions for it. [Interjection] So, I think if we can talk openly about dementia in the church on how it has affected people, family and impacted on career and their children, and their wellbeing, then people might start taking dementia seriously within our community* (Obiora).

Finally, the findings and the empirical evidence, as highlighted in this chapter, suggest that dementia is continually unlearned and relearned, framed, and reframed, a shaped and reshaped reality amongst the participants via culture, education, awareness, and access to technology (TV, adverts, and internet including social media). Nonetheless, some of the participants believed that dementia is a 'syndrome' as narrated:

> *… [Interjection] we were clearly told that dementia is not a specific disease but a syndrome* (Fatou).

Therefore, drawing on the empirical evidence shows that the knowledge of dementia amongst the Black Africans living in London has improved over time, but more work is needed. However, dementia education and information amongst the Black African populations living in London are driven substantially by biomedical concepts.

## Summary

The analysis presented the specific characteristics of the respondents. They were marginalised first-generation migrants originally from West Africa, identified as laypeople, and were churchgoers in the Black African community in London. The empirical findings illuminated the respondents' lay knowledge and beliefs about dementia. The results show that their lay knowledge and beliefs towards dementia are not static but evolving. Sociocultural factors, including religion, prayer, and spirituality guide the group's dementia knowledge and beliefs, and their dementia knowledge is continually unlearned, relearned, framed, and reframed. Indeed, it was a shaped and reshaped reality amongst Black Africans via culture, education, awareness, and access to technology, and the participants appear to reconcile different framings of dementia. The next chapter further presents the findings.

# Chapter 6

## Sociocultural Model

### Introduction

This result chapter further presents the findings of the research analysis. It focuses on five subthemes of the social identity/sociocultural model: (i) lay expertise, (ii) ethnicity, (iii) gender, (iv) older age, and (v) disability/ability. It illuminates the sociocultural factors which shape the sociocultural model for dementia in the Black community. The researcher developed the dementia model inductively from the data and added it to the literature. The model prescribes dementia management for Black African people with dementia and their family in the UK. Therefore, this chapter showcases the empirical evidence and provides in-depth explanations and interpretations of the data as it guides the sociocultural model.

### Lay expertise

Lay expertise as a subtheme in the current study provided the concept of understanding the social class difference and conflicts between laypeople and medical professionals. The public constantly judges lay people regarding their expertise in earning the public or society's trust. Similarly, medical doctors are also judged continuously by the same people or society regarding their professionalism. Moreover, doctors must put on their professional values and attitudes and communicate effectively with patients, their families, and their relatives. These values are acquired all through their medical training over a lifetime. Thus, medical professionalism (Chestnut, 2017) is the clinical competence or skills expected of medical doctors, ascribing medical expertise and a higher social class to medical doctors who are expected to act in noble ways that benefit the medical profession. Indeed, the current empirical data shows that doctors are medical experts, as narrated:

> *The doctors will have the final say [interjection]. I think the doctors will have the final say. That is why they are doctors…You people are doctors, and caring for the sick is your main responsibility. So, … I believe they are experts and knowledgeable in health and disease conditions. They are my learned colleagues [interjection] …they are legally bound to provide healthcare in the appropriate ways that befit their medical practices. Doctors are very important people in our society* (Bello).

Bello is a 55-year-old lawyer from Nigeria who has lived in the UK for 22 years. He perceived medical doctors as his learned colleagues who were more knowledgeable and experts in health and disease conditions. Indeed, 'doctors are legally bound to provide healthcare appropriately in ways that befit their medical practices'. Bello is a legal expert in his firm and may be similar to medical doctors in being knowledgeable and belonging to a similar social class, perhaps sharing similar economic circumstances. He is a church member with religious mores and considers himself a layperson. Notwithstanding, Fatou, in a way, regarded herself as a layperson in her narratives but assessed her knowledge of dementia as professional, which means that her dementia knowledge can be viewed as lay expert knowledge:

> *I believe dementia is caused by many things [interjection]. It is not a simple disease. But I know the disease can lead to the accumulation of abnormal proteins in the brain and then kill the brain cells...And leading to memory loss. But that is a bit professional, not lay, and I have gained that knowledge as a result of my work experience and background* (Fatou).

Indeed, Fatou holds a master's degree in social care and has risen to a care manager position. She is a church member with religious mores and can be considered a lay expert because she has acquired the competence, experience or skills expected to be an expert. Therefore, her dementia knowledge can be regarded as expert knowledge about dementia. Similarly, Zubby, who is also a professional engineer, considered himself a layperson as viewed:

> *I am not a medical doctor…But I think one of the causes of dementia is hereditary. That is what I think. I am talking as a layman. I am talking as a layman…* (Zubby).

Likewise, Kofi considered dementia from a layperson's point of view:

> *From my layman's perspective, [interjection] dementia, from what I understand, is that people at a certain age begin to show signs of forgetfulness [interjection], lack of situational awareness and being withdrawn from society. That is what I feel and know about dementia…We don't so much see it in Africa, but my experience in this country is that most people with dementia are older people. And old age has a link with it, and that is all, and that is also my belief as a layman* (Kofi).

Furthermore, Eze provided his dementia explanation from a layperson's point of view:

> *That is what I think. I would have used the word dementia, but I just wanted to use a layman's explanation for her illness. She showed brain impairment with a lack of memory…* (Eze).

Therefore, all the participants were experts in their chosen fields. So, their dementia knowledge can be considered lay expertise, defined as ‘a general cultural stock of knowledge’. Nonetheless, all participants acknowledged that medical doctors are more knowledgeable in dementia and have expert medical knowledge. Regardless, the participant showed to have valuable lay knowledge about dementia. Nevertheless, the empirical data shows that participants are speaking particularly about their views about medicines and doctors:

> *Here in London if I am worried about dementia. I will go and see my GP [interjection] GPs are medical doctors like you, and they understand dementia better than other people* (Ejiro).

Furthermore, Nonye narrated her dementia experiences to justify her doctor’s expertise:

> *My GP is good at his work. In fact, he is looking after my husband and me. You know, my husband has got Alzheimer’s. I thought I had it as well, but my memory is not affected, so I am yet diagnosed with dementia. The doctors believe I don’t have, and my children are equally convinced that I don’t have dementia. What do you think, my son? Because I know you are a doctor and an important person* (Nonye).

Nonye is a 75-year-old retired teacher who has lived in the UK for 40 years. She referred to the researcher as her son several times to emphasise her age and perhaps wanted to take the position of a mother in the interview whilst designating the researcher in the place of a son. Undoubtedly, the researcher actively listened to Nonye’s narratives, which made her happy. However, some of the participants expressed dissatisfaction with their doctor’s behaviours and communication skills, as narrated:

> *GPs are the people to help deal with it, but not everybody likes their GP because some of them don’t listen to the patient and what they have to say when they visit the doctor’s surgery. They sometimes can be full of themselves. Yeah, it is like, ‘I don’t have the time to waste with you now and let us deal with it as quick as possible. Yeah, they are just equally as sick as well [interjection]; to be honest, I don’t like seeing doctors* (Merida).

Likewise, drawing on Yetunde’s narratives further highlighted the need for doctors in dementia services to be able to ‘listen’, as viewed:

> *It is their job to treat us when we are sick. GPs are good people doing their job. So, I think they are very intelligent people. They went to school to learn it, but the problem is that they don't listen to us as they as supposed to, but they are very good people in our society* (Yetunde).

Therefore, the empirical data suggest that medical doctors were perceived as intelligent people, professionals, or experts in dementia, and well-read. Nevertheless, the empirical evidence also shows that some participants' pragmatic choices towards dementia were limited in 'choice', as narrated:

> *But the point is that as a man, I may be worried about the stigma and may not want to see a doctor. Because as a man, when you start losing your mind, you might become a laughingstock, and your wife and children might also want to keep it secret [interjection]. Having dementia will not make us happy [interjection]. We will do all things to make sure we are okay with dementia, but we will have no choice other than to see our GP for help* (Kaku).

So, the doctors' medical model of dementia care can be limited, and some participants would require a holistic approach to dementia. Indeed, a sociocultural model of dementia can address the stigma in the Black African community. The doctors' understanding of dementia may be limited to the biomedical concepts of dementia as a disease. On the other hand, the Black Africans living in London can be considered to have some expertise in understanding and knowledge of dementia within broader sociocultural, socio-political, and socio-economic contexts. For example, considering the views of some participants can suggest the need for government interventions beyond medicine but rather addressing inequality and inequity in dementia. For instance, Tunde argues that Black Africans in London are 'disadvantaged in education, employment, and dementia care services' as narrated:

> *Let the UK government know that they should provide adequate and proper health services and social care for Black Africans with dementia in London. Black Africans in London are disadvantaged in education, employment, and health care services* (Tunde).

Interestingly, it appears as if Obasi's view provided some connections between socioeconomic status and dementia prevention by suggesting the role of the government in making life 'easier' for its citizens as narrated:

> *I think the only way to prevent dementia is for the government to make provisions for everyone not to live a hard life before they grow old. If government make things easier for people, it will reduce the amount of suffering people are undergoing. That way, people cannot have dementia when they become older* (Obasi).

Furthermore, Yoofi's idea further illuminates the need for dementia awareness and education amongst Black Africans and the need to reduce the rate of unemployment as narrated:

> *I think the government should provide more awareness and education in the African communities about dementia. There is so much stress and unemployment within the Black community in London* (Yoofi).

In addition, laypeople may be limited in their biomedical knowledge or the knowledge of the medical treatment of dementia. Still, they can be considered knowledgeable in the local management or the local community dementia practices as viewed:

> *I am not aware of any particular medication for the treatment of dementia, but we are used roots and herbs from time immemorial. So, we are constantly using these herbs and roots. I believe it is allowed just like the GPs are allowed to use their medicine… I am not aware of any medication that can be applied to treat people with dementia, but there could be a medication like 'XYZ' for dementia, but I am not aware of it. But I believe in eating healthily, doing the right things like not thinking too much, being free from stress, being around family members and advising them to be in good shape. So, that is what I think is the medicine* (Kunle).

Kunle was unaware of any medicine the medical doctors used to treat dementia, presumably because he had no medical background; he is a layperson. However, he knows the local roots and herbs used locally to treat dementia. He was conscious of healthy lifestyle habits that can help individuals be in good shape and considered critical behavioural factors that can aid in dementia prevention. The current study agrees with Kunle on a healthy lifestyle and sociocultural factors; indeed, previous research by Dominguez et al. (2021) illuminated the importance of nutrition, physical activity and other lifestyle factors underscoring a crucial role in dementia prevention.

Similarly, Finda and Yoofi were also lacking in biomedical knowledge, but they were equally aware of the local treatment of dementia, as narrated:

> *In Liberia, they use many things like holy water and holy oil, burn incense, and use local roots and plants. But here in London, they use the medicine, but I don't know the names of the drugs. For the patients on the medication, it will be written in the care plan that we should administer their medications. But I don't know the names of the medications* (Finda).

Moreover, drawing on Yoofi highlighted an indigenous practice in Ghana and compared it with London:

> *Local treatments that are used include things like olive oil, herbs, vegetables, and roots familiar to the community people. Usually, in Ghana, the indigenous people know how to mix the herbs and roots of plants to obtain a mixture that might aid recovery from different sicknesses. It is a practice well known to them, and they still practice it now. Outside of Ghana, you can even get some of these herbs and roots in some shops here in London* (Yoofi).

Furthermore, the empirical evidence suggests that most participants were knowledgeable in the dementia preventative measures practically applicable to dementia. For example, Zubby and Seyi were aware of healthy lifestyle habits as narrated:

> *The only possible way to prevent it is to live a healthy life like doing exercise, eating more vegetables and less of fatty food. Playing games, not drinking too much and smoking too much. And providing education and awareness on dementia in African communities is also important* (Zubby).

Likewise, drawing on Seyi provided additional advice on the prevention of dementia:

> *Dementia comes with older age with increasing death of the brain cells, but lifestyle factors can influence who get dementia and who does not. For example, engaging in mental activities such as studying, going for exercise, eating balance diet, having adequate rest and not being hard on oneself. I also think people should drink less or avoid excessive alcohol intake or cigarette smoking* (Seyi).

Nevertheless, laypeople are limited in medical knowledge and language. Still, they must negotiate lay obligations professionally, which may require lay expertise or lay expert dementia knowledge and probably conflict with medical expertise. For example, drawing on Fatou's view may reflect her expertise, which may suggest that Fatou is a social care expert because she is an adult social care manager with a master's degree in social care, as narrated:

> *I have worked with the council unit and adult social care for some time. So, I think I know a bit more about dementia…It is a bit different to a decline in cognitive ability due to old age but rather more like a disease condition. From my master's degree, I know that I am aware of the social factors that affect ageing in our community. So, a bit knowledgeable about the issues surrounding dementia and Black communities in the UK* (Fatou).

Indeed, drawing from the empirical evidence across the data set and the observations and interactions with the Black African populations living in London suggests that laypeople may be limited in medical knowledge and expertise. However, the participants are from diverse walks of life and have acquired competence and skills in various fields, suggesting that they may be considered lay experts. Moreover, family, friends and relatives' experiences and insights can help medical doctors facilitate collective processes of lay knowledge production and obligations in professional-lay relationships. On these grounds, it is crucial and necessary for physicians to consider the emphasis and ethics of family consent, familism and respect for patients' autonomy which revolves around individual patients with dementia, their families, and relatives, and in conjunction with medical ethics (Losada et al., 2020). Therefore, the current empirical data shows that the participants have lay expertise to offer in dementia care in the Black African community in the UK.

### Ethnicity

Ethnicity as a subtheme provided the concept of understanding the background of the participants in the group. The data description suggested that all the participants were originally from West Africa, and most participants have lived in the UK for 15 years or more (Please refer to demographics). Drawing on the excerpts across the data set suggests that all the participants identified their country of origin but considered themselves Black people either as Black British or Black African. All the participants felt their community was a Black community. For example, Kunle is originally from Nigeria but regards himself as a Black British:

> *I am here from Nigeria to work, although a Black British national* (Kunle).

Moreso, Fatou is originally from Sierra Leone. Still, in her personalised worldview, she considered her community in the UK as a Black community and her people within the community as Black people. Logically insinuating that she is a Black person from Africa living in a Black community in London as well as contributing positively to the Black community as narrated:

> *I don't think dementia is well understood in Sierra Leone, and neither do I think so within the Black community in the UK. But here in London, I think the Black community is starting to embrace the disease [glitches]; they are beginning to understand the disease better. But more work needed to be done within the Black community to create further awareness and understanding of dementia* (Fatou).

On the other hand, Eze is originally from Nigeria. Still, he generalised his worldview about Blackness to include all Black people and Black African populations affected with dementia within the community as viewed:

> *…this is one of the things that I have been saying that we Black people commonly lack so much in our community. I don't want to sound negative, but the truth is out there. It is high time the Black community stand up and finds a way for their voice to be heard. A problem for one is a problem for all…* (Eze).

In addition, Eze's view may also illuminate that some Black African people at certain stages of dementia would require home care. However, it might be considered unpopular amongst the Black African populations living in London, presumably due to their African background or cultural identity, as narrated:

> *If you visit a care home, you don't see any Black African people there. It is not because they don't know about it, but it is just how we are brought up, and that is the reason* (Eze).

Nevertheless, some participants considered themselves a minority in the UK. For example, Kunle felt like a minority in the UK but hoped for better health because of staying in London, as narrated:

> *So, as a minority here in Europe, and especially in the UK, and more, than we are in London, we need to do more for ourselves, not for anything else but to make sure that our health is a big 'superstar' because our condition is no longer the same as where we came from…*(Kunle).

However, none of the participants considered themselves White people, which helped the researcher to clarify their identity and self-concept further because there could be a possibility of ethnicity and identity conflict (Rahim et al., 2021). Indeed, there is a possibility of a multiplicity of selves in dementia (Bomilcar et al., 2021). For example, some participants may decide to self-identify as white or any colour or an alternative ethnicity. Of course, self-identity and self-concept or ethnicity can be complex and multifaceted, encompassing different cognitive processes, personal beliefs, and psychosocial influences. Nonetheless, all the participants self-identified as Black African and participants clarified that they were not Europeans as narrated:

> *… For example, I know that the research is based in London, anyway, but we are not Europeans…* (Kunle).

The data also suggests that some participants shifted their focus slightly towards perceived racial disparity and a bit away from ethnicity. For example, Bello drifted his views of dementia and disparity towards race and racial factors:

> *And I think all races are affected, but I don't think they are equally affected because so many factors may be involved in the cause of dementia* (Bello).

Drawing on Bello's narrative shows that the risks for dementia can involve some factors, including hypertension and diabetes, and may be more common in Black people (Shiekh et al., 2021). For example, a previous study, Wu et al.'s (2017) review investigating the trends in dementia prevalence and incidence from 14 studies across nations, including studies from the UK and Nigeria, suggested that improving living conditions, education, and access to healthcare may reduce the risks of dementia. Nonetheless, Cao et al. (2020) highlighted that the prevalence rate of dementia was higher in Europe than in Africa. Notwithstanding, in the current study, some participants drifted their narratives towards a similar Black and White dichotomy and experiences:

> *White or Black human beings age, there is a possibility of us suffering from dementia* (Eze).

Likewise, Efe drew on her experiences and highlighted cases of Black and white people with dementia:

> *[Interjection] yeah, my experience… I go out to assess dementia patients and assess many patients; with each assessment, I usually come across a few cases of dementia, both male and female, Africans, white, and a lot, it depends. But the few Africans, because we are focusing on Africans, not too many. But a few female and*

> *Black male Africans that I have come across live with dementia. But also talking about the white ones, most of the cases are different* (Efe).

Presumably, there is a need to be careful because perceived racial differences can lead to prejudice, either in-group or out-group conflicts (Tajfel & Turner, 1979). Indeed, when it has to do with racial identity, that might become more important than the individual's self-identity or ethnicity. Race categorising groups based on shared social qualities is an exceedingly complex and challenging concept in public health and health promotion (Cross, 2018). However, racial differences identified in the study incorporate the participants' internalised beliefs about dementia as experienced by some of the participants. Nevertheless, the current empirical evidence suggests some perceived inequalities in dementia care are associated with the time for caregiving linked to some economic issues, as narrated:

> *So, dementia is something that might not have that attention as it were with the Europeans because making money here is more preoccupying for us, especially for people who have relocated from other places, for example, like other Africans down here…but as economic migrants, we are more preoccupied on how to make money and to make our own future better in terms of economic empowerment* (Kunle).

Nevertheless, for Eze, the inequalities and inequities in dementia may be related to some sociocultural issues, as narrated:

> *I said it before; it is how we are being brought up or cultured. We are more home-based people than a general care home, and they can be taken care of at home and, at the same time, access the hospital when the need arises. But for me, in my own personal opinion, we don't know much about care homes. If you visit a care home, you don't see any Black African people there. It is not because they don't know about it, but it is just how we are brought up, and that is the reason* (Eze).

Seemingly, the disparity may be associated with the caregiving behaviour of the person with dementia as narrated:

> *From the little that I have said before, if you visit a care home, you will see less than 5% of Black people there, which may not even be up to 2% because most Black people with dementia stay in their home* (Eze).

However, for Okafor, the inequality and inequity in dementia may be associated with lower life expectancy amongst the Black African populations as narrated:

> *You know, [Interjection] the way they manage dementia here is different from how they manage it in Africa. That is why you see abroad, or in the Western world, people with dementia live longer, not only with dementia older people. In Africa, you will see obituaries 80 years, and they say 'to God be the glory. Eighty years is not 'to God be the glory'; rather, that is the time the person is supposed to live and enjoy life in full. But 80 years or 85 years in Africa, the person is gone. But here in Europe, you will see 96, 100 years old* (Okafor).

Indeed, life expectancy is a reduction in the expected length of life at various thresholds for a population (Liou et al., 2020). Nevertheless, for some of the participants, the inequality and inequity in dementia may be associated with language and positive doctor-patient relationships:

> *The experience with my GP is good [Interjection]. My GP is doing a good job, and I have a good relationship with him. We speak the same language [Interjection]. We speak Igbo. He is an Igbo man originally from Enugu state in Nigeria, and he is quite a good doctor [Interjection]. He knows what he is doing and has been a GP for a long time [Interjection]. He is very good* (Nkem).

Of course, a language barrier may occur when people speak different languages and cannot understand one another, leading to a breakdown in language and communication. For most Black Africans, English is not their first language, and the language barrier may thwart the formation of interpersonal relationships that can lead to misunderstanding and distrust. Interestingly, Nkem felt happy to have a doctor who speaks the same language. However, for some participants, the inequality and inequity in dementia caregiving may be associated with immigration and citizenship. For example, Ben's friend needed a visa for her stepsister to come to the UK, and the family may find getting a visa to the UK problematic:

> *He is thinking of bringing her stepsister from Nigeria to take over caring for her mother for some time here in London, but that is if she would be granted Visa. I hope she gets it because my friend needs her around her mother for now…* (Ben).

Moreover, the inequalities and inequities in dementia may also be associated with inadequate planning for older age as viewed:

> *[Interjection] number one is that we have to start planning for our old age.* (Okafor).

Furthermore, the inequalities and inequities in dementia may be associated with the environment and housing as viewed:

> *[Interjection] we must set the environment right…* (Kunle).

Moreso, drawing on Okafor regarding the inequalities and inequities in dementia could be apportioned to the government and governance.

> *Okay, if you go to communities in Africa, there is nothing like open spaces. They have used all the spaces to build houses. But to have a community is not about building houses, but you also have to create open spaces [Interjection]. Okay, look at London, before you drive 2 kilometres or a kilometre you will see an open space. You see people riding bikes, and you see people sitting down and having a chat, you see people climbing and people playing games of all sorts. It is to keep body and mind going, but in Africa, no! Nobody thinks about that. So, that is where I blame the government. Hence, I also blame the local community. And also, individually, we don't think of such provisions for ourselves and our community* (Okafor).

Of course, drawing on Okafor's narrative can suggest that the dementia disparity associated with environment and housing may be more evident in Africa than in the UK. In London, better environmental supports are available for people affected or who have dementia than for people with dementia in Africa. In addition, the disparity in dementia may also be associated with hard life or adversities, as narrated:

> *…within the circumstance of the huge challenges that we are facing. We should go a long way; just to put in one of the songs of Fela, he said, 'we are suffering and smiling'. But that is not to say that we are smiling in the absence of suffering but that we are overcoming by making sure that there are other things that make us happy in the face of our adversities* (Kunle).

Furthermore, the disparity in dementia may be associated with diet and socioeconomic status. For example, an inappropriate diet may be associated with dementia and may also lead to heart problems, as narrated:

> *One of the things that make people fall sick or start dying slowly or have dementia is when they are unsure of what they will eat tomorrow or the next day. Their hearts will start beating, and some sickness manifesting here and there.* (Okafor).

Finally, the empirical evidence suggests that some of the participants recognised the social responsibility to share the dementia knowledge gained in the UK with their homeland as narrated:

> *I would like to tell many of my African brothers and sisters that dementia is also common among us. We should start doing something to understand it better and prevent it in our community [interjection]. Dementia is not only common among White people but also among Black people, and the earlier we start to deal with it, the better for us… And it is also important that we educate our people back home in Africa about dementia so that they can also start to do things that will make them live longer before developing dementia* (Kaku).

Thus, drawing on the empirical evidence can suggest that any beneficial change towards dementia for Black Africans may have to start with dementia education in the community and their homeland. Therefore, the inequality and inequity in dementia were associated with a disparity in dementia knowledge or the training and teaching about dementia in the community and participants' homeland. Therefore, it informed the sociocultural model for dementia. The researcher is a medical doctor and an applied medical anthropologist and sees the respondents' views as tangible. Indeed, medical doctors are more positioned to help family, friends, and relatives gain the dementia knowledge needed to change their community and homeland because social responsibility and accountability are embedded in community medicine and family medicine (Meili & Buchman, 2013). Moreover, it is seemingly vital for doctors to consider their patient's and family's lived experiences of dementia in providing holistic and socially accountable dementia care, including medical education and training on dementia.

### Gender

Gender as a subtheme within the social identity/sociocultural model theme provided the concept of understanding some gender 'troubles' (Butler, 1999) in the context of performativity, which posits gender as the day-to-day activity of people with dementia following social norms. So, gender needs to be explored or considered as they impact the presentation and progression of dementia and the conflicts with dementia management amongst the participants in the group because 'gender is what the Black African people do, not who they are'. Gender comprises the acts that identify them socially as 'men' and 'women'. Hence, drawing on Butler, the performance of gender will produce the identity it claims to reveal in the dementia understanding and how to diagnose and treat dementia amongst Black Africans in the UK. Indeed, drawing on the empirical evidence across the data set suggests that the conflicts in gender as a social identity are strongly evident within two subthemes: (i) Perceived gender roles and (ii) Gender disparity which structures gender inequality between men and women amongst the Black African populations. Meanwhile, most participants view gender as a risk factor for dementia. For example,

> *... [Interjection], but I have seen more women with dementia than men. I think dementia affects more women than men* (Remi).

The participant's idea is that women are more predisposed to dementia than men, delineating women as a determinant associated with an increased risk of developing dementia, thus highlighting inequality in dementia prevalence. Although, some previous studies provided evidence that sex is associated with dementia (Wu et al., 2017), with the prevalence of dementia more significant in women than men (Cao et al., 2020). Indeed, women are disproportionately affected by dementia in getting dementia and becoming dementia caregivers (Erol et al., 2016).

### Perceived gender roles

Men and women appear to differ in many respects, leading to a difference in perceived gender roles in dementia amongst the Black African populations living in London. For example, Tunde's discourse provided what may be perceived as his belief towards the gender role in dementia based on personality, which he considered women to differ from men:

> *In Nigeria, it is mostly women that take care of the elderly people in the family. Women are more appropriate for caring for older people, including both men and women, because they would have to wash them, cook for them, and feed them. Women have patience more than men, and men usually do not have the time because they might be busy chasing money or doing one business or the other. So, women are usually the main carer, and they provide good care for the older people in the family* (Tunde).

Indeed, Tunde regards women as having more patience than men. However, for Seyi, the perceived gender role may have little to do with the individual personality but more with the community care culture. He considered women to be more disposed and inclined to nursing and health care than men and thought men as 'subordinate' in the role as narrated:

> *I think anybody can take care of the older people in the family. It is just that women in our community are more geared towards nursing and health care, so most caring is done by women in the family, and men as subordinate in the role of caregivers within families* (Seyi).

Likewise, drawing on Yetunde illuminated women predominantly as dementia carers.

> *But I am saying that in our community, caring for people is done mainly by women in the family. To be honest with you, even here in London, most carers are women, and it is mostly women who are doing care work. Most of the care workers that I know, including myself, are women* (Yetunde).

So, Yetunde acknowledged that caring for a person with dementia is done mainly by women; therefore, women are disproportionately affected by dementia in becoming caregivers, as the previous study had illuminated (Erol et al., 2016). Framing of Yetunde's experience as a carer further strengthened Seyi's view about the perceived gender roles in the group based on culture rather than on personality and men as an accessory in the role of a caregiver, which led the current researcher to question the doctrine of egalitarianism in the dementia services. However, the Black African dementia caregiving practices based on culture may often be considered secretive and have inherent value and privacy, as illuminated in previous studies (e.g., Berwald et al., 2016). Nevertheless, drawing on the current researcher's background as a medical doctor can tell that male and female doctors have equal opportunities to attend to and care for their patients irrespective of gender or sex. Strikingly, some of the participants considered male caregivers inappropriate to provide the care needed for female patients with dementia:

> *As I said before, I did not provide care for plenty of dementia persons as a carer because most of the dementia people were women. As a male carer, I was not allowed to provide care for women because it was inappropriate to do so* (Tunde).

Indeed, drawing on Okafor's narrative highlighted issues of 'privacy' in dementia caregiving:

> *[Interjection] No! I will say a man to a man and a woman to a woman because of privacy. Do you understand me? But naturally, women are better carers than men* (Okafor).

However, Okafor’s view may infer that a man should care for a man and a woman should care for women because a male and a female are generally considered biological sex. So, the researcher would like to take a moment to reflect on sex and gender. Gender identity may be viewed as a biological and social construct. It is biologically constructed as sex and defined generally by the human chromosomes as XY for the male and XX for the female. Nevertheless, Okafor’s narrative may refer to intimacy and person-centred care or dignity in dementia caregiving, which may be shared across cultures as reflected in many studies (e.g., Sun et al., 2012; Bentwich et al., 2018; Huang et al., 2020).

Nonetheless, social constructionists will generally view gender as a social identity beyond sex and the male and female essential category. Notwithstanding, gender as a social identity is a fluid concept defined and moulded by culture and social relationships. Indeed, gender can be complex and political, developed through social interaction and culturally laden (Butler, 1999). As a result, in some cultures or groups, men and women may be taught to behave in acceptable or appropriate gender roles. Nevertheless, the Black African populations emphasised that the perceived gender roles in dementia care are premised on culture, which may be transmissible from mothers to daughters, as narrated by some of the participants:

> *Yes, it is expected that children should take care of their parents in the African community. Especially the female children…Our African mothers usually teach their daughters how to do these things, and the women carry it from generation to generation. There is an expectation for children to take care of their parents when they grow older* (Tunde).

Indeed, drawing on Yetunde highlighted the responsibility of caring for a person with dementia assigned to the person’s ‘first daughter’ in the family:

> *[interjection] in our African setup, or let me say in our community, it is expected that children and family members should take care of their older members of the family who cannot take care of themselves. And as I told you, it is mainly women that are doing the caring in the family, and it is the person’s first daughter* (Yetunde).

So, drawing on the empirical evidence suggests that African cultures expect children to care for their parents. However, it is also a common practice and understanding across cultures. For example, in Eastern cultures, filial piety is considered a Confucian concept derived from Chinese culture, which advocates caring for one’s parents. It may be associated with a longstanding parent-child relationship (Li et al., 2021). It shows that caring for one's parent is not limited to the Black African population in the UK.

**Gender disparity**

The empirical evidence across the dataset suggests a gender disparity in caregiving and the prevalence of dementia. Gender intersects to shape inequalities in dementia caregiving and the prevalence of dementia as viewed:

> *I am a carer, and I have been in the job for many years now [interjection], and I have seen many cases of dementia, and they are mainly women. I don't know the reason, but they are mostly women. But I think it is because women do everything in this country. They take care of the home, the children, work, and pay bills [interjection]… men are no longer men [laughs]. I think men are just lazing around and allowing women to do everything. It is very wrong, which is why most women suffer from dementia* (Bimbo).

Drawing on Bimbo's narrative can suggest an increasing family burden and responsibility imposed on women in dementia caregiving, thus shaping the risk of dementia in women. Another reason that may shape the risk of dementia in women may be that men tend not to reach the same age as women as they die younger than women. Thus, women have a higher life expectancy than men, as hinted in previous studies (e.g., Hosseinpoor et al., 2012). Therefore, gender identification amongst the participants has a robust cultural component as a social identity based on performance and productivity, as viewed by Bimbo. Still, for Ade, gender identity is based on relationships as considered:

> *It is a pity that women are more affected than men...I have been pastoring for more than 30 years [interjection]. For example, the divorce rate has risen up to 60% in our community; consequently, we now have a lot of single mothers in our society struggling and busy raising children all by themselves...* (Ade).

However, gender is not a fixed or innate fact but a fluid concept that varies across culture, time, and place. For example, drawing on Marie and her narratives can suggest that a traditional African society assigned power to women:

> *I could not believe my mother died...she was a very strong woman. Stronger than many men...* (Marie)

Indeed, a previous study in Nigeria had shown that power is assigned to women to feed their families and as the primary source of income and act as the protector of children and society (Kalu, 1996). Nonetheless, in modern African society or community, men must take on the primary responsibility of providing for and protecting their household, as can be delineated in some of the participant's narratives:

> *Ah, my brother, we men like to chase after money, and we don't have that kind of time to sit at home to look after an older person. The problem in this life is too much, and man must look for money…* (Obasi).

**Older age**

Older age as a subtheme within the social identity/sociocultural model theme provided the concept of understanding the lay causality of dementia amongst the participants in the group. And based on the empirical evidence, perceived older and younger age is ambiguous, not a fixed concept across the group, and they both need more clarity and meaning. Nevertheless, what is clear from the study is that dementia is mainly associated with older age, as most participants narrated. For example, Yemi believes that dementia is sporadic and 'uncommon' at a younger age as viewed:

> *I do not expect a younger person, a 13 or 14-year-old person, to suffer from dementia. I am not saying that there could not be one or two cases, but it is very rare. It is totally very uncommon for a younger person to suffer from dementia.* (Yemi).

However, Eze believes that dementia is not limited to only older age but is also associated with younger age as viewed:

> *Dementia can take different forms based on age. We are talking about older people, and older people can suffer from dementia. It is not only limited to older people but also young people but affects older people more than young people* (Eze).

Nonetheless, Ade's narrative is linked to older age as causality for dementia:

> *[Interjection] I read about dementia; it is mainly caused by old age…* (Ade).

Therefore, this subsection explores lay perspectives of the causality of dementia and the participants' observations about people with dementia. So, older age may be considered as a lay causality for dementia. However, older, and younger ages are ageing factors in the context of adulthood, and it was evident in their narratives that dementia is associated with ageing. Notwithstanding, Fatou made it more apparent that dementia may occur at a younger age, 'in that case, known as young-onset dementia'. Still, dementia is mainly affecting people within 65 years and above, as narrated:

> *It can also affect younger people and, in that case, is known as young-onset dementia, but normally it affects people within 65 years and above [interjection]* (Fatou).

So, the data above illuminated that dementia is an ageing problem. Nevertheless, there may be four kinds of ageing: biological ageing, chronological ageing, social ageing, and psychological or cognitive ageing. Biological ageing (senescence) is not substantially the same as chronological ageing or cognitive. For example, biological age may be based on the setting of biological markers, which are biomedical parameters that are used to evaluate the functional status of an individual in the absence of dementia, and fundamental prognostic indices for medical doctors in the diagnosis and treatment of dementia (Neugroschl & Davis, 2002; Bai, 2018). For example, the pathological hallmarks of dementia included the deposition of β-amyloid (Aβ) in amyloid plaques in the cortex and structural conformational changes in tau protein (Kumar & Clark, 2021), seemingly as informed by some of the participants:

> *Then I began to understand the dementia condition and what it was, that is, the attack on the brain cells and the breakdown of some of the proteins in the brain, and the cutting off some of the cognitive function of the brain cells* (Yemi).

Similarly, drawing on Fatou suggested the cause of dementia is 'the accumulation of abnormal proteins in the brain' as narrated:

> *I believe dementia is caused by so many things [interjection]. It is not a simple disease. But I know the disease can lead to the accumulation of abnormal proteins in the brain and then kill the brain cells…* (Fatou).

Indeed, these protein aggregates damage synapses, leading to neuronal death. The neuronal death may be associated with memory loss and poor coordination at an older age, as narrated by some of the participants, for instance:

> *...At times, age can play a significant part in the loss of memory. As someone ages, the person may lack what we call coordination functions like thinking, of which Bola actually has such behaviour because of her age. She has developed a loss of*

> *memory imbalance in remembering things. For example, when she was thinking it was morning when it was night and trying to do one thing or the other at odd times, unable to understand that it was still night. But her brain tells her it was morning, so it is because of an imbalance in remembering things, the time, or the day she is in* (Eze).

The deposition of the proteins in the brain cells leading to memory loss may be considered a process of the 'human lifecycle' ostensibly used by Eze in his narratives. Furthermore, it can be assumed that memory loss is a 'natural retrogression' as used by Kunle in framing his life experiences:

> *With life experiences, you know that the brain is more loaded, and it is a natural retrogression of the brain which affects the quality of thinking and things we can remember. As earlier mentioned, with the older generation of my family or friends and family, we could tell that they were not able to remember things. When I was younger, I noticed that when they grew into their 60s, 70s, and 80s, they could not remember many things, and it was difficult for them to grasp things. So, there were issues relating to their memory as they aged* (Kunle).

Indeed, memory loss because of ageing may be considered a process of the 'human lifecycle' as viewed by Eze:

> *So, age can affect the loss of memory from my perspective because as someone ages, he will have dead cells that will affect some part of the brain, some immune cells, and some of our cells start dying off ...But at times, when we eat food, it might not replace them because it is the process of the human lifecycle; as we age, there are things that follow ageing in human life* (Eze).

Nonetheless, as most participants narrated, people may become naturally forgetful at an older age due to continuous inactivity in the brain. Respectively, Ejiro and Okafor used a metaphorical analogy by comparing older age with an 'old machine' and 'old motor car':

> *And if somebody is getting older, they will also start to forget things naturally because the brain is getting older as well. It is just like an old machine that starts to wear out and eventually will pack up… So, we cannot prevent it [interjection] dementia is due to old age, and we cannot prevent old age* (Ejiro).

Indeed, drawing on Okafor, forgetfulness at an older age was associated with a metaphor, delineated as an ‘old motor car’, as narrated:

> *[Interjection] The more you get older, the more your brain gets inactive. Especially when you are not reading or engaging in financial activities or day to day activities, then your brain gets to forget a lot of things…The motor car we drive, the motor car we drive, is just like a resemblance of a human being. If you park a car for too long, many things go wrong with it. Either the tire goes flat, the battery runs down, or the brain box is affected [Interjection], the power steering becomes stiff just like a man* (Okafor).

Regardless, drawing on the participants’ narratives may seemingly suggest ageing and bodily activity as a correlation between dementia causality and prevention, for example:

> *…So, when somebody is not active, that part of the body goes inactive* (Okafor).

However, ageing or the meaning of older age is a complicated, complex, and non-homogenous process. So, it means that each person is imbued and affected by a diverse set of circumstances that may include environmental, social, and biological factors, thus leading to differences in older age or ageing for any individual in the group. It appears for Kunle that a person’s age may be associated with the person’s behaviour and the ability to engage in meaningful social conversation, thus inferring psychological or social ageing:

> *In my community, we can actually model our pattern of behaviour once we engage with someone. Firstly, I can tell who is older or the age range they belong to base on the quality of what they say and what they discuss at that current moment…* (Kunle).

Furthermore, the perceived pattern of the behaviour, as mentioned by Kunle, may infer implicitly to some events based on social parameters, such as being reasonable amongst peers within the group or gaining wisdom and character. Whilst for Zubby, it appears that a person’s age may be associated with the person’s cognitive skills and the ability of the person to remember and retain information, thus inferring psychological or cognitive ageing, as can be inferred from his narrative:

> *At my age what I can say about forgetfulness is that it is not easy. You put things where you don’t remember; you kept them there. You understand! And, then little mental arithmetic you could do when you were little, presently it is not as easy as*

> *it used to be. Like, a thousand five hundred minus a thousand three hundred and ten. When I was little, I could easily give you the answer in a second, but now it takes me a little bit of time to work it out. I don't mean using a pen and paper but doing it mentally. It is not very easy as it used to be when I was little. At a certain age, as you are ageing, you forget easily. You put things in one place you might not remember you kept them there. So, you keep looking for your keys all the time in your pockets [laughing] because you have forgotten where you kept them. You understand, especially when you are wearing clothes with a lot of pockets. You put it on the right-hand side of the pocket, but you start looking for it on the left-hand side of the pocket. It is constant* (Zubby).

However, drawing on Zubby's narrative may suggest that cases, where a person's cognitive skills and inability to remember and retain information become constant may represent signs of mild cognitive impairment (MCI). Although, some individuals' MCI may revert to normal cognition or remain stable. Furthermore, drawing on Eze's narrative, it appears that a person's age may be associated with the individual's cognitive skills and the ability to reason, thus inferring cognitive or psychological ageing:

> *It is part of ageing...Because I still can do some part of mathematical reasoning, I don't actually see it as a big problem that warrants me to have a second opinion, like discussing it with a medical practitioner or someone more knowledgeable than myself. I don't see it as something challenging anyway, and that is why I just take it like that* (Eze).

Seemingly, for Sesan, it instead implied that a person's age is biologically determined and that any individual can be prone to dementia disease at older age 'when something is wrong with their brain', as narrated:

> *[Interjection] dementia is when somebody has the problem of forgetting things because they are getting old or because there is something wrong with their brain…* (Sesan).

Therefore, biological age is based on the setting of the biological markers, as earlier mentioned, whilst chronological or social age is the evaluation of the indicators of time scales in the ageing process into adulthood delineated by events based on social parameters as viewed by the participants. Moreover, this may include a person's graduation from school, getting a job, getting a mortgage, getting married, and having a child, as demonstrated in a previous study

(Neugarten & Hagestead, 1976). Furthermore, the ability to use one's mind actively to make a judgement or form a well-connected idea at an older age as viewed:

> *You don't expect somebody who is 80 years to think like a person of 25 years* (Sesan).

These parameters vary widely within societies and cultures but can be used by individuals to determine their age within their groups. Therefore, using biological markers or biological age alone for the pathological basis of dementia may be deceptive, limiting, and inconclusive. Indeed, the social ageing parameters also need to be considered because older age can be viewed as a biological and social construct, as seen in the data. Furthermore, despite their physical or biological decline, many older people may have a sense of 'the ageless self' (Kaufman, 1986) even when diagnosed with dementia. Thus, old age is also a social construct indicating wide variations in how age and dementia are defined and perceived within groups. For example, some of the participants acknowledged that some older people might not develop dementia as viewed:

> *...Although not everyone that is old will develop dementia* (Ben).

Thus, dementia may be perceived as an illness, but ageing may be considered normal for the person and those around them. Moreover, older people can recreate self-identity within groups, which is a lifelong process (Kaufman, 1986). Meaning that cultures vary widely in the status they give to the older person. Hence, certain old age in one group may not be regarded as older age in another group. For example, Nwanne perceived herself as a young woman who is not old but 'bubbling':

> *[Interjection] at the moment, I am not forgetful because I am still young. I am a young woman, doctor. Doctor, I am not old yet [laughs]. I am still a young woman and bubbling. I am not old* (Nwanne).

Although the data may have illuminated power dynamics between the participant and researcher, and the intersectionality around class, gender, older age, and professional status in this study and our modern world, nonetheless, there may be more emphasis on youthfulness, intelligence, beauty, productivity, independence, and individualism in our modern world. So, older age can be associated with negative age stereotypes as being less productive, less flexible, overwhelmingly dependent on others and less adaptable, as illuminated in previous studies (e.g., Rippon et al., 2014). In that case, older age is less valued, leading to prejudice against older people as they may be considered mentally deficient, empty-headed, half-witted, or brainless. In the West, older age may be perceived with negative connotations such as a 'social death' or 'tragedy' (Sweeting & Gilhooly, 1997, p. 98; McParland et al., 2017, p. 261) and can be diagnosed with dementia. Nevertheless, older people are held in Africa as belonging to a religious age group to be treated with reference and respect and considered guardians of the clan's tradition and history (Ndamba-Bandzouzi et al., 2014). However, against this backdrop, older people in Africa may have dementia but are unaware of it.

Furthermore, our modern society has entered the information age of computers, global communication, information technology, and artificial intelligence, thus giving a more substantial biological importance to the brain rather than the entire being. So, we now specifically value the cognitive brain functions such as reasoning, memory, thinking and arithmetic or mathematical calculations more than our sociocultural or entire well-being, as explicitly expressed by some of the participants:

> *…little mental arithmetic you could do when you were little; presently, it is not as easy as it used to be* (Zubby).

Indeed, Zubby considered cognitive brain function as 'mental arithmetic', whilst Eze considered it as 'mathematical reasoning':

> *At the moment, because I still can do some part of mathematical reasoning, I don't actually see it as a big problem that warrants me to have a second opinion, like discussing it with a medical practitioner or someone more knowledgeable than myself* (Eze).

Furthermore, such a biological bias tends to devalue many older people, especially if they are suffering from memory loss or cognitive impairment, as narrated:

> *…in Nigeria, they might say let the person go back and stay in the village... They might say you are an old man or an old woman, go back to the village and stay for your time is gone* (Okafor).

Moreso, in our modern world, artificial intelligence (AI) and computer communication, as illuminated in a previous study (Danowski & Sacks, 1980), has become the respect of the 'second self' (Helman, 2007, p. 10), which has older people as irrelevant or less important in our modern society. Indeed, discrimination towards older people in our community. The data shows older age is premised on the biological and cognitive frame of ageing, consequently illuminating the prejudice against older people with memory loss, forgetfulness, and brain impairment or inadequate cognitive skills, as may be found amongst people with dementia.

**Disability/Ability**

Disability as a subtheme within the social identity/sociocultural model theme provided the concept of understanding the disability discourse amongst the Black African populations as a group. For example, Bello considered dementia a disability as viewed:

> *…dementia could be a form of disability* (Bello).

Disability generally puts an individual in a disadvantageous stance, while ability puts an individual in an advantageous position. Still, both depend on the capacity to perform a task. Most participants associated dementia with the lack of ability to perform daily tasks:

> *[interjection]…like I go to his house and help him with some activities like shopping, washing and many things that he needs [interjection] I assist him with many, many things* (Finda).

Similarly, drawing on Kuku suggests that people with dementia would need help with 'daily activities':

> *But somebody suffering from dementia would need help, daily care and assistance with all his daily activities* (Kuku).

Finda and Kuku's discourse discusses dementia as the inability to perform needed daily care activities by the individual with dementia and the inability to understand people with dementia due to the difficulties in their communication. For example, Titi particularly expressed her views about communication and the need for extra time to spend with people with dementia, as the current time allocated for the services is short of what is required:

> *I used to clean her, do her shopping, and make her food…What is very challenging is the inability to understand them. Some of them cannot talk properly, and some of them find it difficult to follow a conversation [interjection]. They always forget things that are said to them or what they are told to do. That is very challenging for us as carers, especially when the time allocated for the service is short of what is needed for their care* (Titi).

Likewise, Bello perceived dementia as a biological problem, an issue with communication, progressive memory loss and forgetfulness:

> *…they may have progressive memory loss with signs of forgetfulness and the inability to take care of themselves. Sometimes they may have difficulty with language* (Bello).

So, people with dementia can have language and memory problems and may not be able to perform their daily activities, as informed by the participants. The significant complexities with people with dementia appear to be an issue of dependency and poor communication, as elucidated by the participants. However, it seems as if the dependency and poor communication are mainly due to biological factors in the individual with dementia that may result in progressive memory loss and can lead to confusion, as accentuated by some of the participants:

> *So, a person that is confused will have it difficult being in control of life and when it comes to conversation. The person cannot have a decent conversation with family and friends any longer due to dementia. And will find it hard to carry out daily tasks…Especially the confusion! The confusion! The confusion! When a person is confused, I tell you, when a person is confused, it is hard for them to carry out their daily task. They find it difficult to be able to deal with their affairs of life. They get confused and sometimes with loss of capacity. They cannot reason effectively and deal with their daily affairs as they would have loved to. So, a friend or family member has to step in on their behalf to carry out the task that they would have done* (Yemi).

Consequently, it appears as if the confusion in individuals with dementia is associated with cognitive impairment or impairment of the brain, as viewed by most of the participants:

> *[Interjection] I think I would rather consider dementia as a cognitive impairment with difficulty in reasoning. It is associated with the impairment of the brain* (Kelechi).

Indeed, Yoofi considered the inability a result of ‘cognitive impairment’, as viewed:

> *They usually lack the ability to coordinate daily activities due to cognitive impairment* (Yoofi).

Nonetheless, Bello suggests a need for an attorney for people with dementia because the people with dementia may lack the capacity to make informed decisions as viewed, as such, delineating dementia as a disability.

> *…and people with dementia may lack the capacity to make an informed decision and may require an attorney* (Bello).

However, Yemi considered dementia a ‘pathology’ requiring extra support. As such, dementia may be regarded as a disability:

> *Dementia is regarded as a pathology, and the hours you would probably spend with someone with dementia is different from someone who hasn’t got the pathology at all, whom you just need to support. You don’t need to go shopping and all that…You probably just what to escort the person because they know what they are doing, they just what to buy bread or they want to buy milk but just that they can’t go alone just because of old age. But the person with dementia would probably need the support because they would just sit at home, and you would also make the lists of things to buy, okay, let’s look at the cupboard; he probably needs tea, and he does not know what he needs* (Yemi).

However, Marks (1997) argued that disability could not be understood outside its sociocultural context. Indeed, disability is not only localised in the biological factors of an individual, as Yemi considered dementia a pathology. Nevertheless, most participants illuminated the environment as an essential factor in believing in dementia disability, as viewed:

> *People with dementia can also be confused with their condition, environment, and even the house* (Marie).

Thus, disability is not just situated in the intrinsic characteristics of the individual but also within the individual’s cultural and social environments. Perhaps this led some of the participants to view dementia as a ‘hard life’, meaning lacking governmental support at an older age, as narrated:

> *That is why I am saying that the government should help us enjoy our old age instead of us becoming sick when we are supposed to be resting from our hard work. I just they beg [interjection] government should help us. Give us a job, employment, better school, better social amenities, better hospital, and better welfare. I am only begging because this life is too hard* (Obasi).

Indeed, drawing on Nonye provided some clarity on the meaning of ‘hard life’ in the current study as viewed:

> *When I say hard life, I mean living a difficult life full of stress, unemployment, financial distress, and loneliness* (Nonye).

So, individuals may vary in a particular bodily and intellectual capacity. However, the common denominator between the disabled and the able person lies in their material, cultural and social environment. It means that the conflicts between disability and ability remain within the sociocultural, environmental, and economic context, as highlighted by some participants, including the need for employment, education, better dementia care services, and social amenities. Thus, it informed the sociocultural model for dementia amongst the Black Africans living in London. Therefore, society can empower the person with dementia to perform needed or daily care tasks by providing the right sociocultural environment for those with dementia and their families. Perhaps, which led Okafor to give some advice for families on the issue as illuminated:

> *That someone has dementia does not necessarily mean that the person is incapacitated. So, you should allow the person to do something, but you should not allow the person to drive or use a knife or handle weapons. But take the person out. You know! Say, ‘mummy or daddy let us go out’, take them to the park, and let them talk with people. By the time they see their old friends, they will start to recollect past information, such as in days, weeks, months, and years. I think talking and talking will make the brain get sharp again* (Okafor).

Essentially, a sociocultural environment is shared or held in common between individuals in different bodies. Therefore, it is logical or reasonable to consider an individual’s body, mind, or biological circumstances as a non-variable element, whilst the sociocultural environment can be regarded as a variable element. Thus, the variables factors rather than the non-variable characteristics of the individual with dementia should localise the primary focus on dementia disability or ability because dementia disability or ability may be interchangeable. If we alter the sociocultural environment negatively for a person with dementia, it will become a disability. However, changing the sociocultural environment positively for a person with dementia would become an ability, and some studies have shown it. Therefore, as previously stated in this study’s review, dementia as a disability is not an individual’s intrinsic characteristic but an outcome produced by the cultural and social environment. Disability does not exist purely at the level of the individual pathology as in a person with dementia. However, a condition created by a combination of social and cultural factors in the individual with dementia. As can be highlighted in some of the participants' narratives:

> *[Interjection] It also has its financial burden because people suffering from dementia are withdrawn from their economic resources or aspects. For example, they can no longer work, and you know, they become unproductive* (Kofi).

Nonetheless, Okafor's narrative can delineate that people with dementia are not just a burden to the community, but they can contribute to society in many ways as viewed:

> *…That somebody has dementia does not mean that the person has nothing to contribute to society* (Okafor).

Of course, there can be many benefits for both formal and informal dementia caregivers. Dementia caregiving can be described as reflecting a standing relationship between the carer and the person with dementia. Such relationships can offer learning opportunities for dementia knowledge and awareness, training, and education. Dementia caregivers can also experience empathy and resilience, which can be considered as a protective factor favouring adaptation of the Black Africans in the UK and may reduce negative moods as illuminated by some of the participants:

> *We should look after each other, take things more seriously, live together as one family, and love as a community. Bod Marley said, 'one love keeps us together' We must love in everything that we do* (Kunle).

Nonetheless, some of the carers were formal dementia caregivers, and perceived benefits and motivation for the dementia caregivers can include the income or livelihood they get in providing care for the person with dementia. In addition, studies have shown that people concerned with another person's well-being, such as in dementia care, may create a sense of selflessness and empathy that can add altruistic motivation to any existing selfish and egalitarian reason (Van Lange, 2008). Moreover, dementia caregivers can also benefit from resilience and inspiration, including reciprocity, filial piety, duty, love, learning, and obligation, as illuminated in some studies (e.g., Greenwood & Smith, 2019).

Finally, in addition to the economic issues, the disability experienced amongst the Black African populations living in London can also be associated with immigration and citizenship, as viewed by some of the participants:

> *…Some of our generations are immigrants here in the UK* (Kunle).

Therefore, the empirical evidence suggests that dementia can be considered a disability. Nevertheless, dementia as a disability is not only localised within the individual's body and mind but also in the relationship between people with dementia and their sociocultural environment, including issues with income, employment, housing, language difficulty, education, immigration, and citizenship thus informs the sociocultural model for dementia care in the Black African community in the UK. Indeed, lay expertise is a 'general cultural stock of knowledge' (Wilcox, 2010, p. 45) or a body of cultural knowledge (Grundmann, 2017).

## Summary

The analysis illuminated the group's lay knowledge and beliefs about dementia and focused on five subthemes: lay expertise, ethnicity, gender, older age, and disability/ability. It highlighted inequality and inequity associated with dementia in the Black African community, revealing the power structures underpinning them at macro and micro levels. The analysis illuminated the dynamics of the privileged medical expertise and the disadvantaged lay dementia support, such as in prayer, which provided a sense of comfort, and the lay expertise informed by performativity, environmental, and sociocultural factors, including income, age, race, gender, disability, employment, housing, language difficulty, education, immigration and citizenship, religion and spirituality, and professional status. Even so, the analysis shows that the Black Africans, first-generation migrants from West Africa, who are indeed churchgoers, have lay dementia expertise. This 'general cultural stock of knowledge' is not static but evolving, intersecting biomedical and lay knowledge about dementia. It can be adequate for dementia management in the Black African community in the UK when combined with further education and training. The next chapter presents the other key themes.

# Chapter 7

## Disease and Illness

### Introduction

This results chapter presents the thematic analysis of the interviews amongst the Black African populations living in London by analysing the participants' narratives and views about the dementia phenomenon. The chapter focuses on the key theme disease and illness that emerged from the study. The chapter differentiates dementia disease from illness. Thus, four subthemes emerged from the disease and illness theme: (i) dementia viewed as an illness, (ii) dementia viewed as ageing/older age, (iii) dementia viewed as a disease, and (iv) dementia viewed as forgetfulness. The chapter showcases the empirical evidence and provides in-depth explanations and interpretations of the data.

### Disease and Illness

> *I think it is a terrible illness. God help us to find a cure for this dementia. It is a terrible thing to see your loved one suffer from such an illness… God help us…dementia is a very terrible illness* (Ben).

Drawing on Ben's narratives as above suggests that dementia has a lay dimension imbued within social and cultural meaning used by the participants to interpret their experiences of dementia in everyday life. Therefore, dementia, viewed as a terrible illness, is personally constructed, and embedded in religion and culture, meaning that dementia as an illness reflects a personal perspective but is also a cultural construct. Likewise, based on Kofi and Bello's narratives below, dementia was also viewed as a disease informed by the professional perspective but also a cultural construct:

> *So, I think she is suffering from a condition [interjection], you know, accessible medical condition. Personally, I think it is a medical condition, even though certain people believe otherwise. But personally, I think it is a medical condition* (Kofi).

Indeed, drawing on Bello suggests that dementia is a 'disease of the brain'. Of course, drawn from a biomedical perspective:

> *Dementia or Alzheimer's disease is a disease of the brain, just the way some other parts of the body may malfunction, so also it could be with the brain. For example,*

> *the heart, liver, kidney, and prostate can also be affected by a disease and then start to fail similarly to the brain. So, dementia is a disease of the brain* (Bello).

Reflecting on the data, Kofi and Bello viewed dementia as a medical condition or disease drawn from medical knowledge. Interestingly, Bello associated dementia with the brain and compared it with other organs in the body that could also be 'affected' by a disease. So, dementia as a disease was associated with medical culture. However, dementia was also viewed as an illness attributed to a supernatural force. Hence, lay knowledge informed by culture is a powerful force in defining what a condition is, either an illness or disease (King, 1954). However, the medical profession or culture is the major player in determining a disease (Roger, 2003). Therefore, dementia as a disease is a medical concept and a professional phenomenon. Furthermore, medical doctors can often use quantitative bodily measurements or positivism to define dementia disease (Gale et al., 2018), unlike dementia illness which is a personal phenomenon.

So, dementia illness and dementia disease are not necessarily the same. Dementia disease is a doctor's diagnosis, therefore, a pathology. Whilst dementia illnesses are personal concerns but not a pathology. Consequently, it depends on how individuals in the group experienced and viewed the dementia phenomenon centred on sociocultural factors bearing in mind that all the respondents were immigrants from West Africa living in London. Thus, dementia relationships with culture and environment (Brooke et al., 2018) were vital in the group. Therefore, the interaction with culture and social environment determined the normality and pathology within the group because most respondents considered themselves 'lay' rather than 'medical'. Thus, laypeople can hold a lay view of dementia separate from medical culture. For example, Ben and Kaku acknowledged that they were not medical doctors and perhaps would not draw their experiences from a medical point of view as narrated:

> *[Interjection] I don't know much about dementia because I am not a doctor like you. But as I told you before, I have a friend whose mother is suffering from dementia…I have seen it in Nigeria whilst living in Nigeria, but we didn't call it dementia* (Ben).

Nevertheless, drawing on Kaku suggested that he was not a medical doctor but that he had a different kind of dementia knowledge, as narrated:

> *I don't know much about dementia because I am not a medical doctor, but I know that it normally affects older people* (Kaku).

Buttressing further, Ben acknowledged that they did not call it dementia in Nigeria. Indeed, many participants called dementia ‘witchcraft’. However, Kaku suggests that his views are less critical to medical doctors. Of course, medical doctors are professionals. Regardless, all the participants drew their experiences from what they considered a ‘lay perspective’ as viewed by Kofi:

> *From my layman’s perspective, [Interjection] dementia, from what I understand, is that people at a certain age begin to show signs of forgetfulness [Interjection]* (Kofi).

Therefore, the concepts of disease and illness emphasise different perspectives on important aspects of the participant’s knowledge of dementia, as illuminated.

### Dementia viewed as an Illness

What constitutes dementia as an illness may vary between groups, societies, and cultures. However, dementia as an illness is viewed by the respondents as a subjective response of those around the person who has dementia as being sick or unwell. For example, Bimbo considered Bola, the person who has dementia, as sick and unwell as narrated:

> *Bola is a woman that is living with her family in Woolwich, but she is not well; she is sick, but her family does not know about her illness...* (Bimbo).

Thus, illness can be considered something Bola has. It can be defined as a negative phenomenon conceived by the individual (Hofmann, 2002; Helman, 2007); in this case, Bola has the illness, ‘but her family does not know about her illness’ as narrated. Indeed, suggesting that they do not know the cause and course of her dementia illness because illness is a personal phenomenon (Hofmann, 2002). Thus, dementia as illness or sickness is a lay concept, both as synonyms because of the fluidity between illness and sickness (Hofmann, 2002). So, dementia illness and dementia sickness are used interchangeably in contrast to dementia as a disease, but dementia sickness intersects dementia as illness and disease. However, dementia sickness is a social phenomenon associated with behavioural changes. Therefore, from a social perspective, dementia as a sickness is a social identity (Twaddle, 1994a; Hofmann, 2002; Haslem et al., 2021). Moreover, illness can be considered a subjective interpretation of the individual’s health status (Twaddle, 1994a).

On the other hand, sickness can be considered a health problem of the individual as defined by others such as family, friends, and relatives (Twaddle, 1994a). Accordingly, most participants thought Bola was sick based on her health condition. Meaning that Bola has dementia, as most of the participants viewed dementia as an illness:

> *I think Bola, the person you are talking about, is not well. The person is sick, and the family is worried about the condition of her health… My belief towards dementia is that it is an illness* (Kaku).

Furthermore, drawing on Ade suggested that dementia is an illness by drawing on the 'sign of dementia' as narrated:

> *Bola is obviously ill as she is murmuring and muttering to herself and unable to recognise the times of the day; she is forgetful. That is a sign of dementia; I can tell because she is having an illness and cannot remember* (Ade).

So, going by the narrative of Kaku, dementia sickness may be considered a state of change in a person's activity or behaviour (Nordenfelt, 1994). It appears as if Finda's consideration of the dementia phenomenon is in line with such a definition of sickness since the person (Bola) was confused and 'not okay' indicating a state of change in bodily activity in Bola as viewed:

> *…the person is sick [Interjection]. I think she is not well [Interjection] she is sick because she is not okay with herself…I think the person, the Bola is ill and confused [Interjection]…* (Finda).

In addition, sickness can be considered any negative phenomenon (Hofmann, 2002), such as being unwell that the group may conceive. So, sickness and being unwell are synonyms and may be interchangeable. However, sickness and being unwell is how the group interpreted the dementia phenomenon, the sick behaviour of the person with dementia, and the person's relationship with others within the group. For example, Ben considered Bola's behaviour as abnormal, whilst Ade felt she was unable to cope with her life as viewed:

> *I think Bola is sick. Her behaviour is abnormal…* (Ben)

Moreover, drawing on Ade suggested an inability to cope with dementia as an illness:

> *I think it is just about a Nigerian woman living in London that is finding it difficult to cope with her life due to her illness…* (Ade).

Indeed, Bola is a Black African woman living in London diagnosed with dementia. Still, Bola's behaviour may be considered abnormal within the group even though some members lack an understanding of the biomedical concept of dementia. Bola may lack coping strategies such as social support because the group's understanding of dementia is associated with witchcraft. However, for Remi, it appears that for a person to be considered as having dementia illness, the person must have the symptoms associated with the dementia illness:

> *It shows that Bola is having the symptoms of dementia, and that means that Bola is sick; she is not well* (Remi).

Remi appears to be interested in well-being. Indeed, sickness, well-being and disease are interconnected. So, we can consider Remi's view of dementia as an illness. According to the 1948 World Health Organisation (WHO) constitution, health is not merely the absence of disease. Thus, when a person with dementia is unwell or sick, the individual may be given the illness or sickness status (Hofmann, 2002) and social identity (Haslam et al., 2021). Yemi, a 55-year-old female family carer originally from Nigeria who has lived in the UK for 31 years, considered the sickness status as a 'brand new personality' as viewed:

> *…this person, in fact, has become a brand-new personality which was not what they were before the dementia illness* (Yemi).

Therefore, for the person having dementia to be granted an illness or sickness status, the person must manifest the symptoms of dementia that are physically visible to others. The symptoms may be specific for the dementia types but are usually considered undesirable, unacceptable, or disturbing for both the individual and family as viewed:

> *Bola is presenting with the symptoms of dementia, and her family are disturbed about her illness* (Yoofi).

Thus, a symptom is experienced and can be considered a positivist or subjective feeling, as narrated by Yoofi, suggesting how symptoms can be labelled as illness. Moreover, the symptoms may give rise to dementia sickness behaviour or illness behaviour which is based on social ideas and meanings that are not acceptable or desirable and will determine the activity to be taken by the family and the person who has the dementia illness:

> *People with dementia are usually forgetful. [Interjection] They find it difficult to remember things due to their cognitive impairment. So, they usually have memory loss, forgetting recent events, names and faces of their relatives and family*

> *members. [Interjection] They are mostly repeating themselves by asking the same question all the time. They are usually depressed and confused with time and date and have difficulty speaking properly or clearly. They can be withdrawn, murmuring to themselves and pacing up and down. And they can suffer from sleeplessness; they don't sleep well at night…* (Yoofi).

Yoofi is seemingly experienced, a 35-year-old male carer and a university graduate originally from Ghana who has lived in the UK for seven years. His narratives show he has experience with someone with dementia. So, drawing on Yoofi's narratives, with his described constellation of behaviours, a dementia illness in a group may also be regarded as abnormal behaviour in another or the same group. However, how it is perceived on a group and individual level depends on culture (Helman, 2007; Hofmann, 2002). In addition, in the absence of behavioural changes, the group culture may determine whether a particular form of behaviour is defined as dementia illness. For example, on an individual level, some participants viewed dementia symptoms as a normal ageing process:

> *[Interjection] I am forgetful at times which might be normal as I am expected to forget things and events sometimes, and that is the reason why I keep diaries and planners. Although I am not getting any younger but rather ageing, I don't think that disturbs my daily activities and routines…* (Bello).

However, forgetfulness alone does not signal dementia. Nonetheless, at a group level, most participants viewed dementia as forgetfulness. Thus, defining a person as being ill with dementia may be based on the individual's perception of the dementia illness or the perception of the dementia illness by others. For example, most participants considered being forgetful or forgetful, among many other symptoms (for example, in Alzheimer's disease, other symptoms must also be present), which may determine the dementia illness behaviour towards a suitable remedy or treatment.

> *They will forget themselves [interjection], forget people's faces, and forget many things…* (Finda).

Likewise, Kunle suggested dementia as abnormal behaviour due to the inability to remember things, as viewed:

> *My thought is that she seems to be forgetting things and doing things that are not normal…* (Kunle).

Indeed, dementia symptoms are social constructions but can be seen as the struggle to cope with the demands of everyday life. A dementia symptom for Finda is ‘forgetting many things’. For Kunle, it is about ‘doing things that are not normal’, whilst for Sesan, being forgetful is mainly related to ‘time of the day’ and insomnia as viewed:

> *…She does not remember things because she forgets things, such as forgetting the time of the day, and she is not sleeping fine* (Sesan).

Therefore, defining a person as being ill with dementia will usually follow some positivistic or subjective experiences, including identifying the symptoms associated with the dementia illness and the various ways to manage the dementia illness in the community. For example, the individual with dementia may have a memory problem, difficulty remembering things, difficulty with sleep, and aggressiveness and confusion, as narrated by Yemi.

> *[Interjection]…The experience that I will mention is about my dad. I never knew what dementia was all about until with him, I noticed that he had become unnecessarily aggressive. Then he began to say things that didn’t seem true; he could say something like – ‘when you were coming, did you see some cars parked at the door’. I would say to him, ‘I didn’t see your car parked at the door’. You understand, or he could tell you did you see two people on the roof. Strange things like that, then I am thinking what is really going on…* (Yemi).

Thus, vegetative signs, confusion, and forgetfulness can indicate dementia. More importantly, Ngozi emphasised the feelings of the people around Bola as ‘not happy’ due to dementia, and Yemi considered it as ‘very worrying’:

> *… [Interjection] I think Bola is sick, and her children are not happy with her sickness* (Ngozi).

Indeed, drawing on Yemi, dementia can be ‘very worrying’ as narrated:

> *You know it is a very worrying thing or a case for the family when they find out that it is dementia…* (Yemi).

Thus, dementia sickness becomes a social identity (Haslem et al., 2021), which will require the person with dementia to cope with the demands of everyday life, including cooperating with medical doctors, non-medical services and social services, and family and friends throughout their dementia sickness. Furthermore, as such may lead the family to take time off to look after the sick person, as observed with Marie:

> *But she later also had problems with her mouth and her voice. She started to lose her voice and the ability to talk as she used to [Interjection]; she was not talking properly and was finding it difficult to say some words in both English and French normally as she used to. A lot of issues were just coming up as the days went by. My mother lost her memory, she lost her voice, she could not walk, she lost her strength…she was just losing everything… [Interjection]. Dementia [Interjection] makes people lose everything and depend on other people for help. And the family will help them in doing everything. It is not a good sickness. I gave up my job just to look after my mother for almost three years…* (Marie).

Therefore, drawing on Marie's narrative would suggest a personal cost for the family regarding time, emotions, and time to support their own families. Moreover, it may involve seeking help from medical and non-medical services such as religion, friends and family, and social services. In addition, due to the progressive decline in dementia, it may also require relinquishing responsibility for one's care to carers, friends, and relatives. Moreso, it may also involve taking time off work, as noted in the case of Marie, whose mother was diagnosed with dementia:

> *My mother was diagnosed with stroke in 2009 here in London but died in 2016. I think about five years ago or so [interjection], but before she died in 2016, the doctors also said she had vascular dementia* (Marie).

Therefore, the criterion for seeking help in the UK dementia care service can be informal and formal. Formal support as viewed, when an individual feels ill or perceived as having dementia, an appointment is made to see the medical doctors who will diagnose the dementia illness as narrated:

> *I will see the GP, they are doctors, and they will tell me what next to do or what tests to go for. GPs are medical doctors, so they will know everything about dementia and what to do so that they can help people suffering from it* (Titi).

Once the dementia illness is confirmed, the community or group can attribute to the individual a sickness status (Hofmann, 2002). Thus, dementia sickness is a social identity that will free the individual with dementia from daily duties leading to dependency. For example, a person with dementia may be unable to engage in daily responsibilities and thus dependent on others for everyday tasks as narrated:

> *A person with dementia may be stressed, restless and confused. They may be aggressive and unable to engage in their daily tasks, thus dependent on others for their daily activities* (Ade).

Indeed, being dependent on others can signify that the person with dementia is freed from daily activities. Dementia sickness as a social identity will also give the individual the right to obtain needed dementia help and support to cope and quickly return to 'normal' health. Nevertheless, normality can mean different things to many people. For Kunle, normal or health may be considered as 'wealth' as viewed:

> *When I was growing up, I was told and with the understanding that 'health is wealth'* (Kunle).

**Dementia viewed as ageing/older age**

Some participants considered dementia a human life cycle, suggesting a condition in which the individual has dementia, but the dementia phenomenon is not regarded as sickness. For example, Eze contemplated dementia as a process of the human life cycle as narrated:

> *But at times, when we eat food, it might not replace ageing because it is the process of the human lifecycle; as we age, some things follow ageing in human life …Dementia is part of the human cycle, and we cannot run away from it. As we age, I would say human beings - White or Black as human beings as we age, there is a possibility of us suffering from dementia. I would say about 70% worldwide suffer from dementia; that is what I can say. I will say it is part of the human cycle, as I have said before, and we cannot run away from it because it is happening.* (Eze).

It appears as if Eze is trying to shed some light and provide a speculative idea that dementia can be a part of the ageing process and that ageing may be considered a risk factor for dementia. Therefore, ageing is relevant in the context of pathology but can be regarded as normal since ageing is focused on lifespan, that is, the longevity of an individual. Hofmann (2002) suggested that medical doctors can diagnose the conditions as negative bodily occurrences in some cases of disease and illness conditions. So, this means that the person in question will commonly experience the dementia illness or disease but will not qualify for dementia sickness within the community group. Consequentially, some participants do not see dementia as an illness or a disease but as ageing and consider dementia as a normal ageing process. For example, Ade emphatically suggested the dementia phenomenon as not an illness but as an ageing process that may lead to slower processes in the brain information and responses as narrated:

> *[Interjection] as I age [Interjection], as we grow older, we tend to be more forgetful, but I don't think it is an illness but rather a factor of our ageing. As we age, I don't expect our brain cells to process information the way they used to when we were younger [Interjection], But that does not make us forgetful all the time. It is just a part of growing old [Interjection], leading to a slow response of the brain cells [Interjection] affecting our mind and thinking* (Ade).

Furthermore, Bello weighed the dementia phenomenon as normal since it does not disturb his daily activities and that the dementia phenomenon is widespread amongst older people, as narrated:

> *[Interjection] I am forgetful at times, which might be normal as I am expected to forget things and events sometimes, which is why I keep diaries and planners. Although I am not getting any younger but rather ageing, I don't think that disturbs my daily activities and routines as in Bola's case. I am not forgetful at all times… [Interjection] dementia is now very common, and people may get dementia as they are ageing or as they are getting older…No, I have not discussed it with anybody, and I don't think it is a serious thing for me. In my case, it is normal. It is a part of me growing old…* (Bello).

Nevertheless, forgetfulness is distinct from dementia; some people are 'forgetful' from a young age and may not be diagnosed with young-onset dementia. Thus, Bello is talking about his biological clock. An essential bodily function and process associated with the human life cycle or ageing. Although ageing can be healthy or unhealthy (Ji et al., 2021), it may depend on each individual's lifespan. Nevertheless, WHO defined healthy ageing as developing and maintaining the functional ability that enables well-being in older age (Rudnicka et al., 2020, p. 7). Functional ability refers to the capacity of the individual to meet his basic needs, learn, grow, and make decisions, achieve adequate mobility, engage, and maintain relationships, and as well able to contribute to society (Rudnicka et al., 2020, p. 7). Therefore, the functional ability can be achieved in people with mild dementia or minor forgetfulness. Regardless, Ejiro metaphorically considered older age as an 'old machine', as narrated:

> *And if somebody is getting older, they will also start to forget things naturally because the brain is getting older as well. It is like an old machine that starts to wear out and eventually packs up. So, as a person is getting older, the brain is also getting older, and when the person dies, the brain will also die…I don't think there is anything we can do to prevent dementia; it is not a disease. So, we cannot prevent it [Interjection]. Dementia is due to old age, and we cannot prevent old age* (Ejiro).

Presumably, Ejiro suggests that some people may be unable to contribute to their societies at an older age. They may develop some physical changes, such as grey or white hair, as a part of the ageing process. Some older people may develop musculoskeletal pain or weakness as he likened ageing to a process subject to wear and tear of the body and brain, thus affecting the individual's mobility and thinking. Ejiro suggests that ageing may be detrimental to the body and brain. Indeed, Marie's view also supported this:

> *The brain just becomes weak, weak, and weaker; I mean not as strong as it used to be when the person was younger or when the person was still going to school [Interjection]. As people grow older, they start to develop all sorts* (Marie).

However, Ejiro emphasised that dementia is not a disease, given his earlier comment and acknowledged that older age is unpreventable except if one dies younger. Nonetheless, Yetunde, Merida and Yoofi, ostensibly from their narratives, may suggest that ageing can be healthy and that we can achieve healthy ageing through a healthy lifestyle and exercise:

> *Doing exercise…keeping a healthy lifestyle is the key* (Yetunde).

Similarly, Merida advises on exercise:

> *[Interjection]…keep doing exercise, keep fit and have fun. Yeah, just have fun because life is short* (Merida).

Likewise, Yoofi advises on the prevention of dementia by engaging in exercise as a way to 'live a healthy life' as viewed:

> *The only possible way to prevent it is to live a healthy life by doing exercise…* (Yoofi).

Thus, exercise may help to improve the individual's mobility, ease any musculoskeletal pain or weakness as the individual is ageing and as well in improving blood circulation, as narrated by Yemi:

> *I have shared as much information as I can. As I said, the most important thing is to prevent, provide support if a person has dementia [cough] and partake in bodily exercise. You don't have to be a member of a gym before you can do exercises. You can sit up; you can do stretches, you know, you can watch videos and do some small exercises. This help as much as possible to improve blood flow through all part of the body through to the brain and to all the other parts of your body. It keeps you healthy* (Yemi).

Again, it appears as if Obiora is particularly recommending mental and physical activity for healthy ageing:

> *…engaging in some mental activities and as well as doing some physical activities* (Obiora).

Indeed, the request is a pearl of common lay wisdom. Nevertheless, the current study shows that many older adults do not meet such recommendations (Eckstrom et al., 2020). However, some health problems may come with ageing, but it does not necessarily mean that ageing is pathological, and we must strive to avoid ageism. Of course, the researcher noted Eze's views on the human life cycle, which involves the stages of being a human through the ageing process unto older age, death and dying. Supposedly, Eze thought the consequences of getting older are unreplaceable with food, even though food and vitamins will fuel the ageing process positively. For example, optimisation of vitamin B status in older people is beneficial in preventing dementia and unhealthy ageing since vitamin B deficiency is associated with a degenerative disease (Mikkelsen & Apostolopoulos, 2018). Moreover, many respondents considered a balanced diet one of the most critical influences on ageing. For example, as viewed by Marie:

> *As I have said, people should…eat healthily and eat a balanced diet* (Marie).

In addition, there is evidence that optimal eating is associated with increased life expectancy and decreased disease conditions (Campisi et al., 2019). Nonetheless, as noted, Ejiro's view suggests that dementia is not a disease and ageing is unpreventable because it is an essential life process. Likewise, Nkem considered the dementia phenomenon as a part of normal ageing, whilst Ben concluded that dementia has no cure, as narrated:

> *People in my community may get dementia as they start ageing* (Nkem).

Contrarily, drawing on Ben suggested that dementia has no cure despite being a pathology because the ‘brain cells are dying’ as viewed:

> *His mum is also on medication, but I don’t think there is a cure for the illness. There is no cure for dementia because the brain cells are dying or worn out* (Ben).

Therefore, there are several reasons why the group considered dementia a human life cycle or normal ageing process rather than pathological. First and foremost, drawing on Ejiro and Ben’s narratives may suggest that dementia as an illness or disease may lack prevention and cure. Secondly, drawing on all the others may indicate that dementia is common amongst older people, and forgetfulness or being forgetful is associated with ageing; consequently, a normal process as viewed. Indeed, most participants equate forgetfulness with dementia. Therefore, the status of sickness may not be given to the dementia phenomenon, especially when there is a limited resource, as narrated:

> *I am saying that extra time is needed; we will consider that as extra time. More time is needed, and because you pay for the support, you pay for people’s time to take care of others. So, it could be more expensive* (Yemi).

Moreover, Hofmann (2002) suggested several reasons why the status of sickness may not be given when a health condition is considered both disease and illness (p. 660). For example, dementia sickness, mainly when there is a lack of resources. Of course, dementia sickness is a social identity associated with dependency. Indeed, when the health condition is common or equally distributed in the population, such as minor forgetfulness or mild dementia, and when there is no cure for the health condition as eulogised by most participants for the dementia phenomenon. For example, Kunle’s view is that dementia will be a natural occurrence to anyone as they are ageing:

> *It is also going to come naturally as we grow old, especially in our older age. So, that is one thing I know about dementia, and it affects a lot of older people* (Kunle).

Contrarily, Ben is of the view that not everyone will develop dementia as they start to age:

> *...not everyone old will develop dementia* (Ben).

Indeed, Ben’s view is shifting towards the concept of ‘healthy ageing’ amongst the group of which many of the participants considered to be dependent on biological and sociocultural factors, including lifestyle, as viewed by Remi:

> *We should try and live a healthy life before our death. Some older people may have dementia, and some may not. So, the important thing for us is to have a healthy lifestyle* (Remi).

It appears as if Remi is emphasising that some group members may have dementia as they are ageing. Whilst some may not, the probability of some members not having dementia as they are ageing depends on healthy lifestyles and diets. Moreover, most of the participants emphasised the need for a healthy lifestyle and diet which can help to prevent dementia as viewed:

> *Eating healthy food… can also help us to maintain good health. In short, keeping a healthy lifestyle is the key* (Yetunde).

Moreso, drawing on Merida included drinking 'enough water' rather than juice would assist healthy ageing as viewed:

> *We are just to make sure we eat the right food and drink enough water as we grow older. I think drinking enough water every morning than just drinking juice every day is good for us as we are ageing* (Merida).

In addition, Fatou emphasised the need for a better quality of life and to avoid unhealthy lifestyles. More importantly, avoiding unsaturated red oil such as the 'Nigerian palm oil and Sierra Leone palm oil' as narrated:

> *…but I think dementia can be associated with a person's quality of life in some ways [interjection]. As an African, I think dementia can be caused by a poor or unhealthy lifestyle, such as not eating healthily. We need more fresh vegetables in our diet rather than the unsaturated red oil, the 'Sierra Leone palm oil' or the 'Nigerian palm oil' we get from our local shops, you know we use it daily [interjection] not too good for our health* (Fatou).

However, it appears as if Seyi and Marie highlighted what may be considered good food by suggesting that members should eat a balanced diet:

> *…I think people should eat a balanced diet* (Seyi).

Moreso, drawing on Marie emphasised the essentiality of healthy eating:

> *As I have said, people should…eat healthily and eat a balanced diet (*Marie).

However, food is a social representation and culture (Lo Monaco & Bonetto, 2019) imbued with cultural and social identity (Plastow et al., 2015). So, it should not be medicalised as a risk factor for dementia. Still, some foods are not suitable for the body, and eating healthy is essential (Krebs-Smith et al., 2018). Seemingly, Seyi and Marie did not elaborate on a balanced diet. Regardless, a balanced diet is a food that contains an adequate proportion of calories, proteins, minerals, vitamins, and alternative nutrients to make us eat healthily. So, eating healthy food is a healthy lifestyle that can assist healthy ageing and can also prevent obesity and other risk factors associated with dementia, as narrated by Fatou:

> *A healthy lifestyle can help you not develop obesity and high blood pressure, which are also risk factors for dementia [interjection]* (Fatou).

Nevertheless, proteins, vitamins, and minerals are often insufficient in older people's diets. So, their diet should be adapted for ageing and prevent other pathologies associated with ageing (Gimeno-Mallench et al., 2020). Furthermore, most participants considered that having a better quality of life as their members are ageing would mean giving away habits such as smoking and avoiding excessive alcohol intake. The respondents generally considered alcohol and tobacco as a risk and prevention for dementia:

> *Dementia can also be prevented by not drinking alcohol and smoking. Alcohol and smoking are not good for our well-being* (Bimbo).

Furthermore, Nwanne and Kelechi acknowledged the need for a safe environment for a better quality of life and developing resilience as part of the healthy lifestyle for healthy ageing as viewed:

> *…but other things like noise pollution, air pollution* (Nwanne).

Likewise, drawing on Kelechi:

> *…being free from stress by being resilient, socialising and being in a safe and good environment that is not noisy and dirty* (Kelechi).

So, drawing on Kelech's view about resilience may suggest that Black African populations living in the UK who navigate adversities such as unemployment and poverty may maintain a high level of bodily functioning and healthy ageing (Cosco et al., 2017). Nonetheless, some of the participants acknowledged loneliness to be associated with poor quality of life and unhealthy ageing or dementia, as narrated by Yemi, Fatou and Yetunde:

> *[Interjection] I believe [Interjection] as much as we can; it is important for us to have the support of family and friends and people checking upon each other. But of course, these days and age, and people with their hustling and bustling of life do not allow these ways that we want to, and because of this, we may have many more like it. Here can be a very lonely society. People don't check up on each other. You can have your neighbour [Interjection] next door, and you don't even know them. You might run into them outside or on the road; people don't check on you, and you don't know what is happening. You know, a good chat, a good cup of tea with a friend, you know [Interjection] playing Bingo, seeing people of your age, your age mate having a cup of tea together, having lunch together playing a game, and I believe all these could stimulate their brain so that it does not die* (Yemi).

Furthermore, going out and having fun can mitigate loneliness as viewed:

> *Avoid being lonely and do some exercise on a regular basis. Keep yourself busy, play games and read papers or magazines on a regular basis to keep your mind stimulated. Go out, have fun, and meet people* (Fatou).

Indeed, some Black Africans in the UK went to the church to mitigate loneliness:

> *…Avoid loneliness by going to church and meeting nice people* (Yetunde).

Nevertheless, recent studies showed that the conceptualisation of loneliness could be social, emotional, and existential (Mansfield et al., 2021). The relationship between loneliness and dementia is inconclusive (Victor, 2021). However, the participants in the current study narrated that loneliness could cause dementia:

> *And I also feel when a person is not finding himself in a social circle enough, I mean, as people grow older, they lose friends, lose companions, and their children may have gone to do their own things, so usually, you are lonesome. And when a person is lonesome and lonely, lacking social events, that could lead to dementia… My dad has been lonely; he stays all by himself, he does not sleep well, and he does not get involved in social events. He does not go out…* (Yemi).

Indeed, social isolation is a risk for dementia independent of loneliness (Shen et al., 2022). Presumably, those lonely are more likely to present late for dementia diagnosis. Aside from loneliness, most respondents suggest that lack of adequate sleep may lead to unhealthy ageing and dementia, drawing on the vignette. For example:

> *They may also not be able to sleep at night but restless and murmuring all through the night, as in your case with Bola* (Kaku).

Moreover, some of the participants considered routine medical checks as a measure of healthy ageing or prevention of dementia, as viewed by Seyi:

> *…Particularly, Black people should learn to monitor their vital signs, such as blood pressure and pulse rate, or they could go for a medical check-up as needed* (Seyi).

It appears as if what the participants are saying is that lack of routine medical checks may predispose members to unhealthy ageing since undetected risks or biological factors can make members vulnerable and susceptible to dementia. Again, Zubby viewed dementia as biologically determined and genetically predisposed as illuminated:

> *But I think one of the causes of dementia is hereditary, and that is what I think. But if it is hereditary, you can't do anything about it, and you have to accept it just the way it comes* (Zubby).

Therefore, drawing on Zubby can suggest that acceptance might be a way to manage dementia behaviourally or psychologically. Notwithstanding, ageing is not a disease but a success because not everyone can achieve older age. Nonetheless, older age can be considered a risk factor for dementia, as most participants responded, and dementia may be hereditary, as suggested by Zubby. Nevertheless, biomarkers can allow for the early identification of people developing age-related dementia and other ageing-related pathologies at a higher level. The ageing summit in London (Imbert, 2014) presented research on biomarkers at the genomic and proteomics levels. It highlighted the relevance of biomarkers as signatures for ageing and age-related diseases. The summit highlighted the importance of genomics and regulatory element in ageing, their potential role in successful ageing and their potential interest in future anti-ageing approaches. Indeed, future breakthroughs in biomarkers for ageing or successful ageing would likely come from a better understanding of the regulatory mechanism behind gene expression, successfully driving heterogeneity in human ageing and differences in ageing. So, Biomarkers can be essential and valuable but could be problematic, creating tension between ageing as a normal process and ageing as a disease condition. Still, they should meet several criteria, such as the ability to predict the rate of ageing, monitor the basic process that underlies the ageing process, and be tested repeatedly without harming the individual (Dodig et al., 2019)

Nonetheless, there is no reliable biomarker that meets all the necessary criteria. However, some promising biomarkers can be used for the purpose and may include epigenetic biomarkers for ageing based on the measurement of DNA methylation at multiple sites (Levine et al., 2018). In addition, AD biomarkers such as the plasma neuron-derived exosomes (Pulliam et al., 2019) and CSF AD biomarkers for cognitive impairment in Alzheimer's disease (Leuzy et al., 2021). We also have biohorology and ageing clocks biomarkers (Galkin et al., 2020). Moreso, an omics-based biomarker that captures multiple physiological domains that influence an individual's health status using a holistic view of intrinsic capacity (Rivero-Segura et al., 2020), and Selenium on biomarker in the elderly in preventing ageing and ageing-related diseases (Alehagen et al., 2021).

### Dementia viewed as a disease

Whilst illness is something a human may have, the disease can be considered something an organ has (Hofmann, 2002; Helman, 2007), each with characteristic signs, symptoms, and causes (Kumar & Clark, 2021; Davison, 2022). Contextually, illness is a lay concept, and disease is a biomedical concept. Logically, dementia as a disease is what the brain as an organ has, as viewed by most participants. For example, Seyi thought of dementia as 'a disease of the brain', as narrated:

> *Vascular dementia may be caused by a decreased blood supply to the brain tissue leading to hypoxia and subsequent damage to that portion of the brain cell, subsequently leading to a decline in brain function. Stroke is a common cause of vascular dementia. On the other hand, Alzheimer's disease is the commonest form of dementia. It is associated with the deposition of proteins in the brain cells, eventually leading to dead cells in the brain…Many people would associate dementia with old age, but studies have shown that dementia is beyond old age; it is more of cognitive impairment or a disease of the brain* (Seyi).

Seyi is a biology teacher at a college in London. He was knowledgeable about the different types of dementia and willing to share his knowledge. He considered dementia a disease of the brain, thus reinforcing dementia disease as an organic phenomenon (Twaddle, 1994a). However, carefully considering Seyi's narratives may suggest that dementia as a disease is localised within cellular levels (Tissues and cells) rather than the brain as an organ because a group of cells is defined as tissue, and a group of tissues form an organ. Therefore, cells build tissues which form organs. Moreover, Seyi considered dementia disease a cognitive impairment. Thus, it suggests that dementia as a disease may consist of a reduction in the physical capacity of the individual (Twaddle, 1994a; Nordenfelt, 1994; Hofmann, 2002) who has dementia perhaps in ways as viewed by Efe and Eze, respectively:

> *…and like I said, dementia is not a specific disease but rather an impaired ability to remember things or think; and it depends on each individual* (Efe).

Indeed, Eze viewed dementia as an impairment in 'reasoning' and 'coordination':

> *I would say that Bola has developed a forgettable thought like what I would call impairment in her reasoning… Her coordination lacked coordination…* (Eze).

Regardless, for Marie and Yemi, respectively, it could mean a weakness of the brain or a dead brain, as viewed:

> *The brain just becomes weak, weak, and weaker* (Marie).

> *I believe all these could stimulate their brain so that it does not die* (Yemi).

Nevertheless, Yemi, the family carer, also consider dementia as a degenerative disease that may lead to a loss of life, as narrated:

> *You know it is a very worrying thing or a case for the family when they find it is dementia – a degenerative disease that usually attacks the brain cells. Once they notice what is happening, they just believe they are losing their loved one* (Yemi).

Of course, dementia may reduce life expectancy, as suggested in Twaddle's (1994a) definitions of a disease. Thus, dementia as a disease would permit medical attention calling doctors towards its diagnosis and treatment, and drawing on Seyi and Yemis's narratives may suggest the different types of dementia as a disease:

> *Dementia is a disease that affects a person's brain, leading to memory loss. There are different types of dementia, with Alzheimer's disease being the commonest type. The other type is vascular dementia. I can't think of the rest because there are so many. I read that there are over 100 types of dementia, but just about four are very common* (Seyi).

Moreso, drawing on Yemi highlighted some of the dementia types as narrated:

> *Sometimes dementia may be severe, and I know of different types of dementia; I have heard about vascular dementia, and I have also heard about Alzheimer's*

> *disease. Usually, my thought was that dementia was under Alzheimer's disease, so dementia was categorised under Alzheimer's disease. And that there are different types of dementia. So, you understand [interjection]…* (Yemi).

So, drawing on Yemi and Seyi's narratives would suggest different types of dementia, but the common types may include Alzheimer's disease (AD), Vascular dementia, Frontotemporal dementia, Dementia with Lewy bodies and Parkinson's disease dementia. Of course, they drew on the medical model, and the doctors' understanding, and knowledge of dementia are localised within the biomedical concept of the dementia phenomenon. Indeed, doctors generally conduct clinical investigations to identify treatable biological causes and help to understand the clinical diagnosis of dementia types, as mentioned by Seyi and Yemi. Regardless, most biological causes of dementia are not treatable by medicine as there is no cure (Kumar & Clark, 2021). Nevertheless, the best evidence-based practice in dementia medical treatment is behavioural (Tisher & Salardini, 2019; Gomez-Romero et al., 2017).

Notwithstanding, for most patients, clinical investigation and diagnosis of dementia may include blood tests such as FBC, ESR, UE, LFT, CT or MRI brain scan, Genetic studies, Electroencephalography, brain biopsy and, more recently, a cerebrospinal fluid including Tau and Aβ42 measurement (Kumar & Clark 2021, p. 881). Nonetheless, cognitive tests have always provided a tentative diagnosis. Indeed, the empirical evidence across the dataset suggests that most of the participants acknowledged the need for dementia tests and diagnosis:

> *I will go to the hospital or to the GP. I think my GP first before the hospital. The GP may give me a referral to the hospital for further tests* (Ben).

Similarly, Marie would want to see her GP if worried about dementia, as narrated:

> *If I am worried about dementia, I will see my GP. I know the GP can carry out some tests to see if I have vascular dementia* (Marie).

It appears that Ben and Marie's narratives acknowledge the need for dementia tests and diagnosis by the GP. Whilst Kunle's narratives may suggest that the members of the group will have no difficulty in accepting any dementia diagnosis:

> *[Interjection] obviously, I will not panic over it. It is just to deal with it and receive the diagnosis in good faith. One has to be strong and firm. If you panic or feel out of strength with your thought process, then it is of no use […glitches]. Yeah …be of a strong mind, keep on managing and being strong for the person. Jittering*

> *would be of no good to the management of the condition of that person. That is how I will take it. It is not the end of life for the person* (Kunle).

Seemingly, Kunle will not jitter going for a dementia diagnosis. Presumably, he will not behave nervously going for a dementia test, as his narratives may suggest. This means that Kunle will be willing to go for a dementia diagnosis if only he will not be stigmatised in the Black community if diagnosed with dementia. However, the medical doctors may have to conduct an extra-needed clinical assessment to confirm any dementia diagnosis, as delineated by Nonye:

> *I was worried about dementia three years ago when my husband was diagnosed with Alzheimer's disease, so I had to see the GP; I was also sent to the memory clinic for assessment* (Nonye).

Reflecting on Nonye's narrative, clinical assessments for dementia in Black Africans are critical. In conducting a clinical evaluation, the doctors aim at two main objectives for the patient. First and foremost, the doctor considers if the patient has dementia. Secondly, the doctor evaluates the pattern of cognitive deficits, the progression tempo, or associated features of a distinct cause. The doctor may perform a bedside cognitive assessment using the Mini-mental state examination (MMSE) or Addenbrooke's cognitive examination (ACE) tools. Indeed, the prospect of dementia can be distressing, causing fear and anxiety, as could be delineated in Nonye's narrative. So, early assessment and help for Black Africans can aid memory and functional difficulty. However, Alzheimer's is the most common type of dementia, and technically a definitive diagnosis can only be made by histopathology (Kumar & Clark, 2021).

In addition, with Fatou's confession concerning her training, it appears as if dementia is more than a disease:

> *…just last week, we had a training on dementia. We were clearly told that dementia is not a specific disease but a syndrome* (Fatou).

Of course, dementia is a clinical syndrome with multiple causes (Kumar & Clark, 2021). Seemingly, it appears as if Fatou's narrative is highlighting the fact that biomedical concepts of dementia as a disease is associated with reductionism; that is, the biomedical concepts of dementia are limited to organ, tissue, and cellular spectrums of human beings rather than a broader sociocultural context of the well-being of individuals. On the other hand, the Black African's knowledge and understanding of dementia aetiology are slightly shifting away from their everyday experience of dementia as witchcraft. Still, people with dementia in the Black community in London may have complex problems. Therefore, dementia, being viewed as a disease or illness, is not independent of each other. Thus, dementia as an illness cannot be reduced to just a dementia disease because the ‘disease’ is a medical concept that limits what medical doctors are expected to do. Moreso, what they should do and can do with the dementia phenomena because most dementia management is probably behavioural, as noted (Tisher & Salardini, 2019; Gomez-Romero et al., 2017). So, dementia medical treatment does not help that much. Nevertheless, medical doctors may provide medicines to those that require medical treatment, as narrated by a few of the respondents, for example, Bimbo and Finda:

> *[Interjection] we usually administer their medications to them either from a dosette box or from the medicine pack, but I don’t know the names of the medicines. They are all different types of medications, and it is not all of them that we give medications to; in some, we may have to, and others may not if they are not on any medications* (Bimbo).

Likewise, drawing on Finda shows that there are medicines that could be used for dementia treatment, as narrated:

> *But here in London, they use dementia medicine, but I don’t know the names of the drugs. For the patients on the medication, it will be written in the care plan that we should administer their medications. But I don’t know the names of the medicines* (Finda).

Indeed, the participants may not know the name of the medicines that medical doctors use to treat dementia. Still, the medication may include a cholinesterase inhibitor, a CNS acetyl-cholinesterase inhibitor (e.g., Donepezil, Rivastigmine and Galantamine) and Memantine, an NMDA receptor antagonist (Kumar & Clark 2021, p. 884). However, no treatment has been shown to influence outcome substantially; instead, mainly palliative, giving false hope with little benefit as suggested by most of the respondents, for example, Nwanne, Yemi, and Okafor as illuminated:

> *I told you earlier that there is no treatment for dementia other than treating the primary causes. If it is due to infection, then you treat the infection. If it is due to a stroke, you treat the stroke. If it is due to trauma, you take care of the trauma in the appropriate ways* (Nwanne).

Moreso, drawing on Yemi suggested that the medicine used for the treatment of dementia is essentially for symptomatic relief as viewed:

> *But usually, when you have vascular dementia, there is nothing to take, but there may be some medications that may help you sleep or help you relax* (Yemi).

Nevertheless, drawing on Okafor suggests better treatment for a person with dementia by providing care and engagement rather than medicine for a cure. He emphasised that he has not seen anybody 'cured of dementia' as narrated:

> *I have not seen anybody cured of dementia, [Interjection] the treatment for a dementia patient is just for you to care for them. Keep the person engaged.* (Okafor).

Hence, these respondents' views and narratives provided an informed understanding of dementia, showing that they are knowledgeable about dementia.

### Dementia viewed as forgetfulness

In addition, most of the participants attributed dementia to forgetfulness. For example, Bimbo, a 45-year-old formal carer, originally from Nigeria and has lived in the UK for 11 years, viewed dementia as 'forgetful'.

> *People with dementia usually forget things, and they usually find it difficult to remember things. You tell them something now, ask then a minute later they will tell you I can't remember. They just don't remember things because they are forgetful* (Bimbo).

Likewise, Ejiro and Ade can suggest that dementia is about 'being forgetful', as viewed:

> *[Interjection] Dementia is being forgetful. That is when someone is forgetful all the time* (Ejiro).

Similarly, drawing on Ade suggested that people with dementia are 'quite forgetful' as viewed:

> *She is forgetful of herself but remembers her past events. I think it is a way dementia can manifest among people or one of the ways it could manifest. People who have dementia can be quite forgetful* (Ade).

Moreso, Merida's narrative suggests that people with dementia forget and are unable to remember things, thus a classical sign of dementia as viewed:

> *They forget things, forget their flat, forget their family, forget their friends, and can't remember things. Then, you could tell, hay, they have got Dementia* (Merida).

Furthermore, Marie's narrative re-enforced Merida's view by affirming that her mother forgot names and family member's faces, thus was forgetful before she was diagnosed with vascular dementia as viewed:

> *My mother started to forget the names and faces of my family people [interjection] when she partially recovered from the stroke. She started to forget us, our looks, our names, she was mixing everyone up, and she was not able to recognise members of our family. My mother was not able to separate the face or the presence of my husband from another church member, and she could not recognise his voice [interjection]. Just like that Bola in your story, my mother also forgets the times and days of the weeks or months. So, the doctor said she had vascular dementia* (Marie).

Fatou and Finda affirmed that people with dementia are forgetful to buttress further. Fatou confirms that people with dementia can forget 'recent events', but Finda's narrative is that they forget 'too much and too many things', as illuminated:

> *They can become forgetful of recent events* (Fatou).

> *They are very forgetful…The problem is that they forget too much and too many things* (Finda).

Indeed, Kofi associated forgetfulness as a sign of dementia as viewed:

> *And also, if the person is showing signs like forgetfulness…these things would point me towards a dementia condition* (Kofi).

However, Kelechi viewed forgetfulness as a part of ageing and not necessarily as dementia as narrated:

> *[Interjection] I think we all notice some form of a change in our memory as we are getting older, I mean, we do observe some level of forgetfulness as we are ageing, but that does not mean we have dementia* (Kelechi).

Contrary to Kelechi's view, Bello's narrative suggests that forgetfulness is not a part of normal ageing but is associated with Alzheimer's disease, and he referred to the vignette:

> *…at my age, I sometimes forget things, maybe many things…Sometimes we may be forgetful in our lives, especially as we get older…However, being very forgetful like Bola is not a normal path to getting old… [Interjection] I am forgetful at times, which might be normal as I am expected to forget things and events sometimes, which is why I keep diaries and planners. Although I am not getting any younger but rather ageing, I don't think that disturbs my daily activities and routines as in Bola's case. I am not forgetful at all times. I think Bola might be suffering from Alzheimer's disease* (Bello).

Therefore, drawing on the participants' views and narratives about dementia suggests that forgetfulness in everyday life is complex.

## Summary

The analysis shows that biological, social, psychological, and cultural factors, including older age and ageing, genetics, diet, exercise, income, training and education, and professional status, shaped the group's lay knowledge and beliefs about dementia in the UK. The analysis highlighted four subthemes from the disease and illness theme, and the findings show that the Black African population, first-generation migrants from West Africa living in London, do not lack biomedical dementia knowledge. Indeed, most of the respondents were carers and had to assimilate a biomedical understanding of dementia to be effective in their role as carers for people with dementia. The analysis shows that their lay knowledge and beliefs towards dementia were not static but evolving and appeared to reconcile different framings of dementia, including biomedical knowledge about dementia and risk factors. The researcher considered dementia disease a biomedical concept based on scientific biological knowledge and supposed dementia illness a lay concept based on general cultural understanding, whilst dementia sickness was regarded as a social identity based on individuals with dementia and their relationship with others in the Black African community. However, the lay and biomedical perspectives are a false dichotomy as each influences the other and is not independent. The analysis illuminated dementia as a complex phenomenon, and forgetfulness in day-to-day life was complex. The next chapter presents the other themes developed from the study.

# Chapter 8

# Help-seeking and Caregiving

## Introduction

This results chapter presents the findings of the analysis of the interviews amongst the Black African populations living in London using thematic analysis. The chapter focuses on the themes developed from the study: help-seeking behaviour and caregiving. However, two subthemes: (i) attitude and (ii) stigma, were identified from the key theme (help-seeking behaviour). In addition, three subthemes of caregiving were also identified: (i) caregiving in care homes (residential caregiving), (ii) caregiving within the home of the person with dementia (domiciliary caregiving), and (iii) caregiving behaviour. The chapter showcases the empirical evidence and provides in-depth explanations and interpretations of the data.

## Help-seeking behaviour

Help-seeking for dementia amongst Black Africans living in London is not straightforward but is crucial for diagnosing and treating dementia. Generally, help-seeking is complex, and the concept is difficult within studies (Werner et al., 2014). However, community dementia services in the UK are the gateway to dementia management in the NHS (Gill Livingston et al., 2020). Nevertheless, drawing on the participants' narratives and views suggests that consultations on dementia, such as seeking dementia advice formally or informally, depended on their experiences. For example, Ade and Bello's narratives below indicate that the consultations on dementia were dependent on families, friends, and relatives or based on the individual's lay knowledge and beliefs about the dementia phenomenon as they informed their decisions to seek help for dementia. As such, Ade's knowledge of dementia within the group is centred on his religious beliefs, which informed his help-seeking as narrated:

> *[Interjection] I will seek Christ to know what the issues are, and I will also wait to hear from Him. I believe He will direct my path. But on the other hand, I will consult doctors for tests. I know you people have a way of doing your things. But like I said, I cannot jump to see the doctors for diagnosis without receiving guidance from God* (Ade).

Contrarily, Bello acknowledged that he could only seek help from the GP because doctors are more inclined to provide the needed services for dementia. He believes 'caring for such sick such as in dementia is the responsibilities of doctors', so he would be less dependent on the opinion of family and friends, as narrated:

> *I would consult my GP, and if there is a need, they will make the necessary referral to a specialist. GP is the best starting point. Consultation with the GP is the best starting point. Don't you think so? Then they can make a referral to a specialist. I mean, doctors are specialists in many health issues. I will definitely not consult a lawyer for my health problems except with health negligence matters and other issues that might be unlawful in this society…Good point [Interjection]; it might be necessary to seek the opinion of those around me, but definitely, the doctors will have the final say [Interjection]. I think the doctors will have the final say. That is why they are doctors. You know what I mean [Interjection] you people are doctors, and caring for the sick is your main responsibility* (Bello).

Therefore, Ade may seek help from 'Christ' as narrated, seemingly his way of help-seeking due to his religious beliefs towards the dementia phenomenon and the understanding of what might be going on with his health based on his beliefs. Although Ade acknowledged that he might also seek help from the doctors but only after he might have consulted with 'Christ', presumably influenced by his occupation. Thus, it appears as if their backgrounds may have influenced their choices for dementia help-seeking. For example, Bello's knowledge of help-seeking for dementia is informed as a Lawyer, and Ade's dementia beliefs seem to have been affected by his background as a church Pastor. Indeed, the respondents drew on their own experiences and skills to reach an understanding of dementia. In addition, the media informed some participants about dementia and help-seeking. For example, Yemi acknowledged the use of the internet for dementia information, as narrated:

> *Normally the first thing is to [Interjection] thank God for Google; people Google up a lot of information* (Yemi).

Seemingly, Eze was informed by a third sector organisation, presumably by Alzheimer's Society or Alzheimer's Research UK or possibly by support groups available online which may do outreach on the internet or by phone about dementia and help-seeking, as narrated:

> *You can also seek any association for help and have a one-to-one discussion with them. Some associations just like the way they have Diabetes UK, which you can Google and get their phone numbers and book an appointment to have a one-to-one discussion with them* (Eze).

Similarly, it appears as if Kunle was informed about dementia and help-seeking by the local authority or members of a commission on dementia, as narrated:

> *But in this part of the world that we are, information is flying all about dementia and how commissioners deal with it. From there, I can say that I understand what dementia is* (Kunle).

However, drawing on Ben's narrative below can suggest that some participants may want to consult the opinion of their families and friends as a part of their decision-making for help-seeking for dementia, particularly at the start of the signs of dementia, as narrated:

> *I will also discuss it with my family and close friends, but I think my family and friends might even notice it before me and may want to discuss it with me before I think of discussing it with them* (Ben).

Likewise, many of the respondents' narratives, for example, Eze, Sesan, and Merida, further pointed towards seeking opinions from family, friends and relatives before making any decision about help-seeking for dementia, as narrated:

> *You can have a one-to-one discussion with your friend who might know more than you* (Eze).

Similarly, drawing on Sesan acknowledged the need to speak to close families, as viewed:

> *I will speak to my people; first, my wife, my children, and my family members* (Sesan).

Moreso, drawing on Merida further acknowledges the need to speak and discuss the dementia phenomenon with friends, as viewed:

> *I would probably talk it through with my family and friends. Yeah, I would have to discuss it with my family and friends* (Merida).

So, it seems as if the group help-seeking and attitudes towards dementia were localised within the lay concepts and people look to their social communities for information. Although, Bello's view is seemingly deviating from that direction as he would instead consult directly with the medical doctors rather than seek the opinion of family, friends, and relatives as viewed:

> *I definitely would make an appointment to see the GP as a priority rather than seek friends' and family's opinions* (Bello).

Thus, the group’s decision to seek help for dementia was not that straightforward for all, nor was it the same for the participants, even though Bello’s narrative may suggest his ability to make decisions regarding help-seeking for dementia. Again, presumably due to his occupational background as a lawyer who may see medical doctors as his learned colleagues. His decision to seek help for dementia from the doctors may also be based on his level of education and social class. Nevertheless, Kaku, a security manager, was particularly concerned about the stigma associated with the dementia phenomenon and may not want to consult a doctor for dementia help, as narrated:

> *But the point is that as a man, I may be worried about the stigma and may not want to see a doctor. Because as a man, when you start losing your mind, you might become a laughingstock, and your wife and children might also want to keep it secret [Interjection]. Having dementia will not make us happy [Interjection]* (Kaku).

It appears that Kaku is talking about an implied shame related to dementia. Shame-induced stigma can further damage those with dementia. It can lead to loss of status, emotional reaction, and discrimination (Andersen et al., 2022), reinforcing the disparity in health associated with dementia. Therefore, stigma can be considered a socially constructed barrier, inhibiting Kaku and his family from seeking a timely dementia diagnosis. Perhaps or failed to disclose the dementia illness to others, as drawn from his narrative, also bearing in mind that Kaku is a minority in the UK, originally from Ghana. So, the shame of dementia can lead to worse or later diagnosis due to delayed help-seeking.

Furthermore, drawing on previous studies, Lopez et al. (2020) suggest that shame was experienced by family and dementia caregivers and was an underlying mechanism by which stigma was enacted and perpetuated, resulting in family and caregiver isolation and delay in access to diagnosis and supportive dementia services. Likewise, a study in Nigeria (Adebiyi et al., 2016) showed concerns about enacted and implied stigma related to dementia within the community. By and large, Yemi, an experienced family carer from Nigeria who has lived in the UK for 31 years, appears to be suggesting a way to dispel the dementia shame amongst the Black African populations in the UK. Referring to the vignette, Yemi indicates the need for family and friends to engage effectively with social services in the UK who may be able to assess individual’s social situations and provide needed help as narrated:

> *This is a situation where family and friends must make moves to seek help and begin by alerting authorities, that is, those who have good knowledge as to what to do. They must be able to report this to medical personnel who can report it to social services, who can assess the situation. They are the ones to do the referral so that Bola can receive the necessary help needed* (Yemi).

Seemingly Yemi refers to widely implemented social prescribing services in the UK National Health Services that integrate medical and social care (Pescheny et al., 2020), which links people with dementia or being assessed for dementia with social services for non-medical help in the community. Usually, the social services will work with the referred dementia patients and issue onward referrals to sources of support for non-medical needs in the community. Furthermore, drawing on the empirical evidence across the data set, help-seeking can be viewed as a decision-making process or an 'act of performance' (Jansen et al., 2021), preceded by the individual's background. For example, Obiora, a church pastor, illuminated that his church members may try very hard to avoid being labelled by professionals such as doctors when being assessed for dementia, as narrated:

> *The only problem with dementia in the Black community is that Black people do not get to accept the condition as quickly as they should because of the stigma associated with it. And they don't want people to feel that they can't recognise them or understand what they are saying, especially when they are being assessed by a professional. So, they try hard to remember the questions and answer and retain them as they are being asked, just because they don't want to be labelled. So, people do not want to be diagnosed with dementia due to the societal stigma* (Obiora).

Thus, drawing on Jansen et al. (2021) 'act of performance' and relating it to Obiora's narrative would mean how asking doctors for dementia help could potentially impart the member's dementia assessment. So, negative attitudes from doctors could increase the barrier to seeking dementia help, whilst positive attitudes from medical doctors can lower the barrier to seeking help for dementia. Indeed, Jasen et al. (2021) described the act of performance as a product of an internal 'balance act' with its core value centred on providing a non-negotiable priority for safe and quality patient care. Therefore, it insinuates that the 'balance act' can be influenced by sociocultural characteristics, which could be formed from a constructive relationship between medical doctors, people with dementia, and their families. Indeed, it can lower the barrier to seeking help for dementia, again emphasising the need for medical doctors to be approachable and perhaps friendly to people with dementia and their family, leading to a ‘balance of care’ (Morton-Chang et al., 2019) in the community. Of course, a balance between lay and medical concepts in dementia care management. More importantly, people with dementia can stay involved with direction until the later phases of dementia. Thus, the Black African population will weigh up the need for a dementia assessment and be assured that they will be accepted as a non-stigmatised member if diagnosed with dementia. In addition, we must also avoid negative dementia messaging in keeping the ‘other’ down in our society. Therefore, as medical doctors, we must avoid using ‘stigma power’ (Link & Phelan, 2014); GPs and consultants in this area probably do the opposite and cut through it. Generally, our primary role is to provide quality dementia care for our patients, regardless of their status or background. It is unethical to enact dementia stigma in our society. People with dementia can be stigmatised when labelled mainly by those who might not know much about it and linked to undesirable dementia characteristics, which leads them to experience status loss, discrimination, and emotional reactions. Indeed, doctors have power over their patients with dementia, and it takes power to stigmatise them (Andersen et al., 2022). Thus, the asymmetrical power relationship between the medical doctors, the people with dementia, and their families would lead to dementia stigma.

Nevertheless, attitudes may be considered the beliefs and willingness (Aihara & Maeda, 2020; Vrijsen et al., 2021) towards help-seeking for dementia, as observed by most participants in the current study, particularly with Ade and Bello. For example, Ade is a church pastor, and his belief in the dementia phenomenon was rooted in religion. Thus, his attitude towards help-seeking was centred on ‘sins’ and forgiveness from God as a part of his religious belief, as narrated:

> *If I am worried about dementia, I would first of all consults with God to find out what the problem is. It could be due to my sins or something else. If it is due to my sins, I would then confess through Christ, who is able and ready to forgive me of my sins. If it is not due to my sins, I will seek help from the doctors. I know you are a good doctor, and doctors are good people, but I will first consult with my God* (Ade).

Ade’s notion of sin can suggest that sin is a concept that emerges from Christian theology that relates to the nature of God and religious beliefs. Thus, it has existential, moral, and ethical dimensions towards dementia and dementia help-seeking in the group (Imrenyi, 2005). Indeed, it explains the 'presumed' rationale for the Black Africans in the UK to seek help from the church based on a feeling of transgression of God's Law. However, it appears as if the willingness towards help-seeking for most of the participants, including Efe and Seyi, were mainly centred on receiving a diagnosis and treatment for dementia, as narrated:

> *I know they have clinics for dementia tests in London. But for me, I would simply call on my doctor. Yeah, I would call on my GP so as to be referred for a test because I can't just walk in because I will have to be diagnosed first. So, if you are worried and not sure that you have dementia, then you have to go through the GP, and the GP will take the necessary process* (Efe).

Likewise, drawing on Seyi suggests that 'GPs are appropriate professionals for dementia diagnosis and treatment and would have the right attitude towards care', as narrated:

> *I believe GPs are the appropriate professionals for diagnosing and treating dementia. GPs are trained like other medical doctors, and they have a broader knowledge of medical conditions. Although they are not specialists, they are the starting point for general consultations in health matters. So, I think they would have the right attitude towards dementia and would point you in the right direction for further help when needed* (Seyi).

So, drawing on these participants' narratives suggests that Black Africans would work with medicine and are not opposed to it. Nonetheless, it emerged that the willingness towards help-seeking for dementia was not a straightforward decision. It was influenced by the participant's backgrounds, such as occupation and educational levels, amongst many other factors, including age, gender, length of stay in the UK, and religious beliefs. For example, Efe, a 35-year-old care supervisor and Seyi, a 55-year-old college teacher, both have university degrees and were willing to consult doctors. Nonetheless, Merida, who is 25 years old, a female sales assistant with only a secondary education and originally from Cameroon and has lived in the UK for 15 years, insisted that she may want to discuss the dementia phenomenon with her family and friends. Presumably, a function of personality and desire for social input and education. However, she acknowledged the need and necessity to also consult with medical doctors; she appears sceptical about such a decision as narrated:

> *GPs are the people to help deal with it, but not everybody likes their GP because some of them don't listen to the patient and what they have to say when they visit*

> *the doctor's surgery. They sometimes can be full of themselves. Yeah, it is like, 'I don't have the time to waste with you now; let us deal with it as quick as possible'. Yeah, they are just equally as sick as well [Interjection]. To be honest, I don't like seeing doctors* (Merida).

However, Merida's scepticism about consulting a medical doctor for the dementia phenomenon was based on perceived poor clinical communication skills from the GP and lack of trust, specifically in the GP's ability to listen and connect rather than on the grounds of her educational level. Indeed, it is expected that doctors must be able to communicate effectively and sensitively with patients and relatives (Ong et al., 1995). Notwithstanding, Yoofi, 35 years old male carer originally from Ghana who has lived in the UK for seven years, believed that GPs should do better as viewed:

> *GPs are medical professionals, and they should be able to deal with dementia appropriately* (Yoofi).

Regardless, for some participants, the willingness to seek dementia help from the medical doctors may be negatively influenced by their lay knowledge and beliefs about dementia. For example:

> *I think the most challenging thing is the stigma; people always want to distance themselves from a person suffering from dementia because of the link to madness, evil spirits, or ancestral curses and so on* (Nwanne).

Nwanne particularly emphasises the stigma that could arise from the lay knowledge and beliefs people may hold towards dementia; a different kind of dementia stigma not enacted by doctors but by the community group. Indeed, most of the participants in the study identified dementia as madness or insanity and some associated dementia with evil spirits and ancestral curses. Nwanne is a 35-year-old female master's degree student from Nigeria studying at one of the prestigious universities in the UK. Moreover, she has lived in the UK for eight years but may not have fully assimilated into the UK culture, although she sounded knowledgeable. In support of her view, studies have illuminated an implied stigma for dementia in Nigeria. Insanity and madness were common derogatory names used to describe dementia (Adebiyi et al., 2016). Therefore, the nature of our behavioural interactions can respect or disrespect people with dementia, as illuminated by Okafor:

> *And when we start to isolate ourselves from someone already isolated, the person's situation will worsen. You know, so when people isolate themselves from people with dementia and do not want to engage them in anything, they would be left on their own…I have told you that there is no treatment, and there is no treatment [Interjection]. There is no treatment for dementia. I have not seen anybody cured of dementia* (Okafor).

Okafor is knowledgeable, and the researcher picked up some key ideas from his experience. For example, the isolation of a person with dementia can only worsen the person's condition. Nonetheless, the researcher recognised dementia has no definitive treatment and seeking help from medical doctors may have little or no value for Okafor. Thus, our behaviour as individuals or medical doctors should be tailored to respect people with dementia and provide them with satisfying engagement. As such, Seyi suggests that doctors may require to work in collaboration with other providers as dementia may be considered a matter beyond a clinical condition, as narrated:

> *People generally would book an appointment to see their GPs, who then would suggest for clinical tests to make a dementia diagnosis. Once the diagnosis of dementia is made, the doctor would prescribe further steps towards the community's treatment and care. So, GPs would also need to collaborate with other health care providers because dementia is a matter beyond a clinical condition and a social problem* (Seyi).

Therefore, as illustrated, the empirical evidence across the data set suggests that help-seeking and attitudes towards dementia amongst the Black African populations living in London were not necessarily straightforward but complex. Indeed, drawing on the participants' views and narratives shows that 'dementia is a matter beyond a clinical and a social problem' Thus, the data illuminated two subthemes: (i) Attitude and (ii) Stigma as emerged from the umbrella theme (Help-seeking behaviour).

### Attitude

The help-seeking behaviour depends on the group's beliefs and knowledge of the dementia symptoms. So, it appears that the group's religious beliefs towards the dementia phenomenon and their lived experience influenced their attitude toward help-seeking for dementia. Their knowledge of the dementia symptoms influenced their help-seeking behaviour for dementia.

For example, Marie's mother died of vascular dementia, which subsequently informed her understanding of vascular dementia and influenced her help-seeking behaviour, as can be drawn from her narratives:

> *I swear Bola has dementia; Bola is having a serious memory problem. I think she has dementia [Interjection]. I know a few things about dementia because my mother had it. Vascular dementia they called it, and the doctors said my mother had vascular dementia…it is similar to what you said about Bola in your [Interjection]…* (Marie).

Furthermore, drawing on Marie highlighted how 'checking' her blood pressure would inform her help-seeking for dementia, as narrated:

> *…I can go and see my GP for a blood pressure check and some other tests. If the GP thinks I have dementia, the GP can refer me to see a specialist in the hospital for more tests [Interjection]. I am now very serious about my blood pressure; I check it all the time. Last night it was around 124/83. I think it is good [Interjection]. I check it myself. Yes, I have to keep checking it. I take checking my blood pressure seriously* (Marie).

Of course, high blood pressure can be associated with increased dementia risks (Ou et al., 2020), and it is a risk of poststroke dementia (Hilkens et al., 2021). Similarly, Yemi's parents presented with dementia symptoms which also influenced her decision to seek the help needed for her parents and as well influenced her help-seeking behaviour for dementia as delineated in her narratives:

> *But the first thing to do is to contact your GP. You would want to contact your GP, and that is the first port of call. You would want to be able to report the whole activities to your GP. For example, mum has stopped sleeping all of a sudden, and dad has stopped sleeping [Interjection]. They are not sleeping, they are getting agitated, and they are a bit confused. Your GP is your first port of call, and then they can make other referrals. And also, the social services, for example, in your local borough, would have the adult social services number you can call. So, your first port of call is either your GP because every one of us is meant to be registered with a GP; they really need to know and also have it on their report. [Interjection] Once the symptoms I have described are reported to them, they would know what it is, that is, the diagnosis, because they know it through their studies. They would*

> *know that dementia is setting in, look at the age range and many other factors, and begin making referrals. So, I believe the GP and the social services are the places where the person should reference when they see that their loved one is losing capacity or has dementia.* (Yemi).

Interestingly, some respondents have previously referenced social services, including Seyi, and Yemi further refers to it in her narrative. Thus, it seems essential for doctors to work collaboratively and in partnership with social services. Indeed, a collaboration between doctors and social care services cannot be overemphasised (Kontrimiene et al., 2021). Nevertheless, Yemi's narrative below suggests that there was some evidence of respect and trust in her consultation with the GP:

> *…when things began to change [Interjection], my dad began to have memory loss. He [GP] was quite good; he seemed to know what he was doing. He asked me to bring him in, and he asked him [my dad] some questions… So, they do those little little tests just to see if his memory is doing well or coordinated if he can think through and process information, just basic [Interjection] information, but I guess he [GP] was quite good, so he was able to ask him those questions… But the doctor was quite good, and he really knew what to look out for. He already saw the symptoms and signs, and he said, 'You know what, your dad has dementia. But you know a lot of people do not want to hear that they are suffering from dementia disease… [Interjection] He was a good doctor, and to be honest, he knows what he was doing* (Yemi).

Although, an in-depth analysis of Yemi's narrative shows that the GP may have practised medical syncretism judging by her view that the doctor was also a 'pastor'. Thus, the GP was perceived as 'good' and more supportive.

> *I think you meant my father's GP… he seems to know about my father. I think he was a pastor, so he seemed to know what my dad got [Interjection]… So, I don't think all GPs have total knowledge about dementia* (Yemi).

Nevertheless, biomedicine dominates any alternative medical system or medical pluralism in the UK (Helman, 2007). Furthermore, Nonye's lived experience and knowledge of the dementia symptoms influenced her help-seeking behaviour, which led her to consult with the medical doctors as narrated:

> *Yes, I do forget things sometimes…I was worried about dementia three years ago after when my husband was diagnosed with Alzheimer's disease, so I had to see the GP. I was also sent to the memory clinic for assessment* (Nonye).

Moreover, it appears as if Okafor's lay knowledge of dementia provided us with a prescription for the treatment of dementia as narrated:

> *As dementia progresses, the person may have a stroke or heart attack. So, the person needs to keep the body going at least in the morning; the person should have 1 to 2 kilometres walk [Interjection], listen to music, watch television and life will go on. You know! The brain or the body is like a motor car* (Okafor).

Therefore, drawing on these narratives suggests that there is a need to engage lay knowledge in the management of dementia in the community, and the lay knowledge of dementia can be considered expert knowledge. Moreover, drawing on Ade's narratives below may suggest gender and divorce as perceived dementia risk factors that can influence help-seeking behaviour, further illuminating lay knowledge about dementia as expert knowledge that we can acknowledge.

> *It is a pity that women are more affected than men. I have been pastoring for more than 30 years [Interjection]. For example, the divorce rate has risen up to 60 % in our community; as a consequence, we now have a lot of single mothers in our society struggling and busy raising children all by themselves without their husbands. It is destroying our community, it is killing our women, and making them anxious, stressed and overthinking things. If only we could live up to the principles given to us by Jesus Christ, I believe dementia and many other mental illnesses will be a history and not affect more women than men in our society* (Ade).

Indeed, we can consider the lay knowledge of dementia as expert knowledge. For example, Ade is a 65-year-old male pastor, originally from Nigeria and has lived in the UK for 23 years, and he has been pastoring for about 30 years. Seemingly, he provided us with an exciting lay theory which can be delineated in his narrative, highlighting that 'dementia is a result of the psychological stress and the huge burden that our society has unknowingly or unconsciously laid upon women' as viewed:

> *I don't believe dementia is a problem of only age, as I have read and many of such, but I believe it is a societal and family problem bestowed on women due to the lack*

> *of the application of the truth and the biblical principles of God. Don't get me wrong, but I just believe that dementia is a result of the psychological stress and the huge burden that our society has unknowingly or unconsciously laid upon women. That is why dementia is mostly affecting women more than men. Men are a bit free from dementia. For example, I have seen about four Nigerian women here in London suffering from dementia, but I am yet to see a single Nigerian man with dementia. I know there are men suffering from dementia, but I have not seen any for now [Interjection]. You see, our women are carrying too much burden upon themselves by trying to raise a family all by themselves. It is not good, it is not the principle of Christ, and it is not good for women's health and well-being. Please don't get me wrong, doctor, but just my candid observation as I see dementia in women as a deviation from the scriptures and the biblical principles of our God* (Ade).

The empirical evidence or the discourse above indicates that the group may focus their help-seeking towards religion rather than medical sources. More interesting is the lay theory, as illuminated by Ade, a social construction based on a societal consensus about the roles and rights of men and women in the community, perceived structural violence against women. Furthermore, drawing on Yemi's view may suggest that family income was an issue in decision-making and may also influence help-seeking behaviour for dementia, as narrated:

> *I am saying that it would be more expensive to take care of a person with dementia because they would need extra time for extra support…I am saying, in effect, that a person with dementia would need extra help and care, and it could be more expensive compared to someone who doesn't suffer from the illness but just from old age* (Yemi).

Although, it appears Yemi is emphasising her stance about relatives and their care expenses for those with dementia compared to those without. As noted, Yemi is a family carer and might be worried about the cost of caring for her father with dementia which might become a possible deterrent to seeking help. However, Eze's view may suggest that the NHS in the UK is government funded. Thus, family or relative's income may not necessarily be an essential issue in dementia help-seeking, and as such, family or relative's income may not influence help-seeking behaviour for dementia in the UK as narrated:

> *I don't know the cost, to be fair, because in the country we are in, when you have issues, you go to the GPs who are there to help you, and it is government funded. NHS is government funded. So that is the little I can say. So that is the only thing I can say about it; in the NHS, the government looks after the people by providing the necessary care for the people with the illness* (Eze).

In contrast, drawing upon Eze's view below could further reinforce Yemi's narrative, delineating that a relative's income can be an essential consideration for the group in dementia help-seeking and behaviour, particularly considering their original backgrounds. The participants were originally from West Africa, and Africa may be regarded as a poor continent, as narrated:

> *Back in Africa, they might not be able to pay hospital bills because of poverty. But those who are average and can afford the cost will be taken to the hospital, and the person will be managed and given medications, unlike how we have it in the UK, where everyone is able to access medical help* (Eze).

Nonetheless, drawing on Okafor's narrative can suggest that in the UK, there are nursing facilities for aged care but not considered a cultural practice in Africa and perhaps Africans in the UK are lesser users of care home facilities for aged care as viewed:

> *[Interjection] preventing dementia is individual; you just have to take care of your parents and the elderly and provide for them. For example, most of us here abroad don't go home, and most of us don't have a living place. I mean a place someone can live and call it home. You know. And we also don't provide it for our aged ones. They are the ones that trained us. So, when you are in a position to do so, put up a place where your aged ones can stay* (Okafor).

Furthermore, it appears as if Okafor is suggesting the need for members to consider using care homes for dementia care both in the UK and in their homeland. In addition, he drew attention to life satisfaction, which can indicate a better quality of life for a person with dementia, perhaps by building a positive relationship as illuminated:

> *Then if there are things that you know that you can do that will make them happy, like having a lawn tennis court or walk-in where they can visit their friends. Above all, let them have financial support. You know. My people will always say that*

> *'when a man has money, he gives to his pocket, and his heart is made strong'* (Okafor).

Interestingly, his quote, 'when a man has money, he gives to his pocket, and his heart is made strong,' is a metaphorical expression. Suggesting that group members ensure their loved ones are not left empty-handed or abused, meaning that people with dementia should not be left needy or financially abused. When people with dementia are given financial support, they are happier and more robust. Moreover, dementia stigma can be dependent on economic and social power. Indeed, it takes economic power to stigmatise (Andersen et al., 2022). Therefore, drawing on the empirical evidence across the data set suggests that help-seeking behaviour is observable as a sequential process within the individual, their families, or relatives. Therefore, help-seeking involves the identification of the dementia symptoms and perceived dementia risks, and subsequently, in identifying help for dementia, as well as having trust in the dementia services or the provider.

**Stigma**

Within a sociocultural context, the Black African populations living in London may hold knowledge of the dementia phenomenon that may be abusive or stigmatising, thus creating resistance or barrier to help-seeking for dementia. For example, drawing on Okafor's experience may suggest that people with dementia in the group may be abandoned, separated, or isolated due to stigma, as narrated:

> *People don't want to hear about dementia; in Nigeria, they will abandon the person in the village. This is personal, and my mother died because nobody was with her. You know! My mother died because nobody was with her and I was in the UK. Others were careless. Had it been that someone was with her talking and doing all sorts of things that she liked, she would not have died. Right from the time I knew my mother very well, she was a talkative type, a busy woman. All of a sudden, she could not talk, could not go out, could not walk [Interjection] … [glitches] a very painful experience* (Okafor).

It appears as if Okafor's mother was abandoned in a village in Nigeria, and she was isolated and left alone to die from dementia due to stigma. Indeed, Okafor's mother was separated and isolated from her children and relatives in a town in Nigeria which impacted her social identity negatively whilst Okafor was in the UK.

So, Okafor's experience in the UK affects his views about dementia positively. Perhaps before he could change his mother's identity in Nigeria by drawing on his newfound dementia knowledge in the UK, his mother died of dementia. Within a sociocultural context, these social identities consist of witchcraft, madness, craziness, insanity, and ancestral curses. Furthermore, the 'spoiled' identity (Goffman, 1963) causes stigmatisation and psychological trauma. Goffman's (1963) concept of spoiled identity can involve attributing people with dementia with a negative or stigmatising characteristic such as witchcraft accusations or ancestral curses. Thus, Okafor felt such a pang of guilt about his family's actions in Nigeria and considered it a 'painful experience' and a feeling of guilt on his part. More so, drawing on Okafor's stigma experience described dementia as shameful and created resistance to help-seeking for his mother, leading to her death. Stigma can change a person's self-concept and social identity. People with dementia could be labelled and shamed, creating a reluctance to help-seeking for dementia:

> *In my community, there is no care; just forget about it. They will just give you food and put you in a room. Maybe in one week, you have not taken your bath. They think that your time is gone. You know! They will just label you. You are finished. They are just waiting for the day you will die. That is, abandonment, just to put it in a word - abandonment! They will abandon the person in the Nigerian community, not in the UK…Some people may not want to associate with a family member with dementia because of shame* (Okafor).

So, Nwanne and Kofi, who were both master's degree students, clarified that the stigma associated with dementia is linked to the spiritual world as viewed:

> *I think the most challenging thing is the dementia stigma. People always want to distance themselves from a person suffering from dementia because of the link to madness, evil spirits or ancestral curses* (Nwanne).

Indeed, sociocultural beliefs link labelled people to undesirable characteristics to negative stereotypes (Andersen et al., 2022). Notwithstanding, a careful analysis of Kofi's narrative below suggests that people may want the person with dementia to be responsible for their illness as a way of blaming the victim, as illuminated:

> *Also, there is associated stigma as well. For example, people who do not understand the causes of dementia tend to, you know, cast [Interjection] uninformed notion or behaviour towards dementia. So, I think there is stigma…*

> *You know, [Interjection] and that she is suffering from her past sins, past evil deeds, and all kinds of things. And people would kind of look at you in a very different life. They would not want to come closer to you and do not want to hear such evils. And it has a very strong impact on people living with that kind of condition. So, that is what I mean when I say there is a stigma attached to dementia* (Kofi).

Of course, Kofi illuminated a practice that is despicable in the group. Indeed, stigma amongst the participants was associated with the links of the dementia phenomenon to the spiritual world. Thus, as identified by Okafor and Fatou, stigma can lead to labelling, and labelling is a social selection of human differences (Andersen et al., 2022). Such labelled difference tends to link dementia to witchcraft or negative stereotypes. Moreover, as such, Fatou suggests the need to support people with dementia in more positive ways, as narrated:

> *We should also try to support those with dementia in positive ways rather than labelling or stigmatising them* (Fatou).

One of the positive ways may include 'opening up' the community towards destigmatising dementia and providing access to dementia information so that people can be active agents rather than acted upon, as illuminated by Eze:

> *I would say we have to open up to get to the right source to seek advice whenever we feel we have some health issues rather than trying to keep it to ourselves. It is good for people to open up [Interjection] to open up and find out how to access information. And use the government's free information to help ourselves* (Eze).

Thus, Obiora, a 55-year-old pastor who has lived in the UK for 24 years, suggests that the church may help improve dementia awareness and enhance dementia help-seeking positively. Probably by the intersection of culture in the provision of dementia care or through the process of acculturation, and by collaborating with medical doctors as narrated:

> *The church can also help stop the dementia stigma by making people aware that dementia is not witchcraft or a curse on people…Personally, I am currently trying to organise a program to bring in different professionals to speak on health issues such as dementia and other worrying issues. I hope to organise the program in my church to sensitise members, create awareness, and keep them informed about*

> *health issues like dementia. [Interjection] what I can also do apart from creating awareness is to also pray for members who may be affected by dementia.* (Obiora).

Indeed, Obiora felt a sense of being socially responsible for members of the group in the UK, and his action backed up with prayer aligns with his worldview. Therefore, church leaders can act as dementia health promoters (Badanta et al., 2020; Epps et al., 2020; Epps et al., 2021; Gore et al., 2022), particularly in helping in the destigmatisation of dementia in the Black community. Acculturation can refer to a process in the intersection of cultures in which the Black African populations living in London could accommodate the medical constructs of dementia into their culture through cultural acquisition or because of living in the UK. Therefore, the intersection of cultures in dementia management in the community may include the knowledge of dementia, dementia care and family roles (Brooke et al., 2018). Indeed, it can signify a cultural change in dementia care management in the community amongst the Black African populations. Moreover, it can be rooted in balancing the lay constructs and the medical constructs of dementia, thus leading to a ‘balance of care’ in the community (Morton-Chang et al., 2019) and destigmatisation of dementia amongst the black African populations in the UK.

### Caregiving

Dementia caregiving emerged as a key theme in the study. It encompassed the quality of care and care activities which involved looking after a person with dementia in the community. Three subthemes identified within the caregiving theme include (i) Caregiving in care homes (residential care), (ii) Caregiving within the home of the person with dementia (domiciliary care) and Caregiving behaviour. As identified, the group knowledge and beliefs towards the dementia phenomenon are that dementia has no definitive treatment or cure. Nevertheless, providing quality care for people with dementia is essential. The caregiving behaviour is centred on showing affection and love, whether it is provided in a care home or within the home of the person with dementia, as narrated:

> *But I think the main treatment for dementia is to be kind to people with dementia and to show love to those suffering from dementia whether they are our family members or not. Giving love to the family with dementia and the person suffering from dementia is the major care apart from other care activities* (Yetunde).

Indeed, studies have reported a discourse on ‘love’ given and experienced in caring for people with dementia (Gilbert et al., 2021). Therefore, the behavioural approach towards caregiving is driven by love and affection for the most participant in the group. Gilbert et al. (2021) considered it a 'labour of love'. Regardless, it appears that through cultural acquisition or enculturation, the burden of dementia care in the community rests mainly on the family. So, the family is considered the primary caregiver, as most participants narrated. For example,

> *As a grown-up child, society expects you to take care of your parents and your grandparents, or whoever is suffering from the condition* (Kofi).

Drawing on Kofi's can suggest some similarities to filial piety (Li et al., 2021) in Eastern cultures, and the idea also exists in many modern Western cultures (Jones et al., 2011). Nonetheless, dementia caregiving enculturation can be considered a process of learning the values and skills a family member may require participating in dementia care in the community. Furthermore, it also appears that psychological factors were a significant factor associated with dementia caregiver burden as a psychological illness. Thus, a family member who gives care may need help in taking care of themselves, as narrated by Yemi, a family carer:

> *And to be honest, the person taking care of a person with dementia needs therapy; they also need therapy for themselves because the labour is so much, and they are watching their loved ones totally change over time, you know [interjection], and it is a lot of hard work* (Yemi).

So, dementia is a degenerative illness, and caregivers are expected to take on more responsibilities as the health condition of the person with dementia declines. Therefore, drawing on Yemi's narrative can suggest that self-care for caregivers seems to be a broad understanding amongst dementia caregivers. However, behavioural problems and psychological symptoms are usually associated with caregiver burden or psychological illness (Chiao et al., 2015; Cheng, 2017). Therefore, dementia caregiving in the community can be considered an arduous task driven by love and affection for people with dementia. Moreover, it may require collaborative teamwork between family, social services and medical doctors or integration of the lay and medical concepts of dementia into the dementia community caregiving. Nevertheless, the cost of dementia may present a problem in community dementia caregiving, as narrated:

> *You see, the reason people are taken into residential care homes is about cost…Sometimes when the social services want to cut down on costs and the person with dementia does not have a 'leg to stand on' or strong support, when I say strong support, I mean friends and family who can put their feet down; they would find*

> *themselves in a care home. You understand! But if the person with dementia can still be managed in the person's residential home, why not? We just support him, and this is managed as the family steps in, and the carer steps in, and they do what they have to do. But if it is getting out of hand and getting more serious, maybe the person might need the intervention of being in a care home. Where there is a 24-hour need for care would be worth a while for this person* (Yemi).

Regardless, drawing on Yemi's narrative suggests that she acknowledges quality in dementia care and the benefits of both in-home and residential care for the different stages of dementia. Nevertheless, Fatou, a social adult care manager, provided further insights as to why the cost was a significant problem in dementia community caregiving as narrated:

> *I think some people may prefer their own home as it is a well-known or a familiar environment. And some may prefer care homes due to their available services and safety. But I think most Black Africans in the UK will prefer their care to be planned within their own home due to cost…And council usually pay a lot less than care homes normally charge. And the council will normally assess your financial situation* (Fatou).

Furthermore, drawing on Fatou suggests the dementia cost is pragmatic and individualised based on the person's financial circumstances:

> *Dementia care can be a bit expensive, and it is usually tailored to the individual's need [interjection] the need of the person with dementia. Although the council will contribute to the care cost of the individual with dementia, payment is means-tested, with the individual paying the rest of the cost* (Fatou).

However, according to many of the participants, including Eze and Kunle, it appears as if the cost of dementia was not just the main problem. Instead, domiciliary caregiving or in-home caregiving was perceived as a cultural norm for most of the Black African populations living in London, as narrated:

> *We are home-based people. We are not mostly into care homes because of our traditions. So we are home-based carers than general care, like taking them to care home and letting them live there for other people to manage them…No! mainly for me, I would say in-home care is more preferred by our African people because I don't know much because I have not done the study, but if you look in the UK care*

> *homes to see how many Black African older people in the care home suffering from dementia or any other thing you would find out that they are very few. From the little that I have said before, if you visit a care home, you will see less than 5% of Black people in there, may not even be up to 2% because most Black people with dementia stay in their home* (Eze).

Interestingly, Eze referred to 2%, and perhaps the figure could be proportionate to the percentage of older Black persons in the population. Notwithstanding, Kunle considered care home 'adequate and appropriate' but preferred in-home care as narrated:

> *I believe the care home is the opportunity for the individuals to be confined to a place that will provide them with adequate and appropriate care that they need. But having said that, if there is an opportunity to take care of them within the family home or in the community, that would be the first choice…Like I said to you many times within the cause of this discussion because we are a community and will prefer along that line* (Kunle).

Drawing on Kunle's narrative can suggest that care homes can be 'adequate and appropriate', providing quality and being culturally appropriate. Still, it appears the Black African population preferred domiciliary care to care homes that they considered culturally relevant. Indeed, it may differ from some white population groups globally (Frochen et al., 2020; Haumann, 2020; Kaambwa et al., 2021; Caffrey et al., 2021). However, some factors that may assist some of the white populations with dementia to remain to live at home longer than expected before onward movement into a care home include family and social support, legal services, and dog ownership (McGrath et al., 2021). Regardless, most respondents, for example, Ngozi, a 25-year-old female carer, believed that care homes are better equipped to provide the needed quality of care for a person with dementia as narrated:

> *London does not have any problem. Because in London, they have all the facilities to take care of people with dementia, they have everything. They have carers and care home, unlike in Nigeria* (Ngozi).

Furthermore, Kelechi, a 35-year-old master's degree student, believed that the care home provides better quality care for the person with dementia as narrated:

> *Some people may prefer their own home because of the familiarity it brings into their care package, but others may prefer a care home despite the fact it could be more expensive but provides a better quality of care* (Kelechi).

Likewise, Kofi, a 35-year-old master's degree student, believed that a care home is better structured to provide the needed quality care for people with dementia as viewed:

> *I think care homes are well trained and structured. So, in my personal view, I think a care home is better tailored to take care of people with dementia or the elderly. So, my preference would be the care home* (Kofi).

In addition, it appears as if Zubby and Titi may also prefer the care home because it can provide better security and safety for the person with dementia, as narrated:

> *...the preference would be to take them to a care home because they normally cannot find their way back home, and because of the loss of memory, they can't find their way back to their house. So, the best thing is to put them in a care home...* (Zubby).

Indeed, drawing on Titi highlighted the need for safety:

> *I think the main risky behaviour for people with dementia is that they can get lost within the community, and their family and friends will start looking for them, or they may report it to the police, and the police will start looking for them. Most of the time, people with dementia usually may not be able to find their way back to their homes when they walk out of their houses* (Titi).

Finally, this chapter illuminates dementia help-seeking behaviour, attitude, stigma, and caregiving amongst Black Africans living in London that also informs the sociocultural model for dementia, developed inductively by the researcher from the data and added to the literature. Interestingly, a participant drew attention to the vital role of anthropologists in dementia care management as viewed:

> *Probably anthropologists will know what all this is all about and put things together. But in our society here, we don't have anything like that...* (Yemi).

## Summary

The analysis showcased the data and presented the findings towards dementia help-seeking and caregiving amongst the respondents, who were Black Africans, first-generation migrants from West Africa and marginalised churchgoers living in London. The analysis shows that religious and cultural beliefs influenced attitudes towards dementia help-seeking and caregiving and were associated with dementia health disparity in the Black African community. Even so, many respondents are willing to seek help from their GPs for dementia. Still, many also believed in the power of prayer, which served as a therapy for dementia and in caregiving. Dementia caregiving was mainly carried out within the home of the person with dementia in the Black African community and less frequently within care homes and churches. The analysis also shows that dementia help-seeking and caregiving were associated with stigma. Still, the attitudes towards dementia help-seeking and caregiving are not static but evolving slowly towards care homes for dementia caregiving in the group. The findings illuminated that collaboration between medical doctors in the NHS, community leaders, and applied medical anthropologists is needed for dementia outreach and to address dementia stigma and dementia health disparities in the Black African community in the UK. The next chapter presents the discussion.

# Chapter 9

# Discussion

## Introduction

This chapter discusses the methodology, explanations, and interpretations of the results in the context of the research questions arising from the literature review and theoretical framework. It discusses their implications in dementia services, acknowledges their limitations, and gives recommendations. Firstly, the research questions are highlighted.

1. What are the lay knowledge and beliefs towards dementia amongst Black African populations living in the UK?
2. What are the lay concepts of dementia, perceptions of dementia risk factors, and dementia help-seeking or attitudes amongst Black Africans living in the UK?
3. What is the dementia help-seeking and caregiving or treatment of people with dementia amongst the Black African populations living in the UK?

It uses confessional and realist tales (Van Maanen, 1988) to discuss and present the methodology, theories, and their development and interactions (see Chapters 3 and 4). This approach presented lay concepts of dementia from a broader and relativist perspective, which suggested that all dementia knowledge is valid but changes with a person, time, geographical context, and culture (Brown, 2008). The concepts were inductively developed from data and formed the lay concepts of health and illness, including holism, individualism, and pragmatism. These theories illuminated the concepts that shape the group's dementia services (see Figure 3 in Chapter 3). The group is a churchgoer, and the respondents were first-generation migrants from West Africa in the Black African community in London (see Chapter 4). The assertion of the absolute equivalence of lay expertise and medical expertise is also revisited in this chapter.

Furthermore, this chapter evaluates the study's rigour using qualitative criteria (Lincoln & Guba, 1985; Lincoln & Guba, 1994; Lincoln et al., 2011). The research findings are discussed alongside existing literature and concepts, followed by the implication for policy, practice, and recommendations.

Finally, the chapter concludes by summarising the research and its value in the context of theory, methods, and results. The researcher mentions the inclusion of witchcraft in the literature on dementia and notes that the discussion on the development of the sociocultural model is beyond this chapter's scope.

## Theory and methods

A *theory* is a way to understand social reality based on empirical data, but it can also go beyond that (Denzin & Lincoln, 2018; Leavy, 2020). A *methodology* is the process of conducting research and combining theory and methods (Boeije, 2010 Grbich, 2013; Braun & Clarke, 2019; Manson, 2018; Denzin & Lincoln, 2018; Leavy, 2020). In this study, the researcher's philosophical beliefs influenced the methodology. The researcher developed a 'dual-axis theoretical framework' underpinned by social constructionism (see Chapter 3) and created a lay conceptual model for dementia and dementia services based on the sociological and anthropological concepts of health and illness (see Figure 3). Dementia was found to be a holistic phenomenon affecting the spirit, body, and mind/brain (Farrell, 1950; Feigl, 1958; Smart, 1959) and associated with metaphysical properties (Nobis, 2011; Nelson-Becker, 2017). Additionally, dementia was found to be relative and person-centred (Kitwood & Bredin, 1992; Kitwood, 1997) amongst the Black African populations in the UK and influenced by extrinsic factors such as culture, ethnicity, gender, education, socioeconomic status, migration status, occupation, religion, spirituality, and environment. Relativism in this study holds that there is no absolute knowledge and belief about dementia (Brown, 2008). Of course, philosophical differences exist between lay knowledge and beliefs about dementia and medical expertise and ideas about dementia. They are drawn from different epistemological perspectives, the lay and medical concepts that underpin dementia services in the Black African community in the UK.

Philosophically, the differences in lay and medical knowledge could be understood by drawing on the 'Gettier cases' (Gettier, 1968), which are designed as a theory. It suggests that medical knowledge of dementia is a justified true belief, insinuating that lay knowledge about dementia is not a justified true dementia belief. Therefore, the respondents as agents must arrive at dementia knowledge and beliefs in seemingly reasonable or justified ways by the medical doctors. Otherwise, the individual is perceived to lack dementia knowledge. Regardless, the researcher argued that the Black African population living in London do not lack knowledge about dementia. Unsurprisingly, some participants did not lack biomedical knowledge about dementia as the researcher previously thought (refer to Chapters 1 & 2). This study found that the respondents identified as laypeople and churchgoers evaluated dementia according to what they considered reasonable given their age, gender, education, occupation, religious beliefs and spirituality, ethnicity and race, socioeconomic status, social class, and migration status, as the participants were first-generation migrants from West Africa. It influenced their understanding of the dementia phenomenon, guided by their social identity and relationships. Therefore, the researcher contended that the lay concepts of dementia are a relative phenomenon which varies depending on culture and individual factors (Kitwood & Bredin, 1992; Kitwood, 1997). Nonetheless, he argued that the Black African population generally share philosophers' intuitions about the dementia phenomenon. Indeed, the researcher perceived the group, including the teachers, pastors, and family carers as lay philosophers with philosophical ideas about dementia.

Furthermore, this study's thematic and social constructionist analysis illuminated the lay knowledge and beliefs about dementia. Before the fieldwork, the researcher initially argued that the biomedical concepts of dementia should not be privileged epidemiologically over the lay concepts of dementia, as all dementia knowledge and beliefs can be considered equal (Armstrong, 1985; Bury, 1986; Monaghan, 1999). Nevertheless, at the end of the fieldwork and data analysis, the researcher argued that lay and biomedical knowledge of dementia are not mutually exclusive. The data shows that the respondents have access to multiple ways of understanding and framing the dementia phenomenon, and the ways intersect both lay and biomedical understanding of dementia. For example, drawing on the data analysis (see Chapter 7) shows that lay and biomedical perspectives are a false dichotomy as each influences the other and is not independent.

Of course, suggesting that the Black Africans' lay knowledge and beliefs about dementia can be as valuable as the biomedical knowledge and beliefs of dementia because there is no way of judging the respondent's lay understanding of dementia as lesser than the biomedical knowledge of dementia (Bury, 1986). Although, there is seemingly a hierarchical dementia knowledge generated in the fieldwork.

The data analysis illuminated epistemological hierarchies of dementia knowledge in the group. The respondents shared the same epistemic concepts with academic philosophers by recognising a difference between biomedical concepts of dementia and lay concepts. They viewed dementia from a broader sociocultural context. They drew on inequality and inequity as a cause of dementia and its impact on the quality of life for people with dementia (Farina et al., 2017), unlike the medical doctors who generally view dementia in a cellular context. However, there was a perceived superiority of biomedical knowledge of dementia over the lay understanding of dementia in the group, as most respondents looked up to the researcher's medical background and knowledge about dementia as a final authority over the sense of their lay knowledge and beliefs about dementia. For example, a participant asked the researcher to diagnose whether she had dementia, suggesting an acknowledgement or the justification of biomedicine over their lay knowledge about dementia. It could reflect the power dynamic between the researcher and the respondents or a piece of evidence to justify medical expertise over their lay expertise. *Lay expertise* is defined as a 'general cultural stock of dementia knowledge' (Wilcox, 2010, p. 45) or a 'body of dementia cultural knowledge' (Grundmann, 2017) that guides dementia decision-making and action in the group. The respondents have marginalised churchgoers in the Black African community, so the empirical evidence can suggest that the group's lay dementia expertise is not equal to medical expertise but intersects with biomedical knowledge about dementia, as most respondents were carers for people with dementia. Still, the researcher can argue that medical doctors hold the highest level of dementia expertise in the principles and practices of medicine among health practitioners (Davidson, 2022), and the carers can be subordinate in dementia services.

Interestingly, respondents referred to the Bible to justify their lay knowledge and beliefs about dementia on religious and spiritual grounds. Therefore, laypeople and medical doctors can differ in their judgement about what constitutes dementia knowledge and beliefs. As such, in the 'Theaetetus', Plato argued that there is a difference between knowledge and beliefs. In this study, lay knowledge about dementia was defined as more comprehensive knowledge (Popay & William, 1996; Popay et al., 1998). Nevertheless, drawing on the literature (evidence synthesis), there are concerns that the lay dementia knowledge and beliefs can lead to abuse, victimisation, and stigma (e.g., Mushi et al., 2014; Adebiyi et al., 2016; Hindley et al., 2016; Mkhonto & Hassen, 2018; Kehoua et al., 2019; Owokuhaisa et al., 2020; Jacobs et al., 2022). Thus, there is an essential need to address dementia stigma in the Black community in London. This also provides a good reason for medical doctors to work collaboratively with community leaders and medical anthropologists in addressing dementia education and awareness in the UK.

The empirical literature on stigma suggests there will be a dementia stigma in dementia practice only if there is labelling, harmful stereotyping, linguistic separation, and power asymmetry (Andersen et al., 2022). Therefore, based on Andersen et al.'s (2022) definition of stigma, the current study highlighted that the dementia stigma could be localised within lay concepts of dementia and equally situated within the biomedical models of dementia. Hence, the current researcher suggests moving dementia education and awareness beyond biomedical knowledge towards a more inclusive culture and value understanding. Generally, our thinking and learning of the dementia phenomenon in the modern epoch have depicted dementia as an intersection between biomedical knowledge and lay knowledge, as found in the present study. Indeed, as a medical doctor and applied medical anthropologist, the researcher believes that dementia education and information amongst the Black African populations living in London are driven substantially by medical concepts. Many of the respondents in this study viewed dementia as a disease and dementia as a clinical syndrome defined within biomedical images with associated clinical signs and symptoms of dementia, and the respondents were willing to seek help for dementia in the hospitals.

However, appropriate help-seeking and attitude towards dementia are crucial for diagnosing and treating dementia, as evident in the current study. The analysis shows that religious and cultural beliefs influenced attitudes towards dementia help-seeking and caregiving, and dementia caregiving was mainly carried out within the home of the person with dementia and less frequently in care homes and churches in the Black African community in the UK. Still, prayer provides comfort and can serve as a therapy for dementia (Rossiter-Thornton, 2002). Also, the attitudes towards dementia help-seeking and caregiving are not static but evolving (see Chapter 8).

Even so, some participants viewed dementia as an illness (Conrad & Barker, 2010). The current researcher argued that dementia as an illness is a lay concept (Hofmann, 2002). Nonetheless, some respondents viewed dementia as ageing and, as such, in many studies (e.g., Higgs & Gilleard, 2017). Moreover, others viewed dementia as forgetfulness reflecting the complexities of day-to-day life. Therefore, dementia help-seeking or behaviour was not that straightforward in the Black African community in the UK. They consequently presented as barriers, leading to delayed diagnosis and treatment for dementia. Consultations on dementia depend on families, friends, and relatives or are based on the individual's knowledge and beliefs about the dementia phenomenon. They influenced the person's decision to seek help for dementia (Mukadam et al., 2011). Backgrounds and sociocultural factors such as social class (Jones, 2017), education (Xu et al., 2016) and occupation (Egan et al., 2006), gender, age, and citizenship (Bartlett et al., 2018) influence an individual's choices for dementia help-seeking. Therefore, help-seeking or behaviour was viewed as a decision-making process or an 'act of performance' (Jansen et al., 2021), preceded by the individual's background or social identity. Indeed, the respondents drew on their own backgrounds, 'lived experiences', and skills to reach an understanding of dementia.

Aside from ‘stigma power’ (Link & Phelan, 2014), some respondents found their doctor’s communication and listening skills a barrier. Poor clinical communication skills from the GP and lack of trust, specifically in the GP’s ability to listen and connect with people with dementia, influenced help-seeking or behaviour. Indeed, it is expected that doctors must be able to communicate effectively and sensitively with patients and relatives (Ong et al., 1995). Therefore, the ‘act of performance’ is a product of an internal ‘balance act’, with its core value centred on providing a non-negotiable priority for safe and quality dementia care (Jansen et al., 2021). Hence, constructive relationships between medical doctors, people with dementia, and their families in the Black African community in the UK will reduce the barrier to help-seeking for dementia. Indeed, it emphasises the need for medical doctors’ approachability and being friendly to people with dementia and their family, incorporating a ‘balance of care’ (Morton-Chang et al., 2019) in the Black community in the UK, thus intersecting a balance between lay and medical culture in dementia management. In this case, the current study developed the sociocultural model for dementia management and care for the Black African community in the UK. The model was developed based on the data collected from Chapters 5, 6, 7, and 8. It considers that the individuals studied were also marginalised churchgoers living in the Black African community in London. Chapter 6 significantly shaped the model, and the researcher plans to publish its development later.

Therefore, in this study, the researcher perceived the participants as lay experts and argued that laypeople from the Black African community in the UK who were churchgoers have lay expertise (Britten & Maguire, 2016; Maslen & Lupton, 2019) and that they can contribute towards effective dementia services in community or the church (Wilcox et al., 2010; Baruth & Wilcox, 2013; Campbell et al., 2007). Lay expertise is a general stock of dementia knowledge (Wilcox, 2010) or a body of cultural dementia knowledge (Grundmann, 2017), which can be equal to that of professionals in public health and health promotion in dementia management in the Black African community in the UK (Parsons & Atkinson, 1992; Popay et al., 1998; Popay & Williams, 1996). Thus, the churchgoers, Black African migrants from West Africa, can weigh up the need for timely dementia assessment and be assured that they would be accepted as non-stigmatised community members if diagnosed with dementia.

In addition, this study suggests that collaboration between doctors in the NHS and social care services (Kontrimiene et al., 2021) is essential in holistic dementia care (please refer to Figure 3). Indeed, prescribing social services can integrate medical and social care (Pescheny et al., 2020) and spiritual care (Nelson-Becker, 2017) into dementia practice. Hence, they can link people with dementia or be assessed for dementia with lay practitioners for non-medical help, such as religion and spiritual care in the community (Nelson-Becker, 2017). The process would help promote well-being and the destigmatisation of dementia in the Black African community in the UK. Of course, drawing on Wilcox (2010) can suggest that the churches in the UK can collaborate with the NHS to improve the dementia care system for this marginalised Black African population. Churches in the UK can influence dementia behaviours, and involving churches in dementia services that incorporate spiritual and cultural contextualisation can be adequate (Campbell et al., 2007). We can encourage community leaders to address dementia health disparity by involving them in dementia service design and delivery in the Black African community in the UK. A church setting can be pragmatic in public health and health promotion programmes on dementia (Wilcox et al., 2010; Baruth & Wilcox, 2013; Campbell et al., 2007).

Regardless, public health and health promotion is a unique discipline that strongly emphasises personal and community autonomy, participation, and empowerment amongst individuals and their communities (Davies, 2013). Health promotion is multidisciplinary, and its concepts are borrowed from major contributory fields of sociology, anthropology, psychology, religion, politics, economics, public health and medicine, and education. Therefore, laypeople are health promotion actors from different life works. The principle of health promotion resonates deeply with well-being, respect for autonomy fostering empowerment of the community, advocating literacy and critical thinking, solidarity amongst people and generations, equity and equality, democratic participation, and sustainable growth for the individual in the community, which are closely embedded in the values and actions areas of the Ottawa Charter (WHO, 2012). Thus, in public health and health promotion, proper education is fundamental in promoting good values, cultural norms, and social progress, such as equality, equity, and solidarity towards dementia (Cahill, 2019; Glos, 2021). It requires ‘cultural competence’ (Watt et al., 2016) and ‘cultural humility’ (Trinh et al., 2021) in dementia services in the Black community in the UK.

Being culturally competent and humble are supplementary skills (Helman, 2007) that doctors can acquire for social desirability, moral reasoning, and critical self-reflectiveness and for promoting anti-racism (Watt et al., 2016; Henderson et al., 2018; Trinh et al., 2021) in dementia practice or dementia services for the Black Africans in the UK. Thus, it refers to providing a dementia service that is equitable and non-discriminatory. Nonetheless, there is a lack of theoretical clarity and consensus over what constitutes cultural competence in dementia services in the literature, but essentially must involve a dementia practice that is desirable and accountable and cultural context taken into account in the provision of dementia services in which health practitioners, including doctors, can understand, respect, and work effectively with groups or individuals from various cultural backgrounds, including different genders, ages, ethnicity, and race (Watt et al., 2016; Henderson et al., 2018), and it requires the right and appropriate behaviours (Trinh et al., 2021). Regardless, Liu et al. (2021) suggest a need for the development of clinical cultural educators to improve clinical practice and education, which the current researcher believes is a needed framework for developing cultural competence in dementia services for the Black community in the UK and should include leadership and communication skills training for medical doctors in the dementia practice. Indeed, the present researcher completed leadership training at the University College London (UCL) to develop his resilient leadership capabilities, cultural competence, and humility.

### Evaluation of the study

The rigour of the qualitative data analysis in this study was a key consideration (Lincoln & Guba, 1985; Creswell, 2006; Schwandt, 2002; Seale, 1999; Lather, 1986; Cooney, 2011). The research process conformed to the criteria for a rigorous thematic analysis (Braun & Clarke, 2019; Manson, 2018) informed by the grounded theory approach (Glaser & Strauss, 1998; Charmaz, 2006; Corbin & Strauss, 2008). A vital issue in this study's rigour is the availability of various textbooks to direct the research (Boeije, 2010; Grbich, 2013; Braun & Clarke, 2014; Manson, 2018; Denzin & Lincoln, 2018). For this reason, the study followed a consistent and standard method in the research process. Nevertheless, this study's rigour is addressed using Lincoln and Guba's (1985) discourse on trustworthiness criteria, which includes credibility, transferability, dependability, confirmability, and authenticity (Lincoln & Guba, 1985; Lincoln & Guba, 1994).

### Credibility

Credibility in this study deals with how congruent the findings of this study were with dementia reality in the Black community in London, and credibility focused on whether the researcher accurately identified and accurately represented the Black African populations living in London in the study. This study's relevance relates to how explanatory findings met the research aim. This study aimed to explore lay knowledge and beliefs towards dementia amongst Black African populations living in London. Furthermore, the researcher has shown credibility and relevance in this study by utilising an exact and standard approach (Cohen &

Crabtree, 2008). Firstly, this research targeted Black African populations living in London, both men and women, and adults aged 20 to 85. Thus, the study adopted purposive sampling methods (Braun & Clarke, 2013; Mason, 2018). A purposive sample is considered a non-probability sample that is selected based on the characteristics of the population (Braun & Clarke, 2013, 2019).

The use of purposive sampling was to ensure the researcher achieved the objectives of the research. Thus, the purposive sampling employed in the study provided heterogeneous and homogenous purposive samples (Mason, 2018). Heterogeneity samplings in age, sex, levels of education, and occupation of the participants helped the researcher to interview as many kinds of Black Africans as possible. Whilst the homogeneity sample was created based on religion, race, and ethnicity. A total of 31 male and female respondents participated in the study. The study included almost an equal number of male and female participants. Although, the study utilised constant comparative analysis to ensure a relatively consistent sample size for both males and females and data saturation (Braun & Clarke, 2014). All the participants were immigrants from West Africa; most were from Nigeria, and a few were from Ghana, Cameroon, Sierra Leone, and Liberia. Therefore, all the participants are Black Africans from West Africa and live in London. Moreover, all the participants are churchgoers, first-generation immigrants from West Africa living in London.

Furthermore, the sample included naturalised citizens, permanent residents, and temporary residents, such as students in London. More importantly, people from various work or occupations participated in the study, thus ensuring adequate data to develop a robust and valid understanding of dementia and achieve data saturation (Mason, 2018). However, the study excluded people in medicine, such as doctors, paramedics, and nurses, but more participants were carers. The process of constant comparison was a primary means of achieving accuracy and data saturation in this study. More so, reflexivity was an essential component of this process, and the findings were grounded in the participants' own words. Their words were accurately represented in emerging interpretations and explanations using the participants' own words. Therefore, in Chapters 5, 6, 7 and 8 of this thesis, direct quotations were used to convey the participants' views and narrative in their own words.

Secondly, the approach for this study adopted thematic analysis (Braun & Clarke, 2013, 2019) informed by a grounded theory approach (Glaser & Strauss, 1998; Corbin & Strauss, 2008) which was drawn upon in the coding and data analysis thematically. In addition, it included constant comparison and coding, as demonstrated in Chapter 3. For example, Grbich (2013) identified coding as a process of grouping and labelling data to make it more manageable for a display and to provide answers to the research questions (Grbich, 2013, p. 259). Functionally, Braun and Clarke (2013) considered coding to identify aspects of the data relating to the research questions (Braun & Clarke, 2013, p. 206). However, Saldana (2013) thought of coding as a thematic analysis. Nonetheless, Mason (2018) considered codes as thematic, descriptive, conceptual, axial, interpretive, and analytic, which could be hierarchical, loose, rough, or open (Manson, 2018, p. 194). Similarly, Miles et al. (2014) considered codes as labels that assign symbolic meaning to the descriptive or inferential information compiled during a study (Miles et al., 2014, p. 72).

Nonetheless, Boeije (2010) considered coding a tool to create order (Boeije, 2010, p. 94). Therefore, coding means categorising data segments with a short name that simultaneously summarises and provides accounts for each piece of data. Hence, codes are primarily, but not exclusively, used to retrieve and categorise similar data chunks so that the researcher can quickly find or pull out the segments relating to the research question (Mile et al., 2014, p. 72). Hence, thematic analysis in this study is used to develop a detailed descriptive account of dementia, as well as a constructionist analysis which identifies the lay concepts and meanings that underpin the explicit data contents, the assumptions, beliefs, and ideas of dementia in the dataset (Braun & Clarke, 2013). As such, in the current study, the researcher sees thematic analysis as one of the leading data analytical options in qualitative research (Grbich, 2013, p. 61), which involves (i) open coding, (ii) focus coding, (iii) categorising, and (iv) thematic coding as used in this study and demonstrated in Chapter 3.

Therefore, the coding provided rigour, transparency, and reflexivity to the research question, illuminating the participants' lay knowledge and beliefs about dementia. The themes provided insights, contexts, an accurate representation of the dataset, participants' narratives and views about dementia, and the events or stories behind the data collected (Braun & Clarke, 2013; Manson, 2018). Likewise, the grounded theory approach and the iterative inquiry (Glaser & Strauss, 1967; Strauss & Corbin, 1998; Corbin & Strauss, 2008), the epistemological perspectives, and the researcher's intellectual puzzles supported the idea that the dementia phenomena could be coded across the dataset and in themes. As previously mentioned, reflexivity is essential to qualitative research, 'bracketing' preconceptions and assumptions (Dorfler & Stierand, 2019), and intersecting the relationships between the participants and the researcher (Dodgson, 2019). It increased the credibility of the findings and expanded the researcher’s work and understanding of dementia. Most importantly, the participant’s views and narratives drove the data coding and analysis.

### Transferability

The conceptual transferability in this study refers to how well this study’s findings can guide dementia management in settings other than London, where the original research is conducted (Kitto et al., 2008; Houghton et al., 2013), as transfer of understanding can occur if both contexts are similar. Indeed, the data collected in the field was sufficiently ‘rich’ to provide a ‘thick description’ of the dementia phenomenon, allowing readers to judge how the instances of the dementia phenomenon may be transferred to other settings or similar situations (Lincoln & Guba, 1985; Guba & Lincoln, 1989; Lincoln et al., 2011). This was provided in the four finding chapters (Chapters 5, 6, 7 and 8) with the reports on the study’s findings involving details, in-depth explanations, descriptions, and interpretations of the participants’ views and narratives drawing on quotes from the respondents.

Therefore, understanding people’s narratives and views on the dementia phenomenon can inform readers about the influences that helped shape their dementia knowledge and beliefs. The tensions and conflicts of differing narratives or ideas can be an ‘opportunity for innovation’ (Tenny et al., 2022). Thus, a ‘thick’ description is more than just presenting data in more detail. Instead, it entails the detailed investigation of the web meaning and the presentation of the different interconnected contexts relevant to understanding the dementia phenomenon (Pool & Geissler, 2007, p. 26). Regardless, the broader context of the dementia phenomenon was influential in the study, and many broader sociocultural factors that influenced dementia knowledge and beliefs were considered. Thus, participants gave a more diverse account of their expertise on dementia cross-culturally, and the researcher achieved and demonstrated quality and rigour in the entire research process.

### Dependability

Dependability in the context of qualitative research allows for the lay knowledge and beliefs towards dementia amongst the Black African living in London to be dependable. Thus, the researcher ensured that the data was dependable. Dependability means transparency in the research process (Aguinis & Solarino, 2019). Thus, the researcher described the research process in sufficient detail to allow others to replicate the study by following the same process and providing an audit trail. Indeed, the researcher provided the methodological process based on his philosophical beliefs that guided the research, a selection of research methods, and the use of theory (Glaser & Strauss, 1967; Strauss & Corbin, 1998; Corbin & Strauss, 2008; Boeije, 2010 Grbich, 2013; Braun & Clarke, 2019; Manson, 2018; Denzin & Lincoln, 2018). Furthermore, the supervisory team provided good advice on the data analysis process, which added rigour and quality and made the study dependable.

### Confirmability

In addition, the researcher ensured confirmability by being self-critical and reflexive on how his own background or ‘positionality’ (Hammersley & Paul, 1995; Kauffman, 1994; Smith, 1999; Tuffour, 2018) and ‘bracketing’ preconceptions and assumptions affected the research (Heidegger, 1962; Husserl, 1931). The researcher ensured that the results were based on and reflective of the information gathered from the participant and not his own interpretations (Johnson et al., 2020). Moreover, the researcher conducted a pilot study to ensure he was better prepared and informed, and indeed, it added quality and rigour to the current study.

### Authenticity

Furthermore, the researcher implemented essential member-checking measures (Birt et al., 2016) to ensure authenticity. This approach aims to promote the study’s representation of diverse viewpoints on dementia amongst the Black African population in London and to emphasise the transformative potential of the findings in enhancing dementia services in the UK. This entails facilitating effective collaboration between Black Africans and medical doctors for impactful dementia initiatives that can foster systemic changes (Lincoln et al., 2011) and promote dementia empowerment and enablement within the community (Rushford & Harvey, 2016). Thus, engaging medical doctors as the ‘end user’ at the end of the research lifecycle (Lincoln et al., 2011, p. 116) was critical to ensuring authenticity and engaging high-quality research. Therefore, during the researcher’s mentorship programme, the researcher shared the study’s findings with the public health registrars in the UK’s Faculty of Public Health, enhancing the study’s external validity (FitzPatrick, 2019) and ensuring a balance of care in dementia services in the Black community in the UK could be implemented by those involved in dementia management.

Moreover, the salience of the methods and qualitative quality indicator adopted from Lincoln & Guba’s (1985) discourse on trustworthiness criteria provided the guideline for evaluating the current study. Nevertheless, as highlighted in the methodology chapter (see Chapter 4), the researcher noted that each qualitative research tradition has its own rationale for quality consideration (Creswell, 2006). For example, others have criticised the trustworthiness criteria (Schwandt, 2002; Seale, 1999). Some have used validity as a broad epistemological concept to justify qualitative inquiry (Lather, 1986), and can also include the provision of a clear rationale for sampling, determination of data saturation, and ethics in research design. Indeed, the current research conceptual framework (see Chapter 3), the literature review (see Chapter 2), and ethical conduct and behaviour were acceptable standards, referred to and aligned with the researcher's moral principles and values. They were part of the research process and helped the researcher to guide and justify his methodological decisions, which was critical to achieving rigour and quality in the current research.

However, other qualitative researchers have suggested best practice guidelines for evaluating qualitative research (Anderson, 2010). Some have advocated for a checklist or strict criteria (Wu et al., 2016). Thus, EQR is evolving, and choosing a set of evaluative criteria is socially constructed (Leavy, 2020). Indeed, some qualitative researchers have provided a five-categorical format of EQR to include a general category of a variety of qualitative research traditions, which is too general for some types of qualitative study and may be specific for others. Other categories include a subtle-realist category, an art-based research category, a post-criteriology category, and a post-validity category (Leavy, 2020). Lincoln and Guba (1985) provided helpful indicators of trustworthiness for this study. However, the researcher added pilot, ethics, and reflexivity as additional EOR indicators to enhance the current study's qualitative rigour and quality (Lather, 1986).

### Data checking

The researcher checked the transcripts with respondents to enhance quality and credibility. Indeed, member checking or sharing transcripts with the participants is also known as the participant or respondent validation technique (Birt et al., 2016). The member checking involved returning the data to the respondents to ensure that the interpretations of the data were accurate representations of the participant's experiences and meaning of dementia, thus adding rigour, credibility, and quality to this study. In addition, the researcher shared data with the supervisory team and checked the results with existing literature, as illuminated in Chapters 5, 6, 7 and 8. Checking findings with existing literature and peers has been suggested to enhance credibility (Busetto et al., 2020). In this study, sharing the data with the supervisory team provided valuable advice, which added quality and credibility to the current study.

## Pilot study

The research was conducted in two churches in London, utilising online platforms due to the increasing spread of coronavirus in England. The researcher avoided in-person contact with participants to maintain a secure COVID-19 environment and comply with the government's legal restrictions and legislation on social distancing during the pandemic. However, potential challenges were anticipated, such as participants' access to appropriate equipment, as noted by Wray et al. (2017). The pilot study was conducted with three individuals recruited from the church sites, following Van Teijlingen and Hundley's (2001) suggestion for a smaller feasibility study. The pilot study tested the feasibility of online platforms, interview guides, vignettes, thematic analysis, and the grounded theory approach. The researcher evaluated critical steps in the main study, including recruitment rate, eligibility criteria, time and resource estimates, data management and effectiveness of the interview guide, dementia vignette, and data collection. Conducting a pilot study allowed the researcher to better prepare for potential difficulties in the primary research.

The researcher became more confident with the data collection and analysis instruments. He found the vignette helpful in the research as it projected the same level of the same knowledge on dementia and mitigated the power dynamic between the respondents and the researcher. Still, participants gave a more diverse account of their expertise on dementia cross-culturally but also allowed the researcher to contribute to constructing the dementia knowledge. Thus, the researcher was confident that success was within his reach. The pilot study potentially increased the rigour and quality of this study as findings from the research informed subsequent parts of the study process. Nevertheless, the researcher needed to check the respondent's standpoint on the pilot process on what worked and did not work. The researcher kept proper documentation, engaged with appropriate documentation and transparency of procedure, and used a checklist to mitigate ethical issues associated with this online study.

## Ethics

In the current study, the researcher's moral responsibility was to nurture and monitor relationships by altering relationships with the participant to ensure mutual respect and dignity (Adams et al., 2015; Ellis, 2007). For example, some participants in the study were perceptive or apprehensive of the researcher's medical background and continued to make references or allusions to it. Indeed, relational ethics (Ellis, 2007) helped the researcher to keep his relationships with the participants limited to the research and away from personal issues. Hence, it added to the research integrity. Of course, the study's ethical concerns were linked to the researcher's epistemological, ontological, and practical imperatives (Leavy, 2020) because power and intergroup relations are complex (Fiske et al., 2016).

Therefore, the researcher ensured he was not a significant power player in the research. He may be perceived as such due to his medical background, highlighting his status and positionality in the study (Holmes, 2020). However, he ensured a fair process to mitigate such power differences by using a vignette and ensuring that the participant's own words drove the study and that the analysis reflected the participants' voices and not his (Braun & Clarke, 2019). Thus, the researcher ensured he was socially accountable, allowed the respondents to engage actively, and was conscious of mitigating power dynamics in the research and evaluation. More so, the researcher understands that change in power relations are at the heart of what Black Africans seek, particularly in dementia empowerment and enablement in their community. Their voices must be heard in the research, and the vignette helped to project their own voices in this dementia research.

The study sought ethical approval from the College of Health, Medicine and Life Sciences Research Ethics Committee, Brunel University London. The Ethics committee authorised the research to proceed. Approval was granted for the study to be conducted between 1 December 2020 to 1 September 2022 with reference number: 25440-MHR-Dec2020-28887-2. In the UK, the role of ethics is primarily to consider the interests of the research participants and ensure that the relevant codes of practice are upheld, thus adding credibility to this study and the results.

### Older age

Older age as a social identity for the group provided the concept of understanding the lay causality of dementia. The study found that younger and older age are individual agencies of ageing in adulthood (Heckhausen et al., 2019). However, there was an emphasis on youthfulness, cognitive intelligence, beauty, productivity, independence, and individualism in the group. Nonetheless, the autobiographies (Dementia UK) show that younger people can have dementia. Thus, older age was associated with negative age stereotypes as being less productive, less flexible, overwhelmingly dependent on others for care, and less adaptable (Rippon et al., 2014). In that case, older age was stigmatised and less valued than younger age, leading to prejudice against older people as they were considered mentally deficient, empty-headed, half-witted, or brainless. Older age can be perceived with negative connotations, such as a ‘social death’ or ‘tragedy’ (Sweeting & Gilhooly, 1997, p. 98; McParland et al., 2017, p. 261), and older people may be diagnosed with dementia and referred for appropriate help in the UK. Contrarily, older people in Africa belong to a religious age group, are treated with reference and respect, and are considered guardians of the clan’s tradition and history (Ndamba-Bandzouzi et al., 2014). This is because old age is a success, and many Africans do not achieve older age. However, against this backdrop, older people in Africa may have dementia but may be unaware of it because they are undiagnosed as having dementia. In that case, older people in Africa with dementia can be stigmatised, neglected, and physically abused (Agunbiade, 2019), unlike in the UK. Hence, older age is a social identity for the marginalised first-generation migrants from West Africa who were churchgoers, as illuminated in this study.

In addition, this study found the use of information technology, computer, and artificial intelligence more worthwhile and likened to the brain (Connor, 2019), thus giving more substantial biological importance to the brain than the entire human being. Indeed, cognitive brain functions such as reasoning, memory, thinking, and arithmetic or mathematical calculations are more valued in the group. Therefore, computer communication (Danowski & Sacks, 1980) has become the respect of the ‘second self’ for the Black Africans in the UK, rendering older people irrelevant and less important because of their inability to use the computer or meet up with the basic arithmetic or mathematical calculations. Nonetheless, older age is premised on the biological and cognitive frame of ageing, consequently illuminating the prejudice against older people with memory loss, forgetfulness, and brain impairment or inadequate cognitive skills found in people with dementia. Notwithstanding, older age is not a disease but a success because not everyone can achieve older age. Nevertheless, older age can be considered a risk factor for dementia (LoGiudice & Watson, 2014).

Regardless, biomarkers can allow for the early identification of people at a higher level of developing age-related dementia and other ageing-related pathologies. Thus, biomarkers can be essential and valuable but problematic, and they can create tension between older age as a normal process and ageing as a disease condition (Imbert, 2014). However, younger people can have dementia at a younger age, as acknowledged in some published autobiographies (see Chapter 1). Many young onset dementias are treatable (Rosser et al., 2010), meaning that ageing biomarkers could be essential in dementia management.

### Forgetfulness

Forgetfulness is a subtheme within the illness and disease theme, shaped by the lay understanding of dementia discourse and the paradigm of forgetfulness (Ballard, 2010; Maxcey et al., 2019) in the group. The group considered people with dementia to be very forgetful. Forgetfulness is a sign of dementia more often for older people and those with dementia than younger people in adulthood (Cherry et al., 2021). Regardless, forgetfulness at a younger age was attributed to the risk of dementia at an older age (Ishtiak-Ahmed et al., 2019). Therefore, perceived forgetfulness is an issue in older individuals' lives, impacting their memory and quality of life (Mol et al., 2007). In this study, the group viewed dementia as forgetfulness and was closely associated with older age and the inability to remember things (Sadeh et al., 2014). However, forgetfulness is complicated and involves embarrassment and shame (Imhof et al., 2006). It is not a social identity for the Black Africans in the UK but rather a medical sign or symptom attributed to dementia. This study acknowledged autobiographies of younger people diagnosed with young onset dementia (Dementia UK), suggesting that forgetfulness is not only associated with older age but also found in younger people, and forgetfulness in day-to-day life is complex.

### Disability

Disability identified as a social identity for the Black Africans in this study provided the concept of understanding the disability discourse in the group. Disability generally puts an individual in a disadvantageous stance, while ability puts an individual in an advantageous position. Still, both depend on the capacity to perform a task (Murphy et al., 2007). The group associated dementia with the lack of ability to perform daily tasks and care. On reflection, medical doctors may focus their understanding of dementia on biological parameters rather than sociocultural factors (Hogan, 2019) and its impact on these marginalised Black Africans in the UK.

Nonetheless, dementia disability is not only localised in the biological characteristics of an individual. Indeed, the group illuminated the environment and sociocultural factors as essential factors to consider in dementia disability. Thus, individuals may vary in a particular bodily and intellectual capacity. Still, the common denominator between the person with dementia and the individual without dementia lies in their material, cultural, and social environment. Thus, the medical doctor may focus their understanding of dementia as a disability on the medical model of disability. However, the group focused their knowledge about dementia disability on the social model (Hogan, 2019). It means that the conflicts between dementia as a disability or ability remain within the sociocultural environment and economic context, as illuminated in this study, including the need for dementia empowerment, such as employment, education, and better dementia care services, and providing the essential social amenities for the Black people with dementia.

Therefore, society can empower the person with dementia to perform needed or daily care tasks by delivering the right sociocultural environment for those with dementia and their families. Hence, changing the sociocultural environment positively for a person with dementia would become an ability. Therefore, dementia as a disability is not an individual’s intrinsic characteristic but an outcome produced by the cultural and social environment (Linden, 2017). Dementia disability is not something that exists purely at the level of the individual psychology as in a person with dementia, a condition created by a combination of social and cultural factors in the individual with or without dementia (Cieza et al., 2018). Therefore, this study found that dementia is a disability, a social identity for these marginalised Black Africans living in London. Of course, dementia as a disability is not only localised within the individual’s body and mind but also tied to the relationship between people with dementia and their sociocultural environment (Linden, 2017; Cieza et al., 2018). This encompasses a range of factors, including economic aspects such as income, employment, and housing, as well as challenges related to language difficulty, education, immigration, and citizenship.

### Witchcraft and curses

Witchcraft and curses emerged as the lay dementia knowledge and beliefs. They were based on social identity (Tajfel & Turner, 1979), which serves as a shared dementia reality amongst the Black African churchgoers in this study based on their relationships with others. Indeed, the group’s dementia knowledge was shaped by looking at the world from a familiar cultural perspective, and the ‘unfamiliar was made familiar’. The ‘unfamiliar made familiar’ means that the lay concepts used in understanding dementia were culturally bound. The previous empirical studies in Africa identified dementia as curses and witchcraft (e.g., Mushi et al., 2014; Mkhonto & Hassen, 2018; Kehoua et al., 2019; Hindley et al., 2016; Owokuhaisa et al., 2020; Kakongi et al., 2020). These findings, therefore, show that these churchgoers and the Black African populations in Africa and London across the demographic groups shared similar epistemic lay concepts of dementia. More so, they used it to externalise dementia causes and in looking for divine or spiritual explanations, such as satanic power or curses (Hindley et al., 2016), punishment from God (Kehoua et al., 2019), possession by the devil (Kehoua et al., 2019), ancestral curse (Mushi et al., 2014), and witchcraft and evil spirits (Owokuhaisa et al., 2020). Therefore, as an applied medical anthropologist, the key finding in the current research is that the perceptions of dementia as witchcraft and curses are sociocultural constructions and not facts but metaphors. It demonstrates how dementia is a diachronic phenomenon (Zeilig, 2014). However, this understanding is not static amongst these first-generation Black African migrants from West Africa in the UK, as their knowledge towards dementia within the geographical context has continued to shift and evolve through education and training, professional status, and media. Nonetheless, dementia as witchcraft is a social identity associated with stigma for these churchgoers who are Black Africans living in London. This association is related to epistemic and normative concepts.

### Madness, craziness, and insanity

Madness, craziness, and insanity also emerged as lay dementia knowledge and beliefs in the current study. The findings were also based on social identity and stigma, epistemic, and normative concepts, which also served as a shared dementia knowledge and beliefs amongst the Black African participants who were first-generation migrants from West Africa in this study, suggesting that the Black African community's dementia knowledge and beliefs in the UK were shaped by looking at the world from a familiar sociocultural perspective. The 'unfamiliar was made familiar', and the categories or the lay concepts used in understanding dementia were socially bound. Previous African studies have also linked dementia to madness (e.g., Adebiyi et al., 2016). However, the lay knowledge and beliefs towards dementia as witchcraft, curses, craziness, madness, and insanity have continued to shift and evolve, given that most participants could assimilate and weigh up conflicting ideas about dementia through education and training. Most were also able to incorporate biomedical ideas with their lay knowledge about dementia because of their roles as a carer and have continued stay in the UK.

Regardless, the lay knowledge and beliefs towards dementia as witchcraft, curses, craziness, madness, and insanity, are social and cultural constructs. It can be viewed as a ritual that changes the social identity of a group of people or the person with dementia in a relationship with others. It is derogatory, leading to stigma, labelling and stereotypes, separation and social isolation, status loss and discrimination, emotional reaction (Andersen et al., 2022), and social death (Sweeting & Gilhooly, 1997). Therefore, the nature of our behaviour and behavioural interactions (the researcher is also a Black African living in London) can respect or disrespect people with dementia, spoil the social identity of people with dementia (Goffman, 1963), and often lead to shame and abuse. Shame permeates the struggle for social identity (Shaughnessy, 2018); as the researcher knows, such prejudice destroys humanity.

Notwithstanding, the group assimilated and compared their newfound dementia knowledge, which they gained during their stay in London, with their previous understanding of dementia before coming to the UK. Of course, the comparison was the anthropologist's equivalent to a scientific experiment. The assumption was that social and natural sciences could be used to study 'facts' (Pool & Geissler, 2007). Dementia is a relative phenomenon (Brown, 2008).

Regardless, the comparison acknowledged the differences in their (the participants) earlier dementia knowledge and beliefs as witchcraft, curses, craziness, madness, and insanity as despicable and abusive. Hence, the dementia phenomenon is a social condition (Bosco et al., 2019), delineating the respondents' common sensual perception of the dementia phenomenon. Indeed, it is a 'common sense' knowledge, but 'common sense' is not common to all cultures, nor is any version of dementia exceptionally sensible from the perspective of anyone outside its cultural context (Herzfeld, 2001); therefore, it is more an issue of 'presence and difference'. This critical approach implies a view of cultural relativism, meaning that cultures should be judged on their terms and that what is perceived as right in one society is not necessarily so in another (Brown, 2008). Thus, the physical presence of Black Africans in the UK changed their views about dementia. Their experience of dementia is being reshaped and shaped by sociocultural factors, such as education, media, and internet use (Schnelli et al., 2021). Drawing on the researcher's professional background, anthropologists distinguished between two perspectives relating to the issues of sociocultural differences associated with the 'presence and difference' as emic and etic (Last, 1981; Pool & Geissler, 2007; Helman, 2007).

Nevertheless, the researcher agrees with most of the respondents in the current study that the beliefs about dementia as witchcraft, curses, craziness, madness, and insanity are stigmatising (Andersen et al., 2022) and derogatory (Adebiyi et al., 2016; Jacobs et al., 2022). Stigma is a fundamental cause of population health inequalities (Hatzenbuehler et al., 2013) at both the macro and micro levels, enacting disparities, and inequality (Phelan et al., 2014), leading to the complete execution of disapproval, rejection, exclusion, and discrimination of people with dementia. Therefore, a better understanding of the sociocultural construction of dementia can improve public health and health promotion approaches to dementia in the context of care and management (Zelig, 2014; Bosco et al., 2019) for the Black African populations in the UK.

### Religion, spirituality, and prayer

Religion, spirituality, and prayer emerged from this study as lay dementia beliefs, playing a significant role in shaping the participants' social identity. Indeed, this study found that all the participants were churchgoers but self-identified as laypeople. They believed in God or supernatural forces (Johnson, 2021), and prayer was one way they communicated or connected with their God (Rossiter-Thornton, 2002; Hamilton et al., 2020). Therefore, as manifested in this study, religion is a shared belief and tradition that includes guidelines for living (Ge et al., 2021). Whilst spirituality manifested as a search for the dementia meaning and connectedness to humanity and the transcendent (Nelson-Becker, 2017), it helped people use coping strategies to deal with dementia and have a better quality of life (Agli et al., 2015). Interestingly, this group of churchgoers, the Black African population, found praying valuable and comforting in dealing with dementia.

Intuitively, there is a difference between dementia's meaning centred on witchcraft, curses, craziness, madness, and insanity and dementia's beliefs centred on religion, spirituality, and prayer. Prayer is a ritual, a search for meaning (Anderson & De Souza, 2021), and contact with the divine. People become comfortable with mediated relationships with God and their beliefs about dementia and attach themselves to God (Cherniak et al., 2021). Therefore, prayer can serve as a therapy for living well with dementia. The study found that religion, spirituality, and prayer were positive psychological and social resources for coping with dementia and alleviating stress and loneliness attributed to the dementia phenomenon, leading respondents to build better relationships by fellowshipping together. The group acknowledged that prayers and church fellowships provided comfort and hope, and the respondents enjoyed attending or going to churches. The group believed in God as their source of protection, hope, courage, and a means to cope with dementia and the complexities of life. Of course, spirituality and religion are complex and multifaceted (Nelson-Becker, 2017), but they provide guidance and support for the challenges of dementia through personal and community experiences. It is experiential but revealed in cognitive and behavioural expressions (Nelson-Becker, 2017).

Thus, religion, spirituality, and prayer were ways of thinking about dementia care in the Black community and, as earlier noted, social identity for these churchgoers in the Black African community in London. Of course, the current study acknowledges that they are not part of the medical system or training (Laing, 1971). However, argues that they occupy the intermediate position between the sociocultural, biopsychosocial, and medical models of dementia care (McKee & Chappel, 1992; Vermette & Doolittle, 2022) and could serve as spiritual care for dementia well-being (Nelson-Becker, 2017) and biopsychosocial-spiritual model (Sulmasy, 2002), for dementia. For example, evidence suggests that religious and spiritual people have higher self-esteem and positive dementia beliefs (Weisman de Mamani et al., 2017).

Moreover, this study argued that prayer could serve as a therapy and be introduced into the dementia practice in the UK in a dignifying way (Rossiter-Thornton, 2002). Indeed, medical doctors encouraging and tapping into these marginalised churchgoers' spiritual beliefs can help these first-generation migrants from West Africa cope and enhance their dementia well-being and quality of life (Best et al., 2016; Soto-Espinosa & Koss-Chirino, 2017). Likewise, internalising a belief, developing, or building a social network, and fellowshipping within a religious and spiritual community can provide a psychological buffer against dementia worry (Robert & Maxfield, 2018), as found in the current study. For example, some of the respondents in this study suggested the need for house fellowships for individuals with dementia and involving people with dementia in church activities such as singing and being part of the church choir. Indeed, people with dementia enjoy music, and music activities can serve as a nonpharmacological treatment for dementia (Baird & Samson, 2015) amongst Black African populations in the UK and can be vital in dementia spiritual care (Nelson-Becker, 2017), which can be incorporated in the biopsychosocial-spiritual model (Sulmasy, 2002), for dementia management.

Even so, Odbehr et al. (2017) explored the meanings of spiritual care and the understanding of religious needs in persons with dementia. They provided a social construction that described the spiritual model of care for the person with dementia as follows:

- The process of performing religious rituals that provide a sense of comfort for people with dementia and their family.
- Knowing the person with dementia offers opportunities to understand the person's life meaning and purpose.
- Attending to the individual with dementia's basic needs allows one to appreciate others' vulnerability and humanness.

Therefore, religion, spirituality, and prayer are intended to help people with dementia and their family to express their faith, spirituality, and religious beliefs, love, and support those with dementia to experience meaning in life, connectedness to self, God or deity, and other people (Odbehr et al., 2017). Interestingly, in the current study, some leaders in the Black African community thought it reasonable to collaborate with medical doctors in disseminating dementia information to community members. Nevertheless, the GPs, as medical doctors, are not encouraged to deliver spiritual care (Appleby et al., 2018). Moreover, many doctors who reject religion and spirituality in dementia care will also reject prayer (Rossiter-Thornton, 2002). Even so, medical doctors are generally not well-trained in asking patients about their interest in spirituality and religion in dementia care (Nelson-Becker, 2017). Of course, there is a 'set of procedures in which medical doctors are trained' (Laing, 1971).

Indeed, doctors' medical education teaches spirituality and religion sporadically and predominantly through optional and non-embedded learning (Appleby et al., 2019). Thus, it may impair the doctor's ability to understand spirituality and religiosity and integrate it into dementia practice. However, this study suggests that religion and spirituality, including prayer and music, inform the basic principle of holistic medicine and can serve as an adjunct in dementia healthcare services for Black African populations in the UK. It provided comfort, hope, and resilience for families and those affected by dementia. Therefore, this study argues for improved medical education for doctors that could teach spirituality and religion in a more embedded way in medical schools (Appleby et al., 2019). Furthermore, it informs medical education, policy, and dementia practice for these churchgoers in the Black African community in the UK.

## Gender

In this study, gender is perceived as a risk factor for dementia (Choi et al., 2020). It emerges as a social identity (Wyndham-West, 2021) for the Black African populations living in London. The current study is particularly not interested in medicalising gender. Still, this study's social constructionist analysis of the gender theme generated a tentative hypothesis that 'dementia is a result of the psychological stress and the huge burden that our society has unknowingly or unconsciously laid upon women', as grounded in the respondent's words. Furthermore, gender provided the lay concept of understanding some gender 'troubles' (Butler, 1999) and conflicts with dementia in the Black African community as a social identity for these first-generation migrants from West Africa. However, gender is not a fixed or innate fact but a fluid concept that varies across culture, time, and place (Polderman et al., 2018), meaning that gender is relative (Brown, 2008). This study found that the conflicts in gender as a social identity are strongly evident in the perceived gender roles and gender disparity (McDonnell & Ryan, 2013; Martinez-Santos et al., 2021), which structures gender inequality between men and women amongst these Black African who are churchgoers in the UK. This study found that women are more predisposed to dementia than men, delineating women as a determinant associated with an increased risk of developing dementia, thus highlighting inequality in dementia prevalence. Previous studies have provided evidence that sex was associated with dementia (Wu et al., 2017), with the prevalence of dementia more significant in women than men (Cao et al., 2020).

Indeed, males and females are generally considered the biological sex. It is biologically constructed as sex and defined generally by the human chromosomes as XY for the male and XX for the female. However, some people can socially identify as ‘X’ for gender neutrality, not based on biological sex but political. The emphasis is for society to stop distinguishing roles according to people’s sex or gender. However, it could be perceived as a label, stigmatising and discriminatory, and a gender-blind ideology in which gender categories are rendered irrelevant when considering gender roles and inequality (Maria Del Rio-Gonzalez, 2021). Gender inclusivity may be acceptable as it acknowledges gender as a source of inequality and recognises the plurality of gender identity beyond male and female (Maria Del Rio-Gonzalez, 2021).

Notwithstanding, women are disproportionately affected by dementia in getting dementia and becoming dementia caregivers (Erol et al., 2016). Moreover, gender identity in dementia services is a biological and social construct shared across cultures (Sun et al., 2012; Bentwich et al., 2018; Huang et al., 2020). Thus, gender as a social identity is a fluid concept defined and moulded by politics, culture, and social relationships. Indeed, gender can be complex and political, developed through social interaction and culturally laden (Butler, 1999); it is biologically and socially constructed. As a result, in some cultures or groups, men’s and women’s personalities differ (Schmitt et al., 2017), and they may be taught to behave in acceptable or appropriate gender roles. This study’s perceived gender roles in dementia care are premised on culture and transmissible from generation to generation and mother to daughter (Li et al., 2021; Nguyen et al., 2021).

Nevertheless, social constructionists will generally view gender as a social identity beyond sex and the male and female essential category but inclusive of gender neutrality. Thus, gender intersects to shape inequalities in dementia care, prevalence, and risk (Choi et al., 2020) amongst Black African populations in the UK. Nonetheless, another reason that may shape the risk of dementia in women is that men tend not to reach the same older ages as women as they die younger, meaning that women have a higher life expectancy than men (Hosseinpoor et al., 2012). Indeed, in this study, gender identification amongst the participants had a robust cultural component as a social identity based on performance and productivity.

## Reflexivity

Reflexivity is an essential component of qualitative research and enhances credibility. Indeed, it refers to how power and bias are reflected in the research process (Leavy, 2020). It is recommended that the researcher use low inference and stay close to the group's account (Braun & Clarke, 2014). Therefore, the current study eulogises the researcher's insight into his own biases, medical stance, and rationale for decision-making as the research progressed, and it was essential to achieving quality, rigour, and best practice. Indeed, reflexivity depends on the researcher's philosophical orientation (Braun & Clarke, 2019; Corbin & Strauss, 2008). Therefore, it was vital for the researcher to 'bracket' his medical views about dementia to limit the effect of his opinions on interpreting the data (McGhee et al., 2007). The researcher is a community physician (trained in Nigeria) and an applied medical anthropologist (trained in the UK) and has the experience of caring for a family member with dementia. Thus, maintaining bracketing was challenging (Dorfler & Stierand, 2019), partly due to a shift from its phenomenological origin (Heidegger, 1962; Husserl, 1931). Regardless, it added clarity and transparency to this study (Ashworth, 1999).

However, as a social researcher with clinical and applied medical anthropological backgrounds, and a Black African living in London like those he was researching, the researcher believes he was caught up between cultures and the 'emic' and 'etic' perspectives on dementia. In this research, the researcher adopted an insider perspective, focusing on the emic account of dementia. This approach was situated within a cultural relativist perspective recognising the Black Africans' lay knowledge and beliefs about dementia as culturally relative. It recognised that their help-seeking behaviour was both rational and meaningful within their culture, bearing in mind that the respondents were churchgoers and first-generation migrants from West Africa. Meanwhile, the outsider perspective is considered an etic account of dementia, which is the biomedical knowledge of dementia situated within a realist perspective. This attempted to describe the Black Africans' lay knowledge and beliefs towards dementia in terms of an external standard that assumed a pre-defined dementia reality. Therefore, the researcher was critically self-reflective about his clinical and medical stance on dementia. Although, the etic account was aimed at being culturally neutral and assumed a position in which the researcher was able to detach himself from the prejudices of the group that considered dementia as witchcraft.

Nevertheless, some participants, like the carers, assimilated the biomedical account of dementia following their move from Africa to the UK. As a result, they could give an etic account of dementia outside of their emic understanding of the dementia phenomenon, that is, a biomedical account of dementia, which helped to describe differences across culture and geographical contexts. Thus, the researcher had more accessible access to the culture being studied. It also mitigated the power dynamic between the researcher and the respondents. They indeed provided both the researcher and the respondents with insider-outsider dialectics (Merton, 1972) in the study, which was advantageous to the researcher not only in terms of power dynamics but on the fact that the researcher was researching a group of people with a similar demographic characteristic and a member of the community (Tuffour, 2018). Of course, the researcher is also a churchgoer, a first-generation migrant from West Africa. To be precise, he is a Nigerian and of the Igbo tribe.

Thus, the researcher was considered ‘one of us’ (Gurchathen & Thapar-Bjorkert, 2008). Indeed, some respondents called him a ‘brother’ and ‘son’, which was an advantage. Therefore, epistemologically, the researcher could present information accurately and truthfully based on his insider position (Holmes, 2020). More so, most participants were willing to share sensitive information they would not have revealed to an outsider who may have no clue about their culture or language or have no future contact. Thus, the participants shared sensitive and honest information with the researcher based on trust.

Nonetheless, some of the study participants were perceptive of the researcher’s medical and clinical backgrounds and continued to refer to them. However, research ethics and integrity helped the researcher to keep his relationships with the participants limited to the research and away from personal issues. Hence, this outsider perspective was advantageous because it allowed the researcher to sufficiently detach himself from the culture to study it without bias. Notwithstanding, as a social researcher and a part of the research instrument, the researcher was inextricably implicated in data generation and interpretation. However, the insider-outsider continuum (Merton, 1972) provided the researcher with a ‘bigger picture’ in dementia research, and the Black African culture was not taken for granted in the study. The researcher provided authentic and 'thick' descriptions and an understanding of the culture (Geertz, 1973). Therefore, the researcher and the respondents were jointly involved in the knowledge creation. In addition to these advantages, the researcher had prior knowledge, which helped him ask more meaningful and insightful questions.

Furthermore, the researcher kept field notes and theoretical memos (see Appendix 14), which allowed data to evolve to a higher interpretative level and constructionist ideas (see Figure 2). The field notes were written records of observational data produced by fieldwork (Hammersley & Atkinson, 2002), which consisted of descriptions of social interaction and its context. On the other hand, the theoretical memos were records of the researcher's developing ideas and thinking processes rather than a description of social context (Glaser, 1998). Data confidentiality was crucial (Kaiser, 2009); hence, the researcher remained compliant with all relevant data protection regulations, particularly the Data Protection Act 2018 and Electronic Communications Regulation 2013, which regulate telephone, email, and text communications. Moreover, the researcher organised and managed the dataset using Excel.

## Strengths and Limitations

A significant strength attributed to this study is its theoretical and empirical strengths. The study developed a theoretical framework for the research theoretically underpinned by social constructionism and sociological and anthropological lay concepts of dementia. They indeed illuminated both epistemic and normative differences between concepts. The lay concepts of dementia are a broader conceptual model of health and illness that can explain how people maintain their health and body and provide lay explanations for the dementia phenomena. Understanding dementia using the lay concepts of health and illness placed dementia within a broader and macroscopic spectrum, including the body, spirit, and mind and sociocultural contexts, unlike the biomedical concepts of dementia. The biomedical concept of dementia is associated with reductionism and is limited to organ, tissue, and cellular spectrums. Regardless, the strengths and limitations of this study are highlighted.

### Strengths:

- Rich empirical data: This study showcased the empirical evidence and provided in-depth explanations and interpretations of the data. Previous studies about dementia amongst Africans in the UK were multi-modelling in ethnicity and provided no separate results for Black Africans in the UK. Moreover, the findings of the studies were not compelling, and the studies were limited in theory and empirical evidence.

- Good sample size: 31 male and female participants participated in the study. The study included almost an equal number of male and female participants.
- Broad age range: The sample included adults aged 20 to 85 to achieve data saturation.
- Laypeople: In this study, laypeople from all walks of life were involved. Indeed, people from various work or occupations participated in the study, thus ensuring adequate data to develop a robust and valid understanding of dementia and achieve data saturation.
- Ethnicity: All the participants were from a Black African ethnic background and lived in London. They were first-generation migrants from West Africa.
- Theoretical underpinning: This study is underpinned by social constructionism and lay concepts of health and Illness.

**Limitations:**

- Foreign-born: The study is limited to foreign-born or first-generation immigrants. However, the study's findings are transferable to second-generation immigrants of similar Black African backgrounds living in London, given by parental bonds or associations.
- Religion: The findings of this study may be transferable to other groups in the context of social identity. However, all the participants in the study identify as churchgoers. Thus, the study may be limited to churchgoers.
- Setting: The study is limited to London, but the findings may be transferable to broader settings in the UK.
- Education: None of the participants was illiterate; all the participants had formal education. Moreover, most of the participants had a university degree. Therefore, a setting where the participants have no formal education can limit the degree of transferability of the findings of this study.
- Respondents with dementia were not involved in the study. However, most of the respondents had experiences with persons with dementia, and most of the participants were carers for people with dementia.

## Overall addition to the literature

The research developed a theoretical framework for the current study that explored lay knowledge and beliefs about dementia and provided the roadmap for developing conceptual arguments. It further illuminates that the present study is grounded in established lay concepts on dementia and added witchcraft to the overall dementia literature.

## Implication for policy, practice, and future research

This thesis suggests that practitioners and policymakers should be more aware of the lay belief systems and consider them while interacting with patients, service users, and carers. In this study, some were positively constructed, and some were negative constructions.

For example, religion, spirituality, and prayer were viewed and narrated as a strength for most of the participants in the study. It provided comfort, hope, and healing in times of need. The Black African population knew dementia from intuitive feelings rather than conscious or clinical reasoning. Therefore, dementia lay knowledge, and beliefs must be understood from the 'native's point of view' by the doctors and social care professionals. Only then can the seemingly irrational dementia constructions in the Black African community in the UK be understood, and only then can programmes of dementia education be developed to work within the local frame of reference.

Furthermore, the findings suggest that dementia was associated with stigma in the Black African community and was a source of a barrier to dementia diagnosis and treatment. Therefore, doctors and social care professionals in dementia practice must collaborate with lay experts in dementia in the Black African community in the UK. Even so, the study shows that the lay experts in the Black African community in London are willing to collaborate with medical doctors in dementia services. The study identifies the need for further research on the willingness of doctors to collaborate with community leaders in the Black African community in the UK in providing dementia care.

In addition, most of the respondents had experiences with persons with dementia, and most of the participants were carers for people with dementia. None of the respondents with dementia were involved in the study. Therefore, there may be a need to explore further the lay knowledge and beliefs towards dementia amongst people with dementia in the Black community.

## Recommendations

This study found that dementia was associated with stigma (Andersen, 2022). The study identified the need for the destigmatisation of dementia in the Black African community in London through proper dementia education, requiring a robust dementia community outreach programme that should involve medical doctors and community leaders. There is a need to move dementia education and awareness beyond biomedical knowledge towards a more inclusive culture and value understanding because the Black Africans thinking of the dementia phenomenon in the modern epoch have depicted dementia as an intersection of ideas between biomedical knowledge and lay knowledge, meaning that there is a more substantial need to provide culturally specific and sensitive dementia services for Black Africans in the UK. Indeed, providing adequate care for the person with dementia and their family in culturally specific and sensitive ways requires 'cultural competence' in dementia management in the Black African community dementia services.

Moreover, being culturally competent is a supplementary skill (Helman, 2007) that doctors can acquire for social desirability, moral reasoning, critical self-reflectiveness, and promoting anti-racism (Watt et al., 2016; Henderson et al., 2018). In addition, applied medical anthropologists are better equipped and positioned to solve dementia problems in collaboration with medical doctors or biomedical health professionals (Pool & Geissler, 2007, p. 31). The Black African's knowledge and beliefs about dementia determined their behaviour directly and rationally. Therefore, an anthropologist can understand and change behaviours positively, as the current study found. Generally, laypeople look to their local and social communities for dementia information. Thus, the applied medical anthropologist provides a perfect backdrop for understanding the dementia culture in the Black African community in London because 'culture' is the knowledge and behaviour characterising a particular group of people (Heyes, 2020), such as understanding the dementia culture in the Black community. The Black Africans in the UK are in no doubt willing to cooperate with applied medical anthropologists, as the extract may suggest:

> *Probably anthropologists will know what all this is all about and put things together. But in our society here, we don't have anything like that . . .* (Yemi).

Indeed, drawing on Yemi's view, applied medical anthropologists can collaborate with medical doctors and the Black African community leaders in London to contribute to dementia care management. Of course, medical anthropologists have contributed globally to the understanding of health and illness. Therefore, they are well-positioned to contribute to the study of dementia and services. It is also worth noting that some of these anthropologists were also trained as physicians. Examples include Arthur Kleinman, Cecil Helman, and Paul Farmer, to mention a few. Therefore, the researcher is making the following recommendations:

1. Joint efforts between medical doctors and applied medical anthropologists in dementia clinical practices and resolving the dementia conflicts in the Black community in the UK are required. An applied medical anthropologist can extend the doctors' ability to a culturally competent diagnosis and treatment for dementia and destigmatisation of dementia in the Black African community.

Furthermore, this study found that religion and spirituality, including prayer and music, shape the basic principle of holistic medicine and can serve as an adjunct in dementia health care services for Black Africans living in London. It provided a sociocultural model, comfort, hope, and resilience for those affected by dementia and their families. However, medical doctors are generally not well-trained in asking patients about their interest in spirituality and religion in dementia care (Nelson-Becker, 2017). There is a 'set of procedures in which medical doctors are trained' (Laing, 1971). Indeed, medical education for doctors teaches spirituality and religion sporadically and predominantly through optional and non-embedded learning (Appleby et al., 2019). Thus, it can impair the doctor's ability to understand religion, spirituality, and prayer and integrate them into dementia practice. Therefore, the researcher is recommending that:

2. Medical education for doctors should teach spirituality and religion as an embedded curriculum in medical schools.
3. Dementia practice in the UK should allow prayer in dementia management in the Black African community. This study suggests that prayer can complement medicine for dementia in a syncretic mechanism in dementia care.

## Future direction for research

This study found that community leaders in the Black African community in London are willing to collaborate with medical doctors in dementia outreach programmes to destigmatise dementia. However, the doctors' willingness in any future collaboration is crucial. Therefore, investigating the doctors' willingness to collaborate with the Black African community leaders for dementia education in the Black African community in the UK will be vital in future research. In addition, exploring further the lay knowledge and beliefs towards dementia with the people with dementia in the Black African community in the UK will be worthwhile, and an alternative theoretical perspective may consider intersectionality.

## Summary and conclusion

Dementia is a public health burden and can be considered a social or cultural phenomenon as much as a biological phenomenon. More than 850,000 people live with dementia in the UK, costing the NHS and the UK government more than £26 billion annually (The Lancet, 2018). Moreover, more than 25,000 people with dementia are from Black and minority ethnic groups. One in 14 people over 65 has dementia, affecting 1 in 6 people over 80 (Alzheimer's Society, 2017). In addition, life expectancy in Black African populations living in the UK has increased. It is expected to rise further from 65 years due to improved quality of life and access to vital health services (Wohland et al., 2015). Therefore, it is expected that dementia will rise amongst Black Africans living in the UK.

Notwithstanding, the Black African population in London is about 580,223, half the total Black population in London, which is approximately 1,101,688 (2011 Census). Drawing on the data from the 2021 Census, about 2.4 million Black individuals reside in the UK, which accounts for 4.2% of the population. Africans comprise more than half of this population, with 1.5 million people representing 2.5%, increasing from 1.8% in 2011. Black African people are the largest ethnic group within this population and are comprised mostly of Nigerians (0.5%), Somalis (0.3%), and Ghanaians (0.2%) (ONS, 2022). Therefore, it suggested a crucial need to engage Black Africans living in the UK for dementia applied research. However, there is a more substantial need to engage medical researchers of medical backgrounds from the Black African community in the dementia research to balance the etic and emic perspectives of the dementia phenomena.

Although some studies have explored dementia amongst the Black community in the UK, the current study is the first in the UK to explore the lay knowledge and beliefs about dementia amongst the Black African population living in London. The research question outlined for this study concerned the lay knowledge and beliefs towards dementia amongst Black Africans in the UK. It illuminated how dementia is constituted and constructed amongst Black African people. The research objective was to explore lay knowledge and beliefs about dementia using qualitative research design and methods. Furthermore, it sought to understand the lay concepts of dementia, perceptions of dementia risk factors, help-seeking behaviours, and the barriers to help-seeking and caregiving or the treatment of people with dementia amongst the Black African population living in London. The question was mainly addressed using semi-structured interviews and a vignette at the start of the inquiry. Social constructionism and sociological and anthropological lay concepts of health and illness underpinned the study.

To generate rich data, the researcher interviewed 31 respondents who identified as laypeople from the Black African community in London. The sample comprises first-generation migrants from West Africa who were churchgoers in the UK. The study utilised thematic data analysis using a grounded theory approach. The researcher developed four interconnected vital themes: lay knowledge and beliefs, illness and disease, help-seeking and behaviour, and caregiving. The findings show that dementia is a complex phenomenon and that the lay knowledge and beliefs about dementia, which entail witchcraft, curses, craziness, madness, and insanity amongst the Black Africans living in London, have improved over time due to the participants' stay in the UK. The researcher reflected and evaluated the study and outlined its rigour, strengths, and limitations regarding what it brings to the literature on dementia. The research is presented in nine chapters, and the group acknowledged that dementia knowledge and beliefs such as witchcraft, curses, craziness, madness, and insanity were stigmatising and abusive. This notion provided an insight that the participants' views about dementia have shifted and evolved through exposure to different ways of making sense of dementia as presented in the results chapters (Chapters 5, 6, 7, and 8). An essential fact in this study is that dementia knowledge is not static but evolving. The group assimilated biomedical views about dementia into their lay understanding of the dementia phenomenon, following their move from Africa to the UK and their ability to provide the needed care for people with dementia within the social and geographical context.

The respondents were churchgoers and laypeople from different walks of life who viewed dementia from a broader sociocultural context. As a result, the researcher regarded their knowledge and beliefs of dementia as lay expertise and was considered as 'a general cultural stock of dementia knowledge' or 'body of dementia knowledge', intersecting both biomedical and lay concepts about dementia. This general cultural stock of knowledge can be valuable in dementia services for people with dementia and their family in the Black African community in the UK. Indeed, the community leaders felt a sense of social responsibility to enhance dementia knowledge in the Black African community in the UK. They also wanted to collaborate with medical doctors and health professionals in the NHS and social services to provide culturally appropriate dementia services for the Black African community. Studies have shown that church settings can be helpful to public health and health promotion programmes (Wilcox et al., 2010; Baruth & Wilcox, 2013; Campbell et al., 2007).

Nevertheless, before the fieldwork, the researcher initially argued that the biomedical concepts of dementia should not be privileged epidemiologically over the lay concepts of dementia, as all dementia knowledge and beliefs can be considered equal (Armstrong, 1985; Bury, 1986; Monaghan, 1999). However, at the end of the fieldwork and data analysis, there was a shift in the researcher's position, acknowledging that there is a hierarchy in dementia knowledge and that the lay and biomedical knowledge of dementia is not mutually exclusive. Moreover, the data shows that the respondents have access to multiple ways of understanding and framing the dementia phenomenon, and the ways intersect both lay and biomedical understanding of dementia. Therefore, the lay and biomedical perspectives are a false dichotomy as each influences the other and is not independent.

Thus, the researcher concluded that the Black African populations in the UK do not lack knowledge of dementia as previous authors had suggested. He believes a group's dementia knowledge and beliefs should be understood, grounded, judged, and evaluated on that group's own culture (Brown, 2008). Of course, the empirical data shows that dementia is a relative phenomenon. Most of the study's participants, as carers, have had to assimilate the dominant Western understanding of dementia for them to be effective in their role. Nevertheless, more work is needed to improve dementia knowledge amongst the Black African population in the UK through education and training. More importantly, practitioners and policymakers should be more aware of the lay belief systems and consider them while interacting with patients, service users, and carers.

Therefore, the research findings were shared with medical doctors with the UK's Faculty of Public Health as the 'end users' in the community and recommended what could be done to reduce dementia stigma and improve dementia outreach to the Black community in the UK. The study provided a direction for future research. Finally, this study met the researcher's learning, cultural competence, and professional development. The researcher attended a leadership in action programme at the University College London (UCL). It was pragmatic, improved, and expanded his resilient leadership capacity and cultural competence.

# References

Abner, E. L., Nelson, P. T., Jicha, G. A., Cooper, G. E., Fardo, D. W., Schmitt, F. A., Kryscio, R. J. (2019) Tobacco Smoking and Dementia in a Kentucky Cohort: A competing risk. *Journal of Alzheimer's Disease,* 68, 625 – 633.

Abrams, J. A., Tabaac A., Jung, S., Else-Quest, N. M. (2020) Considerations for employing intersectionality in qualitative health research. *Social Science & Medicine,* 258, 113138.

Adams, T., Holman, J. S., Ellis, C. (2015) *Authoethnography: Understanding qualitative research.* New York, NY: Oxford University Press.

Adamson, J. (2001) Awareness and understanding of dementia in African / Caribbean and South Asian families. *Health and Social Care in the Community*, 9, 391-396.

Adamson, J., Donovan, J. (2005) 'Normal disruption': South Asian and African / Caribbean relatives caring for an older family member in the UK. *Social Science and Medicine,* 60, 37 - 48.

Adebiyi, A.O., Fagbola., M.A., Olakehinde, O., Ogunniyi, A. (2016) Enacted and implied stigma for dementia in a community in south-west Nigeria. *Psychogeriatrics,* 16, 268-73.

Adinkrah, M. (2019) Crash-landings of flying witches in Ghana: Grand mystical feats or diagnosable psychiatric illnesses? *Transcultural Psychiatry,* 56, 379-397.

Agli, O., Bailly, N., Ferrand, C. (2015) Spirituality and religion in older adults with dementia: a systematic review. *International Psychogeriatric*, 27, 715 – 725.

Aguinis, H., Solarino, A. M. (2019) Transparency and replicability in qualitative research: The case of interviews with elite informants. *Strategic management Journal,* 40, 1291 – 1315.

Agunbiade, O.M. (2019) Explanations around physical abuse, neglect and preventive strategies among older Yoruba people (60+) in urban Ibadan Southwest Nigeria: A qualitative study. *Heliyon,* 5, e02888.

Aihara, Y., Maeda, K. (2020) Dementia Literacy and Willingness to Dementia Screening. *International Journal of Environmental Research in Public Health,* 17, 8134.

Alehagen, U., Opstad, T. B., Alexander, J., Larsson, A., Aaseth, J. (2021) Impact of Selenium on Biomarkers and Clinical Aspects Related to Ageing. A Review. *Biomolecules*, 11, 1478.

Aliotta, G., De Santo, N. G., Iorio, L (2016) Diuretic plants in the Bible: ethnobotanical aspects. *Giomale Italiano di Nefrologia,* 33, (s66).

Allen, D., Carlson, D., Ham, C. (2007) Well-being: new paradigms of wellness-inspiring positive health outcomes and renewing hope. *American Journal of Health Promotion,* 21, 1 – 9.

Allmark, P., Tod, A. (2006) How should public health professionals engage with lay epidemiology? *Journal of Medical Ethics,* 32, 460 – 463.

Alty, J., Farrow, M., Lawler K. (2020) Exercise and dementia prevention. *Practical Neurology,* 20, 234 -240.

Alzheimer's Association. (2021) Alzheimer's disease facts and figures. *Alzheimers & Dementia,* 17*,* 327 - 406.

Alzheimer's Society. (2014) Alzheimer's disease facts and figures. *Alzheimer's Association,* 10, 47 – 92.

Alzheimer's Society. (2017) *The dementia guide: Living well after diagnosis*. UK: NHS.

Andersen, M.M., Varga, S., Folker. A.P. (2022) On the definition of stigma. *Journal of Evaluation in Clinical Practice*, 1 - 7.

Andersen, F., Anjum, R.L., Rocca, E. (2019) Philosophical bias is the one bias that science cannot avoid. *Elife,* 13, e44929 – e44934.

Anderson, D., De Souza, J. (2021) The importance and meaning of prayer rituals at the end of life. *British Journal of Nursing,* 30, 34-39.

Anderson, C. (2010). Presenting and evaluating qualitative research. *America Journal of Pharmacetical education,* 74, 141.

Angus, J., Bowen-Osborn, S. (2014) A self narrative of Life-Long disability: A reflection on resilience and living with dementia. *Dementia,* 13, 147 – 159.

Anstey, K.J., Ee, N., Eramudugolla, R., Jagger, C., Peters, R. (2019) A systematic Review of Meta-Analysis that Evaluate Risk Factors for Dementia to Evaluate the Quality, Quantity, and Global Representativeness of Evidence. *Journal of Alzheimer's disease,* 70, 165 – 186.

Antonovsky, A. (1978) *'Health, Stress and coping'.* San Francisco: Jossey-Bass Publishers.

Appleby, A., Swinton, J., Wilson, P. (2019) Spiritual care training and the GP curriculum: where to now? *Education for Primary Care*, 30, 194-197.

Appleby, A., Wilson, P., Swinton, J. (2018) Spiritual Care in General Practice: Rushing in or Fearing to Tread? An Integrative Review of Qualitative Literature. *Journal of Religion and Health,* 57, 1108-1124.

Appleton, J.P., Scutt, P., Sprugg, N., Bath, P.M. (2017) Hypercholesterolemia and Vascular dementia. *Clinical Science,* 131, 1561 – 1578.

Arce-Renteria, M., Vonk, J.M.J., Felix, G., Avila, J. F., Zahodne, L.B., Dalchand, E., Frazer, K.M., Martinez, M.N., Shouel, H.L., Manly, J.J. (2019) Illiteracy, dementia risk, and cognitive trajectories among older adults with low education. *Neurology,* 24, e2247 – e2256.

Arksey, H. (1994) Expert and lay participation in the construction of medical knowledge. *Sociology of Health and Illness,* 16, 448 – 468.

Armstrong, D. (1985) The subject and the social in medicine: an appreciation of Michel Foucault. *Sociology of Health and Illness,* 7, 108 – 117.

Arora, K., Bhagianadh, D. (2021) Smoking and Alcohol Consumption Following a New Dementia Diagnosis. *Journal of Gerontology series B Psychological science and Social Science,* 76, 745-755.

Arvanitakis, Z., Shah, R.C., Bennett, D.A. (2019) Diagnosis and Management of Dementia: Review. *JAMA*, 322, 1589 – 1599.

Asher, L., Birhanu, R., Baheretibeb, Y., Fekadu, A. (2021) Medical treatments are also part of God’s gift’: Holy water attendants’ perspectives on a collaboration between spiritual and psychiatric treatment for mental illness in Ethiopia. *Transcultural Psychiatry,* 58, 585 -599.

Ashworth, P. (1999) ‘Bracketing’ in Phenomenology: Renouncing Assumptions in Hearing About Student Cheating, *Qualitative Studies in Education,* 12, 707–21.

Assal, F. (2019) History of Dementia. *Frontiers of Neurology and Neurosciences,* 44, 118 – 126.

Astell, A.J., Bouranis, N., Hoey, J., Lindauer, A., Mihailidis, A., Nugent, C., Robillard, J.M., Technology and Dementia Professional Interest (2019) Technology and Dementia: The future is now. *Dementia and Geriatric Cognitive Disorders,* 47, 131 -139.

Badanta, B., Lucchetti, G., de Diego-Cordero, R. (2020) ‘A Temple of God’: A Qualitative Analysis of the connection Between Spiritual/Religious Beliefs and Health Among Mormons. *Journal of Religion and Health,* 59, 1580-1595.

Baddeley, A., Kopelman, M., Wilson, B. (2002) (eds) *The handbook of Memory Disorders*. England: John Wiley and Son.

Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., Currie, K. (2020) A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. *Dementia*, 19, 1672 – 1691.

Baheretibeb, Y., Wondimagegn, D., Law, S. (2021) Holy water and biomedicine: a descriptive study of active collaboration between religious traditional healers and biomedical psychiatry in Ethiopia. *British Journal of Psychiatry Open* 7, e92.

Bai, X. (2018) Biomarkers of Aging. *Advances in Experimental Medicine and Biology,* 1086, 217-234.

Baird, A., Samson, S. (2015) Music and dementia. *Progress in Brain Research*, 217, 207-35.

Ballard, J. (2010) Forgetfulness and older adults: concept analysis. *Journal of Advance Nursing*, 66, 1409-19.

Barbour, R. (eds) (2014) *Introducing Qualitative Research:* A student’s Guide. London: Sage

Barbour, R. (2007) *Doing Focus Groups*: London: Sage.

Barnes, M., Henwood, F., Smith, N. (2016) Information and care: A relational approach. *Dementia,* 15, 510 -525.

Bartlett, R., Gjernes, T., Lotherington, A.T., Obstefelder, A. (2018) Gender, citizenship and dementia care: a scoping review of studies to inform policy and future research. *Health and Social Care in the Community,* 26, 14-26.

Baruth, M., Wilcox, S. (2013) Multiple behaviour change among church members taking part in the faith, activity, and nutrition program. *Journal of Nutrition Education and Behaviour,* 45, 428-34.

Bauer GF, Roy M, Bakibinga P, Contu P, Downe S, Eriksson M, Espnes GA, Jensen BB, Juvinya Canal D, Lindström B, Mana A, Mittelmark MB, Morgan AR, Pelikan JM, Saboga-

Nunes L, Sagy S, Shorey S, Vaandrager L, Vinje HF. (2020) Future directions for the concept of salutogenesis: a position article. *Health Promotion International*, 35, 187 -195.

Bauer GR. (2014) Incorporating intersectionality theory into population health research methodology: challenges and the potential to advance health equity. *Social Science & Medicine*, 110, 10-7.

Baumgart, M., Synder, H.M., Carrilo, M.C., FaZio, S., Kim, H., Johns, H. (2015) Summary of the evidence on modifiable risk factors for cognitive decline and dementia: A population-based perspective. *Alzheimer's and Dementia,* 16, 718 – 726.

Beard, J.R., Araujo, de Carvalho, I., Sumi, Y., Officer, A., Thiyagarajan, J.A. (2017) Healthy ageing: moving forward. *Bulletin of the World Health Organanisation*, 95, 730-730A.

Beck, U. (1992) *Risky Society: Towards a New Modernity*. London: Sage.

Bennett, S., Thomas, A.J. (2014) Depression and Dementia: Cause, Consequences, or Coincidence. *Maturitas,* 79, 184 – 190.

Bentwich, M.E., Dickman, N., Oberman, A (2018). Human dignity and autonomy in the care for patients with dementia: differences among formal caretakers from various cultural backgrounds. *Ethnicity and Health*, 23, 121-141.

Berger, P., Luckmann, T. (1991) *The social construction of reality*. London: Penguin books.

Berger, P., Luckmann, T. (1966) *The social construction of reality: A treatise in the sociology of knowledge.* New York, NY: Anchor Books.

Berger, A.S. (2012) The Evil Eye-an ancient superstition. *Journal of Religion and Health*, 51, 1098-103.

Berwald, S., Roche, M., Adelman, S., Mukadam, N., Livingston, G. (2016) Black African and Caribbean British Communities' Perceptions of Memory Problems: 'We Don't Do Dementia' *PLoS ONE*, 11, 1 – 15.

Best, M., Butow, P., Olver, I. (2016) Doctors discussing religion and spirituality: A systematic literature review. *Palliative Medicine,* 30, 327 -337.

Betzel, R.F., Cutts, S.A., Greenwell, S., Faskowitz, J., Sporns, O. (2022) Individualized event structure drives individual differences in whole-brain functional connectivity. *Neuroimage,* 252, 118993.

Bhavsar, V., Ventriglio, A., Bhugra, D. (2016) Dissociative trance and spirit possession: Challenges for cultures in transition. *Psychiatry and Clinical Neurosciences,* 70, 551-559.

Bir, S.C., Khan, M.W, Javalkar, V., Toledo, E.G., Kelley, R.E. (2021) Emerging Concepts in Vascular Dementia: A Review. *Journal of Stroke and Cerebrovascular Disease,* 30, 105864.

Birt, L., Scott, S., Cavers, D., Campbell, C., Walter, F. (2016) Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research,* 26, 1802-1811.

Birt, L., Poland, F., Csipke, E., Charlesworth, G. (2017) Shifting dementia discourses from deficit to active citizenship. *Sociology of Health and illness,* 39, 199 - 211.

Birt L., Griffiths, R., Charlesworth G., Higgs P., Orrell M., Leung P., Poland F. (2020) Maintaining Social Connections in Dementia: A Qualitative Synthesis. *Qualitative Health Research,* 30, 23 - 42.

Blaxter, M. (eds) (2004) *Health.* Cambridge: Polity Press.

Boeije, H. (2010) *Analysis in Qualitative Research.* London: Sage.

Bokor-Billmann, T., Langan, E.A., Billmann, F. (2020) The reporting of race and/or ethnicity in the medical literature: a retrospective bibliometric analysis confirmed room for improvement. *Journal of Clinical Epidemiology,* 119, 1- 6.

Bomilcar, I., Bertrand, E., Morris, R.G., Mograbi, D.C. (2021) The Seven Selves of Dementia. *Frontiers in Psychiatry,* 14, 646050.

Bosco, A, Schneider, J., Coleston-Shields, D.M., Orrell, M (2018) Dementia care model: promoting personhood through co-production. *Archives of Gerontology and Geriatrics,* 81, 59 - 73.

Bosco, A, Schneider, J., Coleston-Shields, D.M., Higgs, P., Orrell, M. (2019) The social construction of dementia: Systematic review and metacognitive model of enculturation. *Maturitus*, 120, 12 - 22.

Bosco, A, Schneider J., Coleston-Shields, D.M., Sousa, L., Orrell, M (2019) Dyadic construction of dementia: Meta-ethnography and behaviour-process synthesis. *Ageing & Mental Health,* 23, 651 – 659.

Botsford, J., Clarke, C. I., Gibb, C. E. (2012) Dementia and relationship: experience of partners in minority ethnic communities. *Journal of Advanced Nursing,* 68, 2207 – 2217.

Bougea, A., Anagnostouli, M., Angelopoulou, E., Spanou, I., Chrousos, G. (2022) Psychosocial and Trauma-Related Stress and Risk of Dementia: A Meta-Analytic Systematic Review of Longitudinal Studies. *Journal of Geriatric and Psychiatry Neurology,* 35, 24-37.

Bowling, A. (eds) (2018) *Research Methods in Health.* Berkshire: Open University Press.

Bradley, K.L., Goetz, T., Viswanathan, S. (2018) Towards a Contemporary Definition of Health. *Military Medicine,* 183, 204 – 207.

Brannelly, T. (2016) Citizenship and people living with dementia: A case for the ethics of care. *Dementia,* 15, 304 – 314.

Braun, V., Clarke, V. (eds) (2013) *Successful qualitative research: A practical guide for beginners.* London: Sage.

Braun, V., Clarke, V. (2014) What can 'thematic analysis' offer health and wellbeing researchers? *International Journal of Qualitative Studies of Health and Well-being,* 16, 26152.

Braun V., Clarke V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11, 589–597.

Brewin, C.R. (2018) Memory and Forgetting. *Current Psychiatry Reports,* 20, 87.

Brooke, J., Cronin, C., Stiell, M, Ojo, O. (2018) The intersection of culture in the provision of dementia care: A systematic review. *Journal of Clinical Nursing,* 27, 3241-3253.

Brooke, J., Ojo, O. (2019) Contemporary views on dementia as witchcraft in sub-Saharan Africa: A systematic literature review. *Journal of Clinical Nursing,* 29, 20 – 30.

Brown, D. A. (2020) Review of the PubMed PICO Tool: Using Evidence-Based Practice in Health Education. *Health Promotion Practice,* 21, 496-498.

Brown, R. (2020) The social identity approach: Appraising the Tajfellian legacy. *The British Journal of Social Psychology,* 59, 5-25.

Brown, J. (2016) Self and identity over time: dementia. *Journal of Evaluation in Clinical Practice,* 1-7.

Brown, M. F. (2008) Cultural relativism. *Current Anthropology*, 49, 363 -373.

Bryman, A (eds) (2012) *Social Research Methods*. Oxford: Oxford University.

Bryson, D. (2014) The developing professional. *Journal of Visual Communication in Medicine,* 37, 107 -111.

Burr, V. (eds) (2015) *Social constructionism*. London: Routledge.

Burr, V., Dick, P. (2017) Social Constructionism In Gough B (eds) *The Palgrave Handbook of critical social psychology*. London: Palgrave Macmillan.

Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness*, 4, 167 – 182.

Bury, M. (1986) Social constructionism and the development of medical sociology. *Sociology of health and Illness,* 8, 137 - 169.

Bury, M. (1994) Health Promotion and lay Epidemiology: A Sociological View. *Health Care Analysis*, 2, 23 -30.

Busby, H., Williams, G., Roger, A. (1997) Bodies of knowledge: Lay and biomedical understanding of musculoskeletal disorder In Elston, M. A. (ed) *The Sociology of Medical Science and Technology*. Oxford: Blackwell, pp 79 - 99.

Busetto, L., Wick, W., Gumbinger, C. (2020) How to use and assess qualitative research methods. *Neurological Research and Practice,* 27, 2 - 14.

Butler, J. (1999) *Gender Trouble: Feminism and the Subversion of identity*. London: Routledge.

Caffrey, C., Sengupta, M., Melekin, A. (2021) Residential Care Community Resident Characteristics: United States, 2018. *NCHS Data Brief,* 404, 1-8.

Cahill, S. (2019) WHO's global action plan on the public health response to dementia: some challenges and opportunities. *Ageing and Mental Health,* 24, 197-199.

Campbell, P. A. (2021) Lay participation with medical expertise in online self-care practices: Social knowledge (co)production in the Running Mania injury forum. *Social Science and Medicine,* 277:113880.

Campbell, M. K., Hudson, M. A., Resnicow, K., Blakeney, N., Paxton, A., Baskin, M. (2007) Church-based health promotion interventions: evidence and lessons learned. *Annual Review of Public Health,* 28, 213-34.

Cao, Q., Tan, C.C., Xu, W., Hu, H., Cao, X.P., Dong, Q., Tan, L., Yu, J.T. (2020) The Prevalence of Dementia: A Systematic Review and Meta-Analysis. *Journal of Alzheimers Disease,* 73, 1157-1166.

Carbado, D.W., Crenshaw, K.W., Mays, V.M., Tomlinson, B. (2013) INTERSECTIONALITY: Mapping the Movements of a Theory. *Du Bois Review,* 10, 303-312.

Carver, L.F., Buchanan, D. (2016) Successful aging: considering non-biomedical constructs. *Clinical Interventions in Aging,* 11, 1623 -1630.

Casey, C.M., Caulley, J., Phelan, E.A. (2020) The Intersection of Falls and Dementia in Primary Care: Evaluation and Management Considerations. *Medical Clinic of North America,* 104, 791-806.

Cations, M., Withall, A., Draper, B. (2019) Modifiable risk factors for young onset dementia. *Current Opinion in Psychiatry,* 32, 138 -143.

Charmaz, K. (eds) (2013) *Constructing Grounded Theory*. Los Angeles, CA: Sage.

Cherniak, A.D, Mikulincer, M., Shaver, P.R, Granqvist, P. (2021) Attachment theory and religion. *Current Opinion in Psychology*, 40, 126-130.

Cheng, S. T (2017). Dementia Caregiver Burden: a Research Update and Critical Analysis. *Current Psychiatry Reports*, 19, 64.

Cherry, K.E., Brigman, S., Burton-Chase, A.M., Baudoin, K.H. (2021) Perceptions of Forgetfulness in Adulthood. *Journal of Genetic Psychology*, 182, 31-46.

Chiao, C. Y., Wu, H. S., Hsiao, C. Y. (2015) Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62, 340-350.

Childers, K.M. (2019) Sense of coherence and caregivers of person with Dementia. *Behavioural Science*, 9, 14 – 39.

Chiu, H., Tsoh, J. (2009) Commentary on 'Dementia: an anthropological perspective' by Mahnaz Hashmi. *International Journal of Geriatric Psychiatry*, 24, 325 – 327.

Choi, J., Kwon, L.N., Lim, H., Chun, H.W. (2020) Gender-Based Analysis of Risk Factors for Dementia using Senior Cohort. *International Journal of Environmental Research and Public Health,* 17, 7274 – 7286.

Chung, J.C. (2000) Lay interpretation of dementia. International Psychogeriatrics, 12, 369-77.

Cieza, A., Sabariego, C., Bickenbach, J., Chatterji, S. (2018) Rethinking Disability. *BMC Medicine*, 16, 14.

Cipriani, G., Borin, G. (2015) Understanding dementia in the socio-cultural context: A review. *International Journal of Social Psychiatry*, 61, 198 -204.

Cohen, D.J, Crabtree, B.F. (2008) Evaluative criteria for qualitative research in health care: controversies and recommendations. *Annals of Family Medicine*, 6, 331-9.

Connell, C.M., Gibson, G.D. (1997) Racial, ethnic, and cultural differences in dementia caregiving: review and analysis. *Gerontologist*, 37, 355 -364.

Connor, C.W. (2019) Artificial Intelligence and Machine Learning in Anesthesiology. *Anesthesiology,* 131, 1346-1359.

Cooney A. (2011) Rigour and grounded theory. *Nurse Researcher*, 18, 17-22.

Conrad, P. (2007) *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. Baltimore: John Hopkins University Press.

Conrad, P. (1979) Types of medical social control. *Sociology of Health and Illness,* 1, 1-11.

Conti, A.A. (2018) Historical evolution of the concept of health in Western Medicine. *Acta Bio-Medica,* 89, 352 – 354.

Corry, M., Porter, S., McKenna, H. (2019) The redundancy of positivism as a paradigm for nursing research. *Nursing Philosophy,* 20, e12230.

Cosco, T. D., Howse, K., Brayne, C. (2017) Healthy ageing, resilience and wellbeing. *Epidemiology and Psychiatric Sciences,* 26, 579-583.

Crenshaw, K. W. (1989) Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum,* 1989, 139 – 67.

Creswell, J. (eds) (2013) *Qualitative Inquiry and Research Design Choosing Among Five Approaches.* Thousand Oaks, California: Sage Publication.

Creswell, J. (eds) (2009) *Research Design: Qualitative, Quantitative, and Mixed methods approaches.* Thousands Oak, California: Sage Publications.

Crichton, G.E., Bryan, J., Murphy, K.T. (2013) Dietary antioxidants, cognitive function and dementia: a systematic review. *Plant Foods for Human Nutrition*, 68, 279 – 292.

Cross, R. I. (2018) Commentary: Can Critical Race Theory Enhance the Field of Public Health? A Student's Perspective. *Ethnicity and Disease,* 28, 267-270.

Crowther-Heyck, H. (1999) George A. Miller, Language, and the computer metaphor of the mind. *History of Psychology*, 2, 37 – 64.

Curtis, E. A., Drennan, J. (2013) *Quantitative Health Research: Issues and Methods*. London: Open University Press.

Cwikel, J.G. (1994) After epidemiological research: what next? Community action for health promotion. *Public Health Reviews*, 22, 375-94.

da Costa Santos, C.M., de Mattos Pimenta, C.A., Nobre, M.R. (2007) The PICO strategy for the research question construction and evidence search. *Revista Latino Americana de Enfermagem,* 15, 508-11.

Dafni, A., Böck, B (2019) Medicinal plants of the Bible-revisited. *Journal of Ethnobiology and Ethnomedicine,* 15, 57.

Daly, L., Fahey-McCarthy., E. (2014) Attending to the spiritual in dementia care nursing. *British Journal Nursing*, 23, 787 -791.

Dalmer, N. K. (2020) Unsettling Knowledge Synthesis Methods Using Institutional Ethnography: Reflections on the Scoping Review as a Critical Knowledge Synthesis Tool. *Qualitative Health Research*, 30, 2361-2373.

Damiananakis, T., Wilson, K., Marziali, E. (2018) Family caregiver support groups: spiritual reflections' impact on stress management. *Ageing and Mental Health,* 22, 70 – 76.

Danowski, J.A., Sacks, W. (1980) Computer communication and the elderly. *Experimental Aging Research,* 6, 125-35.

Davis, D.H.J. (2004) Dementia: Sociological and philosophical constructions. *Social Sciences and Medicine,* 58, 369 – 378.

Davis, J (2013) *Health promotion: a unique discipline?* Health Promotion Forum of New Zealand: New Zealand.

Davison, S. (eds) (2014) *Davison's Principles and Practice of Medicine*. Elservier: London.

Davison, S. (eds) (2022) *Davison's Principles and Practice of Medicine.* Elservier: London.

Deal, J.A., Power, M.C., Palta, P., Alonso, A., Schneider, A.L.C., Perryman, K., Bandeen-Roche, K., Sharrette, A.R. (2020) Relationship of Cigarette Smoking and Time of Quitting with Incident *Dementia. Journal of the American Geriatrics Society*, 68, 337 – 345.

Deering, K., Williams, J., Stayner, K., Pawson, C. (2021) Giving a voice to patient experience through the insights of pragmatism. *Nursing Philosophy*, 22, e12329.

Dementia UK: https://www.dementiauk.org/about-dementia/young-onset-dementia/young-onset-dementia-resources/books/autobiographies/

Dengri, C., Gill, A., Chopra, J., Dengri, C., Koritala, T., Khedr, A., Korsapati, A.R., Adhikari, R., Jain, S., Zec, S., Chand, M., Kashyap, R., Pattan, V., Khan, S.A., Jain, N.K. (2021) A Review of the Quiz, as a New Dimension in Medical Education. *Cureus*, 13, e18854.

Denzin, N. L., Lincoln, Y. S. (2018) (Eds) *The SAGE Handbook of Qualitative Researcher*. Thousand Oaks: SAGE Publications, Inc.

Dequanter, S., Gagnon, M.P., Ndiaye, M.A., Goru, E., Fobelelets, M., Giguere, A., Bourbonnais, A., Buyl, R. (2020) The effectiveness of e-health solutions for ageing with cognitive impairment: a systematic review. *Gerontologist*, gnaa065.

Dewing, J. (2008) Personhood and dementia: revisiting Tom Kitwood's Ideas. *International Journal of Older People Nursing*, 3, 3 -13.

Di-Lorito, C., Godfrey, M., Dunlop, M., Bosco, A., Pollock, K., Van der Wardt, V., Harwood, R. H. (2020) Adding to the knowledge on Patient and Public Involvement: Reflections from experience of co-research with carers of people with dementia. *Health expectations*, 23, 691 - 707.

Dobkin de Rios, M. (1984) The Vidente Phenomenon in third world traditional healing: an Amazonian example. *Medical Anthropology*, 8, 60 -70.

Dodgson, J.E. (2019) Reflexivity in Qualitative Research. *Journal of Human Lactation*, 35, 220-222.

Dodig, S., Čepelak, I., Pavić, I. (2019) Hallmarks of senescence and aging. *Biochemia Medica*, 29, 030501.

Dominguez, L.J., Veronese, N., Vernuccio, L., Catanese, G., Inzerillo, F., Salemi, G., Barbagallo, M. (2021) Nutrition, Physical Activity, and Other Lifestyle Factors in the Prevention of Cognitive Decline and Dementia. *Nutrients,* 13, 4080 - 4140.

Dube, C. E., Lapane, K. L. (2014) Lay abstracts and summaries: writing advice for scientists. *Journal of Cancer Education*, 29, 577 -579.

Dupras, C., Williams-Jones, B. (2012) 'Dupras and Williams-Jones Respond. *American Journal of Public Health*, 102, 12 -13.

Durazzo, T.C., Mattsson, N., Weiner, M.W., Alzheimer's disease Neuroimaging Initiative (2014) Smoking and Increased Alzheimer's disease risk: a review of potential mechanisms. *Alzheimer's & Dementia*, 10, 122 – 145.

Eckenwiler, L.A. (2020) A Global Ecological Ethic for Human Health Resources. *Journal of Bioethical Inquiry,* 17, 575 – 580.

Eckstrom, E., Neukam, S., Kalin, L., Wright, J. (2020) Physical Activity and Healthy Aging. *Clinics in Geriatric Medicine*, 36, 671-683.

Edwards, J. (2014) Ghana's mental health patients confined to prayer camps. *World report,* 383, 15-16.

Egan, M., Hobson, S., Fearing, V.G. (2006) Dementia and occupation: a review of the literature. *Canadian Journal of Occupational Therapy*, 73, 132-40.

Egher, C. (2019) Bipolar patients and creative online practices: Sharing experiences of controversial treatment. *Health*, 4, 458 – 477.

Ellis, C. (2007) Telling secrets revealing lives: Relational ethics in research with intimate others. *Qualitative inquiry*, 13, 3 -29.

Engel, G. L. (1977) The need for a new medical model: a challenge for biomedicine. *Science.* 196, 129-36.

Epps, F., Heidbreder, V., Alexander, K., Tomlinson, A., Freeman, V., Williams, N. (2021) A dementia-friendly church: How can the African American church support families affected by dementia? *Dementia,* 20, 556-569.

Epps, F., Alexander, K., Brewster, G.S., Parker, L.J., Chester, M., Tomlinson, A., Adkins, A., Zingg, S., Thornton, J. (2020) Promoting dementia awareness in African-American faith communities. *Public Health Nursing*, 37, 715-721.

Epstein, S. (1995) The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology and Human Values*, 20, 408-437.

Erol, R., Brooker, D., Peel, E. (2016) The impact of dementia on women internationally: An integrative review. *Health Care for Women International*, 37, 1320-1341.

Falagas, M.E., Pitsouni, E.I., Malietzis, G.A., Pappas, G. (2008) Comparison of PubMed, Scopus, Web of Science, and Google Scholar: strengths and weaknesses. *FASEB Journal*, 22, 338-42.

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

Farrel, B. A. (1958) 'Experience'. *Mind,* 50, 170 -198.

Feast, A., Orrell. M., Charlesworth, G., Melunsky, N., Poland, F., Moniz-Cook E. (2016) Behavioural and psychological symptoms in dementia and the challenges for family carers: systematic review. *British Journal of Psychiatry,* 208, 429 – 434.

Feigl, H. (1958). 'The 'Mental' and the 'physical', in H. Feigl, M. Scriven and G. Maxwell (eds), *Concepts, Theories and the Mind-Body problem* (Minnesota Studies in the Philosophy of Science, Volum2), Minneapolis: Minnesota Press.

Ferencz, B., Gerritsen, L. (2015) Genetics and underlying pathology of dementia. *Neuropsychology Review*, 25, 113 -124.

Fiske, S. T., Dupree, C. H., Nicolas, G., Swencionis, J. K. (2016) Status, Power, and Intergroup Relations: The Personal Is the Societal. *Current Opinion in Psychology,* 11, 44-48.

Fitouchi, L., Singh, M. (2022) Supernatural punishment beliefs as cognitively compelling tools of social control. *Current Opinion in Psychology,* 44, 252-257.

FitzPatrick B. (2019) Validity in qualitative health education research. *Current Pharmacy Teaching and Learning,* 11, 211-217.

Fleming, R., Bennett, K., Preece, T., Phillipson, L. (2017) The development and testing of the dementia friendly communities environment assessment tool (DFC EAT). *International Psychogeriatric,* 29, 303 -311.

Fletcher, J.R. (2021) Destigmatising dementia: the danger of felt stigma and benevolent othering. *Dementia,* 20, 417 – 426.

Flynn, D. E., Johnson, C., Sands, A., Wong, V., Figueroa C, Baggaley, R. (2017) Can trained lay providers perform HIV testing services? A review of national HIV testing policies. *BMC Research Notes,* 10, 20 -27.

Ford, M. E., Kelly, P. A. (2005) Conceptualizing and categorizing race and ethnicity in health services research. *Health Service Research,* 40, 1658-1675.

Foucault, M. (1973) *The Birth of the Clinic: An Archaeology of medical Perception*. New York: Random House.

Foucault, M. (1977) *Discipline and Punish: The Birth of the Prison*. New York: Random House.

Frankfurt, H. G. (1971) ‘Freedom of the Will and the concept of a person’. *The Journal of philosophy,* 68, 5-7.

Freachem, H.G.M. and Medlin, C.A. (2002) Health is Wealth. *Nature,* 417, 695 -696.

Frochen, S., Rodnyansky, S., Ailshire, J. (2020) Residential care in California. *Journal of Maps,* 16, 138-143.

Gagnon-St-Pierre É., Doucerain, M.M., Markovits, H. (2021) Reasoning strategies explain individual differences in social reasoning. *Journal of Experimental Psychology General,* 150, 340-353.

Gaines, D. (2016) Sociocultural constructions of medical knowledge. *International Encyclopaedia of Public Health* (pages 612-616).

Gale, S.A., Acar, D., Daffner, K.R. (2018) Dementia. *American Journal of Medicine*, 131, 1161 -1169.

Galkin, F., Mamoshina, P., Aliper, A., de Magalhães, J.P., Gladyshev, V.N., Zhavoronkov, A. (2020) Biohorology and biomarkers of aging: Current state-of-the-art, challenges and opportunities. *Ageing Research Reviews*, 60, 101050.

Garre-Olmo J. (2018) Epidemiology of Alzheimer's disease and other dementias, *Revista Neurologia,* 66, 377 -386.

Ge, Y., Sainz, M., Gore, J., Epps, F. (2021) 'Everything is Either Sent by God or Used by God': An Exploratory Study on the Impact of COVID-19 Upon the Religious Lives of Black Families Living with Dementia. *Journal of Religion and Health,* 60, 3193-3208.

Gearing, R. E. (2004) Bracketing in research: a typology. *Qualitative Health Research,* 14, 1429-52.

Gebremariam, M.K., Bjune, G.A., Frich, J.C. (2011) Lay beliefs of TB and TB/HIV co-infection in Addis Ababa, Ethiopia: a qualitative study. *BMC Research Notes,* 4, 277 -282.

Geertz, C. (1986). *Local Knowledged*. New York, NY: Basic Books.

Gergen, K. J. (1986). Social Psychology as social construction: The emerging vision. In C. McGarty & A. Haslam (Eds), *For the message of social psychology: Perspectives on mind in society* (pp. 113 – 128). Oxford, England: Blackwell.

Gery, W. R., Bernard, H. R. (2003) Techniques to Identify Themes. *Field Methods*, 15, 85-109.

Gelinas, L., Pierce, R., Winkler, S., Cohen, I.G., Lynch, H.F., Bierer, B.E. (2017) Using Social Media as a Research Recruitment Tool: Ethical Issues and Recommendations. *American Journal of Bioethics,* 17, 3-14.

Geschwind, M.D. (2016) Rapidly Progressive Dementia. *Dementia,* 22, 510 -537.

Gettier, E. L. (1963) Is Justified True Belief Knowledge? *Analysis,* 23, 121-123.

Gholamnezhad, Z., Boskabady, M.H., Jahangiri, Z. (2020) Exercise and Dementia. *Advances in Experimental Medicine and Biology,* 1228, 303 – 315.

Gibbs, G. (2007) *Analysing Qualitative Data*. London: Sage.

Giebel, C. (2020) 'current dementia care: what are the difficulties and how can we advance care globally?' *BMC Health Service Research,* 20, 414 – 417.

Gilbert, J., Ward, L., Walter, R. (2021) A labour of love: Reward and satisfaction for nurses: Findings from a grounded theory study in dementia care. *Dementia (London),* 20, 1697-1710.

Gilhooly, M., Hanlon, P., Cullen, B., Macdonald, S., Whyte, B. (2007) Successful ageing in area of deprivation: Part 2 – A qualitative exploration of the role of life experience in good health in old age. *Journal of the Royal Institute of Public Health*, 121, 814 – 821.

Gilhooly, K.J, Gilhooly, M.L., Sullivan, M.P, McIntyre, A., Wilson, L., Harding, E., Woodbridge, R., Crutch, S. (2016) A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatrics,* 16, 106.

Gimeno-Mallench, L., Sanchez-Morate, E., Parejo-Pedrajas, S., Mas-Bargues, C., Inglés, M., Sanz-Ros, J., Román-Domínguez, A., Olaso, G., Stromsnes, K., Gambini, J. (2020) The Relationship between Diet and Frailty in Ageing. *Endocrine Metabolic Immune Disorder Drug Targets*, 20, 1373-1382.

Glaser, B. G. (2005) *The grounded theory perspective 111: theoretical coding*. Mill Valley, CA: Sociology Press.

Glaser, B., Strauss, A. (1967) *The discovery of grounded theory: Strategies for qualitative research.* Chicago: Aldine.

Glaser, B. G. (1992) *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.

Glaser, B. G. (1998). *Doing grounded theory: Issues and discussion.* Mill Valley, CA: Sociology Press.

Gleyse, J. (2013) The machine body metaphor: from science and technology to physical education and sport, in France (1825 – 1935). *Scandinavian Journal of Medicine and Science in Sport,* 23, 758 – 765.

Głos, A. (2021) The art of mind changing solidarity in dementia care. *Bioethics,* 35, 315-325.

Goeman, D., King, J., Koch, S. (2016) Development of a model of dementia support and pathway for culturally and linguistically diverse communities using co-creation and participatory action-research. *BMJ Open,* 6, e013064.

Goffman (1963) *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs NJ: Prentice Hall.

Goffman, E. (1974) *Frame Analysis: An Essay on the Organization of Experience*. New York, Harper: Harvard University Press.

Goldman, J.S., van Deerlin, V.M. (2018) Alzheimer's Disease and Frontotemporal Dementia: The Current State of Genetics and Genetic Testing Since the Advent of Next-Generation Sequencing. *Molecular Diagnosis and Therapy,* 22, 505 – 513.

Gómez-Romero, M., Jiménez-Palomares, M., Rodríguez-Mansilla, J., Flores-Nieto, A., Garrido-Ardila, E.M., González López-Arza, M.V (2017). Benefits of music therapy on behaviour disorders in subjects diagnosed with dementia: a systematic review. *Neurologia,* 32, 253-263.

Gonder, U., von Schacky, C., Worm, N., Lechner, B., Bock, M., Lechner, K. (2019) Dementia and Metabolic-Vascular Risk Factors: Strategies for Prevention. *Deutsche Medizinnische Wochenschrift,* 17, 1212 – 1217.

Goncalves-Pereira, M., Zarit. S.H., Papoila, A.L., Mates, R. (2021) Positive and negatives experiences of caregiving of caregiving in dementia: The role of sense of coherence. *International Journal of Geriatric Psychiatry,* 36, 360 – 367.

Gordon, R. M. (2021) Knowledge by default. *The Behavioural and Brain Sciences,* 44, e154.

Gore, J., Toliver, J., Moore, M.A, Aycock, D., Epps, F. (2022) A Mixed-Methods Formative Evaluation of a Dementia-Friendly Congregation Program for Black Churches. *International Journal of Environmental Research and Public Health,* 19, 4498.

Gow, J., Gilhooly., M., Caldwell, S. (2004) *Lay concept of dementia and cognitive decline, including perceptions of risk factors*. University of Paisley (unpublished).

Grbich, C. (eds) (2013) *Qualitative Data Analysis: An Introduction*. London: Sage.

Green, J., Thorogood, N. (eds) (2018) *Qualitative Methods for Health Research*. London: Sage

Green, M. A., Evans, C. R., Subramanian, S.V. (2017) Can intersectionality theory enrich population health research? *Social Science & Medicine,* 178, 214-216.

Greenhalgh, T., Helman, C., Chowdhury, A.M. (1998) Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *BMJ,* 316, 978-83.

Greenwood, N., Smith, R. (2019) Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature. *BMC Geriatrics,* 19, 169.

Grundmann, R. (2017) The Problem of Expertise in Knowledge Societies. *Minerva,* 55, 25- 48.

Gruppetta, M., Mallia, M. (2020) Clinical reasoning: exploring its characteristics and enhancing its learning. *British Journal of Hospital Medicine (London),* 81, 1- 9.

Guba, E. G., & Lincoln, Y. S. (1986). *Fourth generation evaluation.* Thousand Oaks, CA: Sage.

Guba, E. G., & Lincoln, Y. S. (2008). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds), *The landscape of qualitative research (3rd ed.) (pp. 255-286).* Los Angeles: Sage Publications.

Gurchathen. S., Thapar-Björkert, S. (2008) Methodological dilemmas: gatekeepers and positionality in Bradford, *Ethnic and Racial Studies,* 31, 543-562.

Gutwinski, S., Schreiter, S., Priller, J., Henssler, J., Wiers, C.E., Heinz, A. (2018) Drink and Think: Impact of Alcohol on Cognitive Functions and Dementia – Evidence of Dose-Related Effects. *Pharmacopsychiatry,* 51, 136 – 143.

Haapala, I., Biggs, S., Kurrle, S. (2018) Social aspects of dementia and dementia practice. *International Psychogeriatric*, 30, 1579 – 1581.

Habermas, J. (1987) *The Theory of Communicative Action.* Vol. 2, Polity Press, Cambridge: UK.

Hamad, E.O., Ailadi, A.N., Lee, C.J., Savundranayagam, M.Y., Holmes, J.D., Kinsella, E.A., Johnson, A.M. (2017) Assessment of Caregiving Constructs: Toward a Personal, Familial, Group, and Cultural Construction of Dementia Care through the Eyes of Personal Construct Psychology. *Journal of Cross Cultural Gerontology*, 32, 413 – 431.

Hamilton J. B., Kweon, L., Brock, L.B., Moore, A.D (2020) The Use of Prayer During Life-Threatening Illness: A Connectedness to God, Inner-Self, and Others. *Journal of Religion and Health,* 59, 1687-1701.

Hammersley, M., Atkinson, P. (1995) *Ethnography Principle in Practice*. London: Routledge.

Hammersley, M., Atkinson, P. (2002) Ethnography Principle in Practice. London: Routledge.

Hanssen, I. (2013) The influence of cultural background in intercultural dementia care: exemplified by Sami patients. *Scandinavian Journal of Caring Sciences*, 27, 231-237.

Harwood, D. G. and Ownby, R.L. (2000) Ethnicity and Dementia. *Current Psychiatry Report,* 2, 40 – 45.

Haslam, C., Haslam, S.A, Jetten, J., Cruwys, T., Steffens, N.K. (2021) Life Change, Social Identity, and Health. *Annual Review of Psychology,* 4, 72:635-661.

Hatzenbuehler, M.L, Phelan, J.C, Link, B.G. (2013) Stigma as a fundamental cause of population health inequalities. *America Journal of Public Health*, 103, 813-21.

Haumann, W. (2020) Care preferences of the German population: the option of assisted residential groups. *Zeitschrift fur Gerontologie und Geriatrie*, 53, 522-530.

Haw, J., Cunninghams, S., O'Doherty, K. C. (2018) Epistemic tension between people living with asthma and healthcare professionals in clinical encounters. *Social Science and medicine,* 208, 34 – 40.

Hays, D. G., & Singh, A. A. (2012) *Qualitative inquiry in clinical and educational settings.* New York, NY: Guilford Press.

Heard, E., Fitzgerald, L., Wigginton, B., Mutch, A. (2020) Applying intersectionality theory in health promotion research and practice. *Health Promotion International,* 35, 866-876.

Heckhausen, J., Wrosch, C., Schulz, R. (2019) Agency and Motivation in Adulthood and Old Age. *Annual Review of Psychology,* 70, 191-217.

Heidegger M. (1962) *Being and Time.* New York: Harper & Row.

Heiphetz, L. (2018) The development and importance of shared reality in the domains of opinion, morality, and religion. *Current opinion in psychology*, 23, 1-5.

Helman, C. G. (eds) (2007) *Culture, Health and Illness*. London: Hodder Arnold.

Helman, C.G. (1978) 'feed a cold, starve a fever'- folk models of infection in an English suburban community, and their relation to medical treatment. *Culture, Medicine and Psychiatry,* 2, 107 -137.

Henderson, S., Horne, M., Hills, R., Kendall, E. (2018) Cultural competence in healthcare in the community: A concept analysis. *Health and Social Care in the Community*, 26, 590-603.

Henderson, J.N., Henderson, L.C. (2002) Cultural construction of disease: a 'supernormal' construct of dementia in an American Indian tribe. *Journal Cross Cultural Gerontology,* 17, 197 – 212.

Henderson, J.N., Traphagan, J.W. (2005) Cultural factors in dementia: perspectives from the anthropology of aging. *Alzheimer's Disease & Associated Disorder*, 19, 272-273.

Heese, K. (2015) Ageing, dementia and society – an epistemological perspective. *Springer plus,* 4, 135 – 155.

Herzfel, M. (2001) *Anthropology. Theoretical Practice in Culture and Society*. Oxford: Blackwell.

Heyes, C. (2020) Culture. *Current Biology,* 30, R1246-R1250.

Higgs, P, Gilleard, C. (2017) Ageing, dementia and the social mind: past, present and future perspectives. *Sociology of Health Illness,* 39, 175-181.

Hilkens, N.A, Klijn, C.J.M., Richard, E. (2021) Blood pressure, blood pressure variability and the risk of poststroke dementia. *Journal of Hypertension,* 39, 1859-1864.

Hindley, G., Kissima, J., Oates, L. L., Paddick, S., Kisoli, A., Brandsma, C., Gray, W. K., Walker, R. W., Mushi, D., Dotchin, C. (2016) The role of traditional and faith healers in the treatment of dementia in Tanzania and the potential for collaboration with allopathic healthcare services. *Age and Ageing,* 46, 130 – 137.

Hirji, J. (2004) Freedom or folly? Canadians and the consumptions of online health information. *Information, Communication and Society,* 7, 445 – 465.

Hofmann B. (2002) On the triad disease, illness and sickness. *Journal of Medicine and Philosophy,* 27, 651-73.

Hogan, A.J. (2019) Social and medical models of disability and mental health: evolution and renewal. *Canadian Medical Association Journal,* 191, E16-E18.

Hogg, M. A. and Rinella, M. J. (2018) Social identities and shared realities. *Current opinion in psychology,* 23, 6-10.

Hollingshead, A. and Redlich, F. (1958) *Social Class and Mental Illness*. New York: John Wiley and Sons.

Holman, D., Salway, S., Bell, A., Beach, B., Adebajo, A., Ali, N., Butt, J. (2021) Can intersectionality help with understanding and tackling health inequalities? Perspectives of professional stakeholders. *Health Research Policy & Systems,* 19, 97.

Holmes, A. G. D. (2020) Researcher Positionality - A Consideration of Its Influence and Place in Qualitative Research - A New Researcher Guide. *Shanlax International Journal of Education,* 8, 1-10.

Hossain, M.Z., Khan, H.T.A. (2019) Dementia in the Bangladeshi diaspora in England: A qualitative study of the myths and stigmas about dementia. *The Journal of Evaluation of Clinical Practice*, 25, 769 -778.

Hosseinpoor, A.R., Harper, S., Lee, J.H., Lynch, J., Mathers, C., Abou-Zahr, C. (2012) International shortfall inequality in life expectancy in women and in men, 1950-2010. *Bulletin of the World Health Organisation*, 90, 588-94.

Hopwood, J., Walker, N., McDonagh, L., Rait, G., Walters, K., IIiffe, S., Ross, J., Davis, N. (2018) Internet-Based Interventions Aimed at supporting Family Caregivers of People with Dementia: a systematic review. *Journal of Medical Internet Research*, 20, e216.

Houghton, C., Casey, D., Shaw, D., Murphy, K. (2013) Rigour in qualitative case-study research. *Nurse Researcher*, 20, 12-7.

Huang, Y.C., Lei, R.L., Lei, R.W., Ibrahim, F (2020). An exploratory study of dignity in dementia care. *Nursing Ethics*, 27, 433-445.

Hughner, R.S., Kleine, S.S. (2004) Views of health in the lay sector: a compilation and review of how individuals think about health. *Health (London)*, 8, 395-422.

Hunt, S. M., McEwen, J. (1980) The development of subjective health indicator. *Sociology of Health and illness*, 2, 231 – 246.

Husserl, E. (1931) *Ideas: General Introduction to Pure Phenomenology.* New York: Humanities Presss.

Hyman S. E. (2021) Psychiatric Disorders: Grounded in Human Biology but Not Natural Kinds. *Perspectives in Biology and Medicine*, 64, 6-28.

Imbert, I. (2014) Biomarkers and aging. *Biomarkers in Medicine*, 8, 621-3.

Imhof, L., Wallhagen, M.I, Mahrer-Imhof, R., Monsch, A.U. (2006) Becoming forgetful: how elderly people deal with forgetfulness in everyday life. *American Journal of Alzheimer's disease and Other Dementia*, 21, 347-53.

Imrényi, T. (2005) Sin and bioethics. *Christian Bioethics*, 11, 133-45.

Irvine, c. (2020) What do 'Lay' people know about justice? An empirical enquiry. *International Journal of Law in Context*, 16, 146 – 164.

Ishtiak-Ahmed, K., Hansen, Å.M, Mortensen, E.L, Garde, A.H., Brødsgaard Grynderup, M., Gyntelberg, F., Islamoska. S, Lund, R., Phung, T.K.T., Prescott, E., Waldemar, G., Nabe-Nielsen, K. (2019) Midlife Forgetfulness and Risk of Dementia in Old Age: Results from the Danish Working Environment Cohort Study. *Dementia Geriatric and Cognitive Disorder*, 47, 264-273.

Ismail, Z., Black, S.E, Camicioli, R., Chertkow, H., Herrmann, N., Laforce, R., Jr, Montero-Odasso, M., Rockwood, K., Rosa-Neto, P., Seitz, D., Sivananthan, S., Smith, E.E, Soucy, J.P, Vedel, I., Gauthier, S; CCCDTD5 participants (2020). Recommendations of the 5th Canadian Consensus Conference on the diagnosis and treatment of dementia. *Alzheimers & Dementia,* 16, 1182-1195.

Jacobs, R., Schneider, M., Farina, N., Du Toit, P., & Evans-Lacko, S. (2022). Stigma and its implications for dementia in South Africa: A multi-stakeholder exploratory study. *Ageing and Society,* 1-31.

Jaconelli, A., Terracciano, A., Sutin, A.R., Sarrazin, P., Raffard, S., Stephan, Y. (2017) Subjective Age and Dementia. *Clinical Gerontology,* 40, 106 – 113.

Jahn, K. (2019) The Aging Vestibular System: Dizziness and Imbalance in the Elderly. *Advances in Otorhinolaryngology*, 82, 143-149.

Jansen, I., Stalmeijer, R.E., Silkens, M.E.W.M., Lombarts K.M.J.M.H. (2021) An act of performance: Exploring residents' decision-making processes to seek help. *Medical Education,* 55, 758-767.

Ji, L., Jazwinski, S. M., Kim, S. (2021) Frailty and Biological Age. *Annals Geriatric Medicine and research,* 25,141-149.

Johl, N., Patterson, T., Pearson, L. (2016) What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia*, 15, 721 -742.

Johnson, K.A. (2021) God. . . Karma, Jinn, spirits, and other metaphysical forces. *Current Opinion Psychology,* 40, 10-14.

Johnson, L. J., Adkins, D., Chauvin, S. (2020) A Review of Qualitative Indicators of Rigour in Qualitative Research. *America Journal of Pharmacy Education,* 84, 7120.

Jones, I. R. (2017) Social class, dementia and the fourth age. *Sociology of health and illness,* 39, 303 – 317.

Jones, P.S, Lee, J.W, Zhang, X.E. (2011) Clarifying and measuring filial concepts across five cultural groups. *Research in Nursing and Health*, 34, 310-26.

Jónsdóttir, M. K., Pálsdóttir. E. B., Hannesdóttir. S. Ý., Karlsson, T. (2022). Lay Knowledge About Dementia in Iceland: Symptoms and Risk and Protective Factors. *Gerontology and Geriatric Medicine*, 8:23337214221142937.

Jorm, A.F., Korten, A. E., Henderson, A.S. (1987) The prevalence of dementia: a quantitative integration of the literature. *Acta Psychiatrica Scandinavica*, 76, 465 – 479.

Jorm, A.F., Jolley D. (1998) The incidence of dementia: a meta-analysis. *Neurology,* 51, 728 – 733.

Kaambwa, B., Chen, G., Khadka, J., Milte, R., Mpundu-Kaambwa, C., Woods, T.J, Ratcliffe, J. (2021) A preference for quality: Australian general public's willingness to pay for home and residential aged care. *Social Science and Medicine*, 289, 114425.

Kaiser, K. (2009) Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, 19, 1632-1641.

Kakongi, N., Rukundo, G.Z., Gelaye, B., Wakida, E.K, Obua, C., Okello, E.S. (2020) Exploring pathways to Hospital Care for Patients with Alzheimer's disease and related dementias in rural South Western Uganda. *BMC Health Service Research*, 20, 498.

Kallio, H., Pietilä, A.M, Johnson, M., Kangasniemi, M. (2016) Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72, 2954-2965.

Kalu, A. C. (1996) Women and the social construction of gender in African development. *Africa Today*, 43, 269-88.

Kamer, L. (2022) Life expectancy in African countries 2022. *Statista*

https://www.statista.com/statistics/1218173/life-expectancy-in-african-countries.

Kane, A., Murphy, C., Kelly, M. (2010) Assessing implicit and explicit dementia stigma in young adults and care-workers. *Dementia*, 19, 1692 – 1711.

Karnieli-Miller, O., Strier, R., Pessach, L. (2009) Power Relations in Qualitative Research. *Qualitative Health Research*, 19, 279-289.

Kauffman K.S. (1994) The insider/outsider dilemma: field experience of a white researcher ‘getting in’ a poor black community. *Nursing Research* 43, 179-83.

Kaufman, S. R (2002). A commentary: hospital experience and meaning at the end of life. *Gerontologist,* 3, 34-9.

Katz, P.S. (2019) The conservative bias of life scientists. *Current Biology,* 29, R666- R667.

Kehoua, G., Dubreuil, C., Ndamba-Bandzouzi, B., Guerchet, M., Mbelesso, P., Dartigues, J., Preux, P. (2019) People with Dementia in Sub-Saharan Africa: From Support to Abuse by Caregivers: Results of EPIDEMCA-FU Program in Congo. *Dementia and Geriatric Cognitive Disorders,* 9, 163-175.

Kelly, F., Innes, A. (2013) Human rights, citizenship and dementia care nursing. *International Journal of Older People Nursing,* 8, 61 – 70.

Kelly, C., Kasperavicius, D., Duncan, D., Etherington, C., Giangregorio, L., Presseau, J., Sibley, K. M., Straus, S. (2021) ‘Doing’ or ‘using’ intersectionality? Opportunities and challenges in incorporating intersectionality into knowledge translation theory and practice. *International Journal for Equity in Health,* 20, 187-194.

Kenigsberg, P., Aquino, J., Berard, A., Gzil, F., Andrieu, S., Banerjee, S., Bremond, F., Buee, L., Cohen-Mansfield, J., Mangialasche, F., Platel, H., Salmon, E., Robert, P. (2016) Dementia beyond 2025: Knowledge and uncertainties. *Dementia*, 15, 6 -21.

Kennedy, C. E., Yeh, P.T., Johnson, C., Baggaley, S. (2017) Should trained lay providers HIV testing? A systematic review to inform World Health Organisation guidelines: *AIDS care*, 12, 1473 – 1479.

Kenning, C., White, G., Blakemore, A., Panagioti, M., Waheed, W. (2017) Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. *BMC Psychiatry,* 17, 316 – 348.

Kessing, L.V. (2012) Depression and the risk for dementia. *Current Opinion in Psychiatry*, 25, 457 – 461.

Khan, S., Barve, K.H., Kumar, M.S. (2020) Recent Advancements in Pathogenesis, Diagnostics and Treatment of Alzheimer’s Disease. *Current Neuropharmacology,* 18, 1106-1125.

Killin, L.O., Starr, J.M., Shiue, I.J., Russ, T.C. (2016) Environmental risk factors for dementia: a systematic review. *BMC Geriatrics,* 16, 175 – 203.

Kim, S.T., Park, M. (2017) Effectiveness of person-cantered care on people with dementia: a systematic review and meta-analysis. *Clinical Interventions in Ageing,* 12, 381-397.

Kindell, J., Keady, J., Sage, K., Wilkinson, R. (2017) Everyday conversation in dementia: a review of the literature to inform research and practice. *International Journal of Language and Communication Disorders,* 52, 392 – 406.

King, L. (1954) What is a disease? *Philosophy of Science,* 1, 193 -204.

Kitto, S.C., Chesters, J., Grbich, C. (2008) Quality in qualitative research. *Medical Journal of Australia,* 188, 243-6.

Kitwood, T. (1997) *Dementia Reconsidered: the Person Comes First*. Buckingham: Open University Press.

Kitwood, T. (1990a) *Concern for ‘others’ A New Psychology of Conscience and Morality*. Rutledge: London.

Kitwood, T. (1993a) Person and process in dementia. *International Journal of psychiatry*, 8, 541 – 545.

Kitwood, T. (1993b) Towards a theory of dementia care: the interpersonal process. *Ageing and Society*, 13, 51 -67.

Kitwood, T., Bredin, K. (1992) Towards a theory of dementia care: Personhood and wellbeing. *Ageing and Society,* 12, 269 -287.

Kitwood, T., Benson, S. (eds) (1995) *The New Culture of Dementia Care*. London: Hawker

Kirk, M., Tomm-Bonde, L., Schreiber, R. (2014) Public health reform and health promotion in Canada. *Global Public Health Promotion*, 21, 15 – 22.

Kivipelto, M., Mangialasche, F., Ngandu, T. (2018) Lifestyle interventions to prevent cognitive impairment, dementia and Alzheimer’s disease. *Nature Reviews Neurology,* 14, 653 – 666.

Kleinman, A. (1980) *Patient and healer in the context of culture*. Berkely: University Press.

Kleinman, A. (1988) *The illness narrative, Suffering, Healing, and the Human Condition*. New York: Basic Books.

Knottnerus, J.A., Tugwell, P. (2018) Research-agenda bias. *Journal of Clinical Epidemiology,* 98, Vii –Viii.

Koch, M., Dhana, K., Jensen, M.K. (2018) Antioxidants and risk of dementia: recent insight and future opportunities. *Current Opinion Lipidology,* 29, 424 – 425.

Kontos, P., Miller, K., Kontos, A. P. (2017) Relational citizenship: supporting embodied selfhood and relationality in dementia care. *Sociology of Health and Illness,* 39, 182-198.

Kontos, P. (2012) Rethinking sociality in long-term care: an embodied dimension of selfhood. *Dementia,* 11, 329 – 346.

Kontos, P., Martin, W. (2013) Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia,* 12, 288 – 302.

Kontos, P., Miller, K., Mitchell, G., Cott, C. (2011) Dementia care at the intersection of regulation and reflexivity: a critical realist perspective. *Journals of Gerontology Series B*, 66, 119 – 128.

Kontrimiene, A., Blazeviciene, A., Liseckiene, I., Raila, G., Valius, L., Jaruseviciene, L. (2021) Partnership between Primary Health and Social Care Services in the Long-Term Care of Older People with Dementia: A Vignette Study. *Inquiry,* 58, 469580211011933.

Krawczyk, P., Święcicki, Ł. (2020) ICD-11 vs. ICD-10 - a review of updates and novelties introduced in the latest version of the WHO International Classification of Diseases. *Psychiatria Polska*, 54, 7-20.

Krebs-Smith, S.M., Pannucci, T.E., Subar, A.F., Kirkpatrick, S.I., Lerman, J.L., Tooze, J.A, Wilson, M.M, Reedy, J. (2018) Update of the Healthy Eating Index: HEI-2015. *Journal of the Academy Nutrition and Dietetics,* 118, 1591-1602.

Krein, L., Jeon Y, Amberber, A.M.,Fethney, J. (2019) The Assessment of Language and Communication in Dementia: A synthesis of evidence. *The American Journal of geriatric Psychiatry*, 27, 363-377.

Kumar, P and Clark, M. (eds) (2021) *Clinical Medicine.* London: Elsevier.

Kusch, M. (2017) Epistemic relativism, scepticism, pluralism. *Synthese*, 194, 4687-4703.

Laing, R.D. (1971) *The Politics of the Family and Other Essays.* London: Tavistock Publications.

Laios, K., Moschos, M.M., Koukaki, E., Vasilopoulos, E., Karamanou, M., Kontaxaki, M.I., Androutsos, G. (2016) Dreams in ancient Greek medicine. *Psychiatrike*, 27, 215 – 221.

Lamb, S. (2014) Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *Journal Aging Studies*, 29, 41 -52.

Lamb, S.E., Sheehan, B., Atherton, N., Nichols, V., Collins, H., Mistry, D., Dosanjh, S., Slowther, A. M., Khan, I., Petrou, S., Lall, R., DAPA Trial Investigators (2018) Dementia And Physical Activity (DAPA) trial of moderate to high intensity exercise training for people with dementia: randomised control trial. *BMJ*, 361, k1675.

Lamb, S.E., Mistry, D., Alleyne, S., Atherton, N., Brown, D., Copsey, B., Dosanjh, S., Finnegan, S., Fordham, B., Griffiths, F., Hennings, S., Khan, I., Khan, K., Lall, R., Lyle, S., Nichols, V., Petrou, S., Zeh, P., Sheehan, B. (2018) Aerobic and strength training exercise programme for cognitive impairment in people with mild to moderate dementia: the DAPA RCT. *Health Technology Assessment* 22, 1 - 22.

Lamb, S.E., Williamson, E.M., Heine, P.J., Adams, J., Dosanjh, S., Dritsaki, M., Glover, M.J., Lord, J., McConkey, C., Nichols, V., Rahman, A., Underwood, M., Williams, M.A., Strengthening and Stretching for Rheumatoid Arthritis of the Hand Trial (SARAH) Trial Team. (2015) Exercises to improve function of the rheumatoid hand (SARAH): a randomised controlled trial. *Lancet*, 385, 421 -429.

Lancet. (2019) Investment in health is key to boosting wealth. *Lancet*, 393, 1072-1073.

Lancet. (2018) Dementia in the UK: preparing the NHS for new treatments. *Lancet*, 391, 1237.

Landeiro, F., Walsh K., Ghinai, L., Mugbal, S., Nye, E., Wace, H., Roberts, N., Lecomte, P., Wittenberg, R., Wolstenholme, J., Handels, R., Roncancio-Diaz, E., Potashman, M.H., Tockhorn-Heidenreich, A., Gray, A.M. (2018) Measuring quality of life of people with predementia and dementia and their caregivers: a systematic review protocol. *BMJ Open*, 8, e019082.

Landeiro, F., Walsh K., Ghinai, L., Mugbal, S., Nye, E., Wace, H., Roberts, N., Lecomte, P., Wittenberg, R., Wolstenholme, J., Handels, R., Roncancio-Diaz, E., Potashman, M.H., Tockhorn-Heidenreich, A., Gray, A.M. (2018) Resource utilization and cost in predementia and dementia: a systematic review protocol. *BMJ Open*, 8, e019060.

Last, M. (1981) The importance of knowing about not knowing. *Social Science and Medicine,* 15B, 397-92.

Lather, P. (1986). Issues of validity in openly ideological research: Between a rock and a soft place. *Interchange,* 17, 63 – 84.

Lawrence, V., Murray, J., Samsi, K., Banerjee, S. (2008) Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK. *The British Journal of Psychiatry,* 193, 240 – 246.

Lawton, J. (2003) Lay experiences of health and illness: past research and future agendas. *Sociology of Health and Illness*, 25, 23 - 40.

Leavy, P. (2020) (Ed)*The oxford handbook of Qualitative Research*. New York: Oxford University Press.

LeBlanc, T.W., Hesson, A., Williams, A., Feudtner, C., Holmes-Rovner, M., Williamson, L.D., Ubel, P.A. (2014) Patient understanding of medical jargon: a survey study of U.S. medical students. *Patient Education and Counselling*, 95, 238 -242.

Leng, M., Zhao, Y., Xiao, H., Li, C., Wang, Z. (2020) Internet-Based Supportive interventions for Family Caregivers of People with Dementia: Systematic review and Meta-Analysis. *Journal of Medical Internet Research,* 22, e19468.

Lerner, H. (2019) A critical analysis of the definitions of health as balance in a One Health perspective. *Medicine, Health Care and Philosophy,* 22, 453 – 461.

Leuzy, A., Ashton, N.J., Mattsson-Carlgren, N., Dodich, A., Boccardi, M., Corre, J., Drzezga, A., Nordberg, A., Ossenkoppele, R., Zetterberg, H., Blennow, K., Frisoni, G.B., Garibotto, V., Hansson, O. (2021) 2020 update on the clinical validity of cerebrospinal fluid amyloid, tau, and phospho-tau as biomarkers for Alzheimer's disease in the context of a structured 5-phase development framework. *European Journal of Nuclear Medicine and Molecular Imaging*, 48, 2121-2139.

Lexchin, J. (2012) Sponsorship bias in clinical research. *International Journal of Risk and Safety in Medicine,* 24, 233 – 242.

Levine, M. E., Lu, A.T., Quach, A., Chen, B.H., Assimes, T.L., Bandinelli, S., Hou, L., Baccarelli, A. A, Stewart, J.D., Li, Y., Whitsel, E.A., Wilson, J.G., Reiner, A.P., Aviv, A., Lohman, K., Liu, Y., Ferrucci, L., Horvath, S. (2018) An epigenetic biomarker of aging for lifespan and healthspan. *Aging*, 10, 573-591.

Levy, N. (2022) Do your own research! *Synthese*, 200, 356-375.

Li, Y., Li, Y., Li, X., Zhang, S, Zhao, J., Zhu, X., Tian, G. (2017) Head Injury as a Risk Factor for Dementia and Alzheimer's Disease: A systematic Review and Meta-Analysis of 32 Observational Studies. *PLos One*, 12, e0169650.

Li, W.W., Singh, S., Keerthigha, C. (2021) A Cross-Cultural Study of Filial Piety and Palliative Care Knowledge: Moderating Effect of Culture and Universality of Filial Piety. *Frontiers in Psychology*, 12, 787724.

Lian, O.S., Bondevik, H. (2015) Medical constructions of long-term exhaustion, past and present. *Sociology Health and Illness*, 37, 920 -935.

Lian Y., Xiao, LD., Zeng, F., Wu, X., Wang, Z., Ren, H. (2017) The experiences of people with dementia and their caregivers in dementia diagnosis. *Journal of Alzheimer's Disease*, 59, 1203 -1211.

Lillie-Blanton, M., Laveist, T. (1996) Race/ethnicity, the social environment, and health. *Social Science and Medicine*, 43, 83-91.

Lincoln, Y., Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.

Lincoln, Y. S., Lynham, S. A., Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. K. Denzin & Y.S. Lincoln (eds), *The Sage Handbook of Qualitative Research (4th ed; p. 97-128).* Thousand Oak, CA: Sage.

Guba, E. G., Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Sage Publications, Inc.

Linden, M. (2017) Definition and Assessment of Disability in Mental Disorders under the Perspective of the International Classification of Functioning Disability and Health (ICF). *Behavioural Sciences and Law*, 35, 124 -134.

Links, A.R, Callon, W., Wasserman, C., Walsh, J., Beach, M.C., Boss, E.F. (2019) Surgeon use of medical jargon with parents in the outpatient setting. *Patient Education and Counselling,* 102, 1111-1118.

Link, B. G, Phelan, J. (2014) Stigma power. *Social Science and Medicine,* 103, 24-32.

Liou, L., Joe, W., Kumar, A., Subramanian, S. V. (2020) Inequalities in life expectancy: An analysis of 201 countries, 1950-2015. *Social Science and Medicine,* 253, 112964.

Lipworth, L.W., Davey, H.M., Cater, S.M., Hooker, C., Hu, W. (2010) Beliefs and beyond: what can we learn from qualitative studies of lay people's understanding of cancer risks. *Health expectations,* 13, 113-124.

Liu, J., Gill, E., Li, S. (2021) Revisiting cultural competence. *Clinical Teacher,* 18, 191-197.

Ljubenkov, P.A., Geschwind, M.D. (2016) Dementia. *Seminars in Neurology,* 36, 397 – 404.

Livingston G, Huntley J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Manifield, J., Cooper, C., Costafreda, S.G., Dias, A., Fox, N., Gitlin, L.N., Howard, R., Kales H.C., Kivimaki, M., Larson, E.B., Ogunniyi, A., Orgeta, V., Ritchie, K., Rockwood, K., Sapson, E.L., Samus, Q., Schneider, L.S., Selbaek, G., Teri, L., Mukadam, N. (2020) Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet,* 396, 413 – 446.

LoGiudice, D., Watson, R. (2014) Dementia in older people: an update. *Internal Medicine Journal,* 44, 1066-73.

Lo Monaco, G., Bonetto, E. (2019) Social representations and culture in food studies. *Food Research International,* 115, 474-479.

Lopez, R.P., Rose, K.M, Kenney, L., Sanborn, V., Davis, J.D. (2020) Managing Shame: A Grounded Theory of How Stigma Manifests in Families Living with Dementia. *Journal of the American Psychiatric Nurses Association,* 26, 181-188.

Losada, A., Márquez-González, M., Vara-García, C., Barrera-Caballero, S., Cabrera, I., Gallego-Alberto, L., Olmos, R., Romero-Moreno, R. (2020) Measuring familism in dementia family caregivers: the revised familism scale. *Aging and Mental Health,* 24, 784-788.

Lovatt, M., Eadie D., Meier, P.S., Li, J., Bauld, L., Hasting, G., Holmes, J. (2015) Lay epidemiology and interpretation of low-risk drinking guidelines by adults in the United Kingdom. *Addition,* 110, 1912 – 1919.

Luh, A. (2003) A golden age of the elderly? Old age in a historical perspective. *Zeitschrift fur Gerontologie Geriatrie,* 36, 303 -316.

Lulita, M.F., Girouard, H. (2017) Treating Hypertension to Prevent Cognitive Decline and Dementia: Re-Opening the Debate. *Advances in Experimental Medicine and Biology,* 956, 447 – 473.

Lupton, D., Masten, S. (2019) How Women Use Digital Technologies for Health: Qualitative Interview and Focus Group Study. *Journal of Medical Internet Research,* 21, 11481.

Mace, R., Thomas, M.G., Wu, J., He, Q., Ji, T., Tao, Y. (2018) Population structured by witchcraft beliefs. *Nature Human Behaviour,* 2, 39-44.

Mackenzie, J. (2006) Stigma and dementia: East European and South Asian family carers negotiating stigma in the UK. *Dementia,* 5, 233 -247.

Madeleine, A., Rabeharisoa, V. (2012) Lay expertise in patient organisation: an instrument for health democracy. *Sante Publique,* 24, 69 -74.

Maduro, R. (1983) Curanderismo and Latino views of disease and curing. *The Western Journal of Medicine,* 139, 868 – 874.

Maguire, K., Britten, N. (2016) Lay knowledge, social movements and the use of medicines: Personal reflections. *Health (London England),* 20, 77 – 93.

Mahnaz, H. (2009) Dementia: An anthropological perspective: commentary. *International Journal of Geriatric Psychiatry,* 24, 207 – 212.

Mahomed, A., Pretorius, C. (2022) Understanding the lived experiences of family caregivers of individuals with dementia in Soweto, a South African Township. *Dementia (London),* 21, 2264-2287.

Mahomed, A., Pretorius, C. (2021) Availability and utilization of support services for South African male caregivers of people with Alzheimer’s disease in low-income communities. *Dementia (London),* 20, 633-652.

Maki, Y., Takao, M, Hattori, H., Suzuki, T. (2020) Promoting dementia-friendly communities to improve the well-being of individuals with or without dementia. *Geriatrics and gerontology international,* 20, 511 – 519.

Mansfield, L., Victor, C., Meads, C., Daykin, N., Tomlinson, A., Lane, J., Gray, K., Golding, A. (2021) A Conceptual Review of Loneliness in Adults: Qualitative Evidence Synthesis. *International Journal of Environmental Research and Public Health,* 18, 11522.

Marchal, B. (2017) The East, the West, and the Universal Machine. *Progress in Biophysics and Molecular Biology,* 131, 251 – 260.

María Del Río-González, A. (2021) To Latinx or Not to Latinx: A Question of Gender Inclusivity Versus Gender Neutrality. *American Journal of Public Health,* 111, 1018-1021.

Mark, G., Lyons, A. (2014) Conceptualizing mind, body, spirit interconnections through, and beyond, spiritual healing practices. *Explore,* 10, 294 – 299.

Marks, D. (1997) Models of disability. *Disability and Rehabilitation,* 19, 85-91.

Martin, P., Kelly, N., Kahana, B., Kahana, E., Willcox, B.J, Willcox, D.C, Poon, L.W. (2015) Defining successful aging: a tangible or elusive concept? *Gerontologist,* 55, 14 -25.

Martínez-Santos, A.E, Facal, D., Vicho de la Fuente, N., Vilanova-Trillo, L., Gandoy-Crego, M., Rodríguez-González, R. (2021) Gender impact of caring on the health of caregivers of persons with dementia. *Patient Education and Counselling*, 104, 2165-2169.

Mason, J. (eds) (2018) *Qualitative Researching*. London: Sage.

Masten, S., Lupton, D. (2019) ‘keeping it real’: women’s Enactments of Lay Health Knowledge and Expertise on Facebook. *Sociology of health and illness,* 41, 1637 -1651.

Matsuura, H. (2022) Russia’s invasion of Ukraine and the future demographic crisis. *Biodemography and Social Biology*, 67, 1-2.

Maxcey, A.M, Dezso, B., Megla, E., Schneider, A. (2019) Unintentional forgetting is beyond cognitive control. *Cognitive Research Principles and Implications,* 4, 25.

Mbizvo, G.K., Ziso, B., Larner, A.J. (2021) Epilepsy and prion diseases: A narrative review. *Epilepsy Behaviour*, 115, 107630.

McDonnell, E., Ryan, A. (2013) Male caregiving in dementia: a review and commentary. *Dementia (London),* 12, 238-50.

McGrath, T., Blundell, B., Morrisby, C. (2021) The ‘tipping point’: Exploring the factors associated with entry into residential care for people with dementia in Western Australia. *Dementia (London),* 20, 2494-2508.

McGrattan, A.M., McGuiness, B., McKinley, M.C., Kee, F., Passmore, P., Woodside, J.V., McEvoy, C.T. (2019) Diet and Inflammation in Cognitive Ageing and Alzheimer’s disease. *Current Nutritional Reports,* 8, 53 – 65.

McLeod, S. A. (2019) Social identity theory. *Simply Psychology.* https://www.simplypsychology.org/social-identity-theory.html.

McParland, P. M., Kelly, F., Innes, A. (2017) Dichotomising dementia: is there another way? *Sociology of Health and illness,* 39, 258 -269.

McKee, D. D, Chappel, J. N. (1992) Spirituality and medical practice. *Journal of Family Practice*, 201, 205-8.

Meili, R., Buchman, S. (2013) Social accountability: at the heart of family medicine. *Canadian Family Physician,* 59, 335-6.

Mejia-Arango, S., Garcia-Cifuentes, E., Samper-Ternent, R., Borda, M.G., Cano-Gutierrez, C. A. (2021) Socioeconomic Disparities and Gender Inequalities in Dementia: a community – Dwelling Population Study from a middle –income country. *Journal of Cross-Cultural Gerontology*, 36, 105 – 118.

Mendez, M. F. (2017) What is the Relationship of Traumatic Brain Injury to Dementia? *Journal of Alzheimer’s Disease,* 57, 667 – 681.

Meneilly, G.S. (2018) Diabetes and Dementia in the Elderly. *Canadian Journal of Diabetes*, 42, 579.

Mental Health Foundation. (2006) *Feeding Minds: the impact of Food on Mental Health*. London: Mental Health Foundation.

Merton, R. K. (1972) Insiders and Outsiders: A Chapter in the Sociology of Knowledge. *American Journal of Sociology*, 78, 9 -47.

Miah, J., Parsons, S., Lovell, K., Starling, B., Leroi, I., Dawes, P. (2020) Impact of involving people with dementia and their care partners in research: a qualitative study. *BMJ Open*, 10, e039321.

Midtbust, M.H., Alners, R.E., GJengedal, E., Lykkeslet, E. (2018) Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professional's experiences. *BMC Health Services,* 18, 709 – 719.

Mikkelsen, K., Apostolopoulos, V. (2018) B Vitamins and Ageing. *Subcellular Biochemistry,* 90, 451-470.

Miles, M.B., Huberman, A. M., Saldana, J. (2014) *Qualitative Data Analysis: A Methods Sourcebook.* London: Sage.

Mkhonto, F., Hanssen, I. (2018) When people with dementia are perceived as witches. Consequences for patients and nurse education in South Africa. *Journal of Clinical Nursing,* 27, 169-176.

Mockford, C., Murray, M., Seers, K., Oyebode, J., Grant, R., Boex, S., Staniszewska, S., Diment, Y., Leach, J., Sharma, U., Clarke, R., Suleman, R. (2016) A SHARED study – the benefits and cost of setting up health research study involving Lay co-researchers and how we overcame the challenges. *Research Involvement and Engagement,* 2, 8 -20.

Mol, M., Carpay, M., Ramakers, I., Rozendaal, N., Verhey, F., Jolles, J. (2007) The effect of perceived forgetfulness on quality of life in older adults; a qualitative review. *International Journal of Geriatric Psychiatry,* 22, 393-400.

Moll, J., de-Oliveira-Souza, R., Garrido, G.T., Bramati, I.E., Caparelli-Daquer, E.M., Paiva, M.L., Zahn, R., Grafman, J. (2007) The self as a moral agent: Linking the neural bases of social agency and moral sensitivity. *Social Neuroscience,* 2, 336 – 352.

Monaghan, L. (1999) Challenging medicine? Body building, drugs and risk. *Sociology of Health and illness,* 21, 707 -734.

Morton-Chang, F., Williams, A.P., Berta, W., Laporte, A. (2019) Towards a Community-Based Dementia Care strategy: How do We Get There from Here? *World Health Population,* 1, 6 – 29.

Moseby, M. K. (2017) Two regimes of HIV/AIDS: The MMWR and the socio-political construction of HIV/AIDS as a 'black disease'. *Sociology of Health and Illness,* 39, 1068 – 1082.

Moyle, W (2019) The promise of technology in the future of dementia care. *Nature Reviews Neurology,* 15, 353 – 359.

Mukadam, N., Cooper, C., Basit, B., Livingston, G. (2011) Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatric,* 23, 1070 -1077.

Mukadam, N., Cooper, C., Livingston, G. (2011) A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry,* 26, 12-20.

Mukadam, N., Cooper, C., Livingston, G. (2013) Improving access to dementia services for people from minority ethnic groups. *Current Opinion Psychiatry,* 26, 409 – 414.

Murphy, S.L, Gretebeck, K.A, Alexander, N.B. (2007) The bath environment, the bathing task, and the older adult: a review and future directions for bathing disability research. *Disability and Rehabilitation,* 29, 1067-75.

Murray, D.L., Morris, D., Lavoie, C., Leavitt, P.R., MacIsaac, H., Masson, M.E., Villard, M.A. (2016) Bias in Research Grant Evaluation Has Dire Consequences for Small Universities. *PLoS One,* 11, e155876.

Mushi, D., Rongai, A., Paddick, S., Dotchin, C., Mtuya, C., Walker, R. (2014) Social representation and practices related to demntia in Hai District of Tanzania. *BMC Public Health,* 14, 260 – 266.

Myin, E., Zahnoun, F. (2018) Reincarnating the Identity Theory. *Frontiers in Psychology,* 9, 2044.

Ndamba-Bandzouzi, B., Nubukpo, P., Mouanga, A., Mbelesso, P., Tognide, M., Tabo, A., Guerchet, M., Faure-Delage, A., Dubreuil, C., Dassa, V., Dumas, M., Clement, J., Preux, P.M. (2014) Violence and witchcraft accusations against older people in Central and Western Africa: towards a new status for older individuals. *International Journal of Geriatric Psychiatry*, 29, 546 – 549.

Negy, C., Shreve, T.L., Jensen, B.J., Uddin, N. (2003) Ethnic identity, self-esteem, and ethnocentrism: a study of social identity versus multicultural theory of development. *Cultural Diversity and Ethnicity Minority Psychology*, 9, 333-44.

Neitch, S.M., Meadows, C., Patton-Tackett, E., Yingling, K.W. (2016) Dementia Care: Confronting Myths in Clinical Management. *West Virginia Medical Journal,* 112, 32 – 37.

Nelson-Becker (2017) *Spirituality, religion, and ageing: Illuminations for therapeutic practice.* Thousand Oaks, CA: Sage Press.

Nelson, C., Treichler, P. A., Grossberg, L. (1992). Cultural studies. In I. Grossberg, C. Nelson, & P. A. Treichler (Eds), *Cultural studies* (pp. 1 – 16). New York: Routledge.

Nettleton, S. (eds) (2013) *The sociology of Health and Illness.* Cambridge: Polity Press.

Neubauer, B.E, Witkop, C.T., Varpio, L. (2019) How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education,* 8, 90-97.

Neugroschl, J., Davis, K.L. (2002) Biological markers in Alzheimer disease. *The American Journal of Geriatric Psychiatry,* 10, 660-77.

Ng'ang'a, C.M., Bukachi, S.A., Bett, B.K. (2016) Lay perceptions of risk factors for Rift Valley fever in a pastoral community in northeastern Kenya. *BMC Public Health,* 16, 32 – 42.

Nguyen, T., Levkoff, S., Nguyen, H. (2021) 'He is just getting old, you know': the role of cultural and health beliefs in shaping the help-seeking process of family members caring for persons with dementia in Vietnam. *Ethnicity and Health,* 5, 1-22.

Nobis N. (2011) Abortion, metaphysics and morality: a review of Francis Beckwith's defending life: a moral and legal case against abortion choice. *Journal of Medicine and Philosophy*, 36, 261-73.

Nordenfelt, L. (1994) On the disease, Illness and Sickness: A commentary on Andrew Twaddle's System of Concepts. In: A. Twaddle & L. Nordenfelt. (Eds.) *Disease, Illness and Sickness: Three Central Concepts in the Theory of Health* (pp. 19 – 18). Linkopping: Studies on Health & Society, 18.

Oborn, E., Barrett, M., Gibson, S., Gillard, S. (2019) Knowledge and expertise in care practices: the role of the peer worker in mental health teams. *Sociology of Health and illness,* 41, 1305 -1322.

Odbehr, L. S., Hauge, S., Danbolt, L.J., Kvigne, K. (2017) Residents' and caregivers' views on spiritual care and their understanding of spiritual needs in persons with dementia: A meta-synthesis. *Dementia,* 16, 911 – 929.

Office for National Statistic (2019) Population estimates by ethnic group- Experimental Statistics: Census 2011

Office for National Statistic (2022) Ethnic groups, England and Wales: Census 2021

Olonade, O.Y., Oyibode, B O., Idowu, B.O., George, T.O., Iwelumor. O.S., Ozoya, M.I., Egharevba, M.E., Adetunde, C.O. (2021) Understanding gender issues in Nigeria: the imperative for sustainable development. *Heliyon,* 7: e07622.

O'Malley, L., Croucher, K. (2005) Housing and dementia care - a scoping review of the literature. *Health and Social Care in the Community,* 13, 570-7.

Ong, L. M., de Haes, J C., Hoos, A. M., Lammes, F. B. (1995) Doctor-patient communication: a review of the literature. *Social Science and Medicine,* 40, 903-918.

Onyike, C.U., Shinagawa, S., Ellajosyula, R. (2021) Frontotemporal Dementia: A Cross-Cultural Perspective. *Advances in Experimental Medicine and Biology,* 1281:141-150.

Orr, N., Wagstaffe, A., Briscoe, S., Garside, R. (2016) How do older people describe their sensory experiences of the natural world? A systematic review of the qualitative evidence. *BMC Geriatrics*, 16, 116.

Ossorio, P. G. (2013) *The Behaviour of Persons.* Ann Arbor: Descriptive Psychology Press.

Ou, Y.N, Tan, C.C, Shen, X.N, Xu, W., Hou, X.H., Dong, Q., Tan, L., Yu, J.T. (2020) Blood Pressure and Risks of Cognitive Impairment and Dementia: A Systematic Review and Meta-Analysis of 209 Prospective Studies. *Hypertension*, 76, 217-225.

Owokuhaisa, J., Rukundo, G. Z., Wakida, E., Obua, C., Buss, S. S. (2020) Community perceptions about dementia in southwestern Uganda. *BMC Geriatrics*, 20, 135-144.

Papadimitriou, G (2017). The 'Biopsychosocial Model': 40 years of application in Psychiatry. *Psychiatriki,* 28, 107-110.

Park, Y.S., Konge, L., Artino, A.R. (2020) The Positivism Paradigm of Research. *Academic Medicine,* 95, 690 -694.

Parsons, E., Atkinson, P. (1992) Lay construction of genetic risk. *Sociology of Health and Illness,* 14, 437 – 455.

Parson, T (2013) *The social system.* Oxford, England: Routledge.

Parveen, S., Peltier, C., Oyebode, J. R. (2017) Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health and Social Care in the Community,* 25, 734-742.

Patterson, K. M, Clarke, C., Wolverson, E. L., Moniz-Cook, E. D. (2018) Through the eyes of others - the social experiences of people with dementia: a systematic literature review and synthesis. *International Psychogeriatriatrics,* 30, 791-805.

Pedditzi, E., Peters, R., Beckett, N. (2016) The risk of overweight/obesity in mid-life and late life for the development of dementia: a systematic review and meta-analysis of longitudinal studies. *Age and Ageing*, 45, 14 – 21.

Peng B., Yang, Q., Joshi, R.B., Liu, Y., Akbar, M., Song, B., Zhou, S., Wang, X. (2020) Role of Alcohol Drinking in Alzheimer's Disease, Parkinson's disease, and Amyotrophic Lateral Sclerosis. *International Journal of Molecular Science*, 21, 2316 – 2337.

Perkinson, M., Solimeo, S. (2014) Ageing in cultural context and as narrative process: Conceptual foundations of the anthropology of ageing as reflected in the work of Margaret Clark and Sharon Kaufman. *The Gerontologist,* 54, 101-107.

Petersson, S.D., Philippou, E. (2016) Mediterranean Diet, Cognitive Function and Dementia: a systematic review of the evidence. *Advances in Nutrition,* 7, 889 – 904.

Peterson, R.L., Carvajal, S.C., McGuire L.C., Fain, M. J., Bell, M.L (2019) State inequality, socioeconomic position and subjective cognitive decline in the United States. *SSM-Population Health*, 7, 100357.

Pescheny, J.V, Randhawa, G., Pappas, Y. (2020) The impact of social prescribing services on service users: a systematic review of the evidence. *European Journal of Public Health*, 30, 664-673.

Pezalla, A.E., Pettigrew, J., Miller-Day, M. (2012) Researching the researcher-as-instrument: an exercise in interviewer self-reflexivity. *Qualitative Research,* 12, 165 -185.

Pham, T.M., Petersen, I., Walters, K., Raine, R., Manthorpe, J., Mukadam, N., Cooper, C. (2018) Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK primary care data. *Clinical Epidemiology,* 10, 949-960.

Phelan, J.C., Lucas, J.W, Ridgeway, C.L., Taylor, C.J. (2014) Stigma, status, and population health. *Social Science and Medicine,* 103, 15-23.

Phillips, J., Buckwalter, W., Cushman, F., Friedman, O., Martin, A., Turri, J., Santos, L., Knobe, J. (2020) Knowledge before belief. *Behavioural and Brain Sciences,* 44:e140.

Pihl, G. T., Johannessen, H., Ammentorp, J., Jensen, J. S., Kofoed, P. (2017) ‘lay epidemiology’: an important factor in Danish parents’ decision of whether to allow their child to receive a BCG Vaccination. A qualitative exploration of parental perspective. *BMC Paediatrics,* 17, 194 -202.

Pitt, M.B., Hendrickson, M.A. (2020) Eradicating Jargon-Oblivion-A Proposed Classification System of Medical Jargon. *Journal General Internal Medicine,* 35, 1861 -1864.

Plastow, N.A., Atwal, A., Gilhooly, M. (2015) Food activities and identity maintenance in old age: a systematic review and meta-synthesis. *Ageing and Mental Health,* 19, 667-78.

Plastow, N. A. (2013) *Food activities and the maintenance of identities in later life.* Thesis: Brunel University London.

Podcasy, J. L., Eppersson, C. N. (2016) Considering Sex and Gender in Alzheimer’s disease and other dementia. *Dialogue in Clinical Neuroscience,* 18, 437 – 446.

Polderman, T.J.C., Kreukels, B.P.C., Irwig. M.S., Beach, L., Chan, Y.M., Derks, E.M., Esteva, I., Ehrenfeld, J., Heijer, M.D, Posthuma, D., Raynor, L., Tishelman, A., Davis, L.K. (2018) International Gender Diversity Genomics Consortium. The Biological Contributions to Gender Identity and Gender Diversity: Bringing Data to the Table. *Behaviour Genetics,* 48, 95-108.

Pool, R., Gessler, W. (2007) *Medical Anthropology: Understanding Public Health.* Open University Press.

Popay, J., Williams, G. (1996) Public health research and lay knowledge. *Social Science and Medicine,* 42, 759 – 768.

Popay, J., Williams, G., Thomas, C., Gatrell, T. (1998) Theorising inequalities in health. The place of lay knowledge. *Sociology of Health and Illness,* 20, 619 – 644.

Pope, E.D., Cordes, L., Shi, J., Mari, Z., Decourt, B., Sabbagh, M.N. (2021) Dementia with Lewy bodies: emerging drug targets and therapeutics. *Expert Opinion on Investigational Drugs,* 30, 603-609.

Potvin, L., Jones, C.M. (2011) Twenty-five years after the Ottawa Charter: The critical role of health promotion for public health. *Canadian Journal of Public Health,* 102, 244 – 248.

Poveda, A.M. (2003) An anthropological perspective of Alzheimer disease. *Geriatric Nursing,* 24, 26 -31.

Pratt, B. (2019) Engagement as a co-constructing knowledge: A moral necessity in public health research. *Bioethics,* 33, 805 – 813.

Prior, L. (2003) Belief, Knowledge and expertise: the emergence of the lay expertise in medical sociology. *Sociology of Health and Illness,* 25, 41 – 57.

Price, R.W, Sidtis, J.J., Brew, B.J. (1991) AIDS dementia complex and HIV-1 infection: a view from the clinic. *Brain Pathology,* 1, 155-62.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., Ferri, C.P. (2013) The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia*, 9, 63-75.

Pritchard-Jones, L. (2017) 'This man with dementia' – 'Othering' the person with dementia in the court of protection. *Medical Law Review,* 24, 518-543.

Pugazhenthi, S., Qin, L., Reddy, P.H. (2016) Common neurodegenerative pathway in obesity, diabetes and Alzheimer's disease. *Biochimica Biophysica Acta Molecular Basis of Disease,* 1863, 1037 – 1045.

Pulliam, L., Sun, B., Mustapic, M., Chawla, S., Kapogiannis, D. (2019) Plasma neuronal exosomes serve as biomarkers of cognitive impairment in HIV infection and Alzheimer's disease. *Journal of Neurovirology,* 25, 702-709.

Radzvilavicius, A.L, Blackstone, N.W. (2018) The evolution of individuality revisited. *Biological Reviews of the Cambridge Philosophical Society*, 93, 1620-1633.

Ralph, N., Birks, M., Chapman, Y. (2015) The methodological dynamism of grounded theory. *International Journal of Qualitative Methods,* 14, 4.

Rashed, M.A. (2020) More Things in Heaven and Earth: Spirit Possession, Mental Disorder, and Intentionality. *Journal of Medical Humanities,* 41, 363-378.

Ramsay, G. (2016) Taiwanese Stories of Dementia. *Modern China,* 43, 217-24.

Ranscombe, P. (2020) Dispelling myths and legends about dementia. *Lancet Neurology*, 19, 297-298.

Raphael, J.L., Rueda, A., Lion, K.C., Giordano, T.P. (2013) The role of lay health workers in paediatric chronic disease: a systematic review. *Academic Paediatrics*, 13, 408 -420.

Raz, L., Knoefel, J., Bhaskar, K. (2016) The neuropathology and cerebrovascular mechanisms of dementia. *Journal of Cerebral Blood Flow and Metabolism,* 36, 172 -186.

Rew, L., Bechtel, D., Sapp, A. (1993) Self-as-instrument in qualitative research. *Nursing Research,* 42, 300 -301.

Rewerska-Jusko, M., Rejdak, K. (2020) Social Stigma of People with Dementia. *Journal of Alzheimer's Disease,* 78, 1339 – 1343.

Reynolds, J.M. (2017) Being Better Bodies. *The Hastings Centre Report,* 47, 46 – 47.

Richards, M., Ponder, M. (1996) Lay understanding of genetics: a test of a hypothesis. *Journal of Medical Genetics,* 12, 1032 – 1036.

Richardson, V. (2014) Safeguarding adults. *Journal of Perioperative Practice,* 24, 118-20.

Riley, K.E., Hay, J.L., Waters, E.A., Biddle, C., Schofield, E., Li, Y., Orom, H., Kiviniemi, M. (2019) Lay beliefs about risk: relation of risk behaviours and to probabilistic risk perceptions. *Journal of Behavioural Medicine,* 42, 1062 -1072.

Rippon, I., Kneale, D., de Oliveira, C., Demakakos, P., Steptoe, A. (2014) Perceived age discrimination in older adults. *Age & Ageing,* 43, 379-86.

Rivero-Segura, N. A., Bello-Chavolla, O.Y., Barrera-Vázquez, O.S., Gutierrez-Robledo, L.M., Gomez-Verjan, J.C. (2020) Promising biomarkers of human aging: In search of a multi-omics panel to understand the aging process from a multidimensional perspective. *Ageing Research Reviews,* 64, 101164.

Robertson, L.T. (2002) Memory and the brain. *Journal of Dental Education,* 66, 30 -42.

Roberts, J. R., Maxfield, M. (2018) Examining the Relationship Between Religious and Spiritual Motivation and Worry About Alzheimer's Disease in Later Life. *Journal of Religion Health*, 57, 2500 – 2514.

Roche, M., Higgs, P., Aworinde, J., Cooper, C. (2021) A Review of Qualitative Research of Perception and Experiences of Dementia Among Adults from Black, African, and Caribbean Background: What and Whom Are We Researching? *Gerontologist,* 61, e195-e208.

Rogers W. (2008) We still need to ask 'what is disease?' *Journal of Health Services Research Policy*, 8, 245-7.

Román, G.C. (2004) Facts, myths, and controversies in vascular dementia. *Journal of the Neurological Sciences*, 226, 49 – 52.

Rosenberg, M. W., Herron, R. V. (2017) ‘Not there yet’: Examining community support from the perspective of people with dementia and their partners in care. *Social Science and Medicine,* 173, 81-87.

Rossiter-Thornton J. F. (2002) Prayer in your practice. *Complementary Therapy in Nursing and Midwifery,* 8, 21-28.

Rossor, M.N, Fox, N.C, Mummery, C.J, Schott, J.M, Warren, J.D. (2010) The diagnosis of young-onset dementia. *Lancet Neurology,* 9, 793-806.

Rothenberg, M. A. (2004) Down to cases: the ethical value of ‘non-scientificity’ in dyadic psychoanalysis. *Journal of the American Psychoanalytical Association,* 52, 125-50.

Rowe, J.W., Kahn, R.L. (1997) Successful aging. *Gerontologist,* 37, 433-40.

Rubin, R. (2018) Exploring the Relationship Between Depression and Dementia. *JAMA,* 320, 961 – 962.

Rudnicka, E., Napierała, P., Podfigurna, A., Męczekalski, B., Smolarczyk, R., Grymowicz, M. (2020) The World Health Organization (WHO) approach to healthy ageing. *Maturitas,* 139, 6-11.

Rushford, N., Harvey, D. (2016) Dementia as a Disability and Human Rights Issue. *Healthcare Papers,* 16, 45 – 51.

Sadeh, T., Ozubko, J.D., Winocur, G., Moscovitch, M. (2014) How we forget may depend on how we remember. *Trends in Cognitive Sciences*, 18, 26-36.

Saldana, J. (eds) (2013) *The Coding Manual for Qualitative Researchers*. London: Sage.

Sayegh, P., Knight, B. G. (2013) Cross-cultural difference in dementia: the Sociocultural Health Belief Model. *International Psychogeriatrics,* 24, 517 – 530.

Sayer, A. (2002) What are you worth? Why class is an embarrassing subject. *Sociological Research Online,* 7, 3.

Sayer A (2005) *The Moral Significance of Class.* Cambridge: Cambridge University Press.

Scaldding, J.G. (1988) Health and disease: what can medicine do for philosophy? *Journal of Medical Ethics,* 14, 118 – 124.

Schmitt, D.P., Long, A.E., McPhearson, A., O'Brien, K., Remmert, B., Shah, S.H. (2017) Personality and gender differences in global perspective. *International Journal of Psychology,* 52, 45-56.

Schnelli, A., Hirt, J., Zeller, A. (2021) Persons with dementia as internet users: what are their needs? A qualitative study. *Journal of Clinical Nursing,* 30, 849-860.

Schoneberger, T. (2016) Behavioural Pragmatism: Making A Place for Reality and Truth. *The Behavioural Analyst,* 39, 219 – 242.

Schwandt, T (2002) *Evaluation practice reconsidered*. New York, NY: Lang.

Seale, C., Gobo, G., Gubrium, J. F., Silverman, D. (2004). Introduction: Inside qualitative research. In C. Seale, G. Gobo, J. F. Gubrium, & D. Silverman (Eds), *Qualitative research practice* (pp. 1- 11). London: Sage.

Seale, C. (1999). *The quality of qualitative research*. London, England: Sage.

Sedler, M. J. (2016) Medicalization in psychiatry: the medical model, descriptive diagnosis, and lost knowledge. *Medicine, Health Care and Philosophy,* 19, 247-52.

Segall, A., Roberts, L. W. (1980) A comparative analysis of physician estimates and levels of medical knowledge among patients. *Sociology of Health and Illness,* 2, 317 – 334.

Seitz, R.J., Paloutzian, R.F., Angel, H.F. (2018) From Believing to Belief: A General Theoretical Model. *Journal of Cognitive Neuroscience,* 30, 1254-1264.

Serrano-Pozo, A., Das, s., Hyman, B. (2021) APOE and Alzheimer's disease: advances in genetics pathophysiology, and therapeutic approaches. *The Lancet Neurology,* 20, 68 – 80.

Sevinc, A., Buyukberber, S., Camci, C. (2005) Medical jargon: obstacle to effective communication between physicians and patients. *Medical Principles and Practice,* 14, 292.

Shakespeare, T., Zeilig, H., Mittler, P. (2019) Rights in Mind: Thinking Differently About Dementia and Disability. *Dementia,* 3, 1075 – 1088.

Sharabi, A. (2021) The Politics of Madness and Spirit Possession in Northern India. *Medical Anthropology,* 40, 182-195.

Sharps, E.S., Gatz, M. (2011) Relationship between education and dementia: an updated systematic review. *Alzheimer's Disease and Associated Disorders,* 25, 289 – 304.

Shaughnessy, M.J. (2028) Integrative Literature Review on Shame. *Nursing Science Quarterly,* 31, 86-94.

Shen, C., Rolls, E., Cheng, W., Kang, J., Dong, G., Xie, C., Zhao, X.M., Sahakian, B., Feng, J. (2022) Associations of Social Isolation and Loneliness with Later Dementia. *Neurology,* 8, 10.

Sheringham, J., Kuhn, I., Burt, J. (2021) The use of experimental vignette studies to identify drivers of variations in the delivery of health care: a scoping review. *BMC Medical Research Methodology,* 21, 81.

Shiekh, S.I., Cadogan, S.L., Lin, L.Y., Mathur, R., Smeeth, L., Warren-Gash, C. (2021) Ethnic Differences in Dementia Risk: A Systematic Review and Meta-Analysis. *Journal of Alzheimers Disease,* 80, 337-355.

Shirayama, Y., Yuasa, M., Kashimori, S., Kitamura, M., Goto, T., Teranishi, S., Yanagisawa, S., Takeuchi, Y., Ichikawa, T., Usutani, S. (2019) The application and usefulness of virtual reality aimed at encouraging an understanding of and reducing and eliminating prejudice towards dementia patients among local residents. *Nihon Ronen Igakkai Zasshi Japanese Journal of Geriatrics,* 56, 156-163.

Sirgy, M. J. (2019) Positive Balance: a hierarchical perspective of positive mental health. *Quality of Life Research,* 28, 1921 – 1930.

Sivasthiaseelan, H., Marshall, C.R., Agustus, J.L., Benhamou, E., Bond, R.L., van-Leeuwen, J.E.P., Hardy, C.J.D., Rohrer, J.D., Warren, J.D. (2019) Frontotemporal Dementia: A clinical review. *Seminars in neurology,* 39, 251 -263.

Smart, J. J.C. (1959) 'Sensations and Brain Processes' *Philosophical Review,* 68: 141 -156.

Smith, K.E, Anderson, R. (2018) Understanding lay perspectives on socioeconomic health inequalities in Britain: a meta-ethnography. *Sociology of Health & Illness,* 40, 146-170.

Smith, R., Wood, J., Jones, F., Anderson, L., Hurley, M. (2019) Active residents in care homes: A holistic approach to promoting and encouraging meaningful activity for residents living in care homes: Innovative Practice. *Dementia,* 18, 1942 -1947.

Soilemezi, D., Drahota, A., Crossland, J., Stores, R. (2019) The Role of the Home Environment in Dementia Care and Support: Systemic review of Qualitative Research. *Dementia,* 18, 1237 – 1272.

Sorsa, M.A., Kiikkala, I., Åstedt-Kurki, P. (2015) Bracketing as a skill in conducting unstructured qualitative interviews. *Nurse Researcher,* 22, 8-12.

Soto-Espinosa, J., Koss-Chioino, J.D. (2017) Doctors Who Integrate Spirituality and CAM in the Clinic: The Puerto Rican Case. *Journal of Religion and Health,* 56, 149 -157.

Spruce, L. (2019) Back to Basics: Social Determinants of Health. *AORN Journal,* 110, 60 – 69.

Sririam V., Jenkinson, C., Peters, M. (2019) Informal care's experiences of assistive technology use in dementia care at home: a systematic review. *BMC Geriatrics,* 14, 160 – 185.

Stansfeld J, Orrell M, Vernooij-Dassen M, Wenborn J. (2019) Sense of coherence in family caregivers of people living with dementia: a mixed-methods psychometric evaluation. *Health Quality Life Outcomes,* 17, 44- 52.

Starks, H., Trinidad, S. B. (2007) Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research,* 17, 1372-80.

Starmans, C. (2021) Two distinct concepts of knowledge. *The Behavioural Brain Science,* 44, e171.

Strauss, A., Corbin, J. (1994) Grounded Theory methodology: An Overview. In N. Denzin &Y. Lincoln *Handbook of Qualitative Research*. 1st ed. (pp. 273 -284).

Steffens, D.C. (2017) Late-life Depression and the Prodromes of Dementia. *JAMA*, 74, 673 – 674.

Stein, D. J., Illes, J. (2015) Beyond Scientism and Skepticism: An Integrative Approach to Global Mental Health. *Frontiers in Psychiatry,* 6, 166.

Sulmasy, D. P. (2002) A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist,* 3, 24-33.

Sun, F., Ong, R., Burnette, D. (2012) The influence of ethnicity and culture on dementia caregiving: a review of empirical studies on Chinese Americans. *American Journal of Alzheimer 's Disease and Other Dementia,* 27, 13-22.

Sunstrom, A., Adolfsson, A.N., Nordin, M., Adolfsson, R. (2020) Lonliness Increases the Risk of All-Cause Dementia and Alzheimer's Disease. *The Journals of Gerontology, Series B, Psychological Science and Social Sciences,* 75, 919 – 926.

Surtees, A.D.R., Todd, A.R. (2021) Are knowledge- and belief-reasoning automatic, and is this the right question? *Behavioural and Brain Sciences,* 44: e172.

Sutin A.R., Stephan, Y., Luchetti, M., Terracciano, A. (2020) Loneliness and Risk of Dementia. *The Journals of Gerontology, Series B, Psychological Science and Social Sciences,* 75, 1414 – 1422.

Sweeting, H., Gilhooly, M. (1997) Dementia and the phenomenon of social death. *Sociology of Health and illness,* 19, 93 -117.

Tajfel, H., Turner, J. C. (1979) An integrative theory of inter-group conflict. In W.G. Austin and S. Worchel (eds.), *The social psychology of inter-group relations* (pp. 33 -47) Monterey, CA: Brooks/Cole.

Takeuchi, H., Kawashima, R. (2021) Diet and Dementia: A Prospective Study. *Nutrients,* 13, 500.

Tannahill, A (2009) Health Promotion: The Tannahill model revisited. *Public Health,* 123, 396 -399.

Taylor, C. (1985) '*The Concept of a Person', Philosophical Papers*. Cambridge: CambridgeUniversity Press.

Tenny, S., Brannan, G.D., Brannan, J.M., Sharts-Hopko, N.C. (2022) *Qualitative Study*. Treasure Island (FL): StatPearls Publishing.

Twaddle, A. (1994a) Disease, Illness, and Sickness revisited. In: A. Twaddle & L. Nordenfelt. (Eds.) *Disease, Illness and Sickness: Three Central Concepts in the Theory of Health* (pp. 1 – 18). Linkopping: Studies on Health & Society, 18.

The Royal Society (2018) *The principle for good evidence synthesis for policy*. The Society and Academy of Medical Sciences: The Royal Society.

Thomson, L., Stanyon, M., Dening, T., Heron, R., Griffiths, A. (2019) Managing employees with dementia: a systematic review. *Occupational Medicine,* 69, 89 – 98.

Thorsen, K., Johannessen, A. (2021) Metaphors for the Meaning of Caring for a Spouse with Dementia. *Journal of Multidisciplinary Healthcare*, 14, 181-195.

Tisher, A., Salardini, A. (2019) A Comprehensive update on Treatment of Dementia. *Seminars in Neurology*, 39, 167 – 178.

Tobi, H., Kampen, J. A. (2018). Research design: the methodology for interdisciplinary research framework. *Quality and Quality*, 52, 1209 – 1225.

Trinh, N.H, Jahan. A.B, Chen. J.A. (2021) Moving from Cultural Competence to Cultural Humility in Psychiatric Education. *Psychiatric Clinic of North America*, 44, 149-157.

Tuckett, D., Boulton, M., Olson, C., Williams, A. (1985) *Meeting Between Experts. An Approach to Sharing Ideas in Medical Consultation.* London: Tavistock.

Tuffour I. (2018) Reflections of a black African insider researcher. *Nurse Researcher,* 26, 13-18.

Tufford, L., Newman, P. (2012). Bracketing in Qualitative Research. *Qualitative Social Work,* 11, 80–96.

Turner, S. (2001) What's the problem with experts? *Social Studies of Science*, 31, 123 – 149.

Turner, V. (1967) *The forest of Symbols. Aspects of Ndembu Ritual. Ithaca, London*: Cornell University Press.

Turró-Garriga, O., Viñas-Díez, V., Conde-Sala, J.L, Calvó-Perxas, L., Cullell-Juncà, M., Mas-Vall-Llosera, G., Flaqué M, Turon-Estrada, A., Juvinyà-Canal, D., Mioshi E, Garre-Olmo, J. (2020) Caregiver's Sense of Coherence: Implications on Direct and Indirect Cost of Dementia Care. *Journal of Alzheimer's Disease,* 78, 117 -126.

Tuerk, R., Sauer, J. (2015) Dementia in a Black and minority ethnic population: characteristics of presentation to an inner London memory service. *British Journal of Psychology Bulletin,* 39, 162 -166.

Umegaki, H. (2019) Diabetes Mellitus and Dementia. *Brain and Nerve,* 71, 409 – 414.

van Lange, P.A. (2008) Does empathy trigger only altruistic motivation? How about selflessness or justice? *Emotion*, 8, 766-74.

Van Maanen, J. (1988) *Tales of the field: On writing ethnography*. Chicago, IL: University of Chicago Press.

van-Manen, M. (eds) (1997) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy.* The Althouse Press University of Western Ontario: Toronto.

van-Rijn, A., Meiland, F., Droes, R. (2020) Linking two new E-health caregiver interventions to meeting centres for people with dementia and their carers: a process evaluation. *Ageing and mental Health,* 24, 1316 – 1325.

Vatanabe, I.P., Manzine, P.R., Cominetti, M.R. (2020) Historic concepts of dementia and Alzheimer's disease: From ancient times to the present. *Revue Neurolgique,* 176, 140 -147.

Vennik, F. D., Adams, S.A., Faber, M.J., Putters, K. (2014) Expert and experiential knowledge in the same place: patient's experiences with online communities connecting patients and health professionals. *Patient Education and Counselling*, 95, 265-270.

Vermette, D, Doolittle, B. (2022) What Educators Can Learn from the Biopsychosocial-Spiritual Model of Patient Care: Time for Holistic Medical Education. *Journal of General Internal Medicine,* 37, 2062-2066.

Vidmar, N. (2012) Lay decision –makers in the legal process. In Peter Cane and Herbert M. Kritzer (eds.) *The Oxford Handbook of Empirical Legal Research*. Oxford University Press.

Victor, C. R. (2021) Is Loneliness a Cause or Consequence of Dementia? A Public Health Analysis of the Literature. *Frontiers in Psychology*, 11, 612771.

Vrijsen, J., Maeckelberghe, E.L.M., Broekstra, R., de Vries, J.J., Abu-Hanna, A., De Deyn, P.P., Voshaar, R.C.O., Reesink, F.E., Buskens, E., de Rooij, S.E., Smidt, N. (2021) Knowledge, health beliefs and attitudes towards dementia and dementia risk reduction among descendants of people with dementia: a qualitative study using focus group discussions. *BMC Public Health,* 21, 1344.

Walker, K.A., Power, M.C., Gottesman, R.F. (2017) Defining the Relationship between Hypertension, Cognitive Decline, and Dementia: a review. *Current Hypertension Reports,* 19, 24 – 51.

Walker T. (2021) Straddling 'the line' as a Health Communication Scholar: Reflexive Privilege and Positionality in International Contexts. *Health Communication,* 36, 826-828.

Warwick, I., Aggleton, P., Homans, H. (1988) Constructing commonsense young people's belief about AIDS. *Sociology of Health and illness,* 10, 213 – 233.

Watt, K., Abbott, P., Reath, J. (2016) Developing cultural competence in general practitioners: an integrative review of the literature. *BMC Family Practice,* 17, 158-169.

Weisman de Mamani, A., Weintraub, M. J., Gurak, K., Maura, J., Andino de Martinez, A., Brown, C. A. (2017) Free will perceptions, religious coping and other mental health outcomes in caregivers of individuals with dementia. *Journal of Religion, Spirituality and Ageing,* 29, 226 – 247.

Weiner, M. F. (2008) Perspective on race and ethnicity in Alzheimer's disease research. *Alzheimers and Dementia,* 4, 233-238.

Weiner-Levy, N., Abu Rabia Queder, S. (2012) Researching my people, researching the 'other': field experiences of two researchers along shifting positionalities. *Quality and Quantity,* 46, 1151–1166.

Weinstein, D., Weinstein, M. A. (1991). Georg Simmel: Sociological *flaneur bricoleur*. *Theory Culture and society,* 8, 151 – 168.

Werner, P., Goldstein, D., Karpas, D.S., Chan, L., Lai, C. (2014) Help-seeking for dementia: a systematic review of the literature. *Alzheimer Disease and Associated Disorder,* 28, 299-310.

Werner, P. (2005) Lay perceptions about mental health: where is age and where is Alzheimer's disease? *International psychogeriatric,* 17, 371 – 382.

Werner, P., Korczyn, A. D. (2010) Lay person's beliefs and knowledge about Parkinson's disease: prevalence and socio-demographic correlates. *Parkinsonism Related Disorder,* 16, 415-417.

Westra, E. (2021) Why is knowledge faster than (true) belief? *Behavioural and Brain Sciences,* 44:e175.

White, F. J. (2013) Persohood: An Essential Characteristic of the Human Species. *Linacre Q,* 80, 74 – 97.

Willen, S.S. (2019) Health is a Human Right at CDC. *Health and Human Right,* 21, 163 - 177

Williams, G. (1984) The genesis of chronic illness. Narrative re-construction. *Sociology of Health and illness,* 6, 175 – 200.

Wilcox, S. (2010) Lay Knowledge: The missing Middle of the Expertise Debates. In: Harris, R., Wathen, N., Wyatt, S. (eds) *Configuring Health Consumers. Health, Technology and Society*. Palgrave Macmillan: London.

Wilcox, S., Laken, M., Parrott, A.W., Condrasky, M., Saunders, R., Addy, C.L., Evans, R., Baruth, M., Samuel, M. (2010) The faith, activity, and nutrition (FAN) program: design of a participatory research intervention to increase physical activity and improve dietary habits in African American churches. *Contemporary Clinical Trials*, 31, 323-35.

Wilson, C., Janes, G., Williams, J. (2022) Identity, positionality and reflexivity: relevance and application to research paramedics. *British Paramedic Journal,* 7, 43-49.

Wimo, A., Guerchet, M., Ali, G.C., Wu, Y.T., Prina, A.M., Winblad, B., Jönsson, L., Liu, Z., Prince, M. (2017) The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimer's & Dementia,* 13, 1-7.

Whitaker, J.A (2021). Sorcery and well-being: bodily transformation at Beckeranta. *Anthropology and Medicine,* 28, 78-93.

Whitman, N. (1993). A review of constructivism: understanding and using a relatively new theory. *Family Medicine*, 25, 517 -521.

Wohland, P., Rees, P., Nazroo, J., Jagger, C. (2015) Inequalities in healthy life expectancy between ethnic groups in England and Wales in 2001. *Ethnicity & Health*, 20, 341-53.

Woo, K. (2017) Family history and its relationship with dementia stigma beliefs among Chinese Americans. *Geriatrics Gerontology International,* 17, 122-125.

Woodbridge, R. (2018) *Dining with dementia: continuing to find meaning in eating related practices as a social experience among dyads living with typical dementia and posterior cortical atrophy.* Thesis: Brunel University London.

Woodward, M., Arthur, A., Darlington, N., Buckner, S., Killett, A., Thurman, J., Buswell, M., Lafortune, L., Mathie, E., Mayrhofer, A., Goodman, C. (2019) The place for dementia-friendly communities in England and its relationship with epidemiological needs. *International Journal of Geriatric Psychiatry,* 34, 67 – 71.

World health organisation. (2017) *Health Promotion: Promoting health, promoting sustainable development*. Geneva: WHO.

World health organisation (2012) *The 1st International Conference on Health Promotion, Ottawa, 1986*. Geneva: WHO.

World Alzheimer's Day. (2021) *know dementia, know Alzheimer's*. World Alzheimer's day.

Wray, J., Archibong, U., Walton, S. (2017) Why undertake a pilot in a qualitative PhD study? Lessons learned to promote success. *Nurse Researcher,* 24, 31-35.

Wright, M, S. (2019) Dementia HealthCare Decision Making, and Disability Law. *The Journal of Law, Medicine and Ethics,* 47, 25 – 33.

Wright, S., O'Brien, B. C., Nimmon, L., Law, M., Mylopoulos, M. (2016) Research Design Consideration. *Journal of Graduate Medical Education*, 8, 97 – 98.

Wu, Y.T., Beiser, A.S., Breteler, M.M.B., Fratiglioni, L., Helmer, C., Hendrie, H.C., Honda, H., Ikram, M.A., Langa, K.M., Lobo, A., Matthews, F.E., Ohara, T., Pérès, K., Qiu, C., Seshadri, S., Sjölund, B.M., Skoog, I., Brayne, C. (2017) The changing prevalence and incidence of dementia over time - current evidence. *Nature Reviews Neurology,* 13, 327-339.

Wu, S., Wyant, D., Fraser, M. W. (2016) Author guidelines for manuscripts reporting on qualitative research. *Journal of Social Work Research,* 7, 405 – 425.

Wüsten C., Lincoln, T. M. (2022) Cross-cultural comparisons of the effect of a schizophrenia label on stigmatizing family attitudes: A case vignette study. *Journal of Psychopathology Clinical Sciences,* 131, 109-116.

Wyndham-West M. (2021) Gender and dementia national strategy policymaking: Working toward health equity in Canada through gender-based analysis plus. *Dementia (London),* 20, 1664-1687.

Xu, W., Tan, L., Wang, H.F., Tan, M.S, Tan, L., Li, J.Q., Zhao, Q.F, Yu, J.T. (2016) Education and Risk of Dementia: Dose-Response Meta-Analysis of Prospective Cohort Studies. *Molecular Neurobiology,* 53, 3113-3123.

Xue, M., Xu, W., Ou, Y.N., Cao, X.P., Tan, M.S., Tan, L., Yu, J.T. (2019) Diabetes mellitus and risks of cognitive impairments and dementia: A systemic review and meta-analysis of 144 prospective studies. *Ageing Research Review,* 55, 100944 – 100953.

Yen, C., Lin, S. (2019) Justice in dementia care resource allocation: How should we plan for dementia services? *International Journal of Environmental Research and Public Health*, 16, 1754 – 1769.

Yoeli, H., Cattan, M. (2017) Insiders and incomers: how Lay public health workers' knowledge might improve public health practice. *Health and Social Care in the Community,* 25, 1743 – 1751.

Young, A. (1982) The anthropologies of illness and sickness. *Annual Review of Anthropology,* 11, 257 -85.

Yusufov, M., Weyandt, L.L., Piryatinsky, I. (2017) Alzheimer's disease and diet: a systematic review. *The international journal of Neuroscience,* 2, 161 – 175.

Zauszniewski, J.A., Herbell, K., Burant, C. (2019) Is there more to resourcefulness than personal and social skills? *Western Journal of Nursing Research,* 41, 372 – 387.

Zeilig, H. (2012) Dementia As a Cultural Metaphor. *The Gerontologist,* 54, 258 – 267.

Zein, R. A., Suhariadi, F., Hendriani, W. (2017) Estimating the effect of lay knowledge and prior contact with pulmonary TB patients, on health-belief model in a high-risk pulmonary TB transmission population. *Psychology Research and Behaviour Management,* 10, 187 – 194.

# Appendices

## Appendix 1: Interview guide

**Project Title:** Lay knowledge and beliefs towards dementia: A study amongst Black Africans living in London.

**Target Audience**: Black Africans living in London.

**Gender:** Adult male and female

**Age range:** 20 -85 years

**Sampling:** Purposive

**Moderator:** Raphael Mokwenye

**Project date:** December 2020 – September 2022

**Method:** Individual semi-structured interviews

**Venue:** Online

**Research question:**

- What is the lay knowledge and beliefs towards dementia amongst Black Africans living in London?

**Research aim:**

- To explore the lay knowledge and beliefs of dementia amongst Black Africans living in London.

**Research objectives:**

- To use qualitative research methods to explore the lay knowledge and beliefs of dementia amongst Black Africans living in London.
- To understand the lay concepts of dementia, perceptions of dementia risk factors and dementia help-seeking or behaviour amongst Black Africans living in London.
- To enhance understanding of the barriers to help-seeking and treatment of people with dementia amongst the Black Africans living in London.

### Introduction

Good morning/afternoon. My name is Raphael Mokwenye. I am a doctoral researcher at Brunel University London. I will moderate the individual semi-structured interview this morning/afternoon to obtain data for my PhD thesis. Firstly, thank you for taking the time to be online. We will be discussing your thoughts, ideas and beliefs about dementia. Before we begin, I would like to explain an individual interview and then allow you to ask questions.

An individual interview is like a one-to-one discussion. It is a way of probing, listening to people and learning from them. In interviews, people are asked questions about their thoughts and ideas on a subject. I am interested in hearing your thoughts, beliefs, and feelings about dementia. There are no right or wrong answers. I am here to ask questions, listen, and probe your experiences to understand better your knowledge and beliefs towards dementia in your community. The interview would be for about 45 minutes to an hour maximum.

In addition, I will be recording the discussion because I don't want to miss any of your comments. No one outside this meeting will have access to the interview recording, your name will not be included in any reports or transcripts, and your comments are confidential. I hope you now feel free to speak openly with me.

Before we begin, please ensure that you have read the PIS and signed the consent forms. You do not need to provide a personal contact address or email unless you wish to receive a summary of the findings. All data are subject to the Data Protection Act 2018.

Any questions?

May I turn on the recorder?

Let's begin…

So, tell me about yourself…

Finally, I would like to introduce the topic of discussion, and I will read out the vignette…

**Draft interview guide prepared based on the research question**

**1. To explore dementia lay knowledge and beliefs**

- What are your thoughts about the vignette?
- Tell me what you have noticed about forgetfulness as you age. (e.g., as observed with Bola in the vignette – forgetful and often not recognising close family members).
- If you have noticed changes, whom would you discuss them with or tell me whom you have discussed them with?
- What do you know about dementia?
- What are your beliefs towards dementia?
- Tell me about your experience with dementia.

Prompt - tell me a bit more.

**2. To explore the causes of dementia**

- What are the causes of dementia in your community?
- What is your belief about these causes of dementia in your community?
- Tell me about these causes of dementia in your community.

Prompt – tell me a bit more.

**3. To explore how dementia is understood or named (framing)**

- What words would you associate with dementia in your community?
- Tell me about these words associated with dementia in your community.
- What are your beliefs and concerns about these words?

Prompt – tell me a bit more.

**4. To explore signs and symptoms of dementia**

- How would you know you or someone has dementia in your community?
- How do people in your community recognise dementia?
- Tell me about any experience of dementia signs and symptoms.

Prompt – tell me a bit more.

**5. To explore dementia diagnosis and help-seeking for dementia**

- If you were worried about dementia, where would you go for help?
- Who would usually attend the appointment with you?
- Who receives the diagnosis?
- How would the diagnosis of dementia usually be accepted?
- What are your beliefs about professionals like doctors such as your GP towards dementia?
- What are your experiences with your GP towards dementia?
- Tell me about the problems in trying to get help for dementia in your community.
- What is the cost of dementia in your community?
- How do people pay the cost of dementia in your community?

Prompt – tell me more about it.

**6. To explore dementia treatment and caregiving**

- How do people in your community treat and care for a person with dementia?
- What are your experiences with caring for dementia in your community?
- What do you find most challenging in taking care of a person with dementia?
- Who is the main person likely to take care of older person or the person with dementia in the family?
- Is there an expectation that children/family will provide care?
- Who is the most likely person in the family to explore treatment options and services available that can assist in managing dementia?
- Is there a preference for people to be taken care of at home / residential facility/ clinic/ or church?
- What are your beliefs about the preference?
- What support would you say is available from your church and its leaders?
- What more might your church and its leaders do to help with dementia?
- What do you believe about your faith and support for dementia?
- Tell me about any experience of dementia support in your church.
- Aside from your church, what other dementia support services are available in your community?
- What are the local treatments for dementia in your community?
- Tell me about the local medicines used for treating people with dementia in your community.

Prompt – tell me about it.

**7. To explore the perception of dementia risk factors**

- How are people affected (lifestyle changes observed in individuals) with dementia in your community?

- How do people in your community get dementia?
- What are the risky behaviours for dementia in your community?
- What can people in your community do to prevent dementia?
- Prompt – tell me more about it.

**Conclusion**

- What insights and lessons from your experience would you wish to share with others?
- Is there anything we should have talked about but didn’t?
- Do you want to ask me any questions?

**Acknowledgements**

- Thank you very much for coming today. I appreciate your thoughts and ideas.

## Appendix 2: Vignette

### Dementia Vignette

**Project Title**: Lay knowledge and beliefs towards dementia: A study amongst Black Africans living in London.

**Target Audience:** Black Africans living in London.

**Gender:** Adult male and female

**Age range**: 20 – 85 years

**Sampling:** Purposive

**Moderator:** Raphael Mokwenye

**Project date:** December 2020 – September 2022

**Methods:** Individual semi-structured interviews

**Venue:** Online

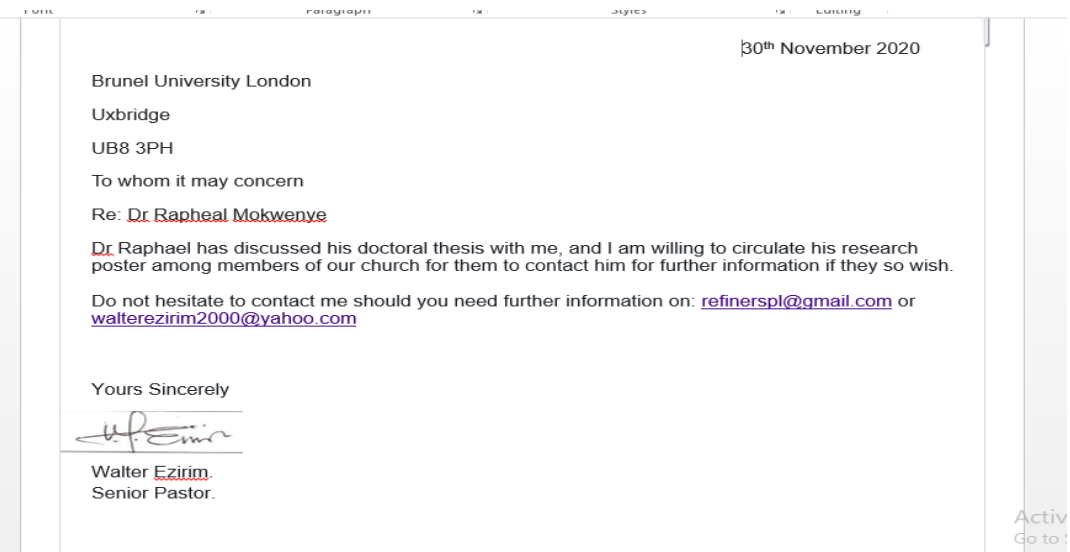
Bola is a ‘Nigerian’ woman living in Woolwich with her son and daughter-in-law, who identified themselves as ‘Black Africans’ although they are of British nationality. She is in reasonably good physical health. For the past 3 – 4 years, her family has noticed that she is becoming increasingly withdrawn, inactive, and sometimes careless about her appearance and has become very forgetful, often not recognising close family members. However, she does remember details of her younger days and can spend hours talking about the events of her youth, even though she frequently forgets things that happened yesterday.

She currently does not go out but spends most of her time in her room, seemingly doing nothing. The family have noticed that when she is left on her own, she mutters and mumbles to herself. When asked what she is talking about, she does not reply.

She sometimes wakes up at odd hours of the night and starts getting ready for the day, insisting that it is morning. Her family has a hard job persuading her to get back to bed at these times.

Adapted from Uppal et al. (2014:404)

# Appendix 3: Community access letters



30th November 2020

Brunel University London

Uxbridge

UB8 3PH

To whom it may concern

Re: Dr Rapheal Mokwenye

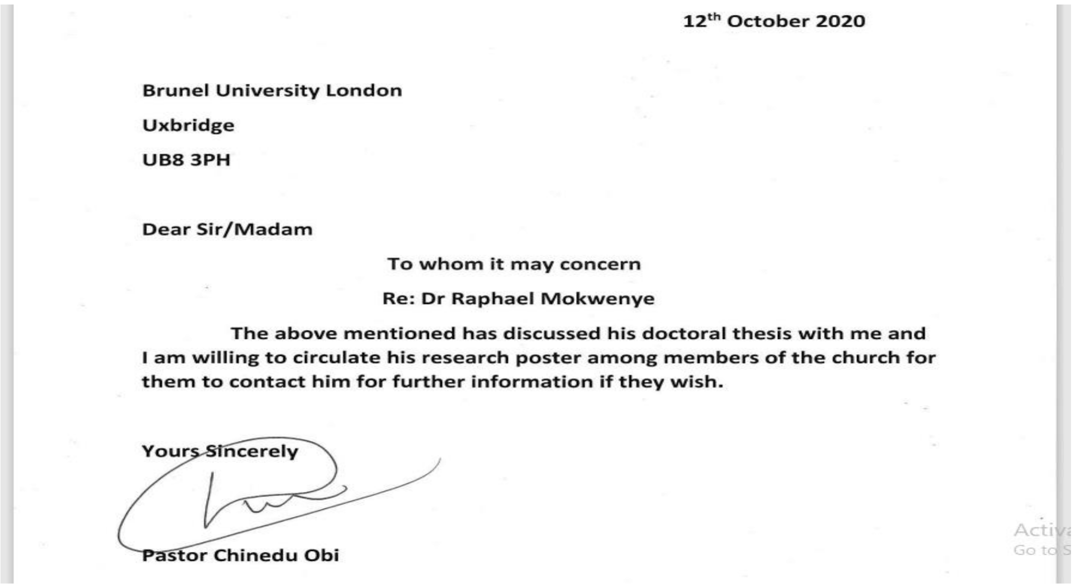
Dr Raphael has discussed his doctoral thesis with me, and I am willing to circulate his research poster among members of our church for them to contact him for further information if they so wish.

Do not hesitate to contact me should you need further information on: refinerspl@gmail.com or walterezirim2000@yahoo.com

Yours Sincerely

Walter Ezirim.
Senior Pastor.

---



**12th October 2020**

**Brunel University London**

**Uxbridge**

**UB8 3PH**

**Dear Sir/Madam**

**To whom it may concern**

**Re: Dr Raphael Mokwenye**

**The above mentioned has discussed his doctoral thesis with me and I am willing to circulate his research poster among members of the church for them to contact him for further information if they wish.**

**Yours Sincerely**

**Pastor Chinedu Obi**

# Appendix 4: Research poster

## Lay knowledge and beliefs towards dementia: A study amongst Black Africans living in London

### Introduction

Dementia impacts on people's health and behaviour. The understanding of dementia varies in many ways, and can be considered as illness or a disease condition. More than 850,000 people are living with dementia in the UK, and more than 25,000 people with dementia are from Black and minority ethnic groups. Generally, 1 in 14 people over the age of 65 have dementia, and the condition affects 1 in 6 people over 80 years.

### Research aim

The aim of the study is to explore ideas, beliefs and the meaning of dementia amongst Black Africans living in London.

### Methods

### Interviews

You will participate in an online interview (e.g. using Zoom, WhatsApp, Facebook, Skype or Telephone). The researcher will moderate the interview using an interview guide and will ask you some questions. The online interviews will last for about 45 minutes to an hour maximum and will be recorded.

### Target population:

We are looking for both male and female Black Africans living in London who are between the ages 20 – 85 years to participate in the research

### Results:

The findings may provide new ideas for the dementia illness or disease as they are, and may inform our knowledge for further public health and health promotion interventions.

### Invitation:

I kindly invite you to participate in the research but before you decide to take part in this study, it is important for you to understand why the research is being done and what it will involve. Please contact the researcher to enrol in the study and for further information.

**Venue:** Online platform

**Contact:**

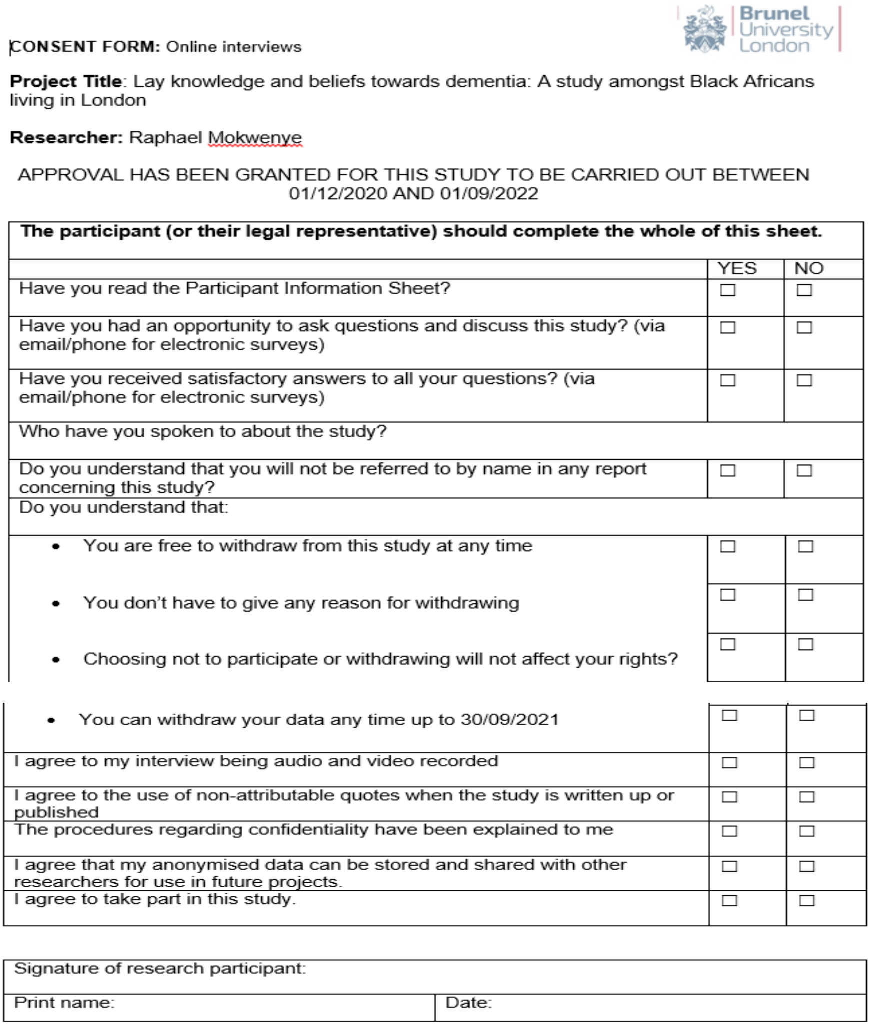
**Mobile: 07399538071 (Research only)**

**Email: Raphael.mokwenye@brunel.ac.uk**

Brunel University London

The research has been approved by the College of Health, Medicine and Life Sciences Research Ethics Committee, Brunel University London.

# Appendix 5: Consent form



Brunel University London

**CONSENT FORM:** Online interviews

**Project Title**: Lay knowledge and beliefs towards dementia: A study amongst Black Africans living in London

**Researcher:** Raphael Mokwenye

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 01/12/2020 AND 01/09/2022

| | | |
|---|---|---|
| **The participant (or their legal representative) should complete the whole of this sheet.** | | |
| | YES | NO |
| Have you read the Participant Information Sheet? | ☐ | ☐ |
| Have you had an opportunity to ask questions and discuss this study? (via email/phone for electronic surveys) | ☐ | ☐ |
| Have you received satisfactory answers to all your questions? (via email/phone for electronic surveys) | ☐ | ☐ |
| Who have you spoken to about the study? | | |
| Do you understand that you will not be referred to by name in any report concerning this study? | ☐ | ☐ |
| Do you understand that: | | |
| • You are free to withdraw from this study at any time | ☐ | ☐ |
| • You don't have to give any reason for withdrawing | ☐ | ☐ |
| • Choosing not to participate or withdrawing will not affect your rights? | ☐ | ☐ |
| • You can withdraw your data any time up to 30/09/2021 | ☐ | ☐ |
| I agree to my interview being audio and video recorded | ☐ | ☐ |
| I agree to the use of non-attributable quotes when the study is written up or published | ☐ | ☐ |
| The procedures regarding confidentiality have been explained to me | ☐ | ☐ |
| I agree that my anonymised data can be stored and shared with other researchers for use in future projects. | ☐ | ☐ |
| I agree to take part in this study. | ☐ | ☐ |

| | |
|---|---|
| Signature of research participant: | |
| Print name: | Date: |

## Appendix 6: Participant information sheet (PIS)

College of Health, Medicine and Life Sciences

Department of Health Sciences

### Participant Information Sheet for Interviews

### Research title

Lay knowledge and beliefs towards dementia: A study amongst Black Africans living in London.

### Invitation

I kindly invite you to participate in a study, but before you decide to participate in it, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. You can contact the researcher if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

### Purpose of this study

I am a doctoral researcher at Brunel University London. I will be exploring the lay knowledge and beliefs of dementia amongst Black Africans living in London as a part of my project to complete my PhD thesis.

### Why have I been chosen?

You have been invited to take part in this study because you are a Black African living in London. I am approaching Black Africans living in London with the exemption of registered professionals in medicine and health care, e.g., doctors, nurses, pharmacists, occupational therapists, physiotherapists, and social workers, and you must be aged between 20 – 85 years.

### Do I have to take part?

Your participation in the study is entirely voluntary, and refusal or withdrawal from the research will involve no penalty or affect your attendance at church services or worships, now or in the future. The study is independent of the church. Participants can withdraw from the study at any time before the start of data analysis without any reason or consequences.

### What will happen to me if I take part?

Individual semi-structured interviews will be conducted using Zoom or other platforms, e.g., WhatsApp, Facebook, Skype, or Telephone. Before the interview meeting, you will be provided with a copy of the participant information sheet (PIS), and you will be required to sign a consent form.

### What do I have to do?

If you decide to take part in the interview, your participation in the study will last for 45 minutes to an hour maximum. The researcher will moderate the sessions and ask you questions with prompts. The interview will be recorded (I will be recording the interview because I don't want to miss any of your comments). The audio recordings will not be used or made available for purposes other than the research project. The audio recordings will be destroyed five years after the data are collected.

### Are there possible disadvantages and/or risks in taking part?

The discussion of a sensitive topic such as dementia in an interview may potentially cause distress to participants. Therefore, I have provided a list of local counselling resources below that may be helpful for advice. In addition, you are encouraged to speak to your GP for advice.

- Mind - 03001233393
- South East London Counselling – 02077718113.
- South London Counselling services – 02088523400.
- The church counselling services - 02083167193

### What are the possible benefits of taking part?

There are no personal benefits. However, you will get a £10 Amazon voucher for taking part, and by taking part, you will help the researcher to complete his PhD thesis. The findings may provide a new perspective on dementia as they are and may inform our knowledge for further public health and health promotion interventions.

### Will my taking part in the project be kept confidential?

All information collected about you will be kept strictly confidential, including the interview audio recordings and transcripts. All names will be anonymised (the researcher will use pseudo-names). Therefore, your name will not appear in the thesis or any publications. All data (e.g., transcripts) will be stored in the Brunel University figshare data repository. The data will be kept for a maximum of 10 years post-research publication, but the audio recordings will be destroyed five years after data are collected. You do not need to provide a personal contact address or email unless you wish to receive a summary of the findings. All data are subject to the Data Protection Act 2018.

### What will happen to the results of the study?

A summary of the findings will be sent to all participants who request it. The results will be presented at conferences and written up in journals. An item will be submitted to a health professional newsletter, and an article will be submitted to a medical sociological or public health journal. Participants will not be identified in any reports or publications.

### Who is organising and funding the research?

Brunel University London is organising the study, and the research is self-funded.

### Ethical review of the study

The project has been reviewed by the College of Health, Medicine and Life Science Research Ethics Committee of Brunel University London and has been allowed to proceed.

**What if something goes wrong?**

If you have any concerns or complaints about the conduct of this study, please contact Professor Christina Victor, Chair of the College of Health, Medicine and Life Sciences Research Ethics Committee.

Email: christina.victor@brunel.ac.uk

Contact for further information.

If you would like to discuss this study in more detail or for further information, don't hesitate to contact Raphael Mokwenye (doctoral researcher) or the supervisor as indicated below.

Email: Raphael.mokwenye@brunel.ac.uk

**Supervisor: Dr Wendy Martin**

Email: wendy.martin@brunel.ac.uk

Please keep this information sheet for future reference.

Thank you for your time in reading this Participant Information Sheet.

Yours sincerely

Raphael Mokwenye (Researcher)

Email: Raphael.mokwenye@brunel.ac.uk

**NOTE:**

The research has been approved by the College of Health, Medicine and Life Sciences Research Ethics Committee, Brunel University London.

## Appendix 7: Interview invitation letter

College of Health, Medicine and Life Sciences

Department of Health Sciences

### INTERVIEW INVITATION LETTER

Dear Church member

I am writing to ask you to participate in a research project exploring the knowledge and attitudes towards dementia amongst Africans living in London. Your participation in the study is entirely voluntary, and refusal or withdrawal will involve no penalty or affect your attendance at church services or worship, now or in the future. The study is independent of the church. You can withdraw from the study at any time before the completion of the thesis without any reason or consequences. But before you decide to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the Participant Information Sheet (PIS) carefully and discuss it with your families, colleagues, and friends if you wish.

Please contact the researcher if there is anything that is not clear or if you would like more information or would like to enrol in the study. Please take time to decide whether or not you wish to take part.

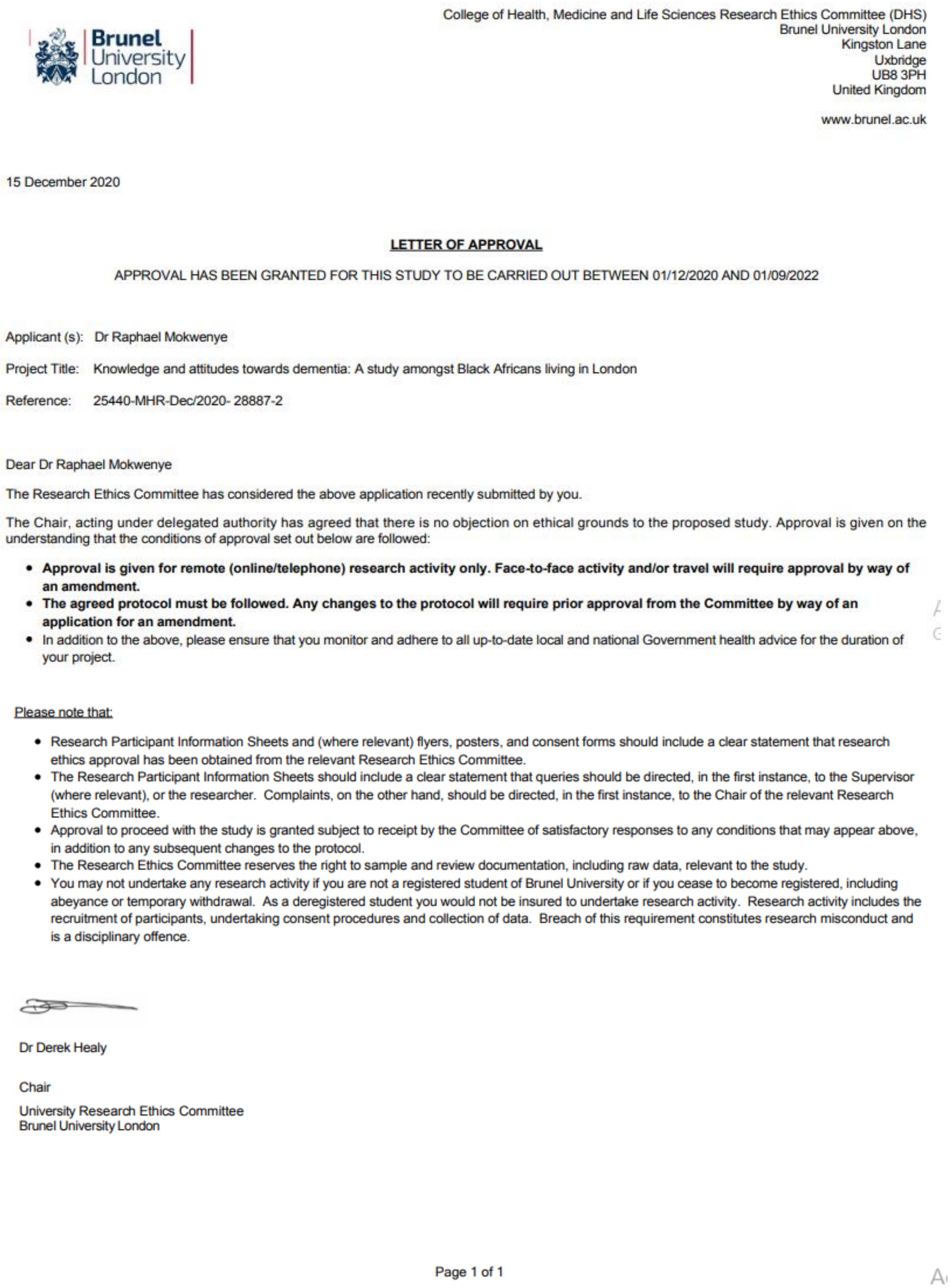
Kind regards

Raphael Mokwenye (Researcher)

Tel: 07780512763

Email: Raphael.mokwenye@brunel.ac.uk

# Appendix 8: Letter of ethics approval



Brunel University London

College of Health, Medicine and Life Sciences Research Ethics Committee (DHS)
Brunel University London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom

www.brunel.ac.uk

15 December 2020

**LETTER OF APPROVAL**

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 01/12/2020 AND 01/09/2022

Applicant (s): Dr Raphael Mokwenye

Project Title: Knowledge and attitudes towards dementia: A study amongst Black Africans living in London

Reference: 25440-MHR-Dec/2020- 28887-2

Dear Dr Raphael Mokwenye

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **Approval is given for remote (online/telephone) research activity only. Face-to-face activity and/or travel will require approval by way of an amendment.**
- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**
- In addition to the above, please ensure that you monitor and adhere to all up-to-date local and national Government health advice for the duration of your project.

Please note that:

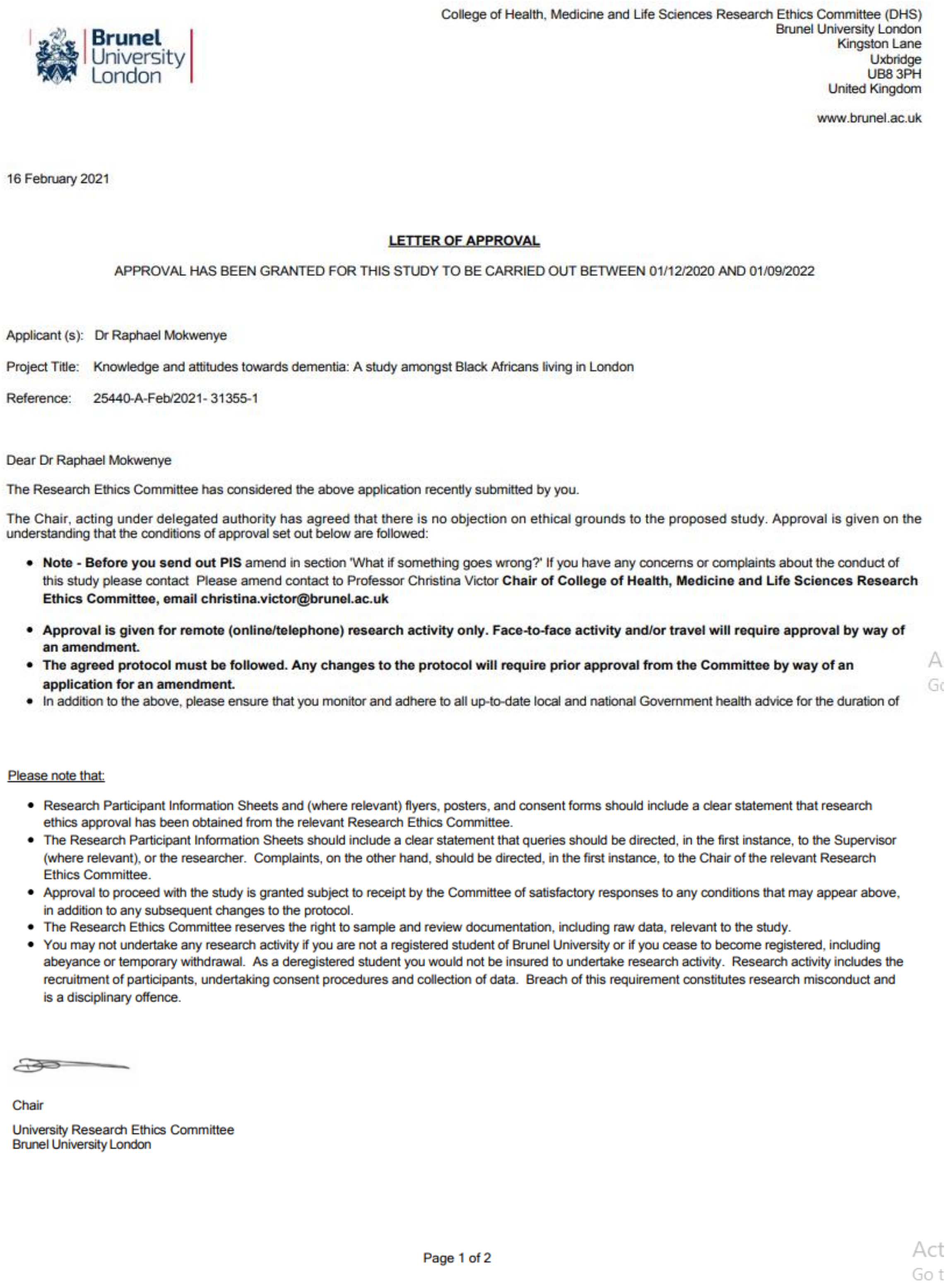
- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

Dr Derek Healy

Chair

University Research Ethics Committee
Brunel University London

# Appendix 8: Letter of ethics approval (amendment)



College of Health, Medicine and Life Sciences Research Ethics Committee (DHS)
Brunel University London
Kingston Lane
Uxbridge
UB8 3PH
United Kingdom

www.brunel.ac.uk

16 February 2021

**LETTER OF APPROVAL**

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 01/12/2020 AND 01/09/2022

Applicant (s): Dr Raphael Mokwenye

Project Title: Knowledge and attitudes towards dementia: A study amongst Black Africans living in London

Reference: 25440-A-Feb/2021- 31355-1

Dear Dr Raphael Mokwenye

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **Note - Before you send out PIS** amend in section 'What if something goes wrong?' If you have any concerns or complaints about the conduct of this study please contact Please amend contact to Professor Christina Victor **Chair of College of Health, Medicine and Life Sciences Research Ethics Committee, email christina.victor@brunel.ac.uk**

- **Approval is given for remote (online/telephone) research activity only. Face-to-face activity and/or travel will require approval by way of an amendment.**
- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**
- In addition to the above, please ensure that you monitor and adhere to all up-to-date local and national Government health advice for the duration of

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.

Chair

University Research Ethics Committee
Brunel University London

## Appendix 9: Interview transcript

Interview transcript

Recording 200628_001; 200628_002

Interview date: 28th June 2021

Interview venue: Online

Interviewer: Raphael Mokwenye (Researcher)

Interviewee: ‘Yemi’ (false name - anonymised participant)

Demographic data:

Gender: Female

Age range: 50 - 59 years

Occupation: family carer

Ethnicity: Black African

Country of origin (migration): Nigeria

Religion: Christian

Level of education: University

Years of living in the UK: 31 years.

**Researcher: What are your thoughts about the vignette I just read you?**

Yemi: [Interjection] that is, significantly we can see that Bola has some issues, at least she wasn’t like that before [cough]. We can see. I don’t know what she looked like before, probably she could have been seen as a bubbling person, but now you described her as withdrawn. So, for her to have been withdrawn and noticed by her family, something has gone wrong, and usually, what would have gone wrong would have been a case of depression and memory loss. You mentioned Bola not remembering things in her present situation but remembering things that happened a long time ago. What I am saying is that these are symptoms of dementia setting in. This is a situation where family and friends must make moves to seek help and begin by alerting authorities, that is, those with good knowledge of what to do. They must be able to report this to medical personnel who can report it to social services who can assess the situation. They are the ones to do the referral so Bola can receive the necessary help. One thing about dementia is that it is degenerative, so it is a condition that doesn’t get any better. There could be one or more cases, I mean someone with dementia that got better, but usually, cases that I know are degenerative, it gets worse over time. One of the symptoms of dementia is memory loss, which you pointed out in the case of Bola; that is, she was forgetful and withdrawn. Why? Because this person got confused. So, a person that is confused will have it difficult being in control of life and when it comes to conversation. The person can no longer have a decent conversation with family and friends due to dementia. And will find it hard to carry out daily tasks, she will be withdrawn and confused, and usually, one of the symptoms of dementia is struggling to follow a conversation. When you start a conversation, you would see them steering and struggling to concentrate, and some of them may be saying things that are incorrect, and then you are thinking – what is going on here? [Interjection] and usually it is with a lot of confusion. So, that is probably the reason why Bola was withdrawn, being withdrawn, something I can liken to some sort of confusion. You know one of the symptoms of confusion is that your mood just changes, and you are not your normal self. Then you are thinking – mama wasn't like this, which is mother wasn't like this, and or papa wasn't like that. You are like – what is going on here? You know it is a very worrying thing or a case for the family when they find out that it is dementia – a degenerative disease which is usually an attack on the brain cells. I mean, once they notice what is happening, they just believe they are losing their loved one; this person, in fact, has become a brand-new personality which was not what they were before dementia. Sometimes dementia may be severe, and there are different types of dementia that I know of. I have heard about vascular dementia, and I have also heard about Alzheimer's disease; usually, my thinking was that dementia was under Alzheimer's disease, so dementia was a category under Alzheimer's disease. And that there are different types of dementia. So, you understand [Interjection] that is the reason for the scenario that I think Bola had changed.

**Researcher: Thank you very much. So, tell me about your experience with dementia.**

Yemi: [interjection] that is a good one. The experience that I will mention is about my dad. I never knew what dementia was all about until, with him, I began to notice that he had become unnecessarily aggressive. Then he began to say things that didn't seem true; he could say things like – 'when you were coming, did you see some cars parked at the door'. I would say to him, 'I didn't see your car parked at the door'. You understand, or he could say to you did you see two people on the roof? Strange things like that, then I am thinking what is really going on. So, you, as a friend or family, do not really understand because you are thinking is he seeing things or is he really imagining things? So, those are my experiences, but about memory loss, one terrible thing is about you having to repeat yourself. He can ask you the same question over 50 times, and as soon as you explain, he is asking you the same question again, and you would say to him I just explained it to you, and I gave you an answer then he would say to you 'I can't remember'. He could ask you [interjection] how about my medication? I have not seen anyone attend to me. I have not seen anyone apply my medication. He could say no one has been here to see me, and I am hungry. Then I was worried and would ask the person caring for him about the things he had complained about, but they were all lies. Then I began to understand the dementia condition and what it was, that is, the attack on the brain cells and the breakdown of some of the proteins in the brain, and the cutting off of some of the cognitive function of the brain cells. This also reminds me, back in Africa, when people with this condition say things that are untrue, lying and lying about things. Let me borrow the word 'lying' about things that are untrue. I don't know why. Remember, in Africa, when we see older people with this condition, a lot of people used to stone them. Society used to stone them. I know of a woman just across the road where I used to live. The woman had a lot of children but was saying that she was the one who killed her daughters, that is, saying things that were not true, and people would begin to stone her. But here we are talking about Africa, but in the UK, and it seems some studies have been done about dementia here in the UK, and they know how to manage the dementia condition just like that. As I have said, dementia is associated with memory loss, and maybe my daddy gets frustrated when he sees you don't even understand him or his condition. Sometimes he does not recognise people, but he recognises me. I just don't understand why his frustration. Sometimes he gets so angry and agitated, and you thinking what the problem is. It is really hard for him to concentrate, but he can tell you stories probably when he was back then in secondary school, when he was a sportsman, when he did play football, he loved his football. But when you tell him present things, he would ask you over and over again, for example, that I have just told you like; dad, remember in two-week time I will come to pick you up for your eye test but don't worry I will remind you again. On the same premise, he is asking you when you are coming to pick me up? My eyes are getting bad! My eyes are getting bad! Then I would say to him; dad, I have just said to you that I have booked an appointment, don't worry, in two weeks I will come to take you, don't worry, I will remind you and I will come to get you ready for the appointment as soon as you said that he would ask you again. And that is frustrating for a friend or family; you have to be extra patient with these people and show them some love. So, those are the few things I can remember at the moment.

**Researcher: So, what do you think are the causes of dementia?**

Yemi: [interjection] that is a very good question. One of the things that I feel may be one of the causes may be – a lack of decent sleep. [Interjection] My dad doesn't sleep; he has been sleeping on his chair for years. I think an elderly person should have himself well rested in his bed with his arms and legs nicely stretched out and have a good rest, and then their brain can rest as well, but he has been sitting on his chair for years. I don't know, but I feel it is a factor that could have contributed to his dementia. And I also feel when a person is not finding himself in a social circle enough, I mean, as people grow older, they lose friends, lose companions, and their children may have gone to do their own things, so usually, you are lonesome. And when a person is lonesome and lonely, lacking social events, that could lead to dementia. And also, when you are not exercising your brain enough as you ought to, that could lead to dementia. I also think when someone has suffered from a stroke, it could accelerate or causes some form of dementia. [Interjection] So, those are what I feel about; I am not medical personnel, but those are the things I feel strongly about. I have known him for a long time. My dad has been lonely; he stays all by himself, he does not sleep well, and he does not get involved in social events. He does not go out, maybe to play bingo, but only sits down with his cigarette puffing away, and that could be too hard on his brain. I may be wrong, but I have sat down to concentrate and think things through. My dad has not had a decent sleep for 20 years, and I would say to him you are the only man, the only man that I know who does not sleep. You are just the only one, especially an old man. I believe old people should sleep. You have been sleeping on your chair for years, your bed is brand new, and we could sell it for brand new if anybody was ready to buy it because you have never laid on it. I myself that is younger I sleep, you know. So, those are the few things that I know, but there could be much more. A person who is looking at it from a medical perspective could have a broader description than I have.

**Researcher: Thank you very much, thank you!**

**Researcher: You mentioned earlier that in Africa, people could say things that are untrue, and people could stone them to death, meaning that somehow and somehow, there could be a way dementia is framed or recognised. So, how do you think dementia is being framed in the Black community? Or how is dementia being understood in your community?**

Yemi: You know you can coin a word from a person being demented. Being a demented person in Africa means you are a crazy man! [Interjection] So, they would regard somebody like that as has gone derailed, that is, a crazy person. They would say it is either they are into witchcraft or that they are crazy. I don't know, but they could say they are into 'Africa juju' and that when you get your finger burned in your 'Africa juju', it is when you begin to say things that are untrue. I don't know how true, but this is how our society deals with people with dementia. They are not knowledgeable enough to take the time to study and say no, that this person, this person has dementia and that the brain cells are dying. And the person needs to be treated with tender loving care, but they would rather stone them to death. Some people have burned their mothers or fathers alive because they would say she is a witch, he is a wizard, but it is totally untrue. But they would cover up and say that woman was my mother, but a witch and that man was my father but a wizard. They would stone them and kill them, not realising that it is dementia and that those things they were saying were totally untrue. But a person from this society [London] would see it from a different perspective. Why?

Because we here already know, okay, that dementia is already setting in and would seek how to deal with the issue. But let us hope that there will be some light in the African community about dementia and would have some people [Interjection] go educate the society out there that there are things like dementia where the brain cells just die gradually, and people get confused, unable to remember things, agitated and say things that are untrue. And when they say things like that, they should not take laws into their hands and kill that person, burn that person or injure the person. At least they would say they are burning a witch [Interjection]. So, those are the few things that I can say, and as I said, they call it ‘ya were’ and ‘were’ meaning the person is being demented or crazy. We never knew back home until now. The woman I earlier talked about that lived across the road to my house would leave her home and begin to wade in the gutter, and she got clothes on, and some children would take drums and would begin to beat the drums for her, and she would dance in the gutter. [Interjection] I am sure you don’t want to hear the rest, but I am just saying to you, that is the way that society deals with dementia. Until light comes and people who are learned and are able to educate people in that society that there is a condition called dementia and that anyone could suffer from it in their old age. I do not expect a younger person, a 13 or 14-year-old person, to suffer from dementia. I am not saying that there could not be one or two cases, but it is very rare. It is totally very uncommon for a younger person to suffer from dementia.

**Researcher: Thank you very much.**

**Researcher: So, tell me of any experience of dementia signs and symptoms you know of.**

Yemi: I think you have asked the question.

**Researcher: The signs and symptoms of dementia?**

Yemi: Yes, I think you have asked about the signs and symptoms of dementia which we have described in the scenario. Like when people are withdrawn, when people are a bit agitated, when people are depressed, when people are aggressive in their dealings, and when they become confused [interjection] it could even be as bad as when people go to bed and are unable find rest and sleep, and saying things that are untrue [interjection] those are the things that I can remember so far. Especially the confusion! The confusion! The confusion! When a person is confused, I tell you, when a person is confused, it is hard for them to carry out their daily task. They find it difficult to be able to deal with their affairs of life. They get confused and sometimes loss of capacity. They cannot reason effectively and deal with their daily affairs as they would have loved to. So, a friend or family member has to step in on their behalf to carry out the task that they would have done. Take, for example, them having to do the shopping for themselves, go to a cash point or a bank to pick up cash and go shopping. They are not able to coordinate those activities, so someone else has to step in. They are not able to realise that I can pick up cash like £20, I need to buy so, so, and so, itemise what they need to buy, go to the shop, and from there would want to go home, and before going home, have I got enough change, correct change back [interjection]. In fact, some of them with dementia could even get lost, confused, wander out of the house, and have family looking for them when they don’t find their way back home. Sometimes they just wander out of the house and can’t find their way back. Usually, I think the main problem is confusion and lack of capacity to reason the way they should; they can’t carry out their daily activities or the task they are supposed to perform. They are unable to do that anymore. If they have properties, they are not able to coordinate them anymore, and somebody has to coordinate them. So, their affairs are actually carried out by somebody else on their behalf just because they can’t reason the way they usually would have done when they haven’t lost their capacity.

**Researcher: Thank you very much.**

**Researcher: So, if you were worried about dementia, where would you go for help?**

Yemi: Normally, the first thing is to [interjection] thank God for Google; people Google up a lot of information. But the first thing to do is to contact your GP. You would want to contact your GP, and that is the first port of call. You would want to be able to report the whole activities to your GP. For example, all of a sudden, mum has stopped sleeping, dad has stopped sleeping [interjection], they are not sleeping, they are getting agitated, and they are a bit confused. Your GP is your first port of call, and then they can make other referrals. And also, the social services, for example, in your local borough, you would have the adult social services number which you can call. So, your first port of call is either your GP because every one of us is meant to be registered with a GP; they really need to know and also have it on their report. [Interjection] Once the symptoms that I have described are reported to them, they would know what it is, that is, the diagnosis, because they know what it is through their studies. They would know that dementia is setting in, they would look at the age range and all and many other factors and then they will begin to make referrals. So, I believe the GP and the social services are the places where the person should make reference when they see that their loved one is losing capacity or as having dementia.

**Researcher: Thank you! Thank you! Thank you!**

Yemi: I have already spent more than 30 minutes!

**Researcher: [Laugh]**

Yemi: [laugh]

Yemi: But carry on, it is fine.

**Researcher: What are your thoughts about professionals like doctors regarding dementia?**

Yemi: [interjection] I guess it will vary; I am not sure all the doctors are totally knowledgeable about it. I guess they get to know [interjection]. One thing about medicine is that doctors are meant to update themselves. They have magazines, and they read from time to time and are meant to look up stuff from time to time. I would say it really really depend on how good the doctor is; some GPs are better and well informed than some others. But I believe they can work hand in hand. Like when one doctor or GP does not have enough knowledge of dementia, I believe they can write down the signs and symptoms and compare them with one another. For example, a patient has reported this, and what do you think? Usually, in health practice, there is usually more than one or two doctors, and they are usually partners who should have [interjection] a wealth of knowledge, you understand, so they should be able to enlighten or educate themselves or inform themselves [interjection] about these symptoms of dementia setting in for a person. But I don’t believe that all doctors are knowledgeable enough. Sometimes certain things are strange to them, the common ones they might probably know about, but if a person manifest [interjection] in something a bit unusual, they might start thinking of bringing in the person into the hospital or sometimes they could refer them to a big hospital, that is, the GP would refer them to a specialist in the hospital, the specialists in the hospital are expected to have better knowledge. Those ones in the hospital there are usually consultants and are expected to have better knowledge in that area of practice. So, I don't think all GPs have total knowledge about dementia. They could know where to point you to and would point you in the right direction, but I don't think they have absolute knowledge of dementia, especially because there could be different manifestations of the disease, and it depends on each individual concern.

**Researcher: Thank you very much! You seem to be well informed about the GP**

Yemi: I don't know about that.

**Researcher: [laugh]**

Yemi: [Laugh]

**Researcher: Anyway, here comes an interesting question. What are your experiences with your own GP regarding dementia?**

Yemi: [interjection] unfortunately [interjection]… I think you meant my father's GP because this is not concerning me and because he seems to know about my father. I think he was a pastor, so he seemed to know what my dad got [Interjection]. Rather when things began to change [Interjection], my dad began to have memory loss. He [GP] was quite good and seemed to know what he was doing. He asked me to bring him in, and he asked him [dad] some questions; like what is the date today? What is the name of the queen of England? He [dad] got easily irritated and said, 'why should you be asking me? Am I a child?' So, they just do those little little tests just to see if his memory is doing well or coordinated, if he can think through and process information, just basic [interjection] information, but I guess he [GP] was quite good, so he was able to ask him those questions. But dad got agitated and said 'rubbish' and walked out of the room. And he (GP) called me aside and said I got this on my record, but your dad must not see this. So, dad got angry, so we don't mention dementia at home because he doesn't want to hear it. But the doctor was quite good, and he really knew what to look out for. He already saw the symptoms and signs, and he said you know what, your dad has got dementia. But you know a lot of people do not want to hear that they are suffering from dementia disease… [Interjection] He was a good doctor, and to be honest, he knows what he was doing. He seemed to be informed, but to be honest if I was a doctor myself and if I did not know those things, I would know where to go and get the information. At least if I don't know where I am coming from, I know where I am going to…[Interjection] for example, this is what a patient presented, and I don't know how to deal with it, and if I don't know, I think I would need to ask people. There is no harm in asking questions; after all, that is how we get educated and informed. At least we need to ask questions and are able to reason and process the information. So, that is it really.

**Researcher: Thank you! Thank you!**

**Researcher: What is the cost of dementia in your community?**

Yemi: When you say the cost, what does that mean?

**Researcher: I mean, how expensive is dementia? Does it cost much to take care of someone with dementia?**

Yemi: It could, it could, you know why? Because if we consider the social aspect of it, a dementia patient may need extra care, adding extra care hours, you understand. Dementia is regarded as a pathology, and the hours that you would probably spend with someone with dementia are different from someone who hasn't got the pathology at all, whom you just need to support, and you don't need to go shopping and all that. You probably just what to escort the person because they know what they are doing, they just what to buy bread or they want to buy milk but just that they can’t go alone just because of old age. But the person with dementia would probably need the support because they would just sit at home, and you would also make lists of things to buy. Okay, let’s look at the cupboard; he probably needs tea, and he does not know what he needs. So, what I am saying is that it would be more expensive to take care of a person with dementia because they would need extra time for extra support. For example, they cannot take care of themselves, you see people with dementia who are not ready to take a bath and might decide not to take a bath for two months, and if you don’t wash them, that is probably considered as abuse, and you don’t want them to be abused because they can’t take a bath by themselves. But what am I saying? I am saying, in effect, that a person with dementia would need extra support and care, and it could be more expensive compared to someone who doesn’t suffer from the illness but just from old age, but they know what they are doing, where they are going; oh please I need to watch the TV, and they watch the TV and can hear the news and enjoy some music. But the person with dementia can’t do all that. You tell them now you would need to take your bath, and they are wondering what your part is. I am not interested. You understand, and in all that, you have to explain yourself. It would take extra hours [interjection]; for example, if you got to bathe a person with dementia, you first have to prepare their mind. It is different from a person who does not have dementia whom who could get them into the bathroom and take them out in 15 minutes, but in a person who has dementia, it could take you that 15 minutes to convince them that this is what we want to do, this is what you need to do, you need to go to the bathroom, but they may ask you why do I need to wash? And you need to explain it to them because they might get agitated, they might get angry, they might even walk you out of the house, and say to you why do you want to bath me? I don’t need a bath. Get out! And all that, what am I saying? I am saying that extra time is needed; we will consider that as extra time. More time is needed, and because you pay for the support, you pay for people’s time to take care of others. So, it could be more expensive.

**Researcher: Thank you! Thank you very much!**

**Researcher: Who is the main person likely to take care of the older person in the family?**

Yemi: [interjection] that is a hard question. Anyone, anyone could take care of them, anyone who has the time. To be honest, everyone should chip in. If it is a large family and the person has children, they can do it in turns; if they got five or six children, they could do it in turns so that it does not weigh down on a particular person. You understand! Take, for example, if the person has a spouse, the spouse is there to support them. But if they have lost their spouse and their spouse is not there, usually the children, and it depends. I can tell you if they have six children, they can take it in turns. Somebody says, don’t worry, I have dad on Monday; I have dad this week, so don’t worry, but next week you can do dad, and then it takes another six weeks before it goes back to the person in turns [interjection]. So, they take it in turns, but if it is just one person, it is a lot of work and really hard work for that person. And to be honest, the person taking care of a person with dementia needs therapy. They also need therapy for themselves because the labour is so much, and they are watching their loved ones totally change over time, you know [interjection], and it is a lot of hard work. It is a lot of hard work for just a particular person. I don’t think there is a particular person, that is just my opinion, who should take care of a person with dementia in a family. I think it could be everyone. Everyone just needs to chip in, even a friend; it could be a long-time friend of this person who has dementia. He could say let me go and see my friend. They should pop up once in a while to see their friend with dementia. So, I don’t believe that it is a one-person job.

**Researcher: Thank you! Thank you very much!**

**Researcher: Is there any preference for people with dementia to be taken to a care home, or to be taken care of in their residential home or perhaps to be taken to the church?**

Yemi: [interjection] that is a very good question. To be honest, let us rule church out of it because it is not a church matter. The Afro-Caribbean, I mean, we are the ones that do things like that because we think it is a spiritual matter, so we take them to the church. This is a case of brain cells dying. I don't know what the church has to do with it. Of course, you can pray, there is nothing wrong with us praying and asking the lord to take control and heal that person, but you also need the medical aspect of care. Of course, in the spiritual aspect of it, you can pray, you can even go to church, and there is nothing wrong with that. But what about the medicine, so you don't have a choice? I mean, apart from the church, you also need the medical aspect of it.

Yemi: So, what is the other question, I mean the other aspect of the question?

**Researcher: The other question is the preference for people with dementia to be taken to a care home or to be taken care of in their residential home.**

Yemi: [interjection] thank you very much. You see, the reason why people are taken into a residential care home is about cost. Remember we spoke on cost previously, and your question was if it was more expensive to take care of someone who has dementia. Sometimes when the social services want to cut down on costs and the person with dementia does not have a 'leg to stand on' or strong support, when I say strong support, I mean friends and family who can put their feet down; they would find themselves in the care home. And even when it gets to an extent where friends and family are helpless and don't know what to do anymore, they might find themselves in a care home. You understand! But if the person with dementia can still be managed in the person's residential home, why not? We just support him, and this is managed as the family steps in, and the carer steps in, and they do what they have to do. But if it is getting out of hand and getting more and more serious, maybe the person might need the intervention of being in a care home. Where there is a 24-hour need for care would be worth a while for this person.

**Researcher: Thank you very much!**

**Researcher: Tell me about any local treatment for dementia in your community.**

Yemi: When you say local treatment, what do you mean? Is it as in herbs?

**Researcher: Yes, herbs that could be used in treating dementia.**

Yemi: None that I am aware of, especially in this society. Probably back home, back in Africa, when they see that a person is going crazy, they might pick up a few leaves and put them together, I don't know, but there are people who have studied all these things. Probably anthropologists will know what all this is all about and put things together. But in our society here, we don't have anything like that, but you just take medicine properly. But usually, when you have vascular dementia, there is nothing to take that is it, but there may be some medications that may help you to sleep or help you to relax. But I am not sure if there is any actual treatment for dementia because the brain cells are damaged. I am not really sure, but there could be things that we could be able to manage. Otherwise, I am not sure that there is any local treatment for dementia.

**Researcher: Thank you very much! Thank you very much!**

**Researcher: We are coming to the end of the questions, just about one or two more.**

Yemi: Thank God!

**Researcher: I appreciate your calmness and how you deal with the questions. Just one or two more questions we will be at the end.**

**Researcher: [Interjection] how do people in your community get dementia?**

Yemi: [Interjection] not really, but as I have said, I believe one of the main factors is when a person is cut off from society when you are cut off from events. When you are cut off from social life [Interjection] when people are not getting enough sleep when people are going through trauma and from traumatic experiences, I can't really say these are the reasons, but there are factors that you can pinpoint. And sometimes people just think these things just happen, you understand. I don't know how proteins can go into the cells in the brain and damage them. I don't know what causes it, probably food, I don't know, and it could be anything. I don't know how proteins could go into the brain cells and damage cells, I can really say this is the cause [Interjection], but I am just thinking of the factors that allow these things to happen, such as sleeplessness and trauma. I don't have a 100% answer for that.

**Researcher: How about lifestyle behaviour?**

Yemi: Yes, smoking could be one of them; my father is a heavy smoker as he can smoke packs of cigarettes. [Interjection] I remember when his doctor asked about it. Is he a smoker? My daddy is a heavy smoker. I think that is his lifestyle; he drinks, but smoking has become a habit that he cannot seem to get himself off.

**Researcher: Thank you! Thank you!**

**Researcher: The last question! The last question! What can people in your community do to prevent dementia?**

Yemi: [Interjection] I believe [Interjection] as much as we can; it is important for us to have the support of family and friends, and people checking upon each other. But of course, in this day and age, people with their hustling and bustling of life do not allow these ways that we want to, and because of this, we may have many more like it. Here can be a very lonely society. People don't check up on each other. You can have your neighbour [Interjection] next door, and you don't even know them. You might run into them outside or on the road. People don't check on you; you don't know what is happening. You know, a good chat, a good cup of tea with a friend, you know [Interjection] playing Bingo, seeing people of your age, your age mate having a cup of tea together, having lunch together playing a game, and I believe all these could stimulate their brain so that it does not die. I don't have an answer to this, but I just believe, most importantly, getting involved in social events and you showing love and support for people around you can help. You just can't be left alone, I tell you [Interjection] lonesomeness is probably one of the main causes of dementia. It may not have been proven yet, but I believe so.

**Researcher: Thank you very much! But I must say this is one of the best interviews I have had so far. But finally, before I allow you to go.**

Yemi: But you said it was the last question!

**Researcher: [Laugh]**

Yemi: [laugh]

**Researcher: Yes, as I said, I am enjoying the interview. It is the best interview I have had so far. I have had so many interviews, but I put it to you that this is the best interview I have had so far and is quite informative.**

**Researcher: But finally, before I allow you to go, just before I allow you to go, what insight or experience would you wish to share with me and others who might be listening to this?**

Yemi: I have shared as much information as I can. As I said, the most important thing is to prevent, provide support if a person has dementia [cough] and partake in bodily exercise. You don't have to be a member of a gym before you can do exercises. You can sit up; you can do stretches, you know, you can watch videos and do some small exercises. This help as much as possible to improve blood flow through all part of the body through to the brain and to all the other parts of your body. It keeps you healthy. I am not a scientist, but it is just my observations.

**Researcher: Thank you very much!**

**Researcher: Do you have any questions to ask me?**

Yemi: [interjection] Not at the moment. I think you are doing a good job. At the end of the day, I want to know what the results are. I hope and I wish you all the best in your research work, and I hope at the end of the day, you get as much information as you want in order to do a job that will help others to get much more knowledgeable about this terrible disease, and what we can do to support our loved ones that are affected with this disease.

**Researcher: Thank you!**

Yemi: I will keep in contact.

**Researcher: Thank you very much for coming today, and I appreciate all your thoughts and ideas.**

Yemi: You are very welcome, my brother. I hope I have been able to do the little I can to see this move on as you would like it to be.

**Researcher: Thank you, and I appreciate it.**

Yemi: I will still take some time to see whether one or two people might be interested. I don't know; maybe they might not be able to do one hour. It will probably be in this surpass, not in the US. I will let you know if I find one, but if I don't, I wish you all the best.

**Researcher: Thank you very much. I appreciate that. Thanks a lot.**

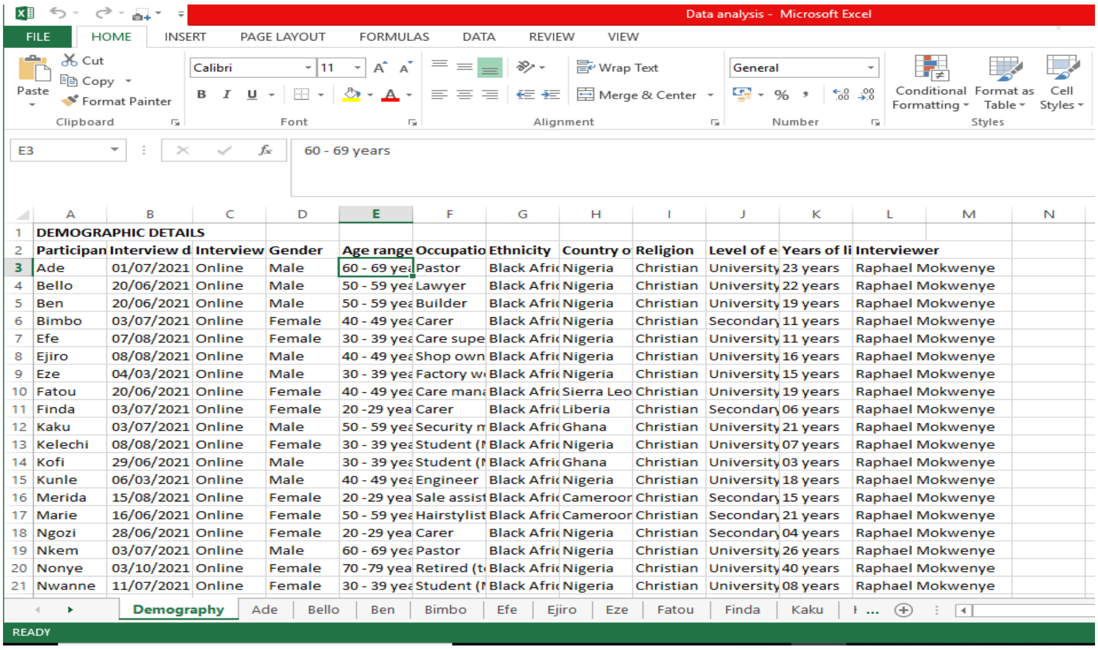
**Researcher: Bye! Bye!**

Yemi: God bless you. I will speak with you soon.

**Researcher: Bye! Bye!**

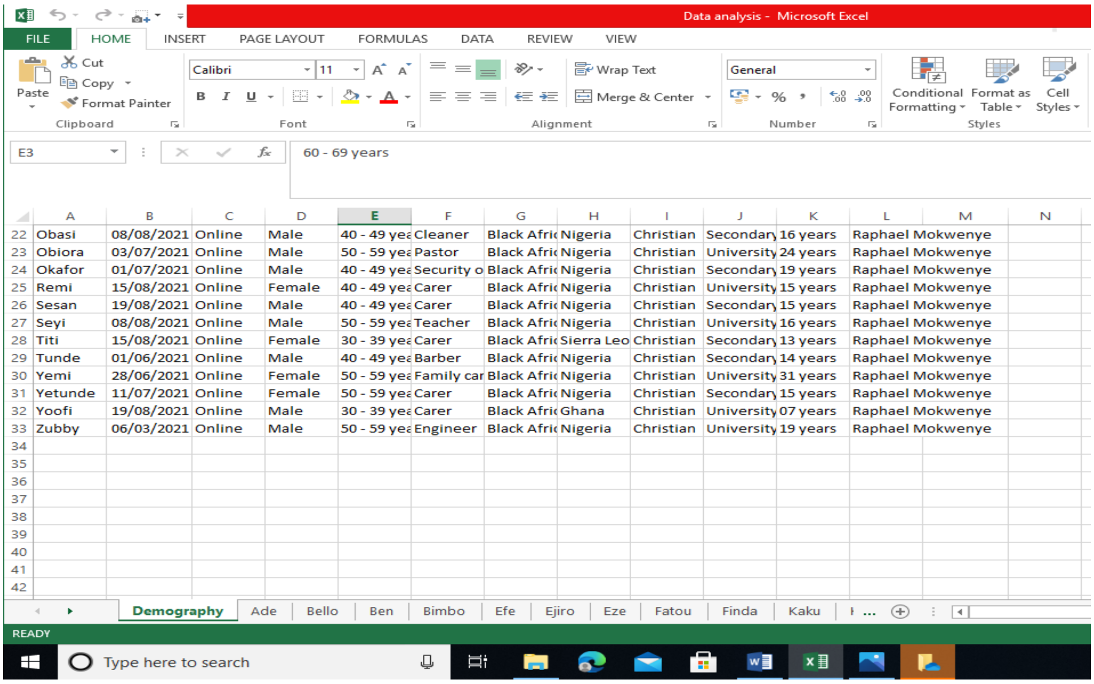
Yemi: Bye! Bye!

## Appendix 10A: Demography



E3 60 - 69 years

| | A | B | C | D | E | F | G | H | I | J | K | L |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | **DEMOGRAPHIC DETAILS** | | | | | | | | | | | |
| 2 | **Participan** | **Interview d** | **Interview** | **Gender** | **Age range** | **Occupatio** | **Ethnicity** | **Country o** | **Religion** | **Level of e** | **Years of li** | **Interviewer** |
| 3 | Ade | 01/07/2021 | Online | Male | 60 - 69 yea | Pastor | Black Afri | Nigeria | Christian | University | 23 years | Raphael Mokwenye |
| 4 | Bello | 20/06/2021 | Online | Male | 50 - 59 yea | Lawyer | Black Afri | Nigeria | Christian | University | 22 years | Raphael Mokwenye |
| 5 | Ben | 20/06/2021 | Online | Male | 50 - 59 yea | Builder | Black Afri | Nigeria | Christian | University | 19 years | Raphael Mokwenye |
| 6 | Bimbo | 03/07/2021 | Online | Female | 40 - 49 yea | Carer | Black Afri | Nigeria | Christian | Secondary | 11 years | Raphael Mokwenye |
| 7 | Efe | 07/08/2021 | Online | Female | 30 - 39 yea | Care supe | Black Afri | Nigeria | Christian | University | 11 years | Raphael Mokwenye |
| 8 | Ejiro | 08/08/2021 | Online | Male | 40 - 49 yea | Shop own | Black Afri | Nigeria | Christian | University | 16 years | Raphael Mokwenye |
| 9 | Eze | 04/03/2021 | Online | Male | 30 - 39 yea | Factory w | Black Afri | Nigeria | Christian | University | 15 years | Raphael Mokwenye |
| 10 | Fatou | 20/06/2021 | Online | Female | 40 - 49 yea | Care mana | Black Afri | Sierra Leo | Christian | University | 19 years | Raphael Mokwenye |
| 11 | Finda | 03/07/2021 | Online | Female | 20 -29 yea | Carer | Black Afri | Liberia | Christian | Secondary | 06 years | Raphael Mokwenye |
| 12 | Kaku | 03/07/2021 | Online | Male | 50 - 59 yea | Security m | Black Afri | Ghana | Christian | University | 21 years | Raphael Mokwenye |
| 13 | Kelechi | 08/08/2021 | Online | Female | 30 - 39 yea | Student (I | Black Afri | Nigeria | Christian | University | 07 years | Raphael Mokwenye |
| 14 | Kofi | 29/06/2021 | Online | Male | 30 - 39 yea | Student (I | Black Afri | Ghana | Christian | University | 03 years | Raphael Mokwenye |
| 15 | Kunle | 06/03/2021 | Online | Male | 40 - 49 yea | Engineer | Black Afri | Nigeria | Christian | University | 18 years | Raphael Mokwenye |
| 16 | Merida | 15/08/2021 | Online | Female | 20 -29 yea | Sale assist | Black Afri | Cameroor | Christian | Secondary | 15 years | Raphael Mokwenye |
| 17 | Marie | 16/06/2021 | Online | Female | 50 - 59 yea | Hairstylist | Black Afri | Cameroor | Christian | Secondary | 21 years | Raphael Mokwenye |
| 18 | Ngozi | 28/06/2021 | Online | Female | 20 -29 yea | Carer | Black Afri | Nigeria | Christian | Secondary | 04 years | Raphael Mokwenye |
| 19 | Nkem | 03/07/2021 | Online | Male | 60 - 69 yea | Pastor | Black Afri | Nigeria | Christian | University | 26 years | Raphael Mokwenye |
| 20 | Nonye | 03/10/2021 | Online | Female | 70 -79 yea | Retired (t | Black Afri | Nigeria | Christian | University | 40 years | Raphael Mokwenye |
| 21 | Nwanne | 11/07/2021 | Online | Female | 30 - 39 yea | Student (I | Black Afri | Nigeria | Christian | University | 08 years | Raphael Mokwenye |



E3 60 - 69 years

| | A | B | C | D | E | F | G | H | I | J | K | L |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 22 | Obasi | 08/08/2021 | Online | Male | 40 - 49 yea | Cleaner | Black Afri | Nigeria | Christian | Secondary | 16 years | Raphael Mokwenye |
| 23 | Obiora | 03/07/2021 | Online | Male | 50 - 59 yea | Pastor | Black Afri | Nigeria | Christian | University | 24 years | Raphael Mokwenye |
| 24 | Okafor | 01/07/2021 | Online | Male | 40 - 49 yea | Security o | Black Afri | Nigeria | Christian | Secondary | 19 years | Raphael Mokwenye |
| 25 | Remi | 15/08/2021 | Online | Female | 40 - 49 yea | Carer | Black Afri | Nigeria | Christian | University | 15 years | Raphael Mokwenye |
| 26 | Sesan | 19/08/2021 | Online | Male | 40 - 49 yea | Carer | Black Afri | Nigeria | Christian | Secondary | 15 years | Raphael Mokwenye |
| 27 | Seyi | 08/08/2021 | Online | Male | 50 - 59 yea | Teacher | Black Afri | Nigeria | Christian | University | 16 years | Raphael Mokwenye |
| 28 | Titi | 15/08/2021 | Online | Female | 30 - 39 yea | Carer | Black Afri | Sierra Leo | Christian | Secondary | 13 years | Raphael Mokwenye |
| 29 | Tunde | 01/06/2021 | Online | Male | 40 - 49 yea | Barber | Black Afri | Nigeria | Christian | Secondary | 14 years | Raphael Mokwenye |
| 30 | Yemi | 28/06/2021 | Online | Female | 50 - 59 yea | Family car | Black Afri | Nigeria | Christian | University | 31 years | Raphael Mokwenye |
| 31 | Yetunde | 11/07/2021 | Online | Female | 50 - 59 yea | Carer | Black Afri | Nigeria | Christian | Secondary | 15 years | Raphael Mokwenye |
| 32 | Yoofi | 19/08/2021 | Online | Male | 30 - 39 yea | Carer | Black Afri | Ghana | Christian | University | 07 years | Raphael Mokwenye |
| 33 | Zubby | 06/03/2021 | Online | Male | 50 - 59 yea | Engineer | Black Afri | Nigeria | Christian | University | 19 years | Raphael Mokwenye |
| 34 | | | | | | | | | | | | |
| 35 | | | | | | | | | | | | |
| 36 | | | | | | | | | | | | |
| 37 | | | | | | | | | | | | |
| 38 | | | | | | | | | | | | |
| 39 | | | | | | | | | | | | |
| 40 | | | | | | | | | | | | |
| 41 | | | | | | | | | | | | |
| 42 | | | | | | | | | | | | |

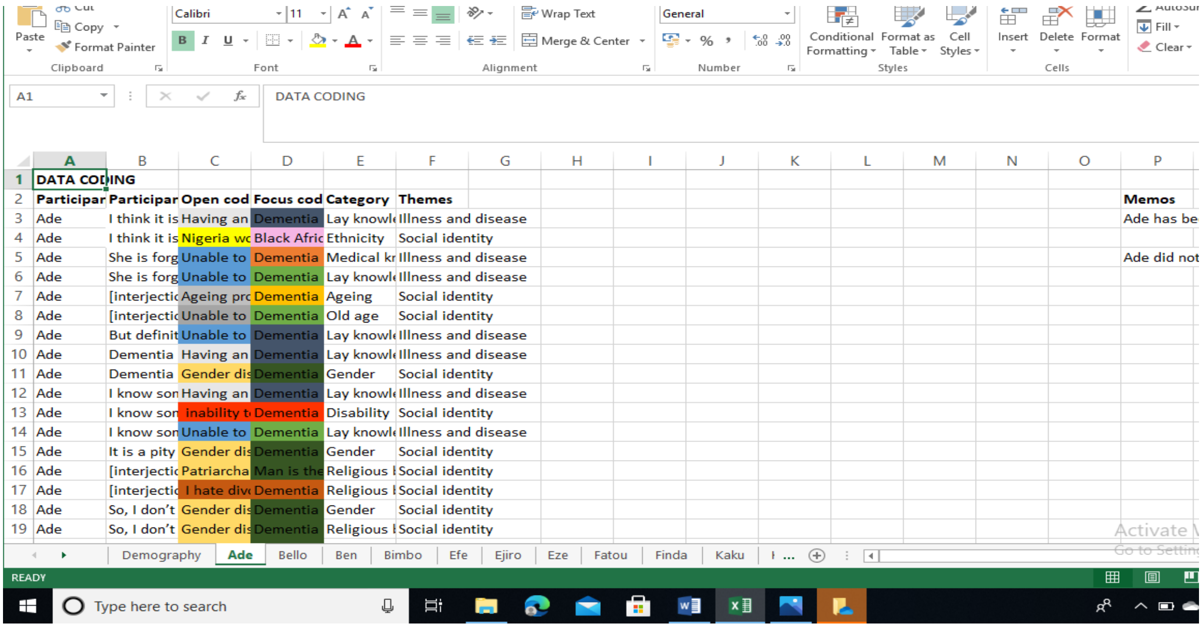
# Appendix 10B: Sample

Table 8: Sample

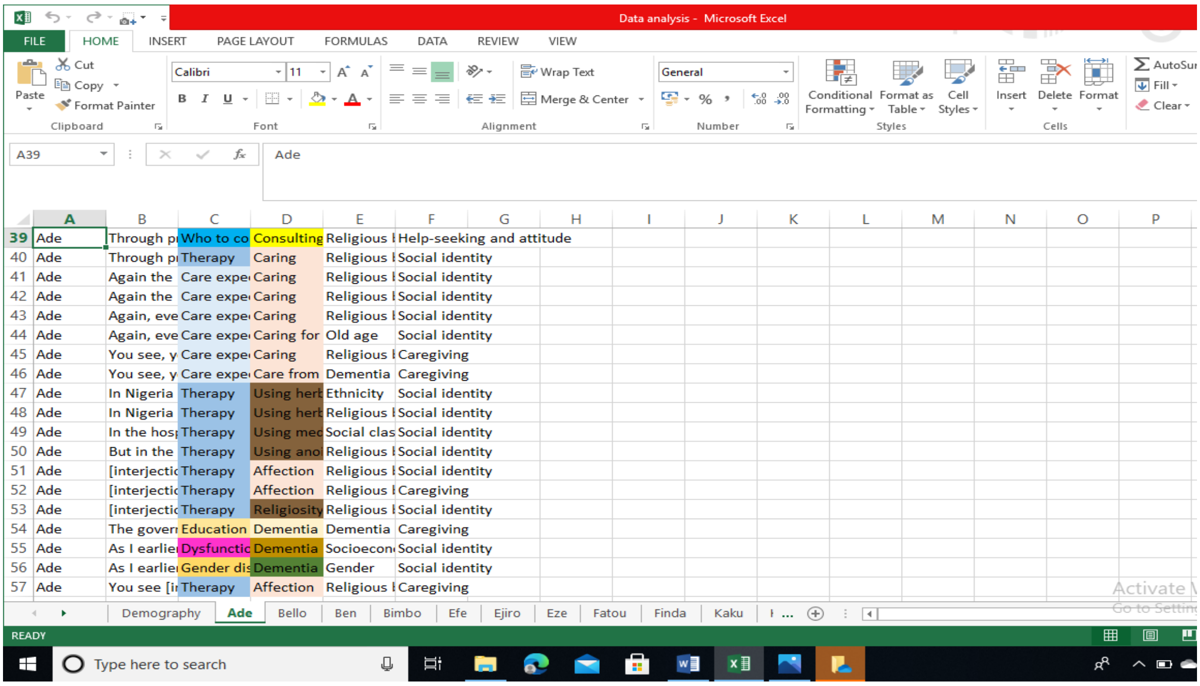
| **Number** | **Participant's name (anonymised)** | **Gender** | **Age range** | **Occupation** | **Ethnicity** | **Country of origin (migration)** | **Religion** | **Educational level** | **Years in the UK** |
|---|---|---|---|---|---|---|---|---|---|
| 1 | Ade | Male | 60 - 69 years | Pastor | Black African | Nigeria | Christian | University education | 23 years |
| 2 | Bello | Male | 50 - 59 years | Lawyer | Black African | Nigeria | Christian | University education | 22 years |
| 3 | Ben | Male | 50 - 59 years | Builder | Black African | Nigeria | Christian | University education | 19 years |
| 4 | Bimbo | Female | 40 - 49 years | Carer | Black African | Nigeria | Christian | Secondary education | 11 years |
| 5 | Efe | Female | 30 - 39 years | Care supervisor | Black African | Nigeria | Christian | University education | 11 years |
| 6 | Ejiro | Male | 40 - 49 years | Shop owner (retailer) | Black African | Nigeria | Christian | University education | 16 years |
| 7 | Eze | Male | 30 - 39 years | Factory worker | Black African | Nigeria | Christian | University education | 15 years |
| 8 | Fatou | Female | 40 - 49 years | Care manager | Black African | Sierra Leone | Christian | University education | 19 years |
| 8 | Finda | Female | 20 -29 years | Carer | Black African | Liberia | Christian | Secondary education | 06 years |
| 10 | Kaku | Male | 50 - 59 years | Security manager | Black African | Ghana | Christian | University education | 21 years |
| 11 | Kelechi | Female | 30 - 39 years | Student (master's degree) | Black African | Nigeria | Christian | University education | 07 years |
| 12 | Kofi | Male | 30 - 39 years | Student (master's degree) | Black African | Ghana | Christian | University education | 03 years |
| 13 | Kunle | Male | 40 - 49 years | Engineer | Black African | Nigeria | Christian | University education | 18 years |
| 14 | Merida | Female | 20 -29 years | Sale assistant | Black African | Cameroon | Christian | Secondary education | 15 years |
| 15 | Marie | Female | 50 - 59 years | Hairstylist | Black African | Cameroon | Christian | Secondary education and vocational qualifications | 21 years |
| 16 | Ngozi | Female | 20 -29 years | Carer | Black African | Nigeria | Christian | Secondary education | 04 years |
| 17 | Nkem | Male | 60 - 69 years | Pastor | Black African | Nigeria | Christian | University education | 26 years |
| 18 | Nonye | Female | 70 -79 years | Retired (teacher) | Black African | Nigeria | Christian | University education | 40 years |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 19 | Nwanne | Female | 30 - 39 years | Student (master’s degree) | Black African | Nigeria | Christian | University education | 08 years |
| 20 | Obasi | Male | 40 - 49 years | Cleaner | Black African | Nigeria | Christian | Secondary education | 16 years |
| 21 | Obiora | Male | 50 - 59 years | Pastor | Black African | Nigeria | Christian | University education | 24 years |
| 22 | Okafor | Male | 40 - 49 years | Security officer | Black African | Nigeria | Christian | Secondary education and vocational qualifications | 19 years |
| 23 | Remi | Female | 40 - 49 years | Carer | Black African | Nigeria | Christian | University education | 15 years |
| 24 | Sesan | Male | 40 - 49 years | Carer | Black African | Nigeria | Christian | Secondary education | 15 years |
| 25 | Seyi | Male | 50 - 59 years | Teacher | Black African | Nigeria | Christian | University education | 16 years |
| 26 | Titi | Female | 30 - 39 years | Carer | Black African | Sierra Leone | Christian | Secondary education | 13 years |
| 27 | Tunde | Male | 40 - 49 years | Barber | Black African | Nigeria | Christian | Secondary education and vocational qualifications | 14 years |
| 28 | Yemi | Female | 50 - 59 years | Family carer | Black African | Nigeria | Christian | University education | 31 years |
| 29 | Yetunde | Female | 50 - 59 years | Carer | Black African | Nigeria | Christian | Secondary education | 15 years |
| 30 | Yoofi | Male | 30 - 39 years | Carer | Black African | Ghana | Christian | University education | 07 years |
| 31 | Zubby | Male | 50 - 59 years | Engineer | Black African | Nigeria | Christian | University education | 19 years |

# Appendix 11: Data coding

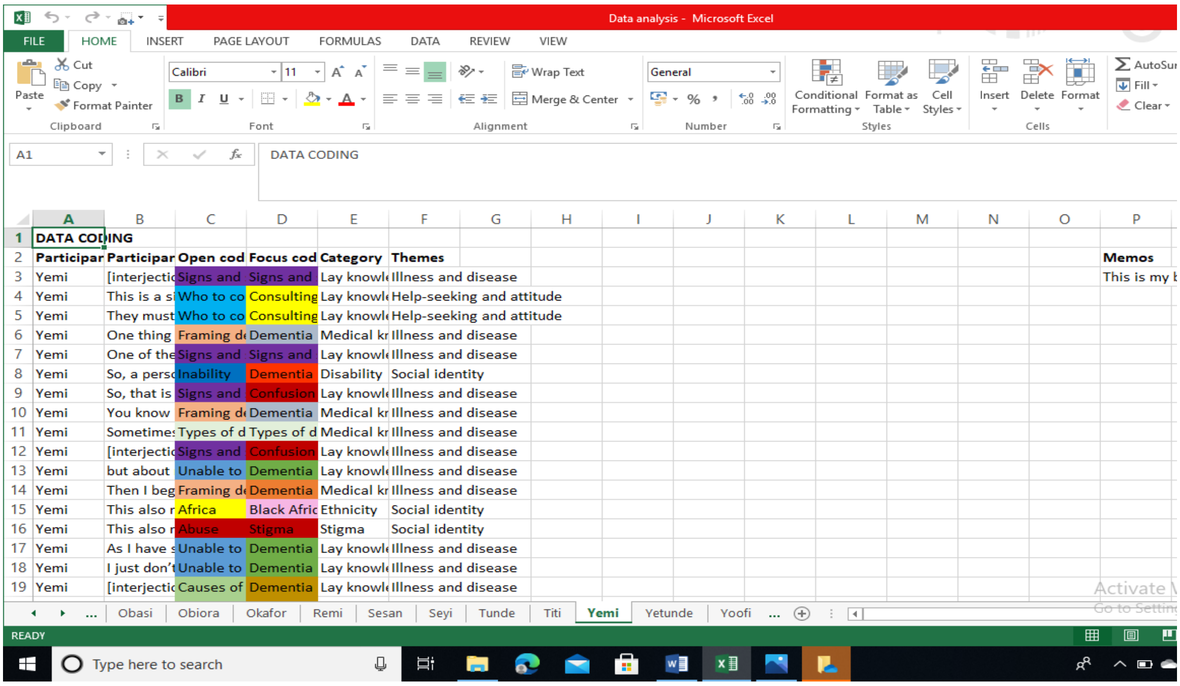


| | A | B | C | D | E | F | P |
|---|---|---|---|---|---|---|---|
| 1 | DATA CODING | | | | | | |
| 2 | Participa | Participa | Open cod | Focus cod | Category | Themes | Memos |
| 3 | Ade | I think it is | Having an | Dementia | Lay knowle | Illness and disease | Ade has be |
| 4 | Ade | I think it is | Nigeria w | Black Afric | Ethnicity | Social identity | |
| 5 | Ade | She is forg | Unable to | Dementia | Medical k | Illness and disease | Ade did not |
| 6 | Ade | She is forg | Unable to | Dementia | Lay knowle | Illness and disease | |
| 7 | Ade | [interjecti | Ageing pr | Dementia | Ageing | Social identity | |
| 8 | Ade | [interjecti | Unable to | Dementia | Old age | Social identity | |
| 9 | Ade | But definit | Unable to | Dementia | Lay knowle | Illness and disease | |
| 10 | Ade | Dementia | Having an | Dementia | Lay knowle | Illness and disease | |
| 11 | Ade | Dementia | Gender dis | Dementia | Gender | Social identity | |
| 12 | Ade | I know so | Having an | Dementia | Lay knowle | Illness and disease | |
| 13 | Ade | I know so | inability t | Dementia | Disability | Social identity | |
| 14 | Ade | I know so | Unable to | Dementia | Lay knowle | Illness and disease | |
| 15 | Ade | It is a pity | Gender dis | Dementia | Gender | Social identity | |
| 16 | Ade | [interjecti | Patriarcha | Man is the | Religious | Social identity | |
| 17 | Ade | [interjecti | I hate div | Dementia | Religious | Social identity | |
| 18 | Ade | So, I don't | Gender dis | Dementia | Gender | Social identity | |
| 19 | Ade | So, I don't | Gender dis | Dementia | Religious | Social identity | |

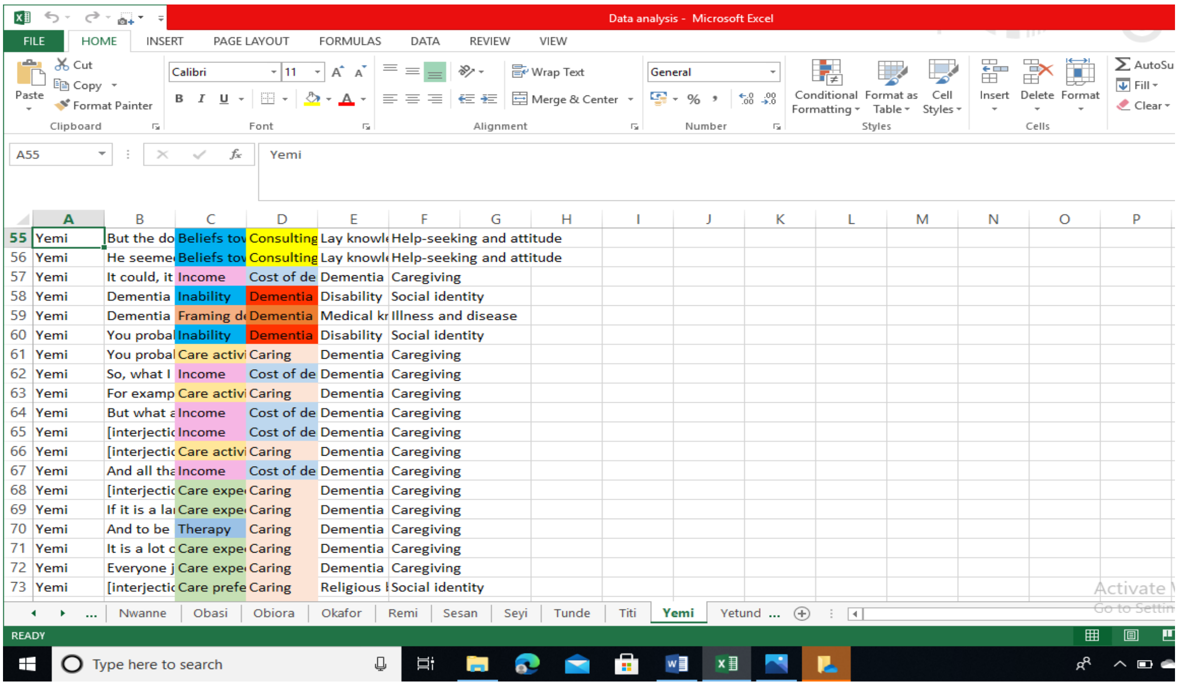


| | A | B | C | D | E | F |
|---|---|---|---|---|---|---|
| 39 | Ade | Through p | Who to co | Consulting | Religious | Help-seeking and attitude |
| 40 | Ade | Through p | Therapy | Caring | Religious | Social identity |
| 41 | Ade | Again the | Care expe | Caring | Religious | Social identity |
| 42 | Ade | Again the | Care expe | Caring | Religious | Social identity |
| 43 | Ade | Again, eve | Care expe | Caring | Religious | Social identity |
| 44 | Ade | Again, eve | Care expe | Caring for | Old age | Social identity |
| 45 | Ade | You see, y | Care expe | Caring | Religious | Caregiving |
| 46 | Ade | You see, y | Care expe | Care from | Dementia | Caregiving |
| 47 | Ade | In Nigeria | Therapy | Using her | Ethnicity | Social identity |
| 48 | Ade | In Nigeria | Therapy | Using her | Religious | Social identity |
| 49 | Ade | In the hos | Therapy | Using med | Social clas | Social identity |
| 50 | Ade | But in the | Therapy | Using ano | Religious | Social identity |
| 51 | Ade | [interjecti | Therapy | Affection | Religious | Social identity |
| 52 | Ade | [interjecti | Therapy | Affection | Religious | Caregiving |
| 53 | Ade | [interjecti | Therapy | Religiosity | Religious | Social identity |
| 54 | Ade | The gover | Education | Dementia | Dementia | Caregiving |
| 55 | Ade | As I earlie | Dysfuncti | Dementia | Socioecon | Social identity |
| 56 | Ade | As I earlie | Gender dis | Dementia | Gender | Social identity |
| 57 | Ade | You see [i | Therapy | Affection | Religious | Caregiving |

# Appendix 11: Data coding



| | A | B | C | D | E | F | P |
|---|---|---|---|---|---|---|---|
| 1 | **DATA CODING** | | | | | | |
| 2 | **Participar** | **Participar** | **Open cod** | **Focus cod** | **Category** | **Themes** | **Memos** |
| 3 | Yemi | [interjectic | Signs and | Signs and | Lay knowle | Illness and disease | This is my b |
| 4 | Yemi | This is a si | Who to co | Consulting | Lay knowle | Help-seeking and attitude | |
| 5 | Yemi | They must | Who to co | Consulting | Lay knowle | Help-seeking and attitude | |
| 6 | Yemi | One thing | Framing de | Dementia | Medical kr | Illness and disease | |
| 7 | Yemi | One of the | Signs and | Signs and | Lay knowle | Illness and disease | |
| 8 | Yemi | So, a perso | Inability | Dementia | Disability | Social identity | |
| 9 | Yemi | So, that is | Signs and | Confusion | Lay knowle | Illness and disease | |
| 10 | Yemi | You know | Framing de | Dementia | Medical kr | Illness and disease | |
| 11 | Yemi | Sometimes | Types of d | Types of d | Medical kr | Illness and disease | |
| 12 | Yemi | [interjectic | Signs and | Confusion | Lay knowle | Illness and disease | |
| 13 | Yemi | but about | Unable to | Dementia | Lay knowle | Illness and disease | |
| 14 | Yemi | Then I beg | Framing de | Dementia | Medical kr | Illness and disease | |
| 15 | Yemi | This also r | Africa | Black Afric | Ethnicity | Social identity | |
| 16 | Yemi | This also r | Abuse | Stigma | Stigma | Social identity | |
| 17 | Yemi | As I have s | Unable to | Dementia | Lay knowle | Illness and disease | |
| 18 | Yemi | I just don't | Unable to | Dementia | Lay knowle | Illness and disease | |
| 19 | Yemi | [interjectic | Causes of | Dementia | Lay knowle | Illness and disease | |



| | A | B | C | D | E | F |
|---|---|---|---|---|---|---|
| 55 | Yemi | But the do | Beliefs tov | Consulting | Lay knowle | Help-seeking and attitude |
| 56 | Yemi | He seeme | Beliefs tov | Consulting | Lay knowle | Help-seeking and attitude |
| 57 | Yemi | It could, it | Income | Cost of de | Dementia | Caregiving |
| 58 | Yemi | Dementia | Inability | Dementia | Disability | Social identity |
| 59 | Yemi | Dementia | Framing de | Dementia | Medical kr | Illness and disease |
| 60 | Yemi | You probal | Inability | Dementia | Disability | Social identity |
| 61 | Yemi | You probal | Care activi | Caring | Dementia | Caregiving |
| 62 | Yemi | So, what I | Income | Cost of de | Dementia | Caregiving |
| 63 | Yemi | For examp | Care activi | Caring | Dementia | Caregiving |
| 64 | Yemi | But what a | Income | Cost of de | Dementia | Caregiving |
| 65 | Yemi | [interjectic | Income | Cost of de | Dementia | Caregiving |
| 66 | Yemi | [interjectic | Care activi | Caring | Dementia | Caregiving |
| 67 | Yemi | And all tha | Income | Cost of de | Dementia | Caregiving |
| 68 | Yemi | [interjectic | Care expe | Caring | Dementia | Caregiving |
| 69 | Yemi | If it is a la | Care expe | Caring | Dementia | Caregiving |
| 70 | Yemi | And to be | Therapy | Caring | Dementia | Caregiving |
| 71 | Yemi | It is a lot c | Care expe | Caring | Dementia | Caregiving |
| 72 | Yemi | Everyone j | Care expe | Caring | Dementia | Caregiving |
| 73 | Yemi | [interjectic | Care prefe | Caring | Religious I | Social identity |

## Appendix 12: Evaluation of included studies

Table 6. Evaluation of included studies

| Study | Aim | Designs | Methods | Sampling | Country | Sample size | Analysis | Findings | Limitations |
|---|---|---|---|---|---|---|---|---|---|
| Adamson (2001) | The study explored awareness, recognition, and understanding of dementia symptoms in African / Caribbean and South Asian Families. | Qualitative | Semi-structured interviews | Purposive<br>18 African/Caribbean<br>12 South Asian.<br>Gender:<br>15 Female<br>3 Male<br>Age: ≤40 >40 yrs.<br>Location: East Midlands, north-west, south-east and south-west of England. | UK | 30 | Grounded theory | The knowledge of dementia was limited in terms of awareness of the condition as well as an understanding of the causes. However, most participants were aware of the condition ‘dementia’ but used different terms to describe the disorder. | All the participants were already accessing services or knew someone accessing services or caring for someone with dementia.<br>The study did not explore the beliefs about dementia held by the participants. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | Multi-modelling of ethnicity in the study and the data did not separate Africans from the Caribbean.<br>The study is more than ten years old. |
| Adamson and Donovan (2005) | The study examined the experiences of caring for an older family member, focusing on minority ethnic carers of a person with dementia. | Qualitative | In-depth semi-structured interviews | Purposive<br>15 South Asian<br>21 African Caribbean<br>Gender: not stated<br>Age: not stated<br>Location: London, Bristol, Leicester, Bradford, or Nottingham. | UK | 36 | Grounded theory | The experience of an informal carer had many similarities to the experience of chronic illness.<br>Participants described highly disruptive elements to change in relationships. | Most of the participants were female. However, the details were not given.<br>Participants were already accessing mental health services. |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |  |  | Multi-modelling of ethnicity in the study and the data did not separate Africans from the Caribbean.<br>The study is more than ten years. |
| Adebiyi et al. (2016) | The study explored enacted and implied stigma for dementia in a community in south-west Nigeria. | Mixed | Focused group discussions | Purposive<br>Focus group discussions were conducted among six groups purposively. Each group had eight participants. Three hundred thirteen (313) individuals were interviewed for the quantitative | Nigeria (Africa) | 48 (focus group)<br>313 (Quantitative interviews). | Thematic analysis | Qualitative data revealed the presence of enacted stigma in the community.<br>The study suggested a need for stigma-reducing interventions in the community. | The study assessed the attitude of people towards dementia but was limited in lay knowledge and beliefs. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | component using cluster sampling.<br>Gender: Male and Female<br>Age: 20 years and older.<br>Location: Lalupon in south-western Nigeria. | | | | | |
| Agyeman et al. (2019) | The study explored the sociocultural beliefs, understandings, perceptions and behaviours related to living with dementia in Kintampo, rural Ghana. | Qualitative | In-depth interviews<br>Case studies | Purposive<br>The study used a total of 28 people, using a series of case studies among ten older people living with dementia.<br>Gender: Male and Female.<br>Age: 73 – 100 yrs.<br>Location: Kintampo in Ghana. | Ghana (Africa) | 28 | Framework analysis | The findings revealed that symptoms of cognitive impairment were generally linked to witchcraft and inexorable bodily decline understood to be characteristic of ‘normal’ ageing. | The study was not entirely focused on dementia but on chronic conditions. |
| Armstrong et al. (2022) | The study explored experiences of | Qualitative | Semi-structured interviews. | Purposive<br>11 family carer | UK | 15 | Thematic analysis | The study identified four main themes. And findings suggested that | The study is limited to south Asian |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  | dementia care from Black and South Asian People living with dementia in the UK during the pandemic. |  |  | 4 people living with dementia.<br>Gender: Male and female<br>Age: 29 – 88 yrs.<br>Location: London |  |  |  | participants' relationships with their community, knowledge of dementia services, identity and faith influenced their experience of dementia during the pandemic. | and black Caribbean participants because all the participants who reported birth from African countries defined themselves as south Asian. |
| Baghirathan et al. (2020) | The study explored the experiences of people from three different BAME communities in Bristol providing care for people with dementia and about access to dementia care services. | Qualitative | Semi-structured Interviews and Focus groups conducted between March and September 2016 | Purposive<br>47 South Asians<br>31 Chinese<br>25 African Caribbean<br>Gender:<br>78 Male<br>25 Female<br>Age: not stated<br>Location: Bristol | UK | 103 | Grounded theory | The study provided two categories: Experiences of diminishment<br>Protection strategies: Dementia can be viewed as a part of a broader process of cultural socialisation in which the norms, attitudes and practices that act as the unique identifiers of a | Multi-modelling of ethnicity in the study and the data did not separate Africans from the Caribbean.<br>No specific age range. I expected the knowledge of dementia to |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |  | community are passed across generations.<br>Dementia stigma created a barrier to seeking assistance outside the family system. | vary with age groups. |
| Berwald et al. (2016) | The study explored the barriers to help-seeking for memory problems within UK Black African and Caribbean communities. | Qualitative | Semi-structured interviews | Purposive<br>28 Black African<br>14 Black Caribbean<br>7 Black British<br>1 Indo-Caribbean<br>Gender:<br>30 Female<br>20 Male<br>Age: 18 – 85 yrs.<br>Location: England | UK | 50 | Thematic analysis | Dementia was viewed as a white person's illness, and there were concerns about stigma. | Modelling of Black African and Caribbean communities in the UK.<br>The study did not provide separate findings for the Black Africans. I do not expect uniform knowledge for the Black Africans and the Caribbean. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | Findings were not separated with age group. |
| Botsford et al. (2011) | The study examined the experience of partners of people with dementia in two BME groups. | Qualitative | 43 In-depth interviews conducted over an 18 months period between 2007 and 2009 | Convenience<br>7 Greek Cypriot<br>6 African Caribbean<br>Gender:<br>7 Female<br>6 Male<br>Age: 60 – 80 yrs.<br>Location: London | UK | 43 | Constructivist grounded theory | Participants engaged in an ongoing process of ‘redefining relationships.’<br><br>Participants accommodated the changes associated with dementia into their lives rather than seeking help. | Participants were already accessing specialist mental health services.<br><br>Multi-modelling of ethnicity in the study and the data did not separate Africans from the Caribbean. |
| Gurayah (2015) | The study explored caregiving experiences for people with | Qualitative | Semi-structured interview | Purposive<br>5 primary caregivers:<br>Gender:<br>4 Female | South Africa | 5 | Thematic analysis | Three themes emerged:<br><br>The views and responsibility of the caregiver. | A small sample size will reduce the power of the study and |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | dementia in rural South Africa. | | | 1 male<br>Age: 46-68 | | | | The impact of caregiving<br>The services to assist the caregiver. | increases the margin of error, which could render the study less meaningful. |
| Hindley et al. (2016) | The study explored how traditional and Christian faith healers understood and treated people with dementia. | Qualitative | In-depth semi-structured interviews | Convenience-purposive Stratified<br>11 traditional healers<br>10 Christian faith healers<br>18 People with dementia<br>17 Family caregivers<br>Gender: Male and female<br>Age : ≤40 – 81+<br>Location: Hai District (Demographic Surveillance Site) | Tanzania (Africa) | 56 | Thematic analysis | A conceptualisation of dementia by the healers as a ‘normal ageing’ process<br>Dementia was also conceptualised by the informal carer and people with dementia (PWD) as witchcraft.<br>Dementia was diagnosed and treated with herbs and prayers.<br>All the participants were open and willing to collaborate with allopathic healthcare services. | The interviews were, in part, conducted through an interpreter. Therefore, subtleties and inconsistencies might have been missed during translation.<br>Payment made to gatekeepers and participants may have undermined informed |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |  |  | consent. Therefore, an ethical concern.<br>The study did not explore attitudes or beliefs towards dementia. Unspecific age range in the study. |
| Jacobs et al. (2022) | The study explored the experiences of stigma among people living with dementia and their carers through understanding their own knowledge, | Qualitative | Semi-structured interviews and focus groups. | Purposive<br>14 General public<br>12 Persons with dementia<br>12 Carers<br>14 Health-care workers<br>Gender: Male and Female.<br>Age: 26 – 90 | South Africa | 52 | Thematic analysis | The study shows that people living with dementia and carers experienced high levels of internalised stigma related to negative public attitudes, which were associated with high levels of isolation, health system unpreparedness and | The study did not explore the conceptualisation of dementia from an indigenous cultural perspective. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | attitudes and beliefs. | | | Location: Across two provinces in South Africa. | | | | limited access to support. | |
| Kakongi et al. (2020) | The study explored the understanding of care-seeking pathways for patients with Alzheimer's disease and related dementias. | Qualitative | In-depth interviews. | Purposive Caregivers to people with dementia.<br>Gender: Male and Female.<br>Age: 22 – 70<br>Location: Across three psychiatry hospitals in the rural South Western Uganda. | Western Uganda | 30 | Thematic analysis | The results show that choice for each point of dementia care depended on several factors, including dementia knowledge and beliefs. Hospital point of care was more frequent at initial health care visits, while places of worship took the lead at subsequent visits. | The study included only those who had a formal dementia diagnosis. |
| Kehoua et al. (2019) | The study explored the perception and social representations of people with dementia. | Qualitative | Nondirective (unstructured) interviews and participant observations | 51 Urban participants<br>42 Rural participants<br>Gender: Male and female<br>Age: ≤36 – 81+ | Republic of Congo (Africa) | 93 | Thematic qualitative analysis | The leaders of syncretic churches and traditional healers were the first therapeutic itineraries for people with dementia.<br><br>People with dementia (PWD) were socially | The study sampling strategy lack clarity.<br><br>The study was conducted in 6 local languages |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | Locations: Brazzaville (urban) and Gamboma (Rural). | | | | stigmatized and accused of witchcraft. | (Lingala, Kituba, Teke, Mbochi, Lari and French. The principal investigator had to speak these languages to conduct unstructured interviews without an interpreter. Therefore, there might have been a possibility of wandering off the subject and lacking linguistic quality. |
| Lawrence et al. (2008) | The study explored the caregiving | Qualitative | In-depth individual interviews | Purposive 10 African Caribbean | UK | 32 | Grounded theory | Carers were identified as holding a 'traditional' or 'non- | Most of the participants were female, |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  | attitudes, experiences and needs of family carers of people with dementia from the three largest BME groups in the UK. |  |  | 10 South Asian<br>12 White British<br>Gender:<br>25 Female<br>7 Male<br>Age: 33 – 87 yrs.<br>Location: London |  |  |  | traditional' caregiving ideology.<br><br>Participants conceptualised caregiving as natural, expected and virtuous—this informed feelings of fulfilment, strained, carer's fear and attitudes towards formal services. | limiting the understanding of the experiences and attitudes of male carers.<br><br>Multi-modelling of ethnicity in the study<br><br>The study did not provide separate findings for the Africans.<br><br>The study is more than ten years. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Mahomed & Pretorius (2021) | The study explored awareness, accessibility and utilisation of support services for South African male caregivers of people with Alzheimer’s disease. | Qualitative | Semi-structured interviews. | Purposive<br>11 adult males<br>Age: 56 – 87yrs<br>Location: Western Cape. | South Africa. | 11 | Thematic analysis | Thematic analysis of the data generated four significant themes. One of the themes included Awareness, Knowledge and Education. | The study was limited to male caregivers. |
| Mahomed & Pretorius (2022) | The study explored the experiences of family caregivers of individuals with dementia in Soweto, a South African Township. | Qualitative | Semi-structured interviews. | Purposive<br>30 family caregivers<br>Age: 20 – 74 yrs.<br>Location: Soweto. | South Africa | 30 | Reflexive thematic analysis | Findings suggested a shift in perception away from the cultural paradigm. | The study was limited in methods. |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
| Mkhonto and Hanssen (2018) | The study explored perception and understanding of the link between culture and dementia care, focusing on the belief in dementia as witchcraft and people with dementia as witches. | Qualitative | In-depth interviews (Narrative) | Purposive<br>19 Nurses<br>18 families<br>Gender:<br>3 Male<br>34 female<br>Age: not stated<br>Location: Tshwane | South Africa | 37 | Hermeneutic analysis | Two main themes emerged:<br>People with dementia were perceived as witches<br>The study identified the need for dementia knowledge and education. | The interview was conducted in a relatively limited geographical area in South Africa.<br>All eight interviewees who talked about witchcraft were seven nurses of African Black background and a family member of African background. |
| Mukadam et al. (2011) | The study explored the connection between attitudes to help-seeking | Qualitative | Semi-structured interviews | Purposive<br>5 Indian<br>5 African or Caribbean<br>1 Irish | UK | 18 | Thematic analysis | BME ethnic carers tended to delay help-seeking until they could no longer cope, and dementia | Participants were accessing formal health services. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | for dementia and the help-seeking pathway in BME and the indigenous people. | | | 1 white other<br>1 Chinese<br>1 Asian other<br>4 white British<br>Gender:<br>13 Female<br>5 Male<br>Age: 27 -85 yrs.<br>Location: London | | | | symptoms were perceived as a normal part of ageing. Beliefs affected their level of engagement with formal services. | Multi-modelling of ethnicity in the study and the data did not separate Africans from the Caribbean. |
| Mushi et al. (2014) | The study explored social representation, perception and practices related to dementia. | Qualitative | In-depth Interviews | Purposive<br>25 PWD and carers (paired interviews)<br>16 carers<br>Gender:<br>26 Female<br>15 Male<br>Age: 70+<br>Location: Hai District (Demographic Surveillance Site) | Tanzania (Africa) | 41 | Content analysis | Four themes emerged:<br>Low knowledge of dementia<br>The conceptualisation of dementia as a normal ageing process.<br>The belief that dementia is a curse or witchcraft.<br>PWD and carer demonstrated pluralistic behaviour in seeking help from | The study was limited by biases from participants that might have given socially desirable answers.<br>Biases limited the study from the paired interviews; the caregivers’ views might have been |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | modern care, prayers and traditional healers. | more dominant in some aspects than those of PWD.<br>The study was Limited by age range. |
| Nwakasi et al. (2021) | The study explored attitudes about dementia and caregiving in Nigeria. | Qualitative | Semi-structured interviews. | Purposive<br>12 adults were interviewed in Nigeria (only women)<br>Age: 32 -76<br>Location: Anambra state in Nigeria.<br>Afterwards, results were presented to focus groups of 21 Nigerian adults residing in the United States. | Nigeria (Africa) | 12 | Thematic analysis | The study suggested that knowledge deficit, poor awareness, and traditional spiritual beliefs drove dementia-related stigmatisation in Nigeria. | The interviews conducted in Nigeria were limited to women. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | Gender: Male and Female.<br>Age: 29 – 59 yrs. | | | | | |
| Owokuhaisa et al. (2020) | The study explored community perceptions about people with dementia in the south of Uganda. | Qualitative | Focus group and in-depth interviews | Purposive<br>2 Traditional healers<br>5 Local council leaders<br>3 community elders<br>10 Religious leaders<br>2 community development officers<br>In December 2018<br><br>Gender:<br>14 Male<br>8 Female<br>Age: 22 -84<br>Location:<br>Nyakabungo<br>Kansharira<br>Nyakakoni | Uganda (Africa) | 22 | Thematic analysis | Five themes emerged and included:<br>Labelling the illness,<br>Presentation of the person with dementia,<br>Causation of dementia and<br>Impact of the disease.<br>How to address unmet needs in dementia care.<br><br>Dementia commonly referred to as ‘mental disorientation’, and dementia was also perceived as a normal part of ageing. The causes of dementia were attributed to witchcraft, life stress, infections and poor nutrition. | The study was focused on rural communities in southern Uganda, thus limited in geographical areas.<br><br>The study did not explore attitudes towards dementia.<br>The study did not separate findings with age. |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Parveen et al. (2017) | The study explored perceptions of dementia and the use of services in minority ethnic communities using Leventhal's Model of Self-Regulation. | Mixed | Discussion groups and dementia knowledge quiz | Roadshows<br>62 British Indians<br>50 Africans and Caribbean<br>63 East and Central Europeans between August 2013 and April 2014.<br>Gender: not stated<br>Age: not stated<br>Location: North of England | UK | 175 | Thematic and framework analysis | All groups attributed a biological cause to dementia.<br>African, Caribbean, and Indian groups focused on religion and spirituality as a method for personal control or cure. And associated stigma.<br>The East and Central European group focused on keeping the mind of a person living with dementia active.<br>There was a lack of awareness of the existence of specialist dementia services. | Findings not contextualised, e.g. no information collected in the context of participants' age, gender or socioeconomic status.<br>A quiz is not a sufficient method to capture quantitative data.<br>Naturally occurring data was hugely relied on.<br>Multi-modelling of ethnicity in the |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | study and the data did not separate Africans from the Caribbean. Participants in the Roadshows were aware of dementia beforehand. |

## Appendix 13: Coding (Evidence synthesis)

Table 7. Thematic analysis (coding) of the included papers using grounded theory approach

| Participants' own words as evidence. | Focus coding | Theoretical coding | Category | Themes |
|---|---|---|---|---|
| 'We think the problem is beyond human control…only God knows the solution' (Mushi et al., 2014:4). | Dementia is a myth. | Cultural construct | Religiosity | Witchcraft paradigm |
| 'We would pray that a miracle happens and see her getting healed' (kakongi et al., 2020:7) | Dementia is a myth | Cultural construct | Religiosity | Witchcraft paradigm |
| 'You know in the village; they will think that somebody is bewitching [or causing evil spell on] that person [with dementia]' (Nwakasi et al., 2021:1452) | Dementia is witchcraft | Cultural construct | Spirituality | Witchcraft paradigm |
| 'Some people are saying somebody [sorcerer/witch] is trying to manipulate her [person with dementia]. (Nwakasi et al., 2021:1453) | Dementia is a myth. | Cultural construct | Sorcery | Witchcraft paradigm |
| 'Churches should open drop-in centres where take our patients during the day…Churches and NGOs should actively be involved in this problem | Dementia is a myth. | Lay concepts | Religiosity | Witchcraft paradigm |

| | | | | |
|---|---|---|---|---|
| like other social problems' (Mushi et al., 2014:5). | | | | |
| '…The family and friends and the congregation and the church people. You know …that helped us a lot. We are going through everything, not without the Lord and that helps us a lot' (Mahomed & Pretorius, 2021:641). | Dementia is myth | Lay concept | Religiosity | Witchcraft paradigm |
| 'I am consulted for my medical and spiritual competence' (Kehoua et al., 2019:169). | Dementia is a myth. | Sociocultural construct | Spirituality | Witchcraft paradigm |
| 'Culture plays an important role [in Nigeria]. Some people think there's no natural illness. It [dementia] could be as a result of karma' (Nwakasi et al., 2021:1453). | Dementia is karma | Sociocultural construct | Spirituality | Witchcraft paradigm |
| 'I have already heard of dementia…but there are demons in all dementia: Matthew 17 verse 21: This type of demons comes out only through prayer and fasting' (Kehoua et al., 2019:170). | Dementia is a myth. | Lay concept | Spirituality | Witchcraft paradigm |

| | | | | |
|---|---|---|---|---|
| '… that's when we got to know that the problem [dementia] was a demonic attacks' (Kakongi et al., 2020: 7). | Dementia is a myth | Lay concept | Spirituality | Witchcraft paradigm |
| 'They say 'that one has been bewitched'…they go to these old people, vandalise their houses, burn their houses …they accuse them of being witches' (Mkhonto and Hassen, 2018:172). | Dementia is witchcraft | Social constructionism | Spirituality | Witchcraft paradigm |
| 'They say 'that one has been bewitched'… (Mkhonto and Hassen, 2018:172). | Dementia is witchcraft | Cultural construct | Spirituality | Witchcraft paradigm |
| 'It took just one death of her grandson for her to be accused of mystical practices…' (Kehoua et al., 2019:171). | Dementia is a myth. | Sociocultural construct | Spirituality | Witchcraft paradigm |
| '…but I noticed that sometimes he will be filled with some powers and because he is not himself…the dwarfs wanted to possess him…' (Agyeman et al., 2019:905). | Dementia is a myth | Sociocultural construct | Spirit possession | Witchcraft paradigm |
| '…that is when the devil left her and got back in, I think, and the healers kept | Dementia is a myth. | Lay concept | Spirituality | Witchcraft paradigm |

| | | | | |
|---|---|---|---|---|
| on saying ‘get out, get out! This is Jesus blood’ (Hindley et al., 2016:134). | | | | |
| ‘…they fight our world through devils while we fight their world through prayers’ (Hindley et al., 2016:134) | Dementia is a myth. | Lay concept | Spirituality | Witchcraft paradigm |
| ‘They must think that if they see the ‘gogo’ [IsiZulu word for ‘Grandmother’ she is a witch…’ (MKhonto and Hanssen, 2018:172). | Dementia is a myth. | Social constructionism | Spirituality | Witchcraft paradigm |
| ‘…I am not going to eat it because the granny is a witch’ (Mkhonto and Hassen, 2018:172). | Dementia is old age. | Social constructionism | Body | Older age paradigm |
| ‘A lot of people, even the relatives, don’t want to be close to her because they believe she is a witch’ (Mkhonto and Hassen, 2018:172). | Dementia is a myth. | Social constructionism | Stigma | Witchcraft paradigm |
| ‘Yes, they don’t go to the doctor, they go to the spiritualist’ (Berwald et al., 2016:11). | Dementia is a myth. | Lay concept | Spirituality | Witchcraft paradigm |
| ‘The church system is now basically discouraging people to go to for medical help because everything is | Dementia is a myth | Lay concept | Spirituality | Witchcraft paradigm |

|  |  |  |  |  |
|---|---|---|---|---|
| spiritual now…that happens a lot in black churches (Berwald et al., 2016:11). |  |  |  |  |
| …'religion is helpful' (Parveen et al., 2017:738). | Dementia is a myth | Lay concept | Religiosity | Witchcraft paradigm |
| 'We pray for the family because remember I have the church. So, we on Wednesday we pray for everybody…we pray for people. We pray…so, we pray…So, we really prayed' (Armstrong et al., 2022:10). | Dementia is a myth | Lay concept | Religiosity | Witchcraft paradigm |
| 'I think my faith has helped me. Not I think, I know my faith has helped me' (Armstrong et al., 2022:10). | Dementia is a myth | Lay concept | Spirituality | Witchcraft paradigm |
| 'they use to give sacrifice to the ancestors so due to her age she cannot afford to give sacrifice to them so they get annoyed and cause all these problems' (Hindley et al., 2016:133). | Dementia is a myth. | Social constructionism | Spirituality | Witchcraft paradigm |
| '…As you get older- What's going to happen to you? (Berwald et al., 2016:11). | Dementia is old age | Lay concept | Body | Older age paradigm |
| '…it is not sickness so that is why we did not tell | Dementia is sickness | Identity theory | Body | Identity paradigm |

| | | | | |
|---|---|---|---|---|
| the doctor' (Agyeman et al., 2019:905). | | | | |
| 'Where I came from there's no definition of dementia, an old person is starting to forget, [it's] part of growing old' (Berwald et al., 2016:11). | Dementia is normal ageing | Social constructionism | Body | Older age paradigm |
| 'They think it's do with old age' (Parveen et al., 2017:738). | Dementia is old age | Social constructionism | Body | Older age paradigm |
| 'We call it old age, when a person becomes elderly his knowledge reduces and he starts forgetting' (Owokuhaisa et al., 2020:3). | Dementia is old age | Social constructionism | Body | Older age paradigm |
| 'I think its old age because old age takes everything, when you become elderly you get disconnected' (Owokuhaisa et al., 2020:5). | Dementia is old age | Social constructionism | Body | Older age paradigm |
| 'For me for, a person become elderly and become forgetful, I think that its old age' (Owokuhaisa et al., 2020:5). | Dementia is forgetfulness | Lay concept | Mind | Older age paradigm |
| 'You see, whoever is forgetful will not be in charge of | Dementia is forgetfulness | Biomedical concept | Mind | Disease and Illness paradigm |

|  |  |  |  |  |
|---|---|---|---|---|
| anything…hardly would he remember…He would say he has forgotten' (Adebiyi et al., 2016:272). |  |  |  |  |
| '… then I already mentioned to you that when I tell her something immediately I come back to ask again she has forgotten about it' (Agyeman et al., 2019:903). | Dementia is forgetfulness | Lay concept | Mind | Disease and Illness paradigm |
| 'I know age is one [cause] of dementia and I believe we all know that the older we become the more our mind becomes stale' (Adebiyi et al., 2016:271). | Dementia is old age | Social constructionism | Mind | Older age paradigm |
| '…I think that is how the human brain is…when you are young it works well but when you grow old it does not work well…so when someone becomes old then every part of the body too becomes old' (Agyeman et al., 2019:904). | Dementia is normal ageing | Social constructionism | Body | Older age paradigm |
| '…we accept that it is age and it has no cure' (Owokuhaisa et al., 2020:5). | Dementia is normal ageing | Social constructionism | Body | Older age paradigm |

| | | | | |
|---|---|---|---|---|
| '… that one (meaning forgetfulness) is old age that has no medicine and there is no cure for it' (Kakongi et al., 2020:8) | Dementia is normal ageing | Social constructionism | Mind | Older age paradigm |
| 'I've been working at the old age [home]. I saw them…' (Mkhonto and Hassen, 2018:172). | Dementia is old age | Social constructionism | Body | Older age paradigm |
| 'There is no name for this problem because I have seen many old people having this problem…' (Hindley et al., 2016:133). | Dementia is old age | Social constructionism | Body | Older age paradigm |
| 'In Africa, when an old man dies, it is a library that burns' (Kehoua et al., 2019:171). | Dementia is old age | Social constructionism | Body | Older age paradigm |
| 'People are like cars: the longer they run, the worse it gets' (Hindley et al., 2016:133). | Dementia is old age | Metaphor | Body | Older age paradigm |
| '…When a person reach sixty he's supposed to start losing his memory' (Botsford et al., 2011:2211). | Dementia is forgetfulness | Lay concept | Mind | Older age paradigm |
| 'akuzire' (old age) (Owokuhaisa et al., 2020:3). | Dementia is old age | Sociocultural construct | Body | Older age paradigm |
| 'empinduka ya bukuru' (old age) (Owokuhaisa et al., 2020:3). | Dementia is old age | Sociocultural construct | Body | Older age paradigm |

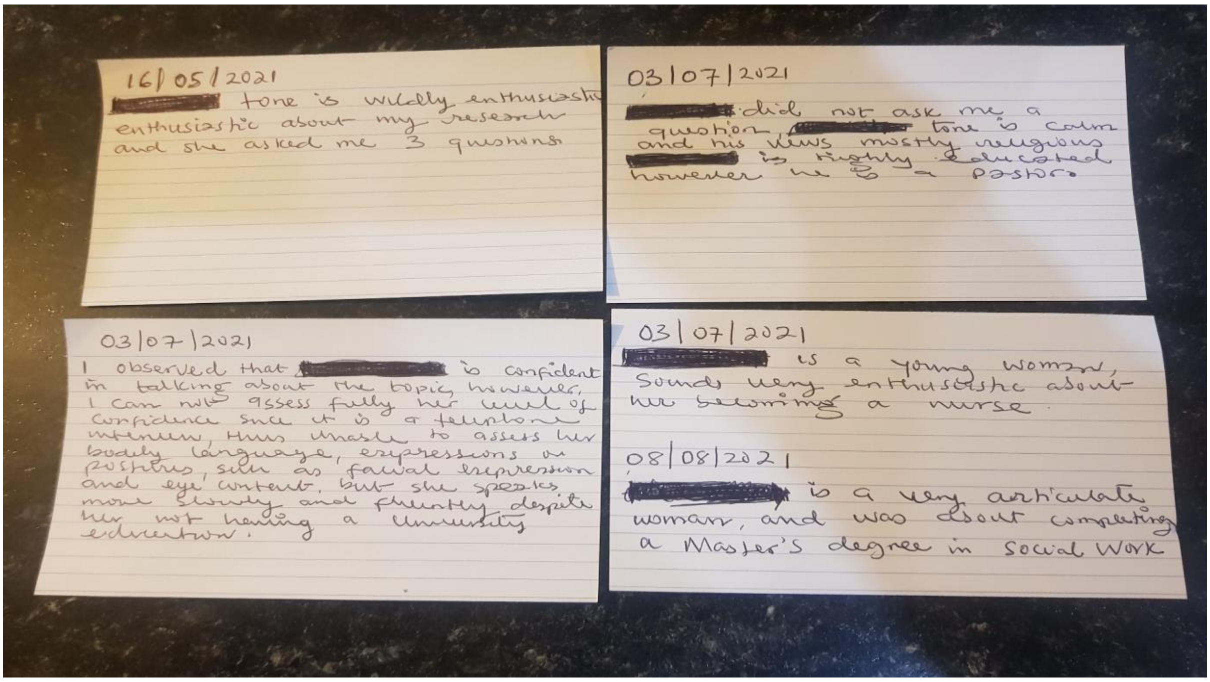
| | | | | |
|---|---|---|---|---|
| ‘People with dementia was HIV-positive and epileptic…’ (Kehoua et al., 2019). | Dementia is a disability | Biomedical concept | Body | Disease and Illness paradigm |
| ‘Dying of brain cell’ (Parveen et al., 2017:737). | Dementia is a disease | Biomedical concept | Body | Disease and Illness paradigm |
| ‘Can it be inherited?’ (Parveen et al., 2017:737). | Dementia is a disease | Biomedical concept | Body | Disease and Illness paradigm |
| ‘The government should look for proper medication for dementia’ (Mushi et al., 2014:5). | Dementia is a disease | Biomedical concept | Body | Disease and Illness paradigm |
| ‘…We did not send him to hospital to treat this kind of illness…’ (Agyeman et al., 2019:906). | Dementia is an illness | Lay concept | Body | Disease and Illness paradigm |
| ‘…But when she grows very old and has all kinds of small, small illness that where the problem can be…’ (Agyeman et al., 2019:908). | Dementia is an illness | Lay concept | Body | Disease and Illness paradigm |
| ‘Another thing which causes forgetfulness among the elderly, there is when you find a person has suffered from a disease for a long time like cancer and he takes different types of | Dementia is a disease | Biomedical concept | Mind | Disease and Illness paradigm |

| | | | | |
|---|---|---|---|---|
| medicine…' (Owokuhaisa et al., 2020:4). | | | | |
| 'I wish I was better educated in terms of knowing and identifying the symptoms…' (Mahomed & Pretorius, 2021:644). | Dementia is a disease | Biomedical concept | Body | Disease and Illness paradigm |
| Syphilis ('ebinyoro'), cancer ('ekokoro'), allergy ('efumbi') as causes of dementia (Owokuhaisa et al., 2020:4). | Dementia is a disease | Biomedical concept | Body | Disease and Illness paradigm |
| 'The hospital, to be honest, were terrible. I will be honest. We were outside clapping for carers, I think they were a disgrace in terms of dementia…the actual medical support she got was very thorough' (Armstrong et al., 2022: 7). | Dementia is an illness | Biomedical concept | Body | Disease and Illness paradigm |
| '…then, when I was allowed, I was told, 'he is ill'… (Armstrong et al., 2022:9). | Dementia is an illness | Biomedical concept | Body | Disease and Illness paradigm |
| 'It is an illness…' (Nwakasi et la., 2021: 1452). | Dementia is an illness | Lay concept | Body | Disease and Illness paradigm |

| | | | | |
|---|---|---|---|---|
| '…and if you see her you won't even know that she is having such sickness' (Nwakasi et al., 2021:1453). | Dementia is a sickness | Identity theory | Body | Dementia identity paradigm |
| 'atabukiire/okuhungutuka' meaning 'mad' or 'mentally disturbed' (Owokuhaisa et al., 2020:3). | Dementia is madness | Social constructionism | Mind | Disease and Illness paradigm |
| '...Had it not been that he is old we will say he is mad' (Agyeman et al., 2019:909). | Dementia is madness | Identity theory | Mind | Dementia identity paradigm |
| 'They [the villagers] called me asking and saying if it is madness that is happening to my gradma' (Nwakasi et al., 2021:1453). | Dementia is madness | Identity theory | Mind | Dementia identity paradigm |
| 'Dementia is a taboo subject; people are ashamed to speak about it (Parveen et al., 2017:738). | Dementia is a taboo | Social constructionism | Stigma | Witchcraft Paradigm |
| 'I have been trying to hide…keeping this to myself' (Jacobs et al., 2022:11). | Dementia is a taboo | Lay concept | Stigma | Witchcraft Paradigm |
| '…now that it is getting worse, [I] hide myself' (Jacobs et al., 2022:11). | Dementia is a taboo | Lay concept | Stigma | Witchcraft Paradigm |

| | | | | |
|---|---|---|---|---|
| ‘Losing their [loved ones] for example children and grandchildren causes memory loss’ (Owokuhaisa et al., 2020:5). | Dementia is memory loss | Biomedical concept | Mind | Disease and Illness paradigm |
| ‘I used to go to the clinic because I had severe headaches, and I was starting to lose memory. I would forget even like simple things in the house. I would put a thing a thing here, and the next 10 minutes, I can’t recall where I put it’ (Jacobs et al 2022:20) | Dementia is memory loss | Biomedical concept | Mind | Disease and Illness paradigm |
| ‘She is crazy…’ (kehoua et al., 2019:169). | Dementia is craziness | Identity theory | Mind | Dementia identity paradigm |
| ‘Oh they are going to think I am crazy or mad…’ (Jacobs et al., 2022:11). | Dementia is craziness | Identity theory | Mind | Dementia identity paradigm |

# Appendix 14: Field Notes/Memos



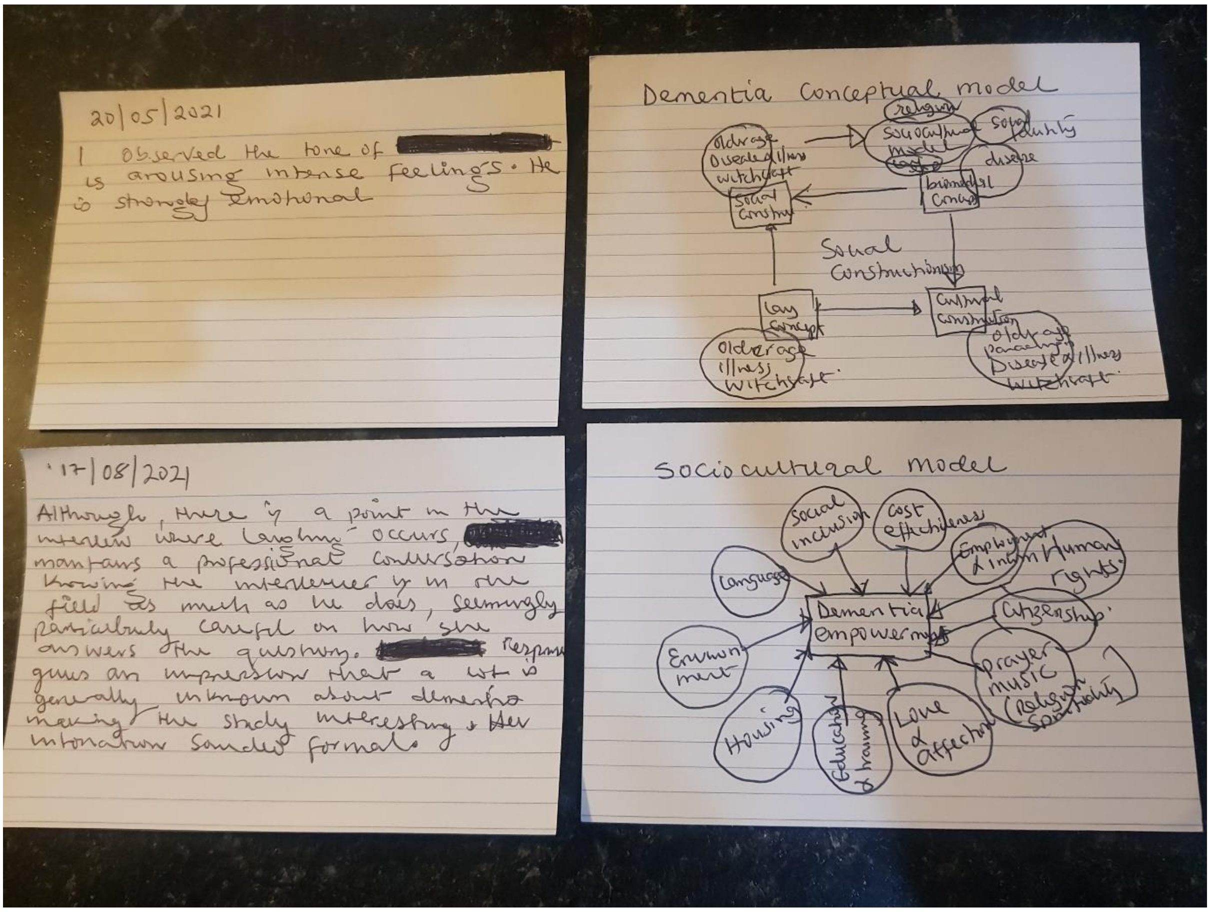
16/05/2021
[redacted] tone is wildly enthusiastic enthusiastic about my research and she asked me 3 questions.

03/07/2021
[redacted] did not ask me a question, [redacted] tone is calm and his views mostly religious [redacted] is highly educated however he is a pastor.

03/07/2021
I observed that [redacted] is confident in talking about the topic, however, I can not assess fully her level of confidence since it is a telephone interview, thus unable to assess her bodily language, expressions or postures, such as facial expression and eye contact, but she speaks more slowly and fluently despite her not having a University education.

03/07/2021
[redacted] is a young woman, sounds very enthusiastic about her becoming a nurse.

08/08/2021
[redacted] is a very articulate woman, and was about completing a Master's degree in Social Work



20/05/2021
I observed the tone of [redacted] is arousing intense feelings. He is strongly emotional

17/08/2021
Although, there is a point in the interview where laughing occurs, [redacted] maintains a professional conversation knowing the interviewer is in the field as much as he does, seemingly particularly careful on how she answers the questions. [redacted] Response gives an impression that a lot is generally unknown about dementia making the study interesting & her intonation sounded formal.