

London South Bank University

**Exploring the lived experience of the individual of Black ethnicity
living with dementia: A phenomenological study**

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Abstract

In the United Kingdom(UK), Black and Minority Ethnic(BME) groups are more at risk of developing Vascular Dementia and experience a higher rate of younger-onset dementia (≤ 65 years), compared with the majority ethnic White British population. Despite this, BME people living with dementia in the UK, are under-represented in health services. They receive a diagnosis later in their disease progression and are less likely to access dementia services. There is a growing body of work in the UK exploring dementia experiences within Asian communities. However, there is limited research, considering the experiences of individuals of Black ethnicity living with dementia in the UK. This study aimed to explore the lived experience of dementia focusing on individuals of Black ethnicity living in four North East London Boroughs. The investigation sought to provide an understanding of what constitutes *'living with dementia as a person of Black ethnicity'*; and presents an interpretation of this. Interpretive phenomenology based on the work of Heidegger (1927) was used to explore the experiences of six participants. Data was collected through a series of three semi-structured interviews with each participant, audio recorded and transcribed verbatim. Thematic data analysis was conducted, using a framework by Braun and Clarke (2006). A phenomenological interpretation identified three overarching themes: Life before Dementia, Journey to Diagnosis and Living with Dementia. The role of God and Religion was significant throughout the different stages of life and influenced the decision-making process to access health services. In totality, the themes represent the lived experience of living with dementia for the individuals of Black ethnicity who participated in this study. Through exploring the lived experience of dementia, this study provides some insight into the barriers to dementia service uptake in this population and their understandings of dementia.

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It is to my family, to whom I dedicate this thesis. Without their constant love and tolerance, I could have never hoped to have finished this work. I can, at last, say to them 'Yes I have finished!'.

Above all, ***I thank my God Jehovah***, for none of this would be possible without His blessing and favour. Never have the words of Psalm 66 verse 16-17 and 19-20 (The Bible - New International Version) meant so much to me.

*'Come and hear, all you who fear God;
let me tell you what he has done for me.
I cried out to him with my mouth;
his praise was on my tongue...but God has surely listened
and has heard my prayer. Praise be to God,
who has not rejected my prayer
or withheld his love from me!'.
Amen.*

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

Dementia remains a national challenge in the UK (Alzheimer's Society, 2015). Due to the increasing incidence rates and cost of care of dementia in the UK, there is an increased momentum to tackle the challenges presented by living with dementia; with a commitment from government to improving diagnosis, care and support, and research (Department of Health [DH], 2015). This thesis focuses on exploring the lived experience of dementia from the perspective of the individual of Black ethnicity. Available studies show that the prevalence of dementia within the Black African and Caribbean groups is higher, with a younger onset of dementia compared with the indigenous White British population in the UK (Adelman *et al.* 2009; 2011). However, people from BME groups present later to dementia services, with a more advanced disease at presentation (Mukadam *et al.* 2011; Tuerk and Sauer, 2015). It is essential therefore that the needs of individuals of BME groups, who are living with dementia, are met by accessible and responsive services (All-Party Parliamentary Group [APPG] on Dementia, 2013).

This chapter introduces the thesis and sets the scene in exploring the lived experience of dementia specifically from the perspective of the individual of Black ethnicity, using a phenomenological approach (Heidegger, 1962). This chapter presents the primary research question, the aim and objectives and a summary of the research methodology as well as the importance of the study. It also presents my motivation for undertaking this study and an overview of the thesis, including the contribution of this study to the existing body of knowledge.

1.2 Background to the study

The overarching aim of this study from the outset was to explore the experience of dementia from the perspective of individuals of Black ethnicity living within the four North East London Boroughs of Barking and Dagenham, Havering, Redbridge and Waltham Forest. Dementia in this study is an umbrella term used to describe a set of cognitive, emotional, behavioural and physical symptoms, caused by structural changes in the brain due to progressive diseases or injuries (World Health Organisation [WHO], 2012; Alzheimer's Disease International [ADI], 2016). The most common is Alzheimer's disease and Vascular Dementia; whilst rarer causes of dementia include dementia with Lewy bodies and frontotemporal dementia (Gupta *et al.* 2009; Alzheimer's Society, 2015; DH, 2015). The term dementia in this study is used to reflect all types of dementia in line with the above definition.

Using the internationally recognised Delphi consensus methodology, it is expected that the number of people living with dementia in the UK will be around 850,000 by 2021 (Alzheimer's Society, 2014). An estimated 25,000 people from Black and Minority Ethnic [BME] groups are thought to also have the condition (APPG, 2013). A study by Etkind *et al.* (2017) estimates that by 2040, 219,409 people in England and Wales will die from dementia - a significant rise from 59,199 in 2014. Therefore, there is a need to make sustainable improvements for people living with dementia; delivering personalised and compassionate care from diagnosis through to end of life (DH, 2015).

1.3 Motivation for the study

My motivation for this research comes partly from my experience as a Modern Matron working within primary care, supporting people living with a dementia diagnosis within inpatient units. At the time, when commencing this work, despite the rising numbers of people living with dementia, public understanding of the condition was limited, with people not understanding dementia or how to support those affected by it (DH, 2013). I conducted an audit within the inpatient wards at a community hospital at which I was employed; to assess the knowledge of dementia among nursing and therapy staff working in the older people's rehabilitation service, to identify the specific needs of nursing staff and to utilise the information obtained to inform an action plan tailored to local context. The questionnaire chosen for this work used the approved Approaches to Dementia Questionnaire (ADQ) developed by Lintern *et al.* (2000); a Likert-type instrument with 19 items. The Approaches to Dementia Questionnaire measured hopefulness and person-centred approaches to dementia (Lintern *et al.* 2000). 90 staff members who regularly participated in the care of dementia patients received a copy of the questionnaire (Lintern *et al.* 2000). This included registered nurses, nursing healthcare assistants, clinical administration staff and inpatient registered therapy and assistant practitioner staff. There was a low response rate of 33 respondents. The training needs analysis utilising the Approaches to Dementia Questionnaire identified that a more positive approach to dementia patients was needed; there were gaps identified in staff knowledge about dementia and the skills required to meet the care needs of dementia patients. Within the NHS organisation at the time the audit was completed, no dementia training was being provided. It became clear to me then, that the health professionals felt they were not equipped to care for patients presenting with dementia. Although at that stage I lacked skills as a researcher, my enthusiasm in this research area and role as a Modern Matron led to my publishing this work in a Journal (Mawaka, 2012). Some four years later, the Alzheimer's Society 2016 report 'Fix Dementia Care: Hospitals' found that good dementia care in hospitals

was still lacking and that the quality of care varied widely between hospitals (Alzheimer's Society, 2016).

My emerging academic interest in dementia suddenly became intertwined with personal experience. The experience of a close family member receiving an early onset diagnosis of dementia came as a surprise; however, it was my own inability to identify early symptoms of dementia that I struggled with. It was not that I was not aware of dementia; rather it was the notion that I immediately dismissed the early symptoms of dementia as '*dementia does not happen to Black people*'; at least, not those of sub-Saharan African origin. Perhaps the nurse in me immediately chose not to acknowledge the reality of the situation and that this was a coping mechanism for dealing with the possibility of a dementia diagnosis within the family and as I could foresee some of the difficulties ahead. Whichever of these rambling thoughts were true, it seemed clear that my immediate reaction did not fit the perspective of the professional nurse. I was left questioning my own understanding of dementia. I wondered if my background, beliefs and culture as an individual of Black African ethnicity, had allowed me to develop a view of dementia that was perhaps too narrow.

Understanding my ethnic and cultural background is essential for any reader of this thesis. I am a woman from a Sub-Sahara African country and of Black ethnicity, born and raised in Zimbabwe. I moved to the UK as an Adult. I recalled that during my 18 years of childhood in Zimbabwe, I had never encountered any relations, friends or elders in my large extended community with a diagnosis of dementia. As I look back I realise, that life was quite simple, with family social structures to look after the elderly - dementia just did not '*happen to Black people*' in Zimbabwe. I recall as a child being aware that there were diseases that affected '*White people*' in the western world and perhaps dementia was one such disease.

Within my community, there is no word for dementia. Symptoms of dementia are culturally most often thought of as a normal part of the ageing process. In addition, the traditional non-nucleus family structure and reliance upon religion and spirituality act as a buffer against deleterious health outcomes such as dementia. Traditional healing, religion and spirituality are indeed deeply embedded in my culture; strength and solace are found in religion and strong familial relationships. Being born of a mother who is a Jehovah's Witness and a father who believed in the traditional African religion of reverence of ancestors, commonly known as '*amadlozi*' in my vernacular language; I know too well how cultural and religious beliefs are intertwined and their influence, ranging from witchcraft to spiritual healing.

My experiences are not unique. Berwald *et al.* (2016) in their UK study of Black African and Caribbean British Communities' perceptions of memory problems observed that participants of African origin also expressed that they did not have to consider dementia in their home country and often thought it only affected their white counterparts. The Alzheimer's Disease International [ADI] (2017) report on dementia in sub-Saharan Africa, found that no equivalent term for dementia was identified in any local languages, and there is a general lack of awareness of dementia among sub-Saharan African communities. In a survey of knowledge, attitudes and practices towards people with dementia in the township of Khayelitsha South Africa; 28% of their participants thought that dementia was associated with witchcraft and 26% thought it was a punishment, from Ancestors and God. The respondents in their study believed traditional healers could cure dementia (Khonje *et al.* 2015). Awareness and understanding of dementia among the sample was very low, which had important implications for individuals' likelihood to seek dementia support, as this may have put them at risk of harm related to the conflation of dementia symptoms with witchcraft (Benade, 2012; De Jager *et al.* 2015; Khonje *et al.* 2015). Therefore, my close encounter with an early onset diagnosis of dementia would certainly be viewed as 'witchcraft', without the label of ageing.

Data on the epidemiology of dementia in Sub-Saharan Africa is limited, as few studies to determine the prevalence of dementia have been conducted in sub-Saharan Africa (George-Carey *et al.* 2012; Prince *et al.* 2013; Olayinka and Mbuyi, 2014). It is estimated that 2.13 million people were living with dementia in sub-Saharan Africa in 2015, with numbers projected to nearly double every 20 years, increasing to 3.48 million by 2030 and 7.62 million by 2050 (ADI, 2017). Available studies note that dementia is often unrecognised by primary care practitioners, with signs and symptoms often ascribed simply to old age (de Jager *et al.* 2015). Research and media attention in the Sub-Saharan is mainly given to the diseases with higher case fatality, such as HIV, AIDS and malaria (George-Carey *et al.* 2012).

Our histories cling to us and I am shaped by where I come from. I retain some cultural and religious values, rooted in my African heritage informed by my education, family and social networks. I write about my Zimbabwean experience because being a Zimbabwean is what I know. By narrating my own experience of facing the reality of a possibility of a dementia diagnosis of a family member, I can perhaps explicate some issues in understanding the lived experience of dementia; the different perspectives that are likely to emerge from the accounts of other individuals specifically of Black ethnicity living with dementia. My background also meant that I stood as an 'insider' in this research study, investigating a phenomenon with participants who came from a similar ethnic background. Like Gilroy (1994 cited in Owusu, 2003 p.128), I am thinking about '*my being Black and growing old in Britain*'. This I believe

influenced the way I have planned, collected, interpreted, analysed and constructed the outcome of this study.

1.4 Ethnicity

Attempting to define the term '*ethnicity*' historically, invites debate and much discussion (Ballard, 1996; Lane and Hearsom, 2007). Ethnicity can be described as a shared culture, language, religion, tradition, heritage and geographical origins (Helman, 2000). It is beyond the scope of this thesis to debate the definition of ethnicity; therefore, the term '*ethnicity*' I used in this study, refers to the working definition of ethnicity from the 2011 Office of National Statistics (ONS) document 'Population Estimates by Ethnic Group: Methodology Paper', - which advises that ethnicity is a way in which individuals define their personal identity; that one's ethnic group is self-assigned. I used the 2011 Census information from the Office of National Statistics as it the recognised national statistical institute of the UK and is the most recent official Census that presents ethnicity statistics for the entire UK.

The paper notes that defining ethnicity is complex and that a person's ethnic group can change over time and description of ethnic groups can evolve or change depending upon different contexts (ONS, 2011). This work focuses on individuals of Black ethnicity living with dementia. The classification adopted in this work is that that is used in National Statistics by the ONS. This 16-way classification was adopted in the 2001 Census and 2011 Census, where individuals of Black ethnic origin identify or describe themselves using the terms below:

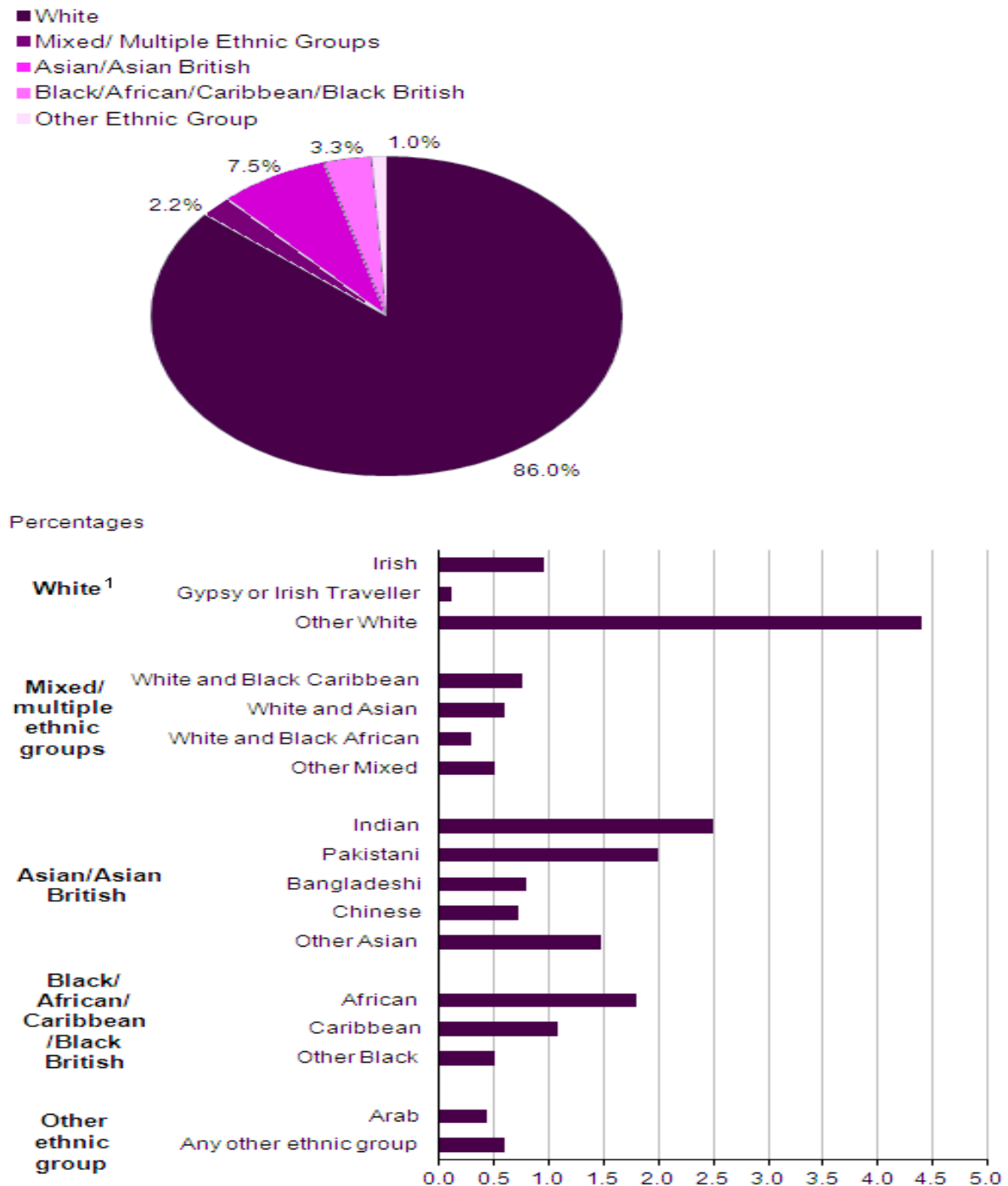
- *Black/ African/Caribbean/Black British*
- *Black African*
- *Black Caribbean*
- *Black British*
- *Any other Black/African/Caribbean background*

As mentioned above, descriptions of ethnic groups or identity changes over time, as such the following terms are also currently in use to describe Black ethnicity:

- *African Caribbean*
- *Afro-Caribbean*

As such this paper considers Black ethnicity to include all the terms as listed above. Ever since 1991, the UK Census has included a question on ethnicity (ONS, 2012). The 2011 Census showed that the White ethnic group accounted for 86.0 % of the usually resident population in 2011 (ONS, 2012). Figure 1.0 provides a further breakdown of the UK ethnicity data showing that *Black/African/Caribbean/Black British* make up almost 3.3% of the UK population (ONS, 2012).

Figure 1.0: Ethnic groups, England and Wales, 2011 (Source: Taken from Office for National Statistics (2012) Ethnicity and National Identity in England and Wales: 2011 p. 3)



Ethnicity is an ever-changing phenomenon, which may change and shift throughout time and life course (Lane and Hearnsum, 2007). However, what has remained fixed over time, is the assumption of an ethnic majority that is White, of British origin, and English-speaking (ONS, 2003). Over the last two decades whilst England and Wales has become more ethnically

diverse (ONS, 2012). The Census shows that the most noticeable growth has been with the Black African ethnic group, which has been growing faster than any other Black ethnic minority group in the last two decades and doubling in each decade to reach 989,628 in 2011 (Jivraj, 2012; ONS, 2012). The Census findings show that Black Africans are the dominant Black ethnic group, over other Black ethnic backgrounds in the UK (see Figure 1.0). Throughout this study, I have used official census categories for different ethnic groups e.g. White British, Black African.

1.4.1 Culture

Ethnicity is related to culture, and one's ethnic background or ethnicity impacts on cultural beliefs or practices. Culture, in this work, is defined as views, beliefs, understandings that are learned, shared and passed on from one generation to the next, and are evident in daily practices, values, norms and way of life (Kreuter *et al.* 2003). An individual's cultural beliefs can impact on one's understandings of the meaning of illness, e.g. their understanding of dementia. Consequently, one's understanding of the meaning of illness may significantly affect an individual's attitude towards approaches or compliance with treatment and access to services (Remennick, 2006).

1.5 Dementia in Black and Minority Ethnic groups

Literature has identified that older people from BME groups in the UK have high rates of general practice registration and consultation, however, their rates of contact with dementia services are low (Shah *et al.* 2005). The underrepresentation of BME groups in dementia services is a policy concern (Daker-White *et al.* 2002; DH, 2016). The next section explores the definition of BME groups and presents the picture in North East London where this study took place.

1.5.1 Black and Minority Ethnic groups defined

A definition of BME groups from Manthorpe and Hettiaratchy (1993) describes BME groups as those with a cultural heritage distinct from the majority population. The definition of BME people used in the UK government document Delivering Race Equality in Mental Health Care (DH, 2005, p.11) was:

“all people of minority ethnic status in England. It does not only refer to skin colour but to people of all groups who may experience discrimination and disadvantage, such as those of Irish origin, those of Mediterranean origin and East European migrants. It does not only

refer to skin colour but to people of all groups who may experience discrimination and disadvantage, such as those of Irish origin, those of Mediterranean origin and East European migrants”.

Whilst the complexity of defining BME groups is acknowledged, it is beyond the scope of this study to debate those complexities; therefore, in this study, this definition was considered as appropriate for this study as it is inclusive of the differences within BME groups. This study also notes that within current literature, the terms ‘*Black and minority ethnic*’, ‘*ethnic minority*’ and ‘*minority ethnic groups*’ are used interchangeably.

1.5.2 Prevalence of Dementia within BME groups in the UK

Even though BME communities make up 14% of the UK’s population in the 2011 Census (ONS, 2012), specific estimates of dementia prevalence for this group are lacking (Knapp *et al.* 2007; Dementia UK, 2014). There is a paucity of prevalence studies of dementia in BME groups (Botsford and Harrison-Dening, 2015). The prevalence of dementia in BME populations is assumed to be similar to that of the UK general population (Knapp *et al.* 2007; Shah *et al.* 2009; Dementia UK, 2014). As mentioned in section 1.2, it is thought that there are approximately 25 000 people from BME groups living with dementia (APPG, 2013). According to Adelman *et al.* (2011); findings from their two-stage cross-sectional study into the prevalence of dementia in Black African-Caribbean participants, compared with UK-born White British older people showed that the BME population in the UK and other Western countries is younger than the majority population and tends to have a higher proportion of younger onset dementia. This will change as a consequence of immigration patterns leading in the future to higher numbers of BME elders with dementia.

1.5.3 Dementia within the BME population in North East London

The 2011 Census showed that London was the most ethnically diverse area in the UK, with above average proportions for most minority ethnic groups including African (7.0%), Indian (6.6%), and Black Caribbean (4.2%). It also had the highest incidence of Any Other White population at 12.6%. This study was conducted within North East London in the Boroughs of Barking and Dagenham, Havering, Redbridge and Waltham Forest. These boroughs were identified because they are the boroughs that I was previously substantively employed; in addition, I lived in North East London. The constituent footprint of the North-East London Sustainability and Transformation Plan [NELSTP] that includes the above four boroughs; show that the four boroughs have an ethnically diverse population and continuing work towards early

diagnosis of dementia a priority (NELSTP 2016). Within the four North East London boroughs, where this study was carried out; using the prevalence estimates as described by Commissioning Support for London (2011), it is estimated that in relation to the prevalence of dementia within BME communities living in this area, the numbers are projected to increase three-fold from 584 in 2001 to 1786 in 2021 (Commissioning Support for London 2011).

The annual reports for three of the four Clinical Commissioning Groups [CCG] within which this study was completed, show that the dementia diagnosis rates for the year to March 2016 are below the national target of 66.7% (Barking and Dagenham, Redbridge and Havering CCG, 2016). Therefore, timely diagnosis of dementia and improving dementia access is a priority in this locality. It is important to note that overall there is currently a dementia diagnosis gap of 27% in London, which means that 73% of those who we would expect to have dementia, based on population prevalence rates are recorded on General Practitioner [GP] practice dementia registers (London Clinical Network, 2017). This is higher than the national average of 67.7%. The number of additional diagnoses required to meet London's population prevalence is 17,821 (≤ 65 only) (London Clinical Network, 2017).

1.5.4 Dementia with BME groups – the need for further research

With an increasingly diverse ethnic population in the UK, more epidemiological research is urgently required to clarify dementia prevalence and risk among BME groups (Alzheimer's Society, 2014) and to raise awareness within the BME community. Achieving timely diagnosis of dementia is a national priority, identified originally in the National Dementia Strategy (DH, 2009) and championed by the Prime Minister's Challenge Dementia 2020 document (DH, 2015). It comes as no surprise that evidence suggests that dementia diagnosis rates in BME groups are particularly poor; this provides the justification for adding ethnicity counts to national data collection, as the number of patients with a dementia diagnosis in their clinical record, broken down by ethnicity, is not currently consistently collected by NHS services (NHS Digital, 2017). Current data (May 2017) shows that 75.2% of patients on GP practice dementia registers had their ethnicity recorded as either 'Not stated' or 'No ethnicity code' (NHS Digital, 2017).

The All-Party Parliamentary Group on Dementia's inquiry report (DH, 2013) was significant in placing issues for BME communities and dementia at a national policy and political level not previously seen. The enquiry investigated the experiences of people from BME communities living with dementia in the UK (APPG, 2013). The report highlighted the few high-quality

services that are tailored to support people with dementia from BME communities (APPG, 2013). The report noted that services are too few and far between, and many people struggle on with too little support from the NHS or local government (APPG, 2013). The inquiry established that there is an urgent need to increase awareness of dementia among BME communities (APPG, 2013) as they remain underrepresented in specialist dementia services (Beattie *et al.* 2005; Parveen *et al.* 2016). Dementia within BME communities has since then, been included in various policy documents and there is a growing body of work exploring BME needs from various perspectives. This is further discussed in the next section.

1.6 National guidelines and policies

In the last few years, dementia has received much focus in terms of UK Government priorities and policy, resulting in the development of a wide range of public policy initiatives. Dementia presents a unique challenge for Health Service Commissioners; recent reports and increasing research have highlighted the shortcomings in the current provision of dementia services in the UK (Commissioning Support for London, 2011). The 'Healthcare for London: A framework for Action' document (2007) and the National Audit Office report: 'Improving services and support for people with dementia' (2007), were the first to highlight the fact that services were not provided consistently well across London for people with dementia and their carer's and that people with dementia, when admitted to acute hospital services, have worst outcomes in terms of length of stay, mortality and institutionalisation. As a result of this evidence the National Dementia Strategy (DH, 2009) was developed to try to ensure the needs of people with dementia were appropriately addressed in the future.

The policy document set out a five-year transformation plan for dementia under four themes: raising awareness and understanding; early diagnosis and support; living well with dementia and making the change (DH, 2009). Following on from this, the Prime Minister's Dementia Challenge was published in March 2012 to build on the National Dementia Strategy for England (DH, 2012). However, as mentioned in section 1.5.3, it was only when the All-Party Parliamentary Group Inquiry Report on Dementia within BME communities was published in 2013 (DH, 2013), that issues faced by BME communities were finally recognised at a national policy and political level (APPG, 2013). This level of political attention has continued as demonstrated by the Prime Minister's Challenge on Dementia 2020, which sets out future work to improve diagnosis rates. This includes reducing variation in rates across the country; improving waiting times for assessments and focusing on improving the diagnosis of dementia for people of Black, Asian and Minority Ethnic communities, for whom the evidence shows that diagnosis rates are particularly poor (DH, 2012).

Following on from this, the NHS Mandate 2015-16 reaffirmed the objective for NHS England to ensure two-thirds of the estimated number of people with dementia in England have a diagnosis, with post-diagnosis support. In March 2016, the Department of Health published an Implementation Plan which details how the Prime Minister's challenge on Dementia 2020 will be met (DH, 2016). The plan sets out priority actions, and the organisation responsible, across four themes:

- Risk reduction
- Health and care delivery
- Dementia awareness (and social action)
- Research

A key work stream detailed in the implementation plan includes working on reducing health inequalities within dementia service provision (DH, 2016). For BME communities, this is positive and includes actions such as the development of a resource to support staff groups working with people with dementia from different cultures and backgrounds. Health Education England released a dementia film- '*Finding Patience*' that focuses on the specific needs of the African Caribbean community within the care process (DH, 2016). In terms of service planning and commissioning, collection and access to ethnicity data will be a priority area of focus over the next year (DH, 2016). Currently, the Implementation Plan will be reviewed and evaluated in 2018.

With an understanding of the above national guidelines and policies, I developed an interest in understanding the lived experience of dementia within Black communities. What was striking; was how few studies directly report the perspectives of people living with dementia of Black ethnicity specifically within individuals who identify themselves as:

- *Black/ African/Caribbean/Black British*
- *Black African*
- *Black Caribbean*
- *Black British*
- *African-Caribbean*
- *Afro-Caribbean*
- *Any other Black/African/Caribbean background*

I noted that there is significant work in progress relating to understanding dementia experiences (as well as dementia caring or carer experiences) within Asian communities living in the UK (e.g. Bowes and Wilkinson, 2003; Turner *et al.* 2005; Mukudam *et al.* 2015; Giebel

et al. 2016); researchers have also built on this by further work focusing specifically on, for example, Sikh communities (e.g. Jutlla and Moorland, 2009; Jutlla, 2010); as well as identifying that further work is required to understand specific ethnic groups such as Bangladeshi communities (see Hossain *et al.* 2014). This study was designed to explore the lived experience of dementia from the perspective of the individuals of Black ethnicity living with dementia using a phenomenological approach. The previously mentioned demographic data in section 1.4 seem to support the view that an increase in the BME population will result in an increased demand for personalised services within Black communities. This work, therefore, aimed to understand the experience of dementia from the individual of Black ethnicity's perspective. The aims of the study are discussed next.

1.7 Aims of the study

The overall aim of this study was to understand the lived experience of the individual of Black ethnic background living with dementia, specifically focusing on Black people living with dementia within the four North East London boroughs of Barking and Dagenham, Havering, Redbridge and Waltham Forest. Phenomenology was chosen as the qualitative research methodology for this study.

1.8 Objectives of the study

This investigation has the following objectives:

- To explore how individuals of Black ethnicity living with dementia see themselves.
- To understand individuals of Black ethnicity living with dementia cope with the day-to-day reality of living with dementia.
- To understand the participants' perspective: how that meaning is constructed in the differing perspectives of living with dementia as an individual of Black ethnicity.

Being an individual of Black ethnicity myself, I felt that it was crucial to tell their stories from their perspective and that perhaps if my research is concerned with that which others have called 'marginalised' voices, or the view of those groups who are harder to engage in research, perhaps my own position as an 'insider' Black female researcher, might be viewed as advantageous and credible in that; I 'know' what it is to be a Black person in the UK and therefore share with the study group the common experience of being of Black ethnicity, immigration, discrimination and inequality. I acknowledge that I am not an expert on all things 'Black' but being a Black African living in North East London, I felt that to conduct research in the lived experience of dementia within individuals of Black ethnicity living in the four North

East London Boroughs; would be of considerable benefit to patients living with dementia and had the potential to inform local policy and practice.

1.9 The research question

The purpose of the research presented in this thesis was to gain a deeper understanding of the experiences of people living with dementia of Black ethnicity. The investigation sought an understanding of what constitutes 'living with dementia as a Black person', developing this to a conceptual framework that considered different meanings of living with dementia among individuals of Black ethnicity. The research questions were:

- What is the lived experience of the individual of Black ethnicity living with dementia?
- How does the individual of Black ethnicity living with dementia describe their experience and everyday lives?

The question driving this work was: '*What is it like to live with dementia?*'. I wanted the participants in the study to tell me their stories about their lives, about their feelings, and their understanding of the events following their diagnosis. I wished to capture a sense of their lived experiences by asking '*What was it like for you as a Black person?*'. Rather than establishing some fundamental truth about their experiences of living with dementia, this work sought to understand the perspective of the person living with dementia and their experiences as a person of Black ethnicity and ideas that informed this perspective.

1.10 Thesis structure

An introduction and background to the context of the study have been presented in Chapter One. Chapter Two presents an overview of the literature relating to the experience of dementia before critically examining the literature on dementia within BME communities, and more specifically; the subjective experience of living with dementia is then critically reviewed. This chapter discusses what is known about the subject and identifies gaps in the current knowledge base, forming the justification for conducting this study. The literature review focused on the findings of qualitative studies. This study aimed to make sense of the reality of living with dementia, to understand the lived experience of dementia within individuals of Black ethnicity using Heidegger's phenomenological approach. The qualitative studies included in the literature review were fitting in with the aims of this study as introduced in section 1.7; and were appropriate to a phenomenological approach to understand the nature experience from the perspective of the individual.

Chapter Three provides the reader with an understanding of the chosen methodology for the research study. The choice of interpretive phenomenology based on the work of the philosopher Martin Heidegger (1927) will be explained in relation to my ontology and its appropriateness in researching the lived experience of dementia within individuals of Black ethnicity. Chapter Three will also discuss ethical considerations, the trustworthiness of the research and how this was maintained throughout with the use of reflexivity and a reflective diary. The findings of the study presented as themes are shared in Chapter Four, ensuring that the views of the participants are presented with my interpretation.

Chapter Five provides a discussion of the findings from the study and highlights the unique contribution of these findings to knowledge. In Chapter Five, the findings are situated within the reviewed literature and policy and the significant findings highlighted. As there is a scarcity of research which specifically addresses the experience of Black people living with dementia in the UK, Chapter Five also discusses the findings in relation to additional literature that is not included in the literature review chapter. For context, it was important that the findings were discussed in relation to other studies investigating the lived experience of long-term conditions within ethnic minority groups.

Chapter Six is the concluding chapter of the thesis; this chapter makes recommendations for policy and practice and the strengths and limitations of the study are discussed. Suggestions for further research and a plan for the dissemination of the findings of the study is then outlined, and the thesis is then concluded.

1.11 Summary of chapter

This chapter has described the background to the study, the reasons why I undertook the research and my research questions. The organisation of the study from the initial idea to the fulfilment of the thesis is given, together with an explanation of the individual chapters. By focusing on the lived experience of dementia in individuals of Black ethnicity, it is hoped the findings will provide an insight into the experiences of the patients themselves and the impact of their condition on their daily lives. These findings may then be used by health professionals to inform the delivery of healthcare services to others living with this progressive condition. The next chapter describes the review of the relevant literature and identifies the gaps in current knowledge that form the basis of the rationale for this study.

CHAPTER TWO: REVIEW OF THE LITERATURE

2.1 Introduction

This chapter discusses and reviews the literature that informed my understanding of the lived experience of dementia within BME communities in the UK. There is a scarcity of research which specifically addresses the experience of Black people living with dementia in the UK. I thus draw on a wider range of literature about the lived experience of dementia regarding BME communities from a more general perspective to understand the broad issues and challenges faced by individuals living with dementia from BME communities in the UK. The literature review chapter aims to provide a critical appraisal of the current research on dementia within individuals of BME backgrounds.

2.2 Reviewing the literature

The next section discusses the process used to review the current literature base, focusing on dementia within BME communities living in the UK.

2.2.1 Literature search strategy

A systematic approach to searching the literature was undertaken. I identified databases that were likely to include relevant literature. The databases are outlined in Box 2.0. I also reviewed reference lists of key papers to ensure that I did not overlook any relevant studies. To remain abreast of the current literature, EBSCO Library alerts were set up using the key search terms.

2.2.2 Databases searched

An electronic search was conducted of the databases listed in Box 2.0 in 2017: These databases were identified as likely to result in the literature that would relate to the investigation of the lived experience of dementia within individuals of Black ethnicity in the UK.

Box 2.0: Healthcare Databases	
1. Social Care Online	6. Medline(PubMed)
2. CINAHL (Cumulative Index of Nursing and Allied Health Literature	7. Psych INFO
3. Internurse	8. Scopus
4. BNI (British Nursing Index)	9. Psych Articles
5. SocIndex with Full Text	

2.2.3 Key search terms employed

Based on my previous experience, knowledge and reading of the current literature related to this group, as mentioned in section 1.4, I was aware that, the terms '*Black and minority ethnic*', '*ethnic minority*' and '*ethnic groups*' are used interchangeably depending on the context of the research. Following consideration of this, the following combined terms were employed using the Boolean operator AND to search the selected databases:

- 1) Dementia AND BME
- 2) Dementia AND Ethnic minority
- 3) Dementia AND Ethnicity
- 4) Dementia AND Ethnic group

2.2.4 Selection criteria

While the searches were not restricted to a particular time frame, the final literature search was conducted on 5th June 2017; consequently, studies published after this date were not considered.

In deciding which papers to review, I considered my study aims and objectives as discussed in section 1.7 and 1.8. I also reflected on the UK immigration patterns. The Census 2011 showed that 13% of the population (7.5 million people) was born outside of the UK (ONS, 2015). When looking at the period of arrival of foreign-born residents in England and Wales, the ONS (2015) 2011 Census analysis: Ethnicity and religion of the non-UK born population in England and Wales: 2011 document highlights that the majority of foreign-born who were White Irish (63%), Black Caribbean (61%) and White British (52%) arrived in the period before 1981. The majority of the Black Caribbean community were Jamaican-born (ONS, 2013). This population saw substantial rises between 1951 and 1971 before peaking in 1971 (ONS, 2013). In contrast, 95% of Black Africans arrived after 1981 (ONS, 2015). Therefore, it seemed logical to consider papers from the year 2000; as migrants of Black ethnicity origin of working age who arrived in the UK would be of the ≤65 age group from the year 2000. To obtain studies that were to be included in the review, inclusion and exclusion search parameters were identified and are discussed in the next section.

2.2.5 Inclusion and exclusion search criteria

The purpose of this study was to understand the lived experience of dementia within individuals of Black ethnicity. As already introduced in section 1.10 (and will be further

discussed in Chapter Three), a phenomenological approach was adopted in this study, to allow for an interpretive method that listens to participant experiences and allows for the participants to express their thoughts. Therefore, only qualitative papers were considered for this review fitting in with the aims of the study. Quantitative studies were not included in this review. Current quantitative studies that include BME participants focus on for example on empirical measures such as prevalence, diagnosis rates and cognitive function tests (see for example Adelman *et al.* 2011; Purandare *et al.* 2007). As gaining empirical data was not the fitting with the aims and objectives of this study, quantitative studies were not included in this review. Mixed Method studies were considered and included in this review to incorporate qualitative findings. Box 2.1 sets out the inclusion and exclusion search criteria that were applied to identify those papers that were to be included for review:

Box 2.1: Inclusion and exclusion search criteria	
Inclusion criteria	Exclusion criteria
Papers published between 2000 and 2017.	Papers prior to 2000
The study participants were recruited within the UK	Non-UK studies
The study participants were from a BME community	The study participants were not from a BME community
The study explored the experiences or needs of BME people living with dementia and their carers or family members using a qualitative approach	Quantitative studies
The study was published in a peer-reviewed journal.	The study was published in a non-peer-reviewed journal.

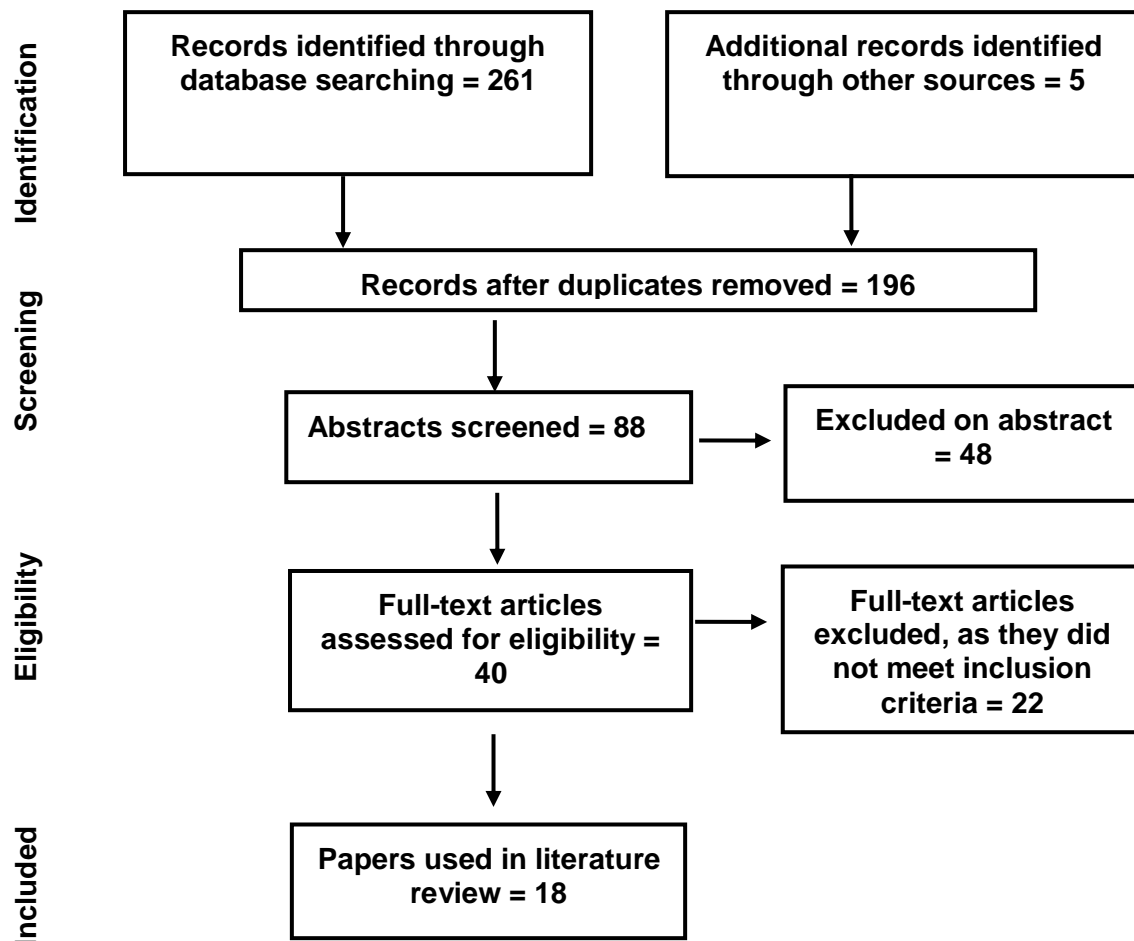
2.2.6 Manual search

A manual search was then performed on the papers identified following application of the above search criteria. The reference lists and citation list of all papers identified within these searches were reviewed to identify sources not found in the initial database search. In addition, related books and health policy documents were reviewed for key themes.

2.3 Identifying relevant papers/studies

As expected there was a considerable replication of results across the databases. In total 40 items of literature were selected and obtained for more detailed review. The study selection process is shown as a flow diagram in Figure 2.0 below. After the study selection process was completed, 18 papers remained.

Figure 2.0 Flow diagram presenting the study selection process (Moher *et al.* 2009)



2.4 Reviewing literature within the qualitative research paradigm

In reviewing the identified papers/studies to be included in this literature review, a quality framework that would adequately appraise the studies was sought. Traditionally, quality frameworks have focused on evaluating quantitative literature (Caldwell, Henshaw and Taylor, 2005). This has resulted in a tendency to evaluate qualitative research against criteria appropriate for quantitative research, which may lead to unfair criticism (Caldwell, Henshaw and Taylor, 2005).

As a novice researcher, the Qualitative Research Checklist developed by the Critical Appraisal Skills Programme (CASP) (2017) was used. The tool that was developed for evaluating qualitative research (which identifies 10 questions to be asked to evaluate study quality); was applied to review the selected 18 qualitative papers that met the identified criteria as described in section 2.2.5. The CASP tool provided a critical framework and a systematic approach to

review each paper. Practically, this meant that following the identification of relevant studies, I applied the 10 CASP questions to each paper and an example of this is included in Appendix 01. This process helped me to identify the aim of each piece paper, whether the research paper had been well designed and conducted, the main findings, whether it has any strengths and limitations; and whether it has any specific findings or implications related to the aims of my study. In completing this process, each paper was reviewed closely to identify the similar phrases or findings. I then considered how the papers addressed my research questions. I grouped similar findings from the papers together to aid the development of key themes of the areas that the papers considered. The key themes were easily identifiable, as this process was systematic; using the same approach to analyse each paper. Following this, similarities and differences between study findings were critically evaluated. Section 2.5 discusses the results of the literature review.

2.5 Results of review

Table 2.0 below details the 18 papers that were reviewed and included in the literature review. All 18 papers were peer-reviewed, and 17 used a qualitative methodology and one adopted a mixed methodology approach. Six of the articles analysed their data using Grounded theory. Most studies used interviews and focus groups to guide data collection. Other methods employed included Case study approach and Interpretative analysis.

The age range and gender of the participants was not always included in the studies, and it was noted that the studies included people of different BME backgrounds. 11 of the articles focused on the experiences of more than one BME community. Seven studies focused on only one BME group. Of the seven studies, three studies focused on South Asian groups, Sikh communities (three studies) and Black ethnicity (one study). Most data was collected from carers with only three studies involving individuals living with dementia (see Daker-White *et al.* 2002; Bowes and Wilkinson 2003; Lawrence *et al.* 2010).

The studies explored various factors which influenced accessing dementia services, views about dementia as well as the experience of caring for a family member living with dementia. The findings from the present literature review are framed in the following themes; Dementia as a normal process of ageing, lacking awareness about dementia, the impact of migration, culture, impact of stigma and stereotypes, language and family support and responsibility to provide care for a family member with dementia.

Table 2.0: Literature Search Results

Author	Aim	Methodology	Sample	Design	Main findings	Limitations
Adamson (2001).	To explore awareness, recognition and understanding of dementia symptoms in families of South Asian and African/Caribbean descent in the UK.	Qualitative	Participants were carers. 18 African/Caribbean participants. (16 were first generation British) 12 South Asian participants (9 first generation, 2-second generation, 1 third generation British).	In-depth semi-structured interviews.	Most participants were aware of the condition 'dementia' but used different terms to describe dementia. Many had not heard of the condition before their relative developed it. Difficulties were noted in the caring relationship due to a lack of understanding of the condition – where family members place blame for the symptoms on the person with dementia.	The carers were recruited from cities in the East Midlands, north-west, south-east and south-west of England, which not representative of the entire UK. The study did not consider the variation that exists within South Asian minority groups as well as African/Caribbean groups. No participants living with dementia took part.
Adamson and Donovan (2005).	To explore the experience of caring for an older family member, focusing on minority ethnic carers of a person living with dementia.	Qualitative (Grounded theory)	Participants were carers. 15 South Asian 21 African/Caribbean	Semi-structured interviews.	Caring was the normal thing to do, delivering informal care was part of a caring relationship in terms of their pre-caring and a continuation of their previous relationship with the person being cared for and their roles within the family.	The study was carried out in London, most participants in the study were female and participants were accessing mental health services. Use of different interpreters used throughout interview stage and this may have impacted on data quality.
Berwald <i>et al.</i> (2016).	To identify and explore the barriers to help-seeking for memory problems, specifically within UK Black African and Caribbean communities.	Qualitative	50 Black African and Caribbean participants.	3 Individual semi-structured interviews and used a vignette plus 8 focus groups.	Many people recognised forgetfulness but neither that it could be indicative of dementia, nor the concept of dementia as applying to them. Dementia was viewed as a white person's illness. Participants felt there was little point in consulting a doctor for forgetfulness. Many thought that seeing a GP was only for severe	The participants were recruited via community organisations; therefore, gatekeepers may have influenced the choice of participants. The study acknowledges that BME groups are not homogenous. The term 'forgetfulness' and 'memory' problems were used

Table 2.0: Literature Search Results

Author	Aim	Methodology	Sample	Design	Main findings	Limitations
					problems. Some said that their culture was secretive and highly valued privacy of personal affairs and therefore did not want to discuss what they regarded as a private and stigmatising problem with a GP. Care should be from the family.	interchangeably. No participants living with dementia took part.
Botsford, Clarke, and Gibb (2011).	To examine the experiences of partners of people with dementia in two BME groups.	Qualitative (Grounded theory)	7 Greek Cypriot participants. 6 African Caribbean participants.	43 in-depth interviews conducted over an 18-month period between 2007 and 2009.	Participants engaged in an on-going process of redefining relationships. Greek Cypriot partners tended to emphasise family relationships. African Caribbean partners tended to view themselves primarily as an individual or as part of a couple. Participants accommodated the changes associated with dementia into their lives rather than seeking help. Participants saw their experience as an extension of their responsibilities as a husband, wife, or partner. There was a universal lack of awareness of symptoms of dementia.	Data collection was in London. The small number of participants were already accessing specialist mental health services. Only 1st generation migrant carers were recruited for the study. Only partners of people living with dementia were recruited to take part in the study. No participants living with dementia took part.
Bowes and Wilkinson (2003).	To examine views and experiences of dementia among older South Asian people, as well as their families and carers, and to explore central issues of service support	Qualitative (Case study/interviews)	11 professionals working with South Asian people with dementia were interviewed. 4 case studies of South Asian people who had a diagnosis of dementia (3 women and 1	Interviews.	The case studies demonstrated overwhelmingly negative experiences of dementia, with the poor quality of life, desperate needs for support, lack of access to appropriate services, little knowledge of dementia, and isolation from community and family life. The interviews with professionals described a strong demand for services, a need to develop awareness and knowledge about dementia in South Asian communities, and a need to promote	Data collection was in Scotland. This study was small. Some of the issues raised in the present study may be specific to South Asian people with dementia but does not consider differences within South Asian communities.

Table 2.0: Literature Search Results

Author	Aim	Methodology	Sample	Design	Main findings	Limitations
			man) their families and carers.		more culturally sensitive, individually responsive services.	
Daker-White <i>et al.</i> (2002).	To examine the needs and provision of services to people with dementia under 65 years of age and people with dementia from Black and minority ethnic groups.	Qualitative	3 Asian and 1 African-Caribbean professionals, users and carers. (1 participant was living with dementia)	Interviews.	1 participant was living with dementia. Key findings include the 'myth' that 'Black people look after their own', the view that Black and Asian people was that they 'tend to stay within their own communities.' Another perceived issue was the stigma of dementia, and an associated unwillingness by family members to "wash their dirty linen in public."	This was a small study, carried out in Bristol, Gloucestershire and Cornwall. Interviews were conducted with professionals, users and carers, no participants were living with dementia. The study does not consider variation within African-Caribbean communities.
Jolley <i>et al.</i> (2009).	To explore dementia within BME groups and how to improve relevant services.	Qualitative	10 African Caribbean carers. 20 South Asian carers.	Interviews conducted over a 6-year period between 2000 and 2006	There was a continuing lack of knowledge and understanding of dementia among carers. Lack of understanding led to stigmatisation, mistaking symptoms of dementia with old age. Carers remain isolated. Variability in knowledge and attitudes between families and between generations. Existing services are seen to lack cultural awareness.	Data collection was specific to Wolverhampton. The study did not state the gender of the participants. In the second stage of the study, only Sikh carers of someone with dementia were interviewed and no African Caribbean carers were used. The study only focused on two BME groups in the UK and collected data from the carer's perspective.
Jutlla and Moreland (2009).	To understand experience of Sikh carers caring for an older person with dementia	Qualitative	2 Sikh carers.	Interviews.	Sikh community is not a homogeneous group. Diversity and differences within the Sikh community can have important implications for care. Factors to be considered include carer's country of origin; migration route and reasons for migration. Services must be flexible and appropriate to carer situation.	The study is based in Wolverhampton, the study had a low sample size. The gender of the carers was not stated. The findings of only two interviews were presented and discussed in the study. The researcher does not state which qualitative method was used.
Jutlla (2010).	To understand the experience of migrant Sikh carers caring for	Qualitative (Grounded theory)	3 male Sikh carers.	2–3 narrative interviews per participant	Participants viewed their caring role as an extension of an existing obligation and identity. Migration	The study was only conducted in one city, Wolverhampton. The findings of the study can only be

Table 2.0: Literature Search Results

Author	Aim	Methodology	Sample	Design	Main findings	Limitations
	an older person with dementia.		9 female Sikh carers.		experiences did impact on experiences of carers. Participants idealised their societies of origin, including the type of support available to them in that society.	generalised to the Sikh community who have migrated to the UK.
La Fontaine <i>et al.</i> (2007).	To explore perceptions of ageing, dementia and ageing-associated mental health difficulties amongst British people of Punjabi Indian origin.	Qualitative.	49 English Hindi and Punjabi-speaking British South Asians from India or of Indian origin.	Focus group conducted between 2001 and 2003.	Ageing was a time of withdrawal and isolation, and problems as physical or emotional; cognitive impairment was seldom mentioned. There was an implication that symptoms of dementia partly resulted from lack of effort by the person themselves and possibly from lack of family care. Therefore, people should overcome their own problems and family action might be part of the solution. There was a sense of stigma and a lack of knowledge about mental illness and services, alongside disillusionment with doctors and exclusion from services.	The study focused on one community in South West London and the sample was small, which limits transferability. The sample included people of both Sikh and Hindu religions yet did not distinguish the influences of each of these. The vignettes were translated by professional interpreters, their possible loss of meaning in translation, there was no back translation.
Lawrence <i>et al.</i> (2008).	To explore the caregiving attitudes, experiences and needs of family carers of people with dementia from the three largest ethnic groups in the UK.	Qualitative (Grounded theory).	Total of 32 carers of people with dementia: 10 Black Caribbean (9 women, 1 man) 10 South Asian, (5 women, 5 men) 12 White British (11 women, 1 man).	In-depth individual interviews.	Carers were identified as holding a 'traditional' or 'non- traditional' caregiver ideology, according to whether they conceptualised caregiving as natural, expected and virtuous. This informed feeling of fulfilment, strain, carers' fears and attitudes towards formal services. The majority of the South Asian, half of the Black Caribbean and a minority of the White British participants were found to possess a traditional ideology.	The study acknowledges that there is considerable heterogeneity within the South Asian and Black Caribbean populations, the study took place in south London. The study noted a dominance of female carers within the participants which limits the understanding of the experiences and attitudes of male carers. Only carers born in the UK were used in the study which limits any comparison

Table 2.0: Literature Search Results

Author	Aim	Methodology	Sample	Design	Main findings	Limitations
						being made between migrant carers.
Lawrence <i>et al.</i> (2010).	To examine the subjective reality of living with dementia from the perspective of people with dementia within the 3 largest ethnic groups in the United Kingdom	Qualitative (Grounded theory).	11 Black Caribbean, 9 South Asian, and 10 White British carers of older people with dementia.	In-depth individual interviews.	Findings indicate that dementia was “threat to valued elements of life.” Participants engaged in a process of appraisal in which they assessed the degree to which their condition and support needs interfered with valued elements of life. The analysis revealed that each element of this process was culturally informed.	This study was based in four south London boroughs, and purposefully recruited people at different stages of dementia, however, due to the heterogeneity of the sample there was no exploration of other factors such as immigration history, gender, and how this might influence the individual’s experience. No discussion regarding transferability of findings. Participants recruited were already accessing dementia services.
Mackenzie (2006).	To identify the support needs of family carers from Eastern European and South Asian groups.	Qualitative (Grounded theory).	11 Pakistani carers. 5 Indian carers. 1 Polish carers. 1 Ukrainian carer.	Semi-structured interviews.	Understanding of dementia differed between Eastern European and South Asian carers. The understanding of dementia in different cultural contexts caused stigma. The management of stigma between eastern European and South Asian carers was similar. The experience of stigma influenced engagement with formal and informal support.	Data collection was in a Northern English city. The study was unclear if participants had migrated to the UK or were born in the UK. The carer’s relationship to the person living with dementia was not stated in the study. Unclear use of the term South Asian limited the generalisation of findings.
Mukadam <i>et al.</i> (2011).	To explore the link between attitudes to help-seeking for dementia and the help-seeking pathway in minority ethnic and indigenous groups.	Qualitative.	Total of 18 carers 4 White British. 5 Indian. 5 Black British. 1 Irish. 1 White other.	Semi-structured interviews.	Minority ethnic carers tended to delay help-seeking until they could no longer cope or until others commented on the problems. Dementia symptoms were a normal part of ageing. Carers thought that families should look after their own	Data was collected in London. The carers recruited for the study were already accessing services with their family member with dementia. Each group of participants contained a mix of genders and carers with a range

Table 2.0: Literature Search Results

Author	Aim	Methodology	Sample	Design	Main findings	Limitations
			1 Chinese. 1 Asian other.		elders. Minority ethnic carers held certain beliefs about the aetiology of Cognitive impairment, psychiatry and their sense of familial responsibility which affected their level of engagement with formal services.	of educational attainment. Socioeconomic and educational differences were not fully explored and how they influence attitudes to help-seeking.
Mukadam <i>et al.</i> (2015).	To understand the barriers to timely help-seeking for dementia among people from South Asian backgrounds and what the features of an intervention to overcome them would be.	Qualitative.	53 English or Bengali speaking South Asian adults.	Focus groups and individual interviews.	Participants identified four main barriers to timely diagnosis: barriers to help-seeking for memory problems; the threshold for seeking help for memory problems; ways to overcome barriers to help-seeking; what features an educational resource should have.	Stud based in Greater London. Participants were mostly female and were 60% Bangladeshi. included those with experience of caring for someone with dementia as well as those without this experience.
Turner et al. (2005)	To explore whether there were differences in views about the nature, causes and treatments for dementia, and who participants believed should provide care.	Mixed Methods Qualitative (Interpretative Phenomenologica I Analysis) and Z test for difference in proportions was used.	96 South Asian and 96 White British older people (age range 58-85 years) were	Semi-Structured Interviews.	South Asian older people had much less specific knowledge about dementia and were much more likely to see it as part of the normal ageing process. More South Asian than white older people thought that care should be provided by family or friends. White older people perceived family and friends as the first choice but thought that the state should also provide care.	This qualitative study was part of a larger study and data collection was in 2 South West London boroughs. No discussion regarding differences within South Asian communities.
Uppal (2014).	To explore the understanding and perceptions of dementia amongst Sikhs living in the UK.	Qualitative.	28 Sikh participants who were recruited from Gurdware (Sikh places of worship).	6 Focus groups.	The themes reported in this paper include “awareness and interpretation of the characteristics of dementia”, “multiple perspectives of the same symptoms” and “causes of dementia”.	The study had a small sample and focused on both Amritdhari and Sehajdhari, findings may not be the complete picture of Sikh perceptions of dementia. 4 individuals aged 41 and older old took part in the study. Location of study not specified.

Table 2.0: Literature Search Results

Author	Aim	Methodology	Sample	Design	Main findings	Limitations
Parveen <i>et al.</i> (2017).	A scoping exercise to explore perceptions of dementia in British Indian, African and Caribbean, and East and Central European communities in the United Kingdom	Qualitative (Thematic and framework analysis).	62 British Indian, 50 African and Caribbean, and 63 East and Central European participants.	Discussion groups and a dementia knowledge quiz held between August 2013 and April 2014, at a culturally specific dementia awareness roadshow, which was attended by people living with dementia, carers and members of the public.	Findings indicate that although groups attributed a biological basis for memory loss, several misconceptions prevailed regarding the cause of dementia. Groups also made use of religion, as opposed to medical healthcare services, as a form of personal and treatment control. Seeking help from healthcare services was hindered by lack of awareness of services and culturally specific barriers such as language.	The analysis was conducted on written notes made by group facilitators rather than being based on recordings and transcripts. No data collected regarding age, gender or socioeconomic status of participants. The groups and quiz occurred in a social setting, so the influence of social desirability cannot be discounted.

2.5.1 Lack of awareness about dementia

The literature review showed that dementia awareness and knowledge is low amongst BME communities; for example, with Adamson (2001), participants in this study were of South Asian and African/ Caribbean heritage, who were not aware of the condition before their relative developed it, suggesting a low general awareness of dementia. This study did not interview individuals living with dementia to get their perspective, all participants were carers. The participants were also of different generations (first and second generations) but the study does not discuss how this may have affected perception and understanding of dementia. The study does not consider the variation that exists within South Asian groups as well as African/Caribbean groups.

Bowes and Wilkinson (2003) interviewed 11 healthcare professionals working with South Asian people with dementia, as well as four case studies of South Asian people who had a diagnosis of dementia (three women and one man) and their families and carers. They showed that participants had little knowledge of dementia or how quality of life could be improved. However, a closer reading of the study findings, note that the authors do not report on the actual views of the individuals living with dementia rather the views of the carers and family members. It is unclear whether it was an assumption that the participants living with dementia would be of the same opinions or views as their carers or family members or whether they did not have the ability to contribute to the study. This is of significance, as my study aimed to gain the views of individuals living with dementia and an understanding of whether the individuals shared the same views or beliefs as their carers would be a key finding in my work.

Similarly, the participants in Uppal *et al.*'s (2013) study, participants who were of the Sikh community also had little awareness of dementia. This study recruited Sikh adults from the East Midlands community, who were neither carers or living with individuals with a diagnosis of dementia. Therefore, they mainly had no direct experience of dementia. Whilst a limitation of this study is that the findings were specific to the Sikh community in East Midlands, this work does give some insight into awareness of dementia.

Berwald *et al.* (2016) recruited 50 Black African and Caribbean individuals living in the UK and noted that although participants recognised forgetfulness, they were unaware that it could be indicative of dementia, nor did they identify the concept of dementia as applying to them. Dementia was viewed as a *White person's illness* (Berwald *et al.* 2016); a concept I previously touched upon in section 1.3. Participants in this study felt there was little point in seeing a doctor for forgetfulness. Many thought that seeing a GP was only for serious illness (Berwald

et al. 2016). These findings are consistent with Botsford *et al.* (2011), who also noted that participants in their study had initially accommodated the changes associated with dementia into their lives rather than seeking help or a diagnosis (Botsford *et al.* 2011). The questions arising for my study would be whether if BME communities have a view of dementia that is linked to their ethnicity or ethnic background, i.e. White persons disease rather than a Black person's disease; whether this view influenced them in accessing health services, hence accommodating dementia symptoms much longer.

Parveen *et al.*'s (2016) findings suggest that although BME individuals attributed biological basis for memory problems, a number of misunderstandings existed regarding the cause of dementia. For example, the Eastern and Central European group believed dementia was caused by old age. The Indian group thought family stress and worry may be a contributory factor to the development of dementia. It is noted that in the study by Parveen *et al.* (2016), no information was collected regarding age, gender or socioeconomic status of participants, or whether they had direct experience of dementia or indeed living with dementia themselves. However, the findings in relation to knowledge of dementia are useful in that they represent a wide view. What is evident in this work, as well as other studies in this review (see Uppal *et al.* 2013), is that further work is required to raise the awareness of dementia within BME communities. The consequences of a lack of knowledge and awareness by individuals living with dementia and their carers has an impact on the lived experience of dementia and ability to access services and available treatment or therapy. The current studies do not specifically focus on individuals of Black ethnicity living with dementia, capturing their views or knowledge about dementia.

2.5.2 Dementia – a normal part of ageing

Evidence from the literature review highlighted that a number of carers from BME communities had different based perceptions of dementia, related to their ethnicity and ethnic background. Botsford *et al.* (2011) conducted 43 in-depth interviews with 13 Greek Cypriot and African Caribbean carers, caring for a family member with dementia in London. They noted the participants had interpreted the changes associated with dementia as part of a normal ageing. This was expressed by participants describing that memory problems were supposed to happen when a person became old. Many participants expressed a general belief that cognitive decline might be expected and therefore forgetfulness was perceived as normal ageing (Botsford *et al.* 2011). Botsford *et al.* (2011) also found that the perception of memory problems being perceived as a normal process of ageing was associated with a delay between

carers noticing a problem and seeking an explanation. Whilst this study highlighted a specific way in which dementia is understood in two BME communities, the findings are limited to only two discrete Greek Cypriot and African Caribbean communities in London. The study did not include participants living with dementia, rather their carers, whose views may be different from the individuals living with dementia.

The findings from Botsford *et al.* (2011), like the study by Jolley *et al.* (2009), found that carers viewed their family member's cognitive decline as a normal ageing. The study highlighted that a lack of information and understanding of dementia, was held by both African Caribbean and South Asian carers, resulting in unawareness of its differentiation from normal ageing. Despite ethnic differences, carers were found not to seek help or access health services due to being unaware that they were caring for someone living with dementia (Jolley *et al.* 2009). Therefore, this raises a significant point, that despite ethnic background differences, there is the cultural commonality that exists in the BME communities within the 2 studies discussed in this section, that dementia is viewed as part of normal ageing and that is distinctly different from White culture. The concept of culture and its influence was introduced in section 1.4.1 of this thesis.

2.5.3 Language

This review has highlighted that due to ethnic differences, there were also linguistic differences to take into consideration. In a study by Adamson (2001), there were differences in the terminology used to describe dementia between some ethnic minority groups; and for some, there was no word for 'dementia'. BME carers reported having not heard about dementia before the person they cared for was diagnosed and did not know the appropriate medical term (Adamson *et al.*, 2001); as such, Asian participants living with dementia who took part in the study by Lawrence *et al.* 2011, did not perceive terms such as dementia or Alzheimer's as applying to them. Parveen *et al.* (2016) also noted that seeking support from health services was delayed by lack of awareness and ethnicity-specific barriers such as language. These current studies do not explore from the perspective of the individual living with dementia their understanding of language and this impacts on the concept of dementia, in line with my study aims and objectives.

2.5.4 Family support

There is evidence to suggest that family support and informal care were viewed as the norm, for example, in Adamson and Donovan's (2005) study, carers did not view themselves as

'carers' but rather as fulfilling a natural role within the family. This finding was like that of Lawrence *et al.* (2008) where sons and daughters caring for parents of South Asian origin viewed caring roles as a cultural norm, whilst this was notably absent in their White British counterparts. Similarly, Turner *et al.* (2005) noted that more South Asian than white older people thought that care should be provided by family or friends. White older people perceived family and friends as the first choice but also thought that the state should also provide care. Due to this family support, the South Asian participants in the study were less likely to present to services at the early stage of dementia. Mackenzie (2006) believes this is due to the stigma of dementia within ethnic minority communities and not wanting the condition to become public knowledge hence the need for family support. Similarly, Daker White *et al.* (2002) noted in their work, the myth that 'Black people look after their own', the view that Black and Asian people tend to stay within their own communities. What is significant is that again, the perspective of the individual living with dementia is not captured, regarding their experience of family support and how this impacts overall on the lived experience of dementia. Stigma and stereotyping is further discussed in the next section.

2.5.5 Stigma and Stereotypes

The experience of stigma when caring for a family member with dementia was present in Mackenzie's work (2006); the study completed semi-structured interviews with 18 carers from Eastern European and South Asian communities in a northern English city. Eastern European carers, caring for a family member with dementia experienced stigma from within their own community, resulting in several carers not seeking help from fellow members of their community and instead described 'hiding' the person with dementia.

A similar concept of stigma featured in the findings of Mukadam *et al.* (2011) who assessed why ethnic elder carers present later to dementia-related health services. By interviewing 18 carers from London, it was found that stigma was a barrier to accessing support from mental health services only for BME carers. The fear of stigma was not present in the four White carers interviewed for the study (Mukadam *et al.* 2011). What was not clear in both Mackenzie (2006) and Mukadam *et al.* (2011) studies as to whether stigma was the direct reason for not accessing health care services; it was suggested as a contributory factor.

Due to this lack of awareness and stigma, research findings indicate that those from BME backgrounds may not know where to get help (Bowes and Wilkinson, 2003; La Fontaine, *et al.* 2007). La Fontaine *et al.* (2007) found that there was a sense of stigma and a lack of knowledge about mental illness and services, alongside disillusionment with doctors and

exclusion from services. Interviews by Jolley *et al.* (2009) revealed that carers perceived mental health services to lack the confidence and competence to address language barriers and cultural differences. This resulted in the carers feeling culturally stereotyped (Jolley *et al.* 2009).

2.5.6 Migration Experiences

The literature review introduced the impact of migration on the caring experiences of BME carers. Jutlla (2010) conducted two to three narrative interviews with 12 carers from a Sikh community in Wolverhampton, about their experiences of caring for a family member with dementia. Jutlla (2010) found that the migration journey of Sikh carers influenced their role. The study coined the process of migration as a '*repositioning of existence*' which occurs when someone migrates to another country and culture. The study suggests that when caring for a family member with dementia, BME carers experience a further episode of '*repositioning of existence*' which may manifest itself in adopting new responsibilities and a role repositioning from a husband or wife to that of a carer (Jutlla, 2010).

The study by Jutlla and Moreland (2009) also identified the influence of migration on Sikh carers. Interviewing five Sikh carers of a family member with dementia from Wolverhampton, it was revealed that within the Sikh community, there was a range of different experiences of migration to the UK. The study revealed how different migration routes, age at which a person migrated, and the reason for the migration influenced their caring experience (Jutlla and Moreland, 2009). This concept of migration influencing a carer's role is supported further by Botsford *et al.* (2011) who conducted interviews with carers from Greek Cypriot and African Caribbean communities in London. Botsford *et al.* (2011) noted the concept of resilience, and how this was believed to be due to the carer having to overcome important challenges and obstacles whilst settling into a new country of residence. This has implications for the individual of Black ethnicity living with dementia taking part in my study, who may have also been an immigrant, and how this experience impacts on the experience of dementia.

2.6 Gaps in the literature and rationale for study

The literature review conducted in this chapter has been unable to obtain any study to date that captures solely the lived experience of dementia within individuals of Black ethnicity origin living in the UK. As demonstrated in this chapter, where evidence on the experience of dementia in Black communities does exist, it is part of a bigger study and is from the perspective of carers. No previous work has captured in detail the lived experiences of the

individual of Black ethnicity living with dementia; their cultural beliefs, values and other factors might affect how individuals perceive themselves, as has been conducted within Asian communities in the UK as shown in this chapter. This study, therefore, wished to investigate the reality of being an individual of Black ethnicity; exploring the ontological question: 'what is it is like' to live with dementia?

2.7 Summary of chapter

This chapter has presented the literature review, which included 18 studies relating to BME communities living in the UK and the experience of dementia, including views of carers and ordinary members of the public. The published studies have produced limited insight into the experience of BME people living in the UK and the impact of dementia. However, the wider implications of the disease are less well known since little work has been done to capture the lived experience of dementia within individuals of Black ethnicity. Only one study has included participants solely of Black ethnicity but since this study incorporated interviews of participants who did not have dementia, the views of people living with dementia were not explored (Berwald *et al.* 2016). My study aims and research questions reflect the need to understand factors that impact on the lived experience of living with dementia as an individual of Black ethnicity. It is not clear why Berwald *et al.* (2016) did not interview participants living with dementia. Although several researchers highlighted their recommendations for further work with this group, there is still a lack of awareness of the lived experience of dementia within individuals of Black ethnicity. This review of the literature has led me to question some of the rationales for researchers not seeking out the perceptions of people living with dementia of Black ethnicity. The literature review reaffirmed my aim to understand the lived experience of dementia. Explored further in the next chapter is the philosophical basis and methodology for the study.

CHAPTER THREE: METHODOLOGY AND METHOD

3.1 Introduction

In the previous chapter, there was an exploration of the literature that indicated that there was a gap in knowledge concerning specifically the understanding of the experience of dementia within individuals of Black ethnicity. This chapter will discuss the epistemology and research design, how a phenomenological approach was chosen, and how it was informed by literature. This chapter describes the methodology that underpins the study and explores the processes undertaken to address the research question. This chapter outlines the philosophical framework underpinning the study. The use of interpretive phenomenology based on the philosophy of Martin Heidegger (1889-1976) in the context of this study will be explained, including ethical issues, sampling, data collection and data analysis.

3.2 Philosophical perspectives

This section sets out my position regarding the nature of reality (ontology), what can be known about it and how that is verified (epistemology). My research is about a social phenomenon: people's experiences of dementia and how they understand the experiences within different frameworks of belief. It is about the reality of living with dementia as individuals of Black ethnicity. The notion of a single reality has no credence here. However, philosophical assumptions underpinning this research study are important (Wainwright and Forbes, 2000), as the researcher's understanding of the philosophy of reality, what can be understood about it (ontology), and the philosophy of knowledge or how we come to know (epistemology), directly impact upon the particular process used to attain knowledge in this enquiry (methodology) and the status of the researcher's accounts (analysis) throughout the research process (Wainwright and Forbes, 2000). The next section considers my epistemological and ontological positions and how these were formulated.

3.2.1 Epistemological Position

Epistemology concerns the theory and nature of knowledge and how this can be acquired (Crotty, 1998). Originating from the Greek word episteme (Trochim, 2000), epistemology examines the how we know what we know and what counts as knowledge. Key epistemological questions concern: what the nature of the relationship is between the knower or would-be knower is and what can be known (Guba and Lincoln, 1994). It is characterised by two predominant paradigms, broadly termed positivism and interpretivism.

3.2.2 Positivism

The positivist paradigm adopts a realist stance whereby the researcher examines independent facts about a single apprehensible reality (Guba and Lincoln, 1994; Lincoln and Guba, 2000). Inherent in this perspective is the belief that objects have intrinsic meaning, as such, knowledge is fixed, stable and follows immutable laws. Language is unproblematic according to this perspective, as words are believed to reflect things (Smith, 1998). Thus, knowledge i.e. scientific research is objective, unbiased, reproducible and valid and is accessible if an appropriate method of inquiry is employed (Guba and Lincoln, 1994; Lincoln and Guba, 2000). Key in this paradigm is that positivists separate themselves from the world they study; the belief is that researchers can separate the researcher from the object of analysis i.e. participant and that her / his values and beliefs will not impact upon the research. Strategies exist to control these variables. Thus, if rigorous methods are employed, reliable science will be produced.

3.2.3 Interpretivism

Interpretivism emerged post-positivism, supporting the ontology that meaning is inherent within an object waiting to be discovered (Schwandt, 2003). The interpretive perspective is interested in exploring the meaning people attach to their experiences and how these meanings are created, negotiated and sustained (Schwandt, 2003). Specifically, this perspective seeks to understand social phenomena from within rather than outside the social context (Wainwright and Forbes, 2000). It is not overly concerned with structure and the way social phenomena are constructed, institutionalised and made into tradition (Crotty, 1998).

3.2.2 Ontological Position

Ontology is concerned with the nature of social reality, specifically, what is the nature of existence and what is there to know about the world. Key ontological questions within social research concern: whether social reality exists independently of human interactions and interpretations. Ontology considers whether there is a common, shared, social reality or just multiple realities and whether social behaviour is generalisable (Snape and Spencer, 2003). The ontological assumption of the interpretative paradigm is based on the idea that reality is indeed complex, holistic and context-dependent (Lincoln and Guba 1985). It focuses its investigation on the cognitive and affective components of human experience. Subjectivity (Omery 1983) rather than objectivity is therefore given greater emphasis and credence.

3.3 Theoretical framework underpinning the research method

Having understood the meaning of epistemology and ontology, as well as the gap in research as identified in Chapter Two, I then considered the research questions to which this study was seeking answers. The research methodology should reflect the most appropriate way to investigate the phenomenon being explored and should also consider the researcher's philosophical perspective. This study seeks an understanding of what constitutes 'living with dementia as a Black person', and sought to answer the following ontological question:

'What is the lived experience of the individual of Black ethnicity living with dementia?'

Therefore, my theoretical perspective is informed by the interpretivist paradigm that considers ways of looking at the human and social world and what can be known about this world, i.e. living with dementia. Understanding of the experience is what is sought rather than empirical knowledge. This naturally led to my choosing constructionism as my ontological position, as this study sought to understand the lived experience of living with dementia as an individual of Black ethnicity, and how the participants in this study understood this.

The primary methodology used in this study is guided by an epistemology that originates in constructionist epistemology. The term 'constructionist' originates from constructionism, which is a broad and diverse perspective developed in strong opposition to the traditional objectivist epistemology of positivism (Heap, 1995). There are many varieties of constructionism and some scholars use the term interchangeably hence, there is considerable confusion around this term. Heap (1995) uses the term 'constructionism' whilst Crotty (1998) uses 'constructivism', but they both come under the umbrella of constructionism.

Crotty (1998) contends that constructionism as an epistemology informs theoretical perspectives and methodologies of interpretivism. Constructionism is an epistemology that is part of the interpretive inquiry and one that informs the theoretical perspective of interpretivism (Crotty, 1998; Denzin and Lincoln, 2003). Crotty (1998, p.42) writes that "meaning is not discovered but constructed." As such, constructionism suggests there are no 'true' or 'valid' interpretations, only useful or helpful interpretations that stand against other accounts (Crotty, 1998). Furthermore, this perspective recognises that description and narration are not straightforward representations of reality, that is they do not simply mirror 'what is there', they are constructed and co-created by both the researcher and the participant (Crotty, 1998). The aim of the study is to understand the participants' perspective; their lived experience and how that meaning is constructed in the differing perspectives of living with dementia as an individual of Black ethnicity. My view is that dementia is a 'construct' which brings different

understandings of the actual experience of living with dementia, regardless of ethnic group, age and other factors. It is my understanding from Crotty (1998) that people can experience the same phenomenon and construct meaning in different ways. Therefore, it is accepted in this study that all the participants are experiencing the same phenomenon: that is living with dementia as individuals of Black ethnicity and construct the meaning or interpret their experiences in different ways based on their life experience which would include factors such as ethnicity. The interpretive perspective is interested in exploring the meaning people attach to their experiences and how these meanings are created, negotiated and understood within their individual context and everyday life. This philosophical stance both informed and guided the study methodology and methods.

Through the course of this study, I have considered my own influences and ontological position and have settled upon constructionist. I understand meaning to be constructed and not discovered, and again highlight Crotty (1998)'s key points, that different people, even in relation to one phenomenon, construct meaning in their own way. At the same time, during this process, I had an awareness of possible cultural bias and the impact of this on the data collection and interpretation process. Cultural bias is described by Mertens (2014) as the tendency or opportunity to see things or judge people based on one's own cultural assumptions. Therefore, I was conscious of this during this study, and steps were taken to reflect on this and is further discussed in section 3.10 and 3.10.1. Whilst this study focused on individuals of Black ethnicity living with dementia, as previously mentioned, in Chapter Two that the Black ethnic minority group is not a homogenous group, as such this work relates to this group of individuals of Black ethnicity who participated in the study and how they experienced living with dementia as individuals of Black ethnicity. Following on from the above, it was fitting that phenomenology; specifically, a Heideggerian phenomenological approach was adopted.

3.4 Phenomenology

A Heideggerian phenomenological approach was chosen as the philosophical paradigm for the study. Heidegger (1889-1976) was interested in ontology, which is how we live in the world, and how we make sense of the world around us. The Heideggerian approach in this study focused on the participants' views of their day to day lives: their lived experience of dementia. Heidegger (1962) writes that phenomenology's task is to question what it is to be in the everyday world. Heidegger described Phenomenology as meaning "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (1962, p.58).

Heidegger found through Husserl's phenomenology movement, a method which would lay open the processes in human existence, in such a way that being, and not simply one's own ideology, might become apparent (Palmer, 1969). Heidegger notes that the fundamental condition of all existence is the discovery of the 'Being' of all beings. Heidegger's phenomenology is based upon the concept of *Dasein*, where one can only understand existing through one's own being, one's own existence (Heidegger, 1962). His famous work - *Being and Time* (Heidegger, 1962) was first published in 1927.

Heidegger (1962) argues in '*Being and Time*' that for an individual to understand their world around them they need to understand '*Being*'. He refers to it as going 'back to the roots' of the phenomenon being studied (Heidegger, 1962). In '*Being and Time*' (Heidegger 1962), Heidegger argues that individuals understand their existence through '*Being*'; and that an understanding of '*Being*' is based on their experiences of encountering phenomena. Therefore, for the participants in this study, their understanding of '*Being*', that is, living with dementia as an individual of black ethnicity, was fundamental to the study process and the analysis of the findings in this study.

3.4.1 Heideggerian interpretative phenomenology

Phenomenology was linked to existentialism and through this, philosophical hermeneutics was developed. Heidegger described his approach to phenomenology as hermeneutic. Hermeneutic is a Greek term, 'hermenia', meaning to express, interpret and to translate. Hermeneutics is a method of interpreting and understanding ways in which people live in the world. The investigations that researchers undertake within their world or society may be things that they have previously taken for granted, and there is a sense of wonder, as their significance and importance is explained. Walters (1995), writes that hermeneutic inquiry entails exploring the meanings of everyday life and is suited to the purpose of this study. A qualitative researcher following Heidegger's hermeneutic philosophy may ask the ontological questions: 'What is it like to be diagnosed with dementia?' or 'What is it like to live with dementia?' The hermeneutic-phenomenological philosophy challenges the notion of meanings, derived from the mental representations of phenomena independent of the reality of a situation. The hermeneutic-phenomenological approach recognises that phenomenology is a process that people use to make sense of their everyday world "*within a cultural background, involving language, personal and bodily practices*" (Walters 1995, p.798).

Heidegger rejected the notion that we are separate from the world of objects about which we try to gain knowledge, rather we are inseparable from an already existing world (Heidegger,

1962). He rejected the central idea of bracketing and maintained that researchers already have background knowledge about the focus of their enquiry (Heidegger, 1962). This approach accommodates my position as a woman of Black ethnicity living in North East London, with personal and professional experience of dementia as an individual of Black ethnicity. Not only does this approach give voice to the opportunity to the participants to tell their story, by placing priority on the phenomenon of study; *'that is the lived experience of dementia as an individual of Black ethnicity'*, it also acknowledges insider perspectives during the research process. My position as a woman of Black ethnicity living in North East London, my background and cultural views and life experience will, to some extent, have influenced the development of theoretical ideas about my data.

Heidegger was influenced by ideas on the possibilities of life and authentic living. Heidegger argued that it was impossible to explain 'things' as products of consciousness when they were detached from their everyday functioning in the world. He believed that it was only possible to understand 'Being' of what it is, so long as it is done through an ontological approach of study. He emphasised that people, as beings, are naturally and inevitably related to, and are part of the world. This hermeneutical phenomenological approach allows for an interpretive philosophical stance that listens to experiences, allows participants to express their feelings and thoughts and the researcher to interpret these. During this study, my values and beliefs had to be recognised within the research process, with the judgement of participants' thoughts put aside. Using a Heideggerian approach in this study, allowed the study to explore the participant's view of living with dementia as they understood it. It requires the researcher to be able to understand their views in a non-judgemental way (Heidegger, 1962). Heidegger argues that everything is interpretable, but this interpretation is tentative and not the final and absolute answer to the truth (Heidegger, 1962). Truth emerges from the interaction of the individual with their world; he writes that for any interpretation to occur there must be prior understanding of the experiences of the interpreter (Heidegger, 1962).

Therefore, having understood that the Heideggerian approach allows this study to understand and focus on the participant's subjective experiences of living with dementia; having considered findings from the literature review, and my own ontological and epistemological views; it was appropriate to then adopt a hermeneutical phenomenological approach that allowed for the interpretive philosophical stance that listens to the participants experiences, allows participants to express their views and the researcher to interpret these. The study does not concentrate on the diagnosis of dementia itself, but the adaption of the participants to the diagnosis and how they viewed their life world. This approach enables a better understanding of what the participant feels and how they experience coping with living with

dementia. It also helps researchers to understand the choices individuals make and the reasons behind them, for example deciding not to access health and social care support services. By taking this position, I understood that there was a philosophical fit between the research paradigm adopted and the chosen methodology.

3.5 Method

Phenomenological research demands a mode of collecting information that will present the participants' experiences precisely from their perspective i.e. in terms of the significance it has had for them personally (Crotty, 1996). To gain an understanding of the human experiences, it is necessary that more suitable methods are used that will illuminate the essence of the phenomena in their wider context. As discussed earlier, the philosophical basis that was used for this research was phenomenology, since phenomenological enquiries are suited to the study of life experiences (Streubert-Speziale and Carpenter, 2003). Given the focus on the 'meaning' of experiences, it was considered the most appropriate method to address the research question. Therefore, a qualitative approach was chosen and adapted to address this question, as qualitative research is concerned with understanding the meaning that people attach to their experiences within their social world (Ritchie *et al.* 2014). It uses written or oral data to obtain rich information about an experience and its meaning in their life. The focus of the study is to gain an insight into how dementia is experienced and understood from the perspective of the individual of Black ethnicity. The following section describes the processes undertaken to address the research question.

3.5.1 Participants: Recruiting and sampling

The sampling strategy aimed to incorporate people of Black ethnicity living with dementia who were willing to talk about their experiences of dementia. Sampling for ethnicity is challenging; participants need to be appropriate for the study, good informants, who are articulate, reflective and willing to share with the researcher (Morse, 2003). Morse (2003) suggests that participants are selected for two criteria: their appropriateness to the research enquiry (that they have experience of the phenomenon under investigation) and their willingness to share that experience. This selection process is known as purposive sampling, a non-random method of obtaining a small group of people with a specific characteristic useful in naturalistic or qualitative research (Bowling, 2009, Holloway and Galvin, 2016), that is designed to gain the depth and richness of the experience (Holloway and Galvin, 2016). Given my need to recruit people who have had the experience of living with dementia as an individual of Black

ethnicity and were able and willing to talk to me about it, purposive sampling technique was used (Holloway and Galvin, 2016).

3.5.2 Selection of the research site

The research site was a large National Health Service (NHS) Trust providing an extensive range of integrated community and mental health services for people living in four London boroughs of Barking and Dagenham, Havering, Redbridge and Waltham Forest and community health services for people living outside of London in the south-west. With an annual budget of £340 million, the NHS Trust provides care and treatment for a population of circa 2.5 million and employs approximately 6,000 staff from various backgrounds and ethnicity. Participants were sought to fit the purpose of the study from services operated by the local NHS Trust. These services were identified because of ease of access and are my previous employment NHS Trust. A letter of access via the NHS Trust Research and Development department was issued (see Appendix 02).

Participants were sought from the following services:

- Memory Clinics
- Community Hospital Inpatient Wards
- Mental Health Community Inpatient Wards
- Community Mental health teams

3.5.3 Inclusion and exclusion criteria

This study included individuals with different types of dementia. Participants met the criteria as outlined in Table 3.0 below. This study included the use of consultees also described in this thesis as 'relative/friend'. This is further discussed in section 3.8.1. Non-English-speaking participants were excluded as not being able to speak English and the use of interpreters could introduce additional complexities which would be better investigated in a separate study. No formal cognitive assessments were conducted to establish what stage participants are at or their cognitive capacity. Conducting mental capacity assessment tests prior to interviews could preclude the sought-after richness, inhibit inclusivity and exclude the very individuals that this work seeks to investigate. Sampling for ethnicity was challenging given that people with dementia are by nature a hard to 'find' population and are underrepresented in research. The overall aim was to be as inclusive as possible.

Table 3.0: Inclusion and exclusion criteria for participants

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none">• Clinical diagnosis of dementia• Black ethnicity• Reside within North East London health sector and receive dementia health care services from the NHS Trust within North East• Has a relative/friend who is willing to act as a Consultee• Has the capacity to understand the information sheet and is competent to give informed consent• Is willing to take part in the interview• Can communicate verbally and in English	<ul style="list-style-type: none">• Without a clinical diagnosis of dementia• Consultee considers that taking part in an interview would be detrimental to the participant• Unable to take part in an interview due to current health condition or likely rapid deterioration• Does not have the capacity to understand the study information and is not competent to give informed consent• Cannot speak English• Cannot communicate verbally

3.5.4 Negotiating access

I was aware that the study population is difficult to recruit, difficult to identify and the condition (the variability and dynamic nature of dementia) meant that the participants would have to not only have the capacity to give informed consent to take part in the study but have a relative/friend who would be happy to be present during and after all the interviews. Therefore, a multi-stage strategy was adopted to recruit participants, that required negotiation with key 'gatekeepers' along the way (Devers and Frankel, 2000). Processes were developed for recruiting and gaining consent from patients, relatives/friends who are admitted to the community inpatient rehabilitation wards based in community hospitals and Mental Health Community Inpatient Wards, Memory Clinics and Day Centres and those who were under the care of the Collaborative Care Team and Community Treatment Team. (See example in Appendix 03).

3.5.5 Identification and recruitment of participants

Recruiting for research studies is time-consuming and is particularly difficult among ethnic minorities (Halcomb *et al.* 2007). In developing this study, as mentioned in section 3.5.4, I

developed a recruitment process for the different settings (see example Appendix 03). During my meetings with health professionals from the NHS, I described my study, how I thought they might be able to help, and could respond to any questions about the study they may have. For those who were happy to assist with recruitment to my study, I was open to any suggestions they may have had in ensuring successful recruitment. Several studies highlighted that researchers from the same ethnicity may be more likely to reach and access people who share their ethnicity (Gunaratnam, 1997, Smaje and Field, 1997, Nazroo, 1998). Given the fact that I belong to the Black community, my ethnic identity appeared to affect the willingness to be involved in the study both positively and negatively. I observed that those whose ethnicity was less close to my own were less willing to be involved. I noted that those of similar ethnicity were very keen to assist me as we shared a common understanding of being from an ethnic minority background. Recruiting for ethnicity is challenging; I was able to recruit 1 participants within 3 months of commencing the study in 2013. The second participant was recruited during the month of April 2014.

Gaining access was therefore quite challenging and frustrating. Whereas I could totally appreciate the enormous strain that senior staff were under, their inability to commit to the study was disappointing. Once the study had the relevant approvals as discussed later in this chapter, (National Health Service (NHS) Research Ethics Committee (see Appendix 03), and NHS Research Governance Committee (see Appendix 05), the next stage was to get buy-in from the Consultants and Senior Nurses/service Managers. These clinicians and managers were gatekeepers (Hammersley and Atkinson, 1983) and had the ability to open or block routes to gaining participants. It is well recognised that 'gatekeepers' can act as a major barrier (Hellstrom *et al.* 2007). Fortunately, they gave their approval wholeheartedly, they invited me to their team meetings and I even had a chance to present at the Trust Annual research conference where the Lead Consultant openly endorsed the study and requested staff to support the recruitment process. Whilst approval was given readily by senior members of the organisation the reaction of frontline staff was slightly more circumspect. Theoretically, they were interested in the study and could see its value, but staff expressed concerns about potential impact on their own workload, it was a minor part of their day to day role and 'another' study.

Other factors also influenced the recruitment process, such as prearranged work and family commitments, achieving a work, study life balance and organisational changes. However, it became apparent during the process that I was finding it difficult to engage with the health professionals who were gatekeepers. During my visits to various teams, staff were interested, however, despite my efforts, I had serious difficulties in recruiting participants and decided to

widen out the recruitment process to include the local branches of Alzheimer's Society who support clients of Black ethnicity living with dementia and may not necessarily be active patients on the NHS Trust caseloads.

Studies have demonstrated that recruiting ethnic minorities can be enhanced by recruiting directly through their affiliated community associations and to ensure that care is taken to engage with the minority ethnic communities in ways that are both culturally appropriate and sustainable (Shiekh *et al.* 2009). The Alzheimer's Society had an interest in ethnic minority communities and was running a specific project- the 'Connecting Communities' project - to raise awareness of dementia within Black and minority ethnic (BME) communities across eight London boroughs. There was no change to the recruitment inclusion/exclusion criteria, the information sheets and consent forms. As such an application was submitted to the NHS REC for approval of substantial amendments. On 16 July 2014 approval was gained to work with Alzheimer's Society (see Appendix 06, 07, 08). I renewed contacts with NHS teams and arranged to meet the Alzheimer's Society staff in another recruitment drive for three more participants. One participant was identified, and she took part in the first interview, however, declined to continue with the remaining process. Alzheimer's Society identified two more potential participants who showed an interest in the study, however, one decided not to progress, and one did not give consent for me to contact her. The fourth participant took part in the study after a member of the NHS Community Mental Health Team contacted me. None of the participants was previously known to me. In a final attempt, I visited an Alzheimer's Society Dementia Café and met a facilitator who was of an ethnic minority background. In line with the NHS approval process, she approached potential participants who were interested in taking part in the study; as such I recruited the final participants of Black ethnicity. Following on from University supervision I soon realised that after six participants, the 'phenomenon had become apparent'. The initial proposal was to recruit up to ten participants, however, recruitment continued until theoretical saturation was achieved, that is, no new themes were emerging from the data. Therefore, the decision was taken in discussion with my University supervisor to finish data collection.

3.6 Use of interviews

Research has been carried out with individuals living with dementia in the general population and has been successful in eliciting subjective experiences and beliefs across a range of impairment with dementia patients (e.g. Keady *et al.* 1995; Gillies, 2000; Clare, 2002, Clare 2003, Pearce *et al.* 2002; Watchman, 2016), it stands to reason that this is also feasible for people of Black ethnicity living with dementia. Interviewing is a well-established research

method that involves an interaction between the researcher and the respondent who has experienced the phenomenon being investigated and is the most effective way of gathering the data (Miles and Huberman, 1994). Interviews may take a variety of forms, such as structured, semi-structured and unstructured. An unstructured interview is one where the researcher asks as few questions as possible, permitting the respondent to talk freely, intervening only to refocus the discussion or asking questions for additional insights into a key area (Morris 2015).

Due to the focus on perceptions, meanings and experiences, individual semi-structured interviews were appropriate for this study as this allowed participant to voice their thoughts; to tell their own stories on their own and at their own pace (Miles and Huberman, 1994). Semi-structured interviews utilising open-ended questions were employed, to invite the participants to describe the presence of dementia in their lives. This approach allowed for a degree of appropriate flexibility during the interview process. A structured interview would have a pre-determined specific set of questions and process that would clearly not allow or lend itself to flexibility in allowing the participant to direct or alter the topics described.

Semi-structured interviews in this study enabled the researcher to have proposed topics to discuss (see the interview topic guide - see Appendix 09); and questions to ask, but also to retain the flexibility to adapt the loosely structured interview process considering what emerges as of significance to the participant (Tod, 2010). Therefore, semi-structured interviews fitted well with the phenomenological approach adopted in this study, in allowing for some level of focus on emerging topics of interest, as described by the participants, whilst enabling new or unexpected directions to be taken during data collection. I, therefore, commenced each interview, using the interview topic guide, with guideline or prompt questions, touching upon their life histories, working and family life, and their journey to diagnosis and living with dementia with prompt questions such as *'When did you first notice something was changing?'*, or *'How did it feel when you received a diagnosis of dementia?'* and I often found that the participant would take the lead in directing the content of the interview in terms of highlighting key aspects of their experiences. I would guide the overall direction of the interview by using the topic guide to ensure that all aspects of the data I required were collected.

3.6.1 The interview process

When developing the study, the study was designed considering that the researcher was the *instrument of choice* to collect the data through interviews. From my clinical experience, I was aware of the clinical presentation of dementia and the associated symptoms of this including

cognitive impairment and its impact on the ability to communicate verbally. However, the aim of this study, was for the participants living with dementia to tell me their stories about what it is like to live with dementia, their understanding of dementia; what their feelings are, and their understanding of their life following their diagnosis of dementia as a person of Black ethnicity. Mills writes that the data from the research interview must reveal, “*depth, feeling and reflexive thought*” (Mills 2006, p. 4). The study was designed that the data collection process would include a series of three interviews conducted with each participant, to achieve the depth and detail producing a sense of completeness of the phenomenon being studied. I wanted to understand from the participants perspective what it was like to live with dementia as an individual of Black ethnicity. Semi-structured in-depth interviews can be repeated so as to build up the rapport between the interviewer and interviewee and enhance the depth and detail of the data collected (Morris 2015).

As the aim of this investigation was to understand the lived experience of living with dementia as an individual of Black ethnicity, I wished to start the enquiry (first interview) from before the time that the diagnosis was made, to understand their background, culture and human stories. The topic guide in Appendix 09 had prompts for example relating to childhood, growing up in their country of origin, family friends and community as well as their immigration history.

The second interview was focused on life with dementia, as a perception of how their lives are now was key to this study. I wanted to understand their journey to gaining a diagnosis, as such the topic guide had prompts that included looking at when the participant started having problems with your memory, when they first noticed this, their everyday lives and important aspects of their lives whilst living with dementia.

The third interview was planned to be determined by the first and second interview, to explore areas that were not fully discussed. On completion of each of the first and second interviews, the collected data was reviewed to ensure that the interview process had covered all areas as identified in the topic guide. I would make notes after each interview to understand which areas were discussed (see exampled Appendix 10). Any areas that were not fully discussed would be explored in the third interview as well as any other areas the participant wished to discuss. An example of a discussion of the third interview is included in Appendix 11 where I was able to remind the participant of our previous discussion regarding coping everyday day as well as further discussion about her childhood and family members.

The interviews were flexible and conversational in nature. There was time for a (re)introduction to the researcher and the study, along with (re)negotiating consent, and orientation to the topic

as well as time to build rapport with the participant. The interview process included three phases: preparation, conducting the interview and the ending the interviews.

3.6.2 Preparation

Mills (2006) describes how constructivist enquiry requires the researcher to prioritise analysis of the interaction between the participant and themselves. In this way, that interaction is inherent to the data that will be produced (Mills 2006). In part, this process is aided by removing wherever possible any unequal sense of a power relationship, where the researcher has more control over the interview setting. Therefore, I was aware of the relationship between myself as the research instrument and the participants; and in doing so, I considered the location of the interviews. The social context in which the interviews took place and the setting, were important factors considered prior to conducting the interviews. The reason being that participant responses may/could have been heavily influenced by these dynamics (Clare, 2002).

For this study, all participants requested to be interviewed in their own homes, with the option of daytime interviews, so that family or friends could be present according to the participant's wishes. The participants chose to have the interviews in a setting that is comfortable for them, and they took place at the best part of the day for the participants and at a time of their choosing. Therefore, the interviews were conducted in participants' homes as it was believed that this was the most comfortable environment for interviewing people living with dementia (Keady *et al.* 1995).

Interviews were conducted at a time convenient to the participants. Price (2002) recommended that the researcher needs to have the flexibility to expect and manage unexpected upheavals during the interview process such as a change in the focus, direction, duration and sequence of discussion. For all interviews, I called by telephone on the morning of the appointment to confirm the interviewee was happy to proceed with the study. Participants' cultural requests were respected; such as having to remove shoes on entering their home when requested. I remained nervous about my ability to build the necessary rapport with the participants to conduct the interview. I was conscious that I am naturally an introvert and not immediately likeable. However, I recognised that my authenticity was very important in gaining the trust of the participants. In addition, the interviews were carried out during my working week, therefore I had to learn to adjust from my day to day manager role to a nurse researcher as I prepared mentally for the interviews. Often, I did this on my journey to the participants' homes.

I also had to think of the use of language and terminology during the interviews; in particular the use of the word 'dementia' or other terms such as 'Alzheimer's Disease' or 'Vascular Dementia'. For example, I observed that Hellstrom *et al.* (2007) in their work used the terms 'memory problem' when interviewing couples where one partner had a diagnosis of dementia and did not use the word 'dementia' until this was introduced by the participants. The term 'dementia' is suggested as a cause of unnecessary harm and distress (Hellstrom *et al.* 2007). This demonstrates the impact of certain phrases and terms that may carry highly negative or (perceived) stigmatising effects. I was also mindful that in choosing to use the term 'memory problems' as opposed to 'dementia,' this could potentially mislead or confuse participants (Langdon *et al.* 2007, Steeman *et al.* 2007). As such, I mainly used the term 'memory problems' rather than dementia, especially at the first interview. I did not use both terms during the same interview interchangeably. If 'dementia' was introduced by the participant and or their friend/relative I would continue to use that term as it indicated to me that they were comfortable with that terminology and that perhaps they had developed some sort of meaning for them. This was a particular benefit of having more than one interview, as the interviews continued I was more aware of the appropriate terminology to use with each participant.

3.6.3 Conducting the interviews

Interviews were started after revisiting the information sheets and obtaining the consent. I followed the interview topic guide (see Appendix 09) that was primarily informed by my preliminary literature review presented in Chapter Two. Meeting a participant was always a nervous moment, one that cannot be hurried or predicted. Time was required to build rapport between the interviewer and the participants as well as their friend and/or representative. I could discuss my journey as an icebreaker and this often helped to relax both the participant and their friend or relative. I then obtained written consent (see Appendix 12 and 13).

During the interviews, I ensured I listened attentively, was accepting of participants as they presented. Hence, my general approach was one of openness in seeking to listen and understand what the participants were trying to share. I was also mindful of the power differential between participants and researcher. I was of Black ethnicity and they were too. I felt they perceived me to be in a position of authority. I interpreted that, as one participant mentioned how nice it was to see Black people carrying out research about Black people and that they would support their own; implying that I was doing a good thing for Black people. Furthermore, I was also aware that participants may be unwilling, or open to discussing their experiences, although this proved not to be the case in this study.

Specific reasons as to why people with dementia would be unwilling to discuss their experiences are linked to stigma and shame, as previously discussed in Chapter Two.

Throughout the interviews, great care was taken to ensure that participants were comfortable and did not become overtired (Keady *et al.* 1995). Attention was paid to ensuring that, if participants display signs of distress or fatigue, either through verbal or non-verbal means, appropriate action would be taken e.g. the the interview would be terminated (Moore and Hollett, 2003). This occurred on one occasion, where the participant was upset, and we ended the interview, and the Consultee who was present reassured the participant, followed by a chat and cup of tea. However, I was also mindful that a delicate balance was required between protecting participants yet allowing them the opportunity to express their feelings.

3.6.4 Recording the interview

The interviews were recorded, and written consent was gained from the participants to do this. All but one participant agreed to be recorded. As such, I had to make notes. This participant also declined to complete the interview process. The participants, once they became comfortable with the recorder, overall were quite at ease with the process and chatted freely as they described their lived experience of dementia. The recorder was placed openly on a table nearby. I used open questions to invite participants to describe their perspectives on the topic of investigation (see Appendix 09 Interview Topic Guide). Interviewees were encouraged, if they felt comfortable to do so, to describe their personal experiences; these served as a guide for the participants to talk freely about the issues on the topic guide (Price, 2002). The interviews lasted between 20 and 58 minutes (see Appendix 14).

3.6.5 Ending the interviews

Interviews were closed with thanking the participants for their contribution. I could tell that it was time to close the interview by using nonverbal and verbal cues, such as by participants giving single-word answers, appearing tired, or informing me they had nothing else to add. Interviews also concluded by asking participants again, if they had any other issues they wanted to discuss. Time was also spent after stopping the recorder, discussing social issues, and, where offered, taking tea and coffee. I accepted tea and coffee as I knew culturally not accepting this would seem disrespectful. This also served not only as a further means of building rapport, it also ensured that participants were well and not distressed following the interview. I was also mindful that participants had given me their time, thus, I felt obligated to

not leave almost immediately. 'taking the data and running' (Clarke and Keady, 2002). Appendix 14 provides further details regarding the interviews, including dates, venue and times record.

3.6.5 Transcription

After the interview, the researcher transferred the recording from the audio-recorder to the professional transcribing service protected online service which can only be accessed by the transcriber. The audio recording was then deleted from the recorder. As part of this process, the transcripts were anonymised, and other identifying information removed. A sample extract of the professional transcript is included in the Appendices (see Appendix 15).

3.7 Ethical considerations

The next section discusses the ethical implications related to completing this study; explaining the process of gaining ethical approval, managing issues around capacity and consent, confidentiality and data management.

3.7.1 The process of gaining ethical approval in the NHS

The safety and welfare of the participants is paramount, and the researcher adhered to ethical principles throughout the study. Ethical approval was sought in line with the National Health Service Research Ethics process (see Appendix 06, 07, 08) and NHS Research and Development approval was gained (see Appendix 05).

The process of obtaining ethical approval from the NHS Research Authority involved attending the Research Ethics Committee meeting and providing the required assurance. An application was made to the University Research Ethics Committee (UREC) (see Appendix 16,17, 18,19). Due to the challenges in recruiting participants, a further application with extended recruitment (as described in Section 3.4.5) was submitted for NHS Research Authority Substantial Amendment Approval, which was granted (see Appendix 08).

3.7.2 Participants who may lack capacity

The NHS Research Authority (DH, 2017) advises that adults who are not able to consent for themselves should be included in the research if this is in line with relevant legal frameworks and ethical principles. The NHS Research Authority notes that the researcher should always

ensure that what capacity an adult has is optimised and used as far as possible to enable that individual to make decisions for themselves. The legal framework that governs the inclusion of adults not able to consent for themselves in research in England and Wales is the Mental Capacity Act (2005). The NHS Research Authority required that the researcher should seek advice from a consultee on whether an adult lacking capacity to consent would wish to be included in the research study or not. Consultees are not asked to give consent on behalf of the adult, but rather to provide an opinion on the views and feelings of the potential participant. Consultees for intrusive research other than Clinical Trials of Investigational Medicinal Products (CTIMPs), in England and Wales, are described as a person who cares for the adult lacking capacity or is interested in that person's welfare but is not doing so for remuneration or acting in a professional capacity; and this was the case in this study.

Reasonable arrangements were in place to consult another person- 'Consultee' -for advice on whether the participant should take part and on what the participant's wishes and feelings might be. In this study, Consultees were either friends or relatives in this study, who supported the participant. If a participant did not have a person identified to be a consultee, then they were excluded from the study. Appropriate information was provided to consultees and participants through information sheets about (a) their role and responsibilities, including possible consultation throughout the study (b) the study itself and its risks and benefits. (see Appendix 20).

3.7.3 Informed consent

An information sheet (see Appendix 20, 21) outlining the study aims and what it involved, was given to all potential participants and their consultees. They were given time to consider the information and were encouraged to discuss the study with family members or friends before taking part. These were intended to fully inform participants of the risks involved in taking part in the study to enable potential participants to make an informed decision (Seymour and Skilbeck, 2002). Participants were given the opportunity to ask questions at any point. Both the consent forms and information sheets are included in the appendices (see Appendix 12, 13, 20, 21).

Seeking consent from people with dementia was treated as an on-going process during this study. This was undertaken in stages and not as a 'one-off' encounter (Pratt, 2002, Hubbard *et al.* 2002, Hellstrom *et al.* 2007) Thus, consent was negotiated and re-negotiated throughout the interviews. A key aim was to provide an opportunity for these individuals to play an active role in the consenting procedure and to

engage in the wider research process. The potential benefits and risks were discussed, for example, talking about experiences of memory problems might prove distressing. Strategies to manage this were also discussed e.g. the interview would be terminated if it was a participant's expressed wish (see Appendix 20, 21).

Written informed consent was obtained from all those who took part in the study to record interviews and publish the findings. Prior to commencing the interview, I took more than 10 minutes to explain and clarify the consent form including outcomes and conduct and the use of personal information before participants signed the consent form. Participants were informed that they could withdraw their consent at any time without giving any explanations and withdraw consent for any personal information to be used in the research. There is evidence that people prefer to receive from, and value the information given by, their family members (Barnes *et al.* 1998). In this study, I gave out consent forms and information sheets, to both the participants and friend or relative to read the information for them and sought their approval before signing a consent form. I also made it clear that participants were not guaranteed any direct and immediate visible benefits for their participation. I informed them that their participation might be an opportunity for them to share experiences, feelings, opinions and their knowledge.

Under the terms of the Mental Capacity Act (2005), a person with dementia is deemed to have the capacity to contribute to decisions affecting their lives unless and until proved otherwise. In relation to gaining consent in research, I had to be confident that the participant, the individual living with dementia had the capacity to consent both at the beginning of the research process when first approached and at all further points when they participated. The NHS Research Ethics Committee as part of the ethics approval process sought clarification as to how and who will be assessing the capacity of the patient with regards to the Mental Capacity Assessment, and whether this would be done with every new interaction. The recruitment protocol developed was designed so that a member of the participant's clinical team completed the initial approach to potential study participants. The nursing and multidisciplinary clinical staff were provided with the inclusion/exclusion criteria. The staff were asked to identify individuals of Black ethnicity with a diagnosis of dementia, who had been assessed by the staff to have the capacity to understand the information sheet and who were competent to give informed consent. The researcher only approached individuals who had been assessed as having capacity by the clinical team. As recommended by the NHS Research Ethics Committee, I completed the Mental Capacity Assessment training on how to assess capacity and fully considered the NHS Trust Procedure for Assessment of Mental Capacity

3.7.4 Developing participant / consultee information sheets

I worked with the Alzheimer's Society Research Programme, Research Network, who are a group of carers, former carers and people living with dementia and are actively involved in setting the dementia research agenda and assessing research proposals. The participant and consultee information sheets, participant letters and interview topic guide were shared with 15 members of the research network volunteers. Whilst not all the volunteers were of Black ethnicity they had some personal experience of dementia, mostly as current and/or former carers. Research Network volunteers had received training in the research process and regularly reviewed research proposals received by Alzheimer's Society. Feedback was received on the 20th of May 2013. The feedback was both critical and insightful. Moreover, the feedback was the first opportunity to receive views from members of the public who use NHS services in the UK. This feedback informed and assisted in reviewing the information sheets, consent forms and recruitment process to producing the final versions. The feedback received is included in Appendix 22.

3.7.5 Managing issues of confidentiality

Before the interviews commenced, I explained to the participants and friend or relative present, my own cultural and ethnic background and the community that I belonged to; mainly because they asked me. Conversations were had around how they felt talking to me about their experiences and if they had any concerns, such as breaches of confidentiality. Privacy was assured by conducting interviews in the participants' venue of choice, mainly in their own home. Interviews were conducted in a private room in the participant's home.

It was made clear during a discussion with participants and their friend or relative, that a participant would be withdrawn if the participant indicated they wished to be withdrawn. As an experienced registered nurse, I was sensitive and attentive to the participants and I could refer participants to suitable support services if needed. Before starting the interviews, I checked if the participant was feeling well enough to be interviewed. I also explained to participants that they could share as much as they felt comfortable with. I explained that if they did not want to answer any specific questions they could let me know. I was mindful that some may not have been used to sharing their stories.

Due to the sensitive topics explored in the interview, there was a possibility that some participants may have found it upsetting or distressing to speak about certain issues. In this situation, participants were asked if they wished to continue with the interview or take a break

or wished to complete the interview at a later date and time. Their friend or relative was also present to provide support pre and post-interviews.

3.7.6 Using Pseudonyms

Pseudonyms (as below) were used to anonymise data to protect the identity of study participants. They are often used in qualitative studies, rather than study numbers or codes, to represent the human facet of the research (Allen and Wiles 2015). I initially called all participants- 'Participant A, Participant B etc. during the initial data analysis process. As part of the doctoral supervision I received, it was suggested having pseudonyms. Researchers are reminded in literature of the importance of participant confidentiality as an ethical requirement of research (Wiles *et al.* 2008; Creswell, 2013; Roberts, 2015); and this includes, using pseudonyms to preserve anonymity (Thomas and Hodges, 2010). In choosing the pseudonyms I did consider whether the culture or ethnic background of participants- whether this should be reflected in the pseudonyms chosen (Thomson and Russo, 2012); however, as I immersed myself in the data, I realised that this was not of relevance as actually none of the participants real names reflected this. Therefore, appropriate pseudonyms were naturally applied. This was part of 'immersion' – in the data analysis process as discussed in section 3.8.1

Table 3.1: Participant(pseudonyms)

Participant (Pseudonyms)	Sex
Alice	Female
Beverley	Female
Catherine	Female
Destiny	Female
Edward	Male
Francis	Male

3.7.7 Data storage

All data collected were kept securely in encrypted files on password protected computers and were locked in a filing cabinet at my NHS employment. Interview recordings were transcribed by a professional transcribing company. As discussed in section 3.7.6 data confidentiality was preserved by giving unique pseudonyms for each participant, which were used throughout the study to prevent individuals being recognised in the research documents. A sample of the

transcript is included in the appendices (see Appendix 15). The collected data were stored and organised in a project file on the university licensed N*Vivo programme. The use of N*Vivo is discussed in section 3.8.3. Any information from this study used to disseminate the outcomes, through conference, publications and public presentations is anonymised to protect participants.

3.8 Data analysis

This study adopted the thematic analysis framework as described by Braun and Clarke (2006). They define thematic analysis as a method for identifying, analysing, and reporting patterns (themes) within data. They advised that it often goes further than this, rather it interprets various aspects of the research topic (Boyatzis, 1998 cited in Braun and Clarke, 2006). They provide a 6-phase process - the six phases of analysis, to be applied when analysing the data. They highlight that analysis is not a linear process, rather a process where one moves back and forth as required, during the data analysis process (Braun and Clarke, 2006). This method was selected because it is best suited to exploring the meaning and significance of experiences of participants to gain insight into the lived experience of dementia. Therefore, an inductive rather than deductive approach was applied, as there were no specified hypotheses to test and I wished to build a knowledge base up from the interview data, as is common practice in qualitative research (Seale *et al.* 2014). Thematic analysis was also seen as a means of analysing lived experience descriptions. Themes enable the researcher to capture '*the phenomenon one tries to understand*' (Van Manen, 1990) by allowing the researcher to simplify and focus on description.

3.8.1 The experience of data analysis

In completing data analysis, I followed the Phases of Thematic Analysis as outlined by Braun and Clarke (2006 p.34) in table 3.2. The process that I followed in reference to the phases of thematic analysis by Braun and Clarke 2006) is further detailed below.

Table 3.2: Phases of Thematic Analysis

Phase	Description of the process
Familiarising yourself with your data:	Transcribing data (if necessary), reading and rereading the data, noting down initial ideas.
Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code

Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic map of the analysis.
Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

Familiarising yourself with your data: In becoming familiar with the data, I listened to audio recordings of interviews within 24 hours to review each interview, with note writing to capture any additional or general observations, impressions or ideas. As the data collection process included a series of three interviews, when I reviewed the first and second audio recordings, when I identified areas that were not fully explored, these notes were used to help develop the interview guide for the third interview with the participant. Each interview was then transcribed verbatim by the transcribing service. On receipt of the transcript, I reviewed it again, to ensure that audio recording and transcript were accurate. This was a necessary step, as on one transcript, the transcriber noted: *‘Transcriber’s note: Strong accents. Mic poorly positioned’*. I was able to use the Annotations function on N*Vivo to make further notes as I reviewed the received transcripts against the audio recording (see Appendix 23).

The object of this study was to interpret the experience of the participants living with dementia of Black ethnicity in the UK, and not just the story itself (Bernard and Ryan, 2010). The interviews gave the participants the opportunity to tell their stories which became the data for the research. For the data analysis to be effective within a phenomenological study the data needs to retell the story in such a way that it is understandable to the reader. Cohen *et al.*

(2000) write that analysis begins during the interviews, as the researcher actively listens to the participant and consciously thinks about the meaning of what is being said. As I was the interviewer I would agree with this – it was difficult not to get excited when I listened to some of the narrations. I recall that I would call my University supervisor to explain the preliminary observations. The more I read and re-read the data, the process of allocating then codes commenced.

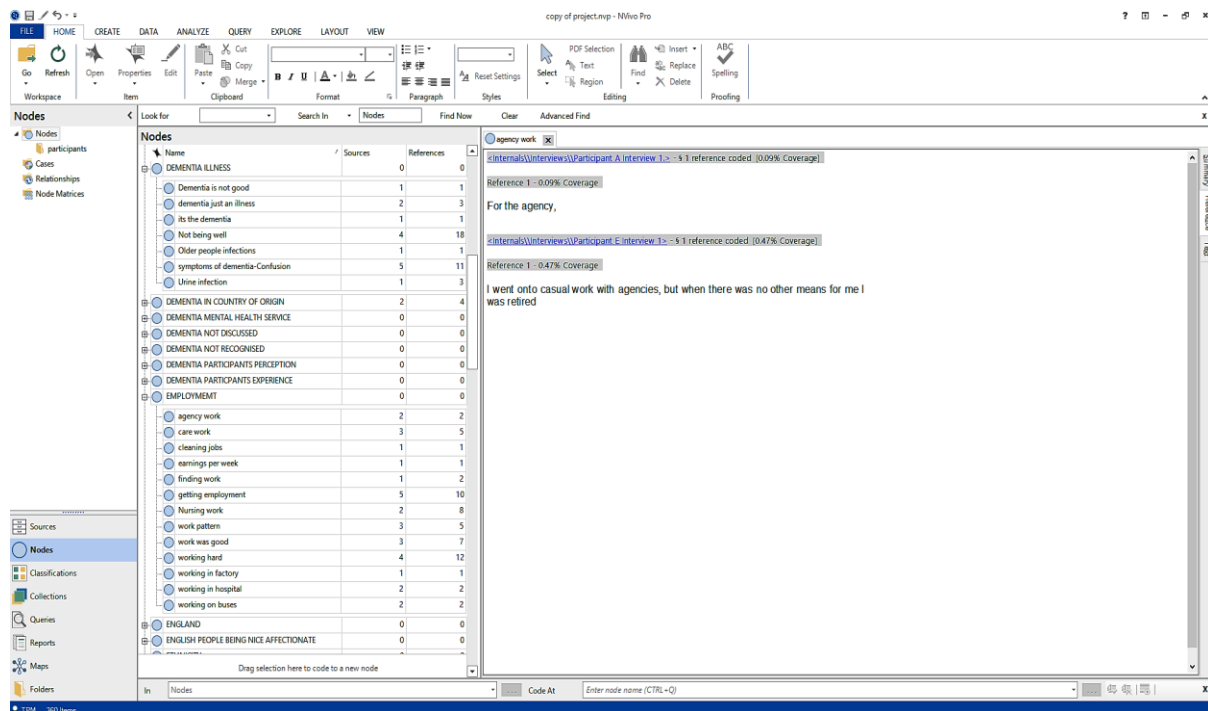
Generating initial codes: The data were explored using coding techniques to establish common themes and any deviant themes that emerge. Once the transcripts were received, the transcripts were uploaded onto NVivo.

I used NVIVO software (QSR International Pty Ltd, V.10, 2012) for initial analysis. Care in coding the data had to be taken to ensure the excerpts documented were in context with the theme it had been placed in. For this study, a line by line scrutiny was undertaken of the 16 transcripts (made up of 5 x 3 interviews and 1 transcript from the participant who did not complete the study) from the semi-structured interviews.

Using N*Vivo, across the whole body of the transcripts, every identifiable significant statement or comment was assigned a code. For example, any content/statements related to participant agency employment -were coded initially under the code 'agency'-see figure 3.0 below. The codes were generated as I was examining the data. I had no predefined codes. I developed a list of over 150 codes.

Searching for themes: I then reviewed the codes list and recognised that certain similar codes occurred more than once and there were related codes with logical connections. Therefore, I grouped these using parent codes to assist in commencing development of the identification of themes. For example, in figure 3.0 all codes relating to employment, types of employment, views about getting work, work patterns were grouped under Employment. Similarly, with regards to the participants views about how they viewed dementia as an illness, what they perceived caused dementia or was related to dementia as an illness was grouped under Dementia as an illness. If a statement fitted into more than one category they were placed in the one that fitted most in the context of the study. Once the codes were grouped under parent codes, I had a list of 51 parent codes. (see Appendix 24).

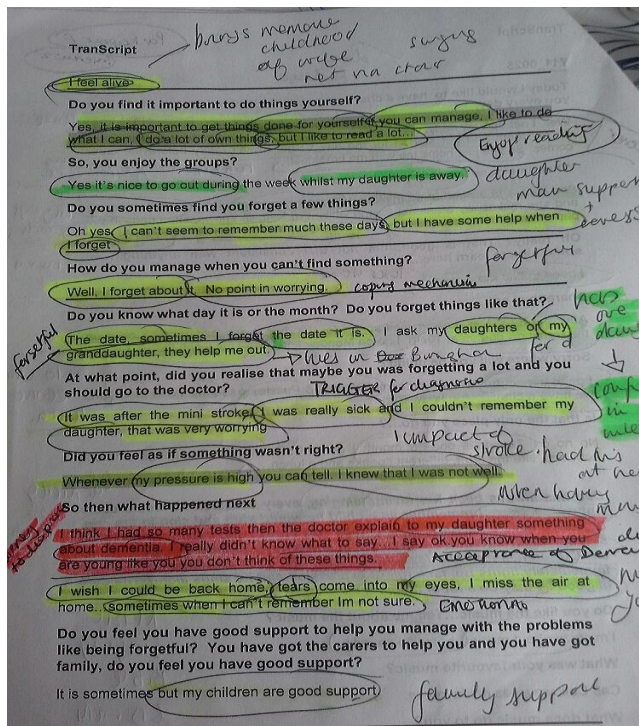
Figure 3.0: Example of N*Vivo coding



N*Vivo was quite helpful with this initial coding process with this process and I could use other features such as Word frequency queries, and this was presented visually as a word cloud (see Appendix 25). This N*Vivo function enabled me to see word frequency and word trees' and also gave me direction for further analysis in the initial stages. Silverman (1993) thought simple counting of themes was of value, as the researcher found in the initial stages of analysis. But for a phenomenological approach, this was not enough, and more in-depth exploration of the data was carried out as described in the next section.

Searching for themes: In order to fully understand the phenomenon that was emerging from the data, I recognised that that functionality of N*Vivo was limited and that I required a deeper immersion. Therefore, I also reviewed the transcripts manually data and coded by the researcher to enable the feeling of the rich data to be experienced first-hand. This was done by a line by line study of each part of the data text and writing emerging themes. I was able to cross-reference to the work already completed on N*Vivo. A practical example of this is seen in the transcript image in Figure 3.1.

Figure 3.1: Example of data coding



Reviewing themes: The participants' stories were told by the researcher through quotes from the transcripts under the headings of emerging themes. Selecting quotes that make it clear how a person really experiences something is challenging to the researcher, requiring an empathic understanding of the phenomenon being studied (Bernard and Ryan, 2010). The participants in the interviews gave a story through conversation with the researcher about their experiences. The process of reading and re-reading is sometimes known as "immersing oneself in the data" (Cohen *et al.* 2000) and is what, in this study, helped to develop an interpretation which later informed the theme development.

Through the repeated reading of the transcripts to allow me to become more familiar with the data and a process of reflective thinking, a gradual awakening of the hidden meanings of the narratives began to emerge. Streubert and Carpenter (2011) term this "interpretive reading". I reviewed the codes and the parent codes and started developing a thematic map of the analysis with the initial development of the overarching themes (see Appendix 26). The data were grouped and re-grouped under the overarching themes to enable the essence of living with dementia as an individual of Black ethnicity to emerge

Defining and naming themes: Once the initial key themes and overall understanding had been developed, ongoing analysis allowed for the specifics of each theme to develop; I then

developed a diagram which helped me to see the whole picture: Life before dementia; Journey to diagnosis and then of course Living with dementia as demonstrated in Appendix 27

All themes were presented as relating to the entire sample. The overarching themes developed and sub-themes, which helped to capture the essential meanings of the overarching themes, were also noted. One interlining theme was also identified. It was a process of writing and rewriting reflexively and it was through this continuous process of re-reading and re-writing that the emerging themes were developed.

Producing the report: Producing the report: The findings of this process are presented fully in Chapter four with a summary of findings presented in section 3.11.

3.9 The 'trustworthiness' of the data

Lincoln and Guba (1985) argued that the issue of trustworthiness is simple; the researcher needs to persuade the audience that the study findings are worthy. Guba and Lincoln (1989) identified four trustworthiness criteria; credibility-that is related to the true picture of the phenomenon; transferability- whether the findings of this study can be transferred to other situations or similar studies; dependability- this considers the consistency between the data and the findings; and lastly confirmability which includes strategies used to minimise cultural bias in the study. Tong *et al.* (2007) also published a criterion for reporting qualitative research, in which they identified three main themes for reporting: (1) research team and reflexivity; (2) study design and (3) analysis and findings.

Hammersley (1992) questioned the view that qualitative data is easier to validate than quantitative data. He was concerned that the researcher may become complacent by claiming that empathy, experience and involvement with the participant group is a the reliable basis for validating data. He also disclaimed the assumption that only the the researcher can be the judge of the study's validity, having the greatest insight into the study. He recommended a mixture of insider and outsider involvement to validate findings.

This study adopted the use of interviews. A criticism of conducting interviews is the issue of trustworthiness since qualitative studies provide readers with little more than brief persuasive data extracts, which may not provide a true perspective of the people being studied. A further weakness is that of reliability. Although the interviews are recorded and may be transcribed verbatim, the issue of the interpretation of the transcriptions by the researcher may be

questioned (Silverman, 2000). In this study, to address any concerns about trustworthiness and reliability, I have documented and illustrated the procedures undertaken at all stages of the study. This it was believed, would will add to the dependability of the study. The main themes and sub-themes were critically reviewed by my academic supervisors. Based on these discussions some changes were made to the themes in terms of groupings and labelling.

3.10 Reflexivity

Phenomenology sits within the interpretive paradigm and the use of critical reflection in the form of reflexivity can help to ensure trustworthiness of the research. Reflection is often linked with practitioner development and reflexivity with ethically sound research methodologies (Yin, 2013). Reflexivity is viewed as the process of a continual internal dialogue and critical self-evaluation of the research process and outcome (Pillow, 2003; Bradbury-Jones, 2007; Stronach et al., 2007). This approach is supported by Koch and Harrington (1998) who promote the use of reflexivity as an effective way of signposting 'what is going on' in the study. Parallel to this, is also the expectation that reflexivity requires the researcher to consider the impact of their own history and issues on their understanding of and reactions to the study participant (Berger 2013). Therefore, as part of this process, I had to consider my positioning, my race, personal experience, culture, biases and intentions in relation to the study.

From the beginning of this study, my ethnic background, my culture and beliefs were made clear in the introductory chapter of this thesis. The purpose of the study and my motivation was made clear, my position in this study is further discussed in section 10.3. During this study it was impossible to achieve total objectivity. Kacen and Chaitin (2006) write that the background of the researcher affects the way in which the study is designed, planned and carried out and how the data gathered from participants is interpreted to making meaning of it. Therefore, I adopted strategies such as the use of supervision and the use of a personal diary to assist with this process.

3.10.1 Supervision

I engaged in regular supervision provided by the supervisory team. This was in the form of a face to face meeting or via telephone discussion, email correspondence. A written record was maintained of the supervision sessions, detailing discussion regarding the study process, as well as outlining guidance and advice given. Mainly the supervision sessions continually challenged my own assumptions, which were at times based on cultural bias. Independent

research supervision created an opportunity for critical reflective learning and this dialogue resulted in new understanding or insight on the phenomena developing (Douglas 2003). Research supervision also highlighted inconsistencies in the study; as a novice researcher at times I did digress. Whilst there was a dependency on the supervisory team to provide feedback, it was also necessary to expose me to opponents of qualitative work, for example through presenting my work at the doctoral support group; this was another way of receiving independent peer feedback. This encouraged me to further critique and reflect on my own work. I believe that the consistency of supervisory support helped to embed reflective practice. This minimised the impact of cultural bias, it was also my view that possibly this contributed to the meaningful interpretation of the study findings.

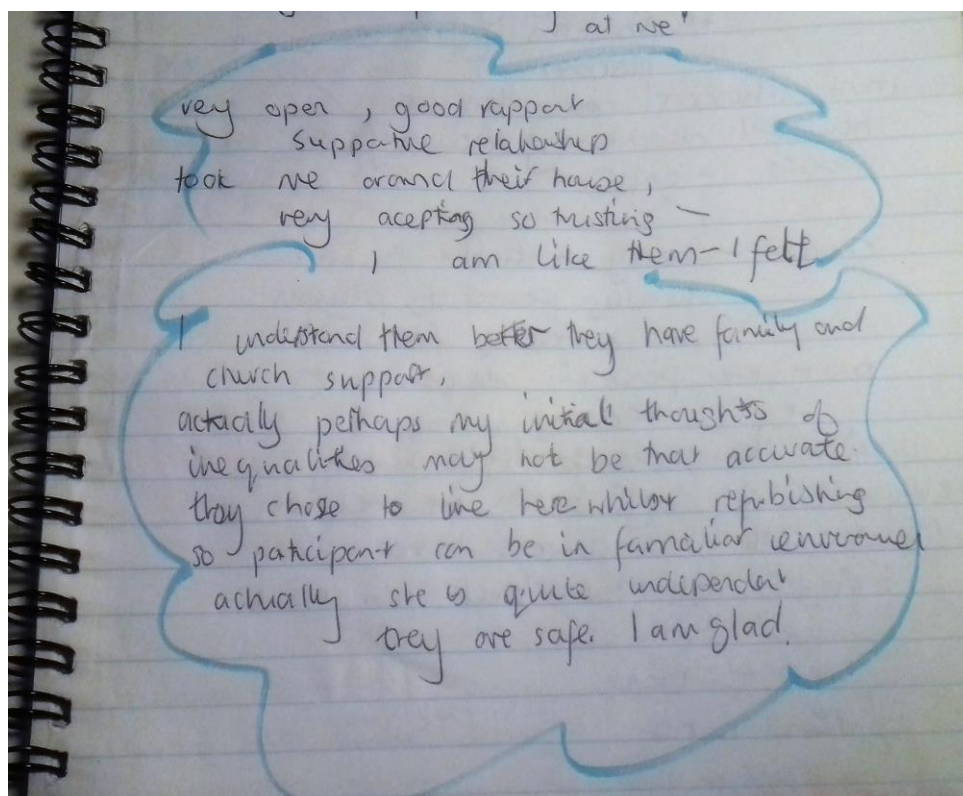
3.10.2 Personal reflection/research diary

Reflexivity played a central role in my attempts to manage my preconceptions and possible cultural bias. I had a personal diary, which was a way of making a conscious effort to be aware of how I conducted the study, how I responded to the participants and how the findings and conclusions were developed. The use of a diary to record the researcher's thoughts, views and observations of the research in progress is a common and recommended practice within phenomenological research and helps to establish rigour. I commenced my own diary because of university supervision, so my initial entries were collated under the heading of "personal thoughts". The aim of the diary was to provide material for reflection whilst increasing self-awareness. Initially, this journal was used to jot down ideas, rationalise what I was thinking and formulate research questions whilst establishing my aims and developing my work. As my knowledge and understanding of the philosophical methodology grew, I realised that the diary would not just increase self-awareness and establish rigour but would be a source of data that captured information gathered from the interviews, specifically post-interview thoughts and emerging ideas, as the research progressed. I also began to note a growth in confidence, daring to write what I really thought, and stating perhaps what people think but do not say.

Excerpt from diary: *'Where do I fit in. I am researching my own ethnic group and I found that I had a lot in common with the participants. I have to acknowledge my own background, social class, gender beliefs and values...I had to keep reminding myself why I was at the interview...I also feel that researching my own community put additional pressures on me. I have a responsibility as to what I write, I work and live in the area, I felt that I was gaining good data, however, I am very conscious that if I was not Black perhaps I would not have got this information'. (25/11/2013)*

Dahlber et al. (2008) warn researchers to avoid reaching and understanding too quickly or too carelessly and that reflexivity is a way of bringing out influences that prompted the research question in the first place. I recognised in my diary that my own beliefs around health inequalities had resulted in me forming an opinion prematurely as demonstrated in Figure 3.2 below- excerpt from diary.

Figure 3.2-Excerpt from diary



Reflexive journals are a common practice in qualitative research in maintaining rigour (Etherington, 2004). The journal helped me to think about the way I asked certain questions in the interviews and to think about how to help widen the conversations. Providing an audit trail over time has been useful as not only does this demonstrate reflexivity over the lifetime of this study, it also shows how this reflexivity changed as my thinking and conceptual abilities developed. As mention in section 3.10, this process involved the researcher, acknowledging their own preconceptions, possible cultural bias and expectations, which can then be critically reviewed by others. In the introduction and methodology chapters, I outlined my epistemological position and the different positions I held that may have shaped the research and the interpretations made. I kept a reflexive research diary to make my thoughts and assumptions more visible and transparent to both myself and others.

3.10.2 Reflections on Interviewing people with dementia

Reflexivity has been achieved in this study by critically examining each stage of the research process to ensure that the final product is both credible and dependable (Koch and Harrington 1998). In this section I reflect on my experience of interviewing people living with dementia.

Some participants and their relatives understood that I was a nurse and held certain expectations as a result. For example, one participant's relative was mainly interested in finding out how her mother's care could be funded by the NHS and subsequently did not complete the interview process as she was not interested in the research study itself but required health funding advice. However, I politely made clear to the participants along with the Consultee, regarding my role as a researcher and the purpose of the interviews. Furthermore, I was a novice qualitative researcher and had no previous experience of researching sensitive topics such as mental health issues among ethnic minority groups. Therefore, this study received ongoing monitoring and mentoring from the study supervisors with an aim to conduct the interviews with due care in a supportive, gentle and responsive way to minimise undue stress. All the participants were informed that interviews would be immediately terminated, if they felt upset or unwell, or at any other time if they wished to stop the session. One participant did become upset; however, this was at the end of the third interview and the interview was stopped, and the participant was reassured by her husband with a cup of tea. I further used continuous ongoing verbal consent throughout the study to confirm their willingness to continue the data collection.

I also observed that the participants did require a lot of prompting and that the Consultee presence and contribution proved to be valuable in understanding the overall experience of living with dementia. The participants who took part in the study sometimes became confused. The 'consultee', friend or relative who was present during the interviews, often contributed to clarify issues and to complete the story that was sometimes difficult to understand. This presented me with a challenge as I had to ensure that I was capturing the views of the participants, however, at the same time, acknowledging that the 'consultee' information was very useful to help understand the lived experience of dementia in its entirety. For example, during the interview with Beverley, when asked about growing up at home she responded

'I don't know anything about that'.

Her daughter then encouraged her to tell me about life in Jamaica, which helped to progress the data collection process. Similarly, Catherine who became confused during the interview, when asked about when she got married, responded:

'Yes, he, my husband is sleeping'

Her daughter advised:

'dad passed away 5 years ago but mum still thinks he is here, she talks to him and call him... (says in low voice...I nod)'

I reflected upon after the interview process: the emotional labour relating to this study as I had to be comfortable with long pauses and sometimes displays of emotion and confusion/hallucination. I also noted that at the end of the series of interviews, one participant, in particular, was quite fond of me and wanted to be affectionate towards me and showed me around her house. From the start of this study, I was aware of some of the issues involving qualitative research e.g. becoming over-involved with participants (Rubin and Rubin, 2005), 'going native' (Hammersley and Atkinson, 1995). On reflection, I referred to views by Miller (1952) who described 'going native' as developing an 'over-rapport' with the participants and the bias that may arise from 'over-rapport' in the data gathering process (Hammersley and Atkinson, 2007); as I had made an effort to develop a good rapport with the participant. In the end whilst remaining professional, I accepted a 'hug' as a way of saying goodbye. I did note however that I do often think of the participants, especially during the write up of this thesis and wonder how they have coped with living with dementia.

3.10.3 The role of the researcher: Insider vs Outsider?

Goodley *et al.* (2004) emphasised the need for reflection in qualitative research, both in relation to the role of the researcher when participants' accounts are collected and the researcher's role in the interpretation and presentation of these. It is acknowledged that I, as the researcher and the participants had different roles in the interviewing process, although the principle of perceiving participants as equal partners was a central driver for this study (Sabat, 2002). Further, I recognised that the interviews were not neutral tools to gather data, but active interactions between participants and myself (Fontana and Frey, 2000). Fundamental to this, was an understanding and recognition of the role of researcher as a research instrument and impact on the data collected, as well described by Silverman (1993, p.172); *'All research is contaminated to some extent by the values of the researcher'*.

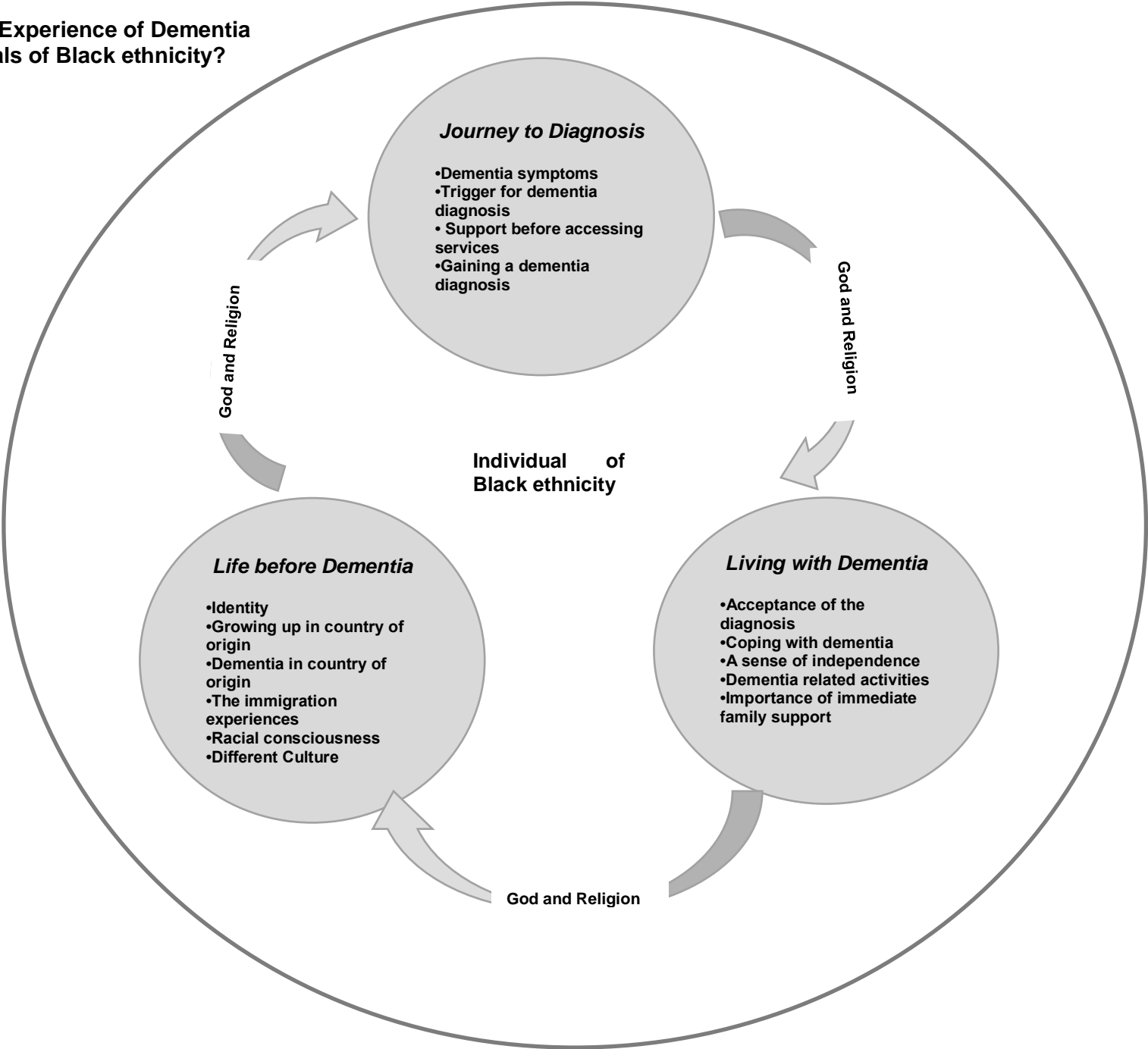
As described in section 3.6.1, I developed a relationship with the participants, to assist in gaining the best possible data. Within this work, critical self-reflection is essential to understand how meanings are interpreted. Accordingly, my position in this study had to be examined. This study benefited from using an 'insider' approach. Literature is positive about the strengths of having an insider as a researcher at the heart of cross-cultural studies (Gunaratnam, 2003). Allen (2004) writes that only insiders who are truly immersed in a setting

can produce an authentic account. Equally, Allen (2004) raises the issue that researchers in a familiar setting may make assumptions about what is being observed without seeking clarification. Kanuha (2000), in a discussion about native and non-native roles, identifies a potential drawback of insider status as being a tendency to be accepting of vague statements and points to the need for insiders to consciously pursue such statements to ensure shared understanding.

I am an individual of Black ethnicity, of African descent. As mentioned in section 3.6.1, I perceived myself as a research instrument, an insider, which added several strengths to this study. I shared many similarities with the participants, such as ethnicity and religious beliefs. I could navigate cultural boundaries in terms of using words, language expression, place, time and relationship with the participants. For example, being able to sense subtle nuances in the meaning of the participants' words, I used the indirect words in which the participant felt comfortable to use... such as one participant did not want me to mention the word 'dementia'....and I spoke about memory problems in a sensitive way. During the interview, the participant was referring to me as '*my daughter*' which culturally shows her respect for my age. It gave me a sense that the participant felt at ease with me. Moreover, being an insider, through the participant and the friend or relative, I could sense the meaning and power of family relationships, which strengthened the quality of my data and rendered it more flexible, enabling research potential to be maximised. I observed the dynamics between the participant and the friend or relative and I could sense during the interviews and informal chat, the cultural indicators of their willingness or dissatisfaction to continue their participation. I could sense the cultural meaning of unsaid words or silence and behave accordingly. By this approach, I believed that participants could understand and were willing to contribute to the study aims.

I was very aware that my own position as a Black person might be viewed as advantageous; I was quickly able to build a rapport with the participant; one participant stated: '*You know how it is to be Black in this country*'. And I agreed. Again, I emphasise that whilst I am no expert on all things '*Black*', despite the generational difference I did share with the participants the common experience of being of Black ethnicity, the immigration experience, discrimination and inequality. There were things that the participants expected I just knew by virtue of being of Black ethnicity. Hammersley and Atkinson (1983) write that it is an existential fact that we are part of the world we study, thus in my view, being a complete outsider in this study was impossible.

Figure 3.3: What is the Lived Experience of Dementia within Individuals of Black ethnicity?



3.11 Summary of findings

In completing the data analysis process as described in section 3.8, the data collected was interpreted and the key themes that have emerged from this study are presented in figure 3.3 above. Each individual described his/her own world and told their story, stories from childhood; prior to the dementia diagnosis, through to their adult life. These themes and sub-themes will be further discussed in Chapter Four.

3.12 Summary of chapter

This chapter has provided an explanation of the methodology, data collection process, a method of analysing the data, identifying the themes and developing the concepts. The aim of the study was to ensure that the participants living with dementia of Black ethnicity had a 'voice' and that it was up to me as the researcher to facilitate that voice through the chosen methods and methodology, as described in this chapter. The next chapter discusses the study findings.

CHAPTER FOUR: FINDINGS

4.1 Introduction

In this chapter, I present interview data and discuss the experiences of the individuals living with dementia in their own words. This chapter follows the participant's life experience; it is an exploration of the experience of living with dementia from the perspective of the participants who took part in the study. The findings are presented as three overarching themes and subthemes.

4.2 Participants

A total of six participants took part in the study. (See Table 4.0 Characteristics of participants). The participants are listed in the order in which they were interviewed. All participants had a diagnosis of dementia, with ages ranging from 72 years to 85 years. The participants who took part in this study were not born in the United Kingdom. Four of the six participants were from Jamaica, with one participant being from St Lucia and another from Uganda. All the participants were currently or had been married. At the time of the interview, all the participants had children, including one with grown-up children still living at home. Four participants were widowed. All participants were of the Christian faith.

4.3 Themes

Phenomenology supports the view that people make sense of their world from within, from the 'inside' or their life-world (Heidegger, 1962). By enabling participants to discuss their original experiences from their world, rich interview data for analysis was produced. This section presents the interview data and discusses the findings. The key findings included the following three overarching themes (also presented in Figure 3.3);

- Life before Dementia
- Journey to Diagnosis
- Living with Dementia

with subthemes themes and one interlinking theme '*God and Religion*'. The interlinking theme of '*God and Religion*' was noted to be significant with all three overarching themes and as such, this interlinking theme '*God and Religion*' is presented in section 4.7 with key reflections discussing the three main overarching themes. In totality, the themes represent the lived experience of living with dementia for the individuals of Black ethnicity who participated in the study. To understand the lived experience, this study submits that the themes can only be understood with reference to each other and that neither can be understood apart from the lived experience.

Table 4.0: Characteristics of Participants

Participant (Pseudonyms)	Sex	Age	Marital Status	Previous Occupation	Living situation	Country of Birth	Diagnosis
Alice	Female	80	Married	Nurse/Carer	Lives with Husband and daughter	Jamaica	Vascular Dementia
Beverley	Female	? 80+	Widowed	Nurse/Carer/ Orderly	Lives on own	Jamaica	Lewy Body Dementia
Catherine	Female	Not discussed	Widowed	Worked in hospital	Lives with Daughter	Jamaica	Alzheimer's Disease
Destiny	Female	72	Widowed	Carer	Lives with Daughter	Uganda	Vascular Dementia
Edward	Male	74	Married	Engineer/Del ivery driver	Lives with Wife	St Lucia	Vascular Dementia
Francis	Male	85	Widowed	Bus Driver	Lives on own	Jamaica	Alzheimer's Disease

4.4 Life before Dementia

4.4.1 Identity: The participants were very aware of not being born in the UK. No participant needed reminding about their identity; who they were or which country they were born, where they came from and their Identity was the starting premise of their lived experience of dementia as an individual of Black ethnicity and how they interpreted the world within which they lived. For example, Beverley could express quite concisely with a bold tone:

'I'm Jamaican, I was born in Jamaica, I grew up in Jamaica'.

Likewise, Destiny also stated:

'No, I was actually born in Uganda and came here 30 years ago'.

Edward could articulate that:

'my background is from the Eastern Caribbean and I have spent more time in Britain than the Caribbean. I came here when I was 24 and now I am 74, so most of my life has been in this country which is in Britain'.

Although the participants were born in different countries; what they had in common was not being born in the UK, which was the first fundamental point of difference from their White British counterparts living with dementia in the UK.

4.4.2 Growing up in the country of origin: The participants in this study, grew up and were raised in their respective countries of origin which shaped the way he/she understood their world. When asked about growing up, Alice, the first participant, expressed:

'... life was good with me because I had my parents and I wasn't working for myself'.

The participants were from large families and grew up surrounded and supported by extended families. Francis explained:

'Well I grew up with my family and went to school and I had my parents and I wasn't working for myself, I had my parents to look after me, me uncles and aunts'.

Destiny recalled how as a child that:

'...every holiday we used to go to the village to visit our grandparents and uncles and aunts who lived there, and we spent the whole school break there. It was quite nice... It was good, the African way of life where the whole village raises a child, all the neighbours knew each other, and they got on, yes'.

However, Edward who was noted to be quite a practical individual, on reflection noted that:

'Family was close together in many aspects and we were divided to go our own way in certain aspects'.

Whilst the above statement by Edward is logical, there was still a sense of community support and family cohesion bound by Black ethnicity and best described by Beverley;

'Oh yes, everybody would help him and if anyone died they would look after you'.

Participants also spoke of discipline and working hard as a child. Beverley explained that as a child:

'You had to behave, you couldn't do anything, or they would tell our parents and then our parents would tell us and come and beat us. The parents really give it us when we come home from school'.

Similarly, Francis confirmed how as a child you had to work hard:

'I keep telling these grandchildren that they have it easy nowadays, for us things were so hard, working in the fields, studying'.

From the discussions, it was observed that the participants were not from wealthy backgrounds, hence perhaps the need to emigrate from their countries of origin. Edward confirmed this quite clearly:

'I know I grew up in a poor background'.

The participants' childhood experiences, being raised outside of the UK, shaped how they developed as adults. Their childhood was influenced by different cultural beliefs and values from their respective countries, which would have been different from White British individuals born and raised in the UK.

4.4.3 Dementia in the country of origin: All participants confirmed that they were not aware of dementia growing up in their respective countries of origin. In the following excerpt, Alice talks about her recollection of dementia in Jamaica:

Researcher: *'Last time we touched upon back home in Jamaica, I was asking about dementia, had you ever heard of dementia?'*

Alice: *'No. We never hear about dementia, we never hear about prostate, we never hear about cancer. Never hear about none of those things. Just for the last few years these just zoom. Never hear about those'.*

With further prompting Alice explained the following:

Researcher: *'Did they not have dementia?'*

Alice: *'No, they were old, then they were dead! When they're old they just die, we never hear about dementia'.*

Researcher: *'Now that you're living here, do you know any people in Jamaica with dementia?'*

Alice: *'No'.*

Alice's husband who often contributed, clarifying points during the interview also responded:

'When we went back, they wouldn't have really seen it as dementia. We saw them with a thyroid problem and things like that'.

This response prompted me to think about how dementia is conceptualised in different societies, was it because dementia did not exist, or was it that dementia symptoms were re-

labelled as other conditions to make them more acceptable to society? On further clarification Alice explained:

Researcher: *'Do you think there is no dementia in Jamaica then?'*

Alice: *'I don't think they recognise it...'*

Researcher: *'... see it the same way?'*

Alice: *'Yes, maybe people say, 'He lose his mind'. They say that, but I don't think they put it in that term. They say he's gone off his head. I think that's the slang they use, they'll say he's gone off his head....? It's like you lose your mind, but you're just forgetful. But no, where we come from there is no dementia people in my district'.*

It soon became clear that it was not only about awareness of dementia but also about the use of language. In the participants' countries of origin, elderly people experienced memory issues such as being forgetful; however, this was not described by the term 'dementia'. As Destiny clarified:

'No in Uganda I did not really know of anyone with dementia because the word was not used...'

Researcher: *'So in your community at home, there were old people weren't they?'*

Destiny: *'Yes of course'.*

Researcher: *'Did they not have dementia?'*

Destiny: *'Not dementia as such...they had similar problems like I have... No, I had not heard of dementia when I was growing up and living at home, what I know was that our elders were forgetful, but that was expected, like my grandmother and my mother lived with the family, and we always helped her if she became forgetful and confused'.*

Similarly, in discussion with Edward he explained from his perspective;

'Not such a thing as dementia, some people used to look at people which I believe could have had dementia, but there was no name such as dementia, it used to be mad people, they thought that a person was mad or crazy, but they were not looking at it as dementia'.

Researcher: *'And as children, you were aware of that, did you have anyone in your family or community?'*

Edward: *'I wouldn't say directly family of mine, but I'd been hearing from other people when they said that person is a mad person and things like that, but there was no name such as the brain diminishing'.*

It is noted that as the participants were from different countries of origin, variables such as life expectancy, leading causes of death in their respective countries of origin also may have played a factor in their awareness of dementia. This will be further discussed in Chapter 5 'Discussion' section. Therefore, it was not that 'dementia' did not entirely exist in their countries of origin, rather it was also the fact that the word 'dementia' itself was not used. Symptoms

that may relate to dementia were regarded as mental health issues- described as being '*mad*', '*lose his mind*' or '*crazy*', with perhaps a stigma attached to this as described below using negative labels:

Researcher: *'How do you think the community viewed those people?'*

Edward: *'I don't think they knew any better than what they were saying because they did not know any better they said it as they liked'.*

Researcher: *'Had you heard of dementia before your diagnosis?'*

Edward: *'I heard of dementia in this country, but when I was back in the Caribbean I had never heard of the word dementia. As I mentioned they said somebody is crazy and they do things and they don't know if they've done it or people call them names that they don't know what it was'.*

Symptoms such as being forgetful were also considered as part of the normal process of ageing, as described by both Edward and Destiny:

Researcher: *'Was there anyone in your family, your parents, with dementia?'*

Edward: *'I would say not in the word dementia, forgetfulness, people always know that there are certain people who forget things and they might put things in places and then they say oh, I thought I took that out and things like that, but in the Caribbean, itself I don't think there was anybody who experienced the word dementia. I don't know about the present, but in the past, I'm pretty positive of that'.*

Destiny: *'Dementia...no I didn't know that word...memory problems yes, our grandparents, they get to a stage in life where they forget things, you know, you tell them your name today, so they know who you are again, but they were just forgetful'.*

Researcher: *'Okay. So, as you were growing up that's what was happening with older people, so was it expected that that's what happens or was it unusual that they were forgetful?'*

Destiny: *'Well a large number it was just expected that they'll just get forgetful, you know, it comes with age, they might not remember what the day is or where they are, but it was a normal thing for them'.*

It was interesting though that Destiny was the only participant who finally recognised retrospectively that perhaps there was dementia in her country of origin:

Researcher: *'Now that you're living here, do you know any people in Uganda with dementia?'*

Destiny: *'Ah...they probably do have dementia...'*

For all participants, their experience of dementia in their countries of origin consequently impacted on how they accessed services to gain a diagnosis and other support services.

4.4.4 The Immigration Experience: All participants grew up in their country of origin then travelled to England once they had left school and were of working age. Francis described:

'I came in the 1950's I was still in college at the time, and I decided to come to England, we came by ship...'

Beverley explained that:

'My father comes first and then my mother'.

This approach was seen in all participants where one member of the family came to England first, and once settled supported other family members to emigrate. Likewise, Catherine confirmed:

'My father comes first and then my mother, then my brothers came first, my sister and I remained in Jamaica my aunt she take care of us'.

From all discussions, it was clear that the participants came to England because of the opportunity to do so and the chance to earn a living and improve their employment and life prospects. Destiny was clear:

'I came by myself to work'.

Alice also clarified:

'Yes, because everybody was coming to England at that time, so I had the opportunity and I just came'.

When Alice was asked why she came to England;

'every literature was about England and most of the time people would say England, there was no Black history about Jamaica, everything you read, every book you read came from England, so most people thought England is gold in the old days, it was the way they portrayed England and people in 59 and 60'.

Similarly, Francis felt that:

'... it was an exciting prospect because I wanted to build my future...Yes, because everybody was coming to England at that time, so I had the opportunity and I just came. Back home, we were brought up that England was our mother country, and I wanted to go there'.

Participants worked in healthcare, transport and general labour jobs, for example, Destiny explained:

'Yes, I was working. I worked in lots of different homes for elderly'.

Obtaining jobs was not difficult. Alice described her experience:

'Yes, it was easy to get a job, you just left there, and you go to the place where they said and then the next thing they asked a question and the next thing they said can you come in tomorrow, and we didn't have a problem'.

Beverley told me that:

'It wasn't easy, it wasn't bad, I never found it bad to get work but after you get work you have to stay'.

Similarly, Francis reflected on how he:

'...worked general labour work, building, then I got a job driving and I trained to be a bus driver. I got married in '65. It was easy to get a job back then, you could go to the labour exchange to help get a job'.

Edward also confirmed that as he was always determined to work hard, therefore, finding a job was not difficult:

'I came directly to a job which was a voucher to the job and within a short time, I went to work with another company. I had not been out of work until I was made redundant and following that I went to learn to do a different trade. Before I went in a trade I was doing a correspondence course and at that time I was not suffering from any dementia or anything like that, and so after I was made redundant I went back into full-time training again...I never looked for a job, a job always looked for me because I was determined to do it'.

Participants once in employment, all spoke of raising children and faced challenges with achieving a balance with childcare and working life. The concept of working hard and coping with the immigration experience and raising families in England required some determination and resilience as described by Beverley in the following excerpt:

Researcher: *'How did you find life in London?'*

Beverley: *'It's a hard life, it's not easy... I worked at the XX XX Hospital... Remember you have your children and you have to have some sleep in the days and having children it is not easy, to look after your children, come back and work nights but you had to make it all some way...I didn't have time to enjoy doing anything else than look after my home and look after my children, send them to school and things like that. It's a hard life, it's a rough life but you had to cope. Coming from work you had to go to the shop to get food, somehow you had to, it's a hard life, it is'.*

This experience was shared by all participants- working hard to raise a family in a foreign land:

Alice: *'Yes, mostly I had to do nights, so I could look after them in the day'.*

Catherine: *'I work hard to raise money, for the children'.*

Francis: *'it was hard with the children and we had help with some Jamaicans who had also settled in Dudley and they helped with the children'.*

The participants in this study had migrated from their countries of origin for economic reasons; experienced multiple stresses, related to employment and achieving work-life balance. Adjustment to a new life was achieved through hard work and resilience. Therefore, this impacted on how they experienced and coped with dementia later in life.

4.4.5 Racial consciousness: There was a sense of racial consciousness that was alluded to by the participants. No participants discussed any specific racial incidents, however, there was a certain consciousness of this through words such as **'any trouble'**:

Francis: *'I worked, got work moved to Brixton to work, I never **had any trouble** as such because I was focused with my work and I wanted to build my future, I was really focused. I wanted to make some money, so I kept to myself... It was not easy living in Brixton those days, some people would say things like why are they here, those were the days.....there were white people in the neighbourhood, I never had any problems'.*

Alice, in the discussion, described her experience of encounters with White British people below. Again, her choice of words such as **'some nice white people'** highlights a consciousness of racial differences:

Alice: *'some of the white people were very nice to you because we used to have a tall sister, a friend and they were ever so nice. so, you've got **some nice white people**.....and **some people say about white people**, and **we all have our ways just as the white people, it's true**'.*

Alice: *'Yes, there wasn't a lot but quite a few, but still there were white or Black people and **we didn't have a problem**'.*

There is no evidence that these views influenced the participant's experience of living with dementia as individuals of Black ethnicity in later life.

4.4.6 Different culture: Participants commented on the difference in cultural norms in England in comparison to their countries of origin. The participants were not born in the UK; they came from small towns or villages from their countries of origin and moved to London, a growing city at the time of their immigration. From the participants' views, it was evident that Black cultural values are embedded in the principles of being respectful to elders; with strong kinship bonds and a sense of community life. Life in England was somewhat different, as described by the participants below:

Alice: *'you know people and they're next door and when they pass you say hello auntie this and auntie that, they're not your auntie but you respect these people because they're older than you, and that went on until I came here And the culture in Jamaica was different when we came here, and we saw England... we were shocked'.*

Destiny: *'Oh yes, very different. In the UK, a lot of people were nice, but you never really got to know anyone, you don't even know who your neighbours are, some didn't talk to you because obviously also they weren't used to having many people coming to their country'.*

Francis: *'It was grey and dismal, it was not as good looking as I thought it would be. Community life was different, in Brixton, the neighbours did not speak to you, that never happened in Jamaica, whether you met in the street or not, it's good morning good evening and hello. I used to greet neighbours, but they never answered me, so I stopped. I would say neighbours were built cold'.*

Migration of the participants involved the loss of the familiar, including language (especially colloquial, dialect or vernacular languages), cultural norms and values, social structures and support networks. This cultural difference would have influenced the participant's decisions to seek help from their community health services, perhaps a slight reluctance, as they sensed a lack of community cohesion in their initial experience of city life.

4.5 Journey to Diagnosis

4.5.1 Dementia Symptoms: Memory loss is a key feature in all types of dementia. Dementia, however, is much more than memory loss. Dementia also affects people's behaviour and their ability to carry out everyday tasks, orientation, attention and registration. Over a two-year period, Alice's husband did recognise symptoms such as being forgetful or memory loss; however, these were not conceptualised as being part of an illness such as dementia by both the participant and her husband. In the following excerpt, Alice's husband (who often contributed clarifying events I did not understand) talks about the early days when he first began to suspect that something was wrong:

Alice's' Husband: *'Two years or more. You can see, this person is forgetful, but you've no experience of what's going on. So, you say the person is forgetful but when it's getting worse now that she looks in her purse and then she says no, somebody steal something out. You know it's only me and her here and then she says, somebody steals something. You know something is not right because only me and her are in the house but still, there is thief in here. Then she starts to think it's XX so now she doesn't recognise me'.*

Like Alice, Edward noticed that he began to struggle with functional tasks, recall and finding his way around things he had completed countless times before for some years:

Edward: *'I was not taking notice of it as such, when I forgot something I said to myself oh I just forgot that, I lost something, and I had it in my pocket and I was looking for it, things like that. Like when I'm going out sometimes I go downstairs, and I go back upstairs because I don't remember if I locked the door. I put on the door papers I have like you can see all the papers. Sometimes if you ask me a question when I wouldn't know if I don't put it on a bit of paper, or if somebody tells me their name I will remember the person's name and I will walk away and if I don't write it down to see it again I wouldn't remember the person's name'.*

Researcher: *'Was it many years ago you started forgetting?'*

Edward: *'I would say that, many years ago'.*

Researcher: *'two years?'*

Edwards Wife: *'about three years he was always forgetting'.*

This experience was consistent with the other participants. Beverley's daughter told me that:
'mum was forgetful for a while'.

Catherine simply did not agree that she was forgetful

'I'm fine, who says I'm not well'.

The fact that being forgetful was perceived a normal part of ageing described as *'nothing unusual'* due to participants' backgrounds, which were discussed previously. This was also highlighted by Destiny in the excerpt below when asked if she recognised this as a symptom of dementia;

'No not really, because old people are often forgetful, nothing is unusual there, I know a lot of elders who are sometimes forgetful'.

As a result, participants did not seek help or access services immediately. The data collected suggests that due to the cultural understanding of illness, that is the perception of memory loss as a normal part of ageing, this along with a lack of dementia awareness possibly hindered Destiny, Alice and Edward in recognising the symptoms of dementia. This also impacted on subsequent decisions to access health services, as will be discussed in section 4.5.3.

4.5.2 Triggers for a dementia diagnosis: For the participants, it was only when day-to-day life became unmanageable or when there was a significant event that they finally decided to visit their GP for support. Triggers for diagnosis were related to a significant event in the individual's life, rather than being identified as early signs and symptoms of dementia. This was consistent with all participants. For example, Alice explained how she fell, which resulted in her dementia diagnosis:

'Listen to me. I'm the one that have it. I never had that before, since I knock the back of my head here. When I had a fall, I knocked the back of my head and there is a bump so big and I find myself start to get funny. I know when I'm getting that way. I

wasn't that way all the time. If I didn't take that fall, I'm not saying it wouldn't have come but it wouldn't have come so quick because I said I was feeling pain in the back here. What happened, it didn't bleed, the blood circulates up into the back and makes it a big thing'.

Beverley's daughter talked emotionally about the day she finally decided to seek help for her mother:

'Mum has always had not a very good memory for quite a long time but more recently obviously, it's got worse and on Sunday when we were going out I said mum, do you know where the keys are? She had no clue where the keys were'.

Researcher: *'At what point did you realise that maybe mum was forgetting a lot and you should go to the doctor?'*

Beverley's daughter: *'It wasn't really the forgetfulness that prompted us to go to the doctor; it is more the low mood and seeing things that prompted us to go to the doctor.... I had to say look, she is getting irritable and aggravated and she could be a danger to herself. It was really bad at one point, mum is really calm now, but it wasn't always the case'.*

Francis advised that he sought help after a stroke:

'it was after the mini-stroke, I was really sick, and I could not remember my daughter, that was very worrying'.

Destiny only began to consider that something was seriously wrong when she lost the ability to find her way home:

'One afternoon, I had just finished a little shopping at Tesco up the road, walking distance; and did not know how to get home. I just could not remember my way home, it was a bit strange. I was just confused. So, I went the way I thought, and I soon realised that I was lost'.

Destiny's daughter: *'I think it was before that...mum was getting forgetful for a while, for about a year really, little things like forgetting where the keys are, or her purse, little things ...it wasn't until she called me when she was lost that we thought maybe there was a problem'.*

Edward had a seizure which resulted in him seeking help, but even then, only gaining the dementia diagnosis as a consequence of the seizure:

Researcher: *'It would be good for you to tell me your story in terms of how you got a diagnosis of dementia, what happened?'*

Edward: *'Basically I did have a seizure once and from there I went to my GP and from there they referred me to the hospital to go and get a test'.*

Researcher: *'So you had a seizure, was that unusual for you?'*

Edward: *'It was rather unusual in one way, but I did not know how to handle myself by then'.*

Researcher: *'Were you working at that time?'*

Edward: *'No, I was not at work when it happened, I was going shopping and when I felt as if I was going to fall down I decided to go and rest on a wall and I stayed there every five blocks from the seizure I was having. From there I took transport and came back home and then after that I went to see my doctor and told him what happened, and then they referred me to go and take a test in the hospital'.*

Although Edward's spouse had suspected for years that 'something' was wrong, she briefly linked this with dementia:

Edward's wife: *'You had started forgetting things, couldn't remember things, saying people had put something there and it wasn't you and all that was piling up and piling up, and we encouraged him to go to the doctor as there was something that was not right. It wasn't the seizure alone because you just don't have a seizure and you see the doctor and they tell you it's dementia, you were forgetting things, all the time you were forever forgetting things and then we encouraged you to go and see the doctor. Then the doctor recommended you to the XX Hospital to see the dementia people, and then that's when he went to neurology and they gave him a head scan. He's forgetting all that, he can't remember any of those things'.*

What is evident here is that all participants could:

- a) Provide a reason as to why their dementia developed, i.e. dementia was as a result of an event. For example, with Alice, it was the fall that caused dementia, for Edward, it was the seizure whilst with Francis, it was the stroke.
- b) The significant event was the reason to seek help or access health services.

This gives some insight into how the participants conceptualised and understood their current situations; as well as some insight into participant beliefs as to what causes dementia, but also the threshold at which to seek assistance. The significant event represented a starting point for 'dementia'. However, the reality is that the dementia symptoms existed prior to the significant events or explanation they provided.

4.5.3 Support before accessing services: All participants and their families had accommodated the initial changes associated with dementia, into their lives rather than seeking support from health services or a diagnosis. As previously discussed, if the participant and their family did not perceive the presenting dementia symptoms to be an illness or concern due to their ethnic or cultural background and lack of awareness, they were less likely to seek support from health services. In addition, if they had family support and maintained some

independence or functionality, they were less likely to access any services. During the interview process Edward explained this well:

Researcher: *'I guess I'm trying to understand why you did not go see the GP sooner?'*

Edward: *'Although my wife did encourage me, there was no need to see the GP, I was able to still do a lot for myself with little help and belief was to keep trying to do my best. I was not worried, and I had the support I needed. I think that if I didn't have the support I would have gone to seek help from the GP.'*

Edwards wife: *'After a while, we encouraged him to go to the doctor as there was something that was not right. All the time you were forever forgetting things and then we encouraged you to go and see the doctor, but I was here to help him every day.'*

Alice's experience was similar, her husband supported her and adapted to the day to day symptoms:

Researcher: *'...as you were supporting Alice, do you think it was at the point when maybe you couldn't cope that you thought, let me go to the doctor, or was it because you were anxious, or you wanted to understand?'*

Alice's Husband: *'It's not because I couldn't cope, it's she can't recognise me that we went to the doctor.'*

Beverley who, when asked, was unable to express herself the reason for not accessing services. Her daughter, who was supporting her explained that:

*'That's right and mum has always been very strong, she's never needed help as such...I felt... culturally it is not something we do, we don't bring these **services in**, we are very private, but I had to because I didn't know what to do, I didn't know how to deal with it'.*

It is important to consider the participant's background here, section 4.4.4 highlights that the participants were immigrants; hard work and being resilient was their norm. As mentioned earlier in section, part of their cultural values includes kinship/familial bonds. Therefore, there was no need to seek any help from health services whilst they had family support and were coping with the challenges of dementia symptoms. This clarifies perhaps the late presentation of BME populations to dementia services in comparison to UK born White British counterparts.

4.5.4 Gaining a diagnosis: When the participants did access services, the process itself of gaining the diagnosis, the actual steps that were taken, were somewhat confusing to the participants. Edward expressed:

'I did have tests, but sometimes you can mix them up';

The medical diagnostic process took time as Alice explains:

Researcher: *"Did it take a long time to get the diagnosis then, for them to actually tell you what it was?"*

Alice: *"Yes, it just went on and on, Yes, it was six months later they say"*

Whilst Destiny described her experience:

'We went to the GP who sent us to the memory clinic for an appointment we had some blood taken, I think two scans. This was at the hospital, then after that, they said I have dementia, vascular dementia.'

Researcher: *'How did you understand that?'*

Destiny: *'To be honest I said to my daughter what is he talking about'*

I was prompted to ask Destiny to explain what she meant:

Researcher: *'Why do you say that?'*

Destiny: *'Yes, I said to my daughter what is he talking about to her, because I did not know what he was talking about. The doctor had to explain to me what was happening, he was very kind he started to explain why I was forgetting so much, and how the disease will progress with time, I am only 72 and I really couldn't understand all this and how it was happening to me...'*

The point Destiny was making was that gaining a diagnosis, is one thing; however, conveying an understanding of what this meant to Destiny and her family, in a context and language that she understood, was not done by the health professional. I highlight again Destiny's background as described earlier in this chapter in sections 4.4.3 and 4.5.1. She was not born in the UK, she had never heard of dementia until this point in her life, and issues related to memory loss were seen as the normal part of ageing in her country of origin. In addition, there is no word for 'dementia' in her vernacular language. This undoubtedly has influenced how she understood dementia and experienced receiving a dementia diagnosis.

For Beverley gaining the actual diagnosis was challenging resulting in a negative *experience of health services*; Beverley's daughter expressed their frustration at the lack of guidance from their General Practitioner:

'The GP didn't make the connection between what was going on, the memory problems, with dementia. So, he didn't then take it further and say it could be this, it could be that he didn't do any further investigations and it was only after I called the Mental Health Team that she got monitored over a period of six weeks and they came back and said it was dementia. So, it's like the GP doesn't know, isn't aware that it even exists...He is the link to all these services, yet we got no referrals to anywhere from the GP.'

In addition, the diagnosis process for Beverley and her family converted to a legal process leaving the family feeling powerless after accessing healthcare services, as her daughter describes below:

Beverley's daughter: *'Then they came and said they might have to section her and this and that'.*

Researcher: *'Did they?'*

Beverley's daughter: *'I was like oh no, no'.*

Researcher: *'Was the mental health team who came here?'*

Beverley's daughter: *'Mum was staying at my house at the time and the doctor, the consultant from XXX came and said, we might have to section her and they tried to get mum to agree to go to a hospital and I said no, no, you can't do that because I'd taken that step and then felt really bad about taking it and calling them in and they came in all guns blazing and I felt like, oh what I have done, what have I opened her up to? I know if they say she has to be then she will be, I can't stop it, so I objected at that point and that's when the Community Mental Health Team started coming in'.*

Beverley had let the '**services in**' and she felt guilty. Again, this relates to familial ties and values held within her family.

After months of uncertainty, gaining a diagnosis of dementia explained the previously unexplainable and somewhat frightening signs and symptoms they had experienced to date. This is further discussed in the next section.

4.6 Living with Dementia

4.6.1 Acceptance of the diagnosis: For some participants, dementia was the last thing they thought could be causing the problem, consequently the diagnosis was both unexpected but offered an alternative explanation. As discussed earlier in section 4.5.2, the participants in this study had already had their own explanations on how their dementia developed or the events that led to their dementia diagnosis, therefore accepting the medical diagnosis of dementia was important. Catherine did not believe she had dementia and had not accepted the diagnosis;

'I'm fine, who say I'm not well?'

When Alice was asked how she felt about the diagnosis:

'There is nothing to worry about because it's just an illness. You come to recognise it as an illness, you cope with it, simple as that'.

Researcher: *'And how did it make you feel when you had to go to the doctor because of the problems?'*

Alice: *'I don't know, I never think of that, I had to go to the GP because my family were worried, I think I accept in the end what the doctor tell me'.*

Beverley with some sadness expressed that:

'I get a little bit tears in my eye, but you still have got to go along really... It is too hard; you have to take your time'.

Similarly, Francis was also quite sad when discussing his diagnosis;

'I think I had so many tests then the doctor explain to my daughter something about dementia. I really didn't know what to say...I say ok. you know when you are young like you don't think of these things. I wish I could be back home, tears come into my eyes, I miss the air at home...sometimes when I can't remember I'm not sure'.

Destiny was accepting of the diagnosis but quite concerned about the future, overwhelmed but was somewhat hopeful:

'when he then explained, what dementia is and the problems as the disease gets worse, I became so worried.... I said is this me... what is he telling me that I will have worse memory problems, loss of coordination...he said slow movements, maybe loss of appetite...he said a lot of things I can't remember; I told myself I cannot change this, but God can...'.

Edward, however, was not one who believed that dementia could happen to him, however, he found a way to be positive about the diagnosis and alluded to this when asked:

Edward: *'...as I mentioned I was never one who believed I was suffering with dementia, not until I was told that my memory was not there. I did tell you that.'*

Researcher: *'How did you feel when the doctor told you that that was the diagnosis, how did you feel?'*

Edward: *'I did not get angry or disappointed or anything like that, I was just carrying on with my life as normal as much as I could and if there is a way for me to participate in helping others that are suffering with the same symptoms I am grateful to do it'.*

Due to the participants' background, as well their cultural understanding of dementia, accepting the medical diagnosis of dementia was the first step in engaging with the phenomenon, that is 'living with dementia'.

4.6.2 Coping with Dementia: With the acceptance of the dementia diagnosis, the participants were now able to actively find ways of coping with the diagnosis. The participants described the day to day challenges of living with dementia, including how they managed the daily symptoms:

Researcher: *'How do you manage when you can't find something?'*

Francis: *'Well, I forget about it. No point in worrying'.*

Researcher: *'Do you know what day it is or the month? Do you forget things like that?'*

Francis: *'The date, sometimes I forget the date it is. I ask my daughters or my granddaughter, they help me out.'*

The participants had adapted to their symptoms and had coping strategies. Their lives had changed, it was different as Alice describes below:

Researcher: *'In what way, what's different'?*

Alice: *'Different because things what you think about you wouldn't bother.'*

Researcher: *'Things like what'*

Alice: *'Anything come up in your head or you feel, like say I'm going ... but once you just take life easy, it just goes.'*

Researcher: *'So now you take life easy?'*

Alice: *'Yes I do. I take it easy now because I don't start to push myself too much. I just try and take it easy.'*

Taking it 'easy' was a coping strategy for Alice. Beverley ensured she took her time and was more careful, however it was hard, but she managed:

Researcher: *'How do you feel now that you have been through all of this?'*

Beverley: *'I still have to take time, I can't just run about. You have to be careful what you do and what you eat and what you drink...But what to do? It's a hard life but you have to do it.'*

Edward was very practical; he saw dementia simply as an illness, that he could cope with through daily routine and pattern. He did have a laborious process of checking and rechecking until he felt assured that he had completed the task; for example, he had a set process to follow to help ease his anxieties regarding leaving his home when going out. He had memory aides in place (for example see *Appendix 28*) to help him cope with the daily challenges of memory loss. This was a process for Edward, of maintaining his independence, which was important to him:

Researcher: *'Since the dementia diagnosis what things are important to you in your life now?'*

Edward: *'Well if there is a medication for it I would carry on taking medication. I am on medications every day myself presently. There are times when I wonder have I taken my tablets today, so what my GP has done, they gave me a dosette box, so every day, twice a day, when it is four times a day it tells you four times a day and I have to take the medications. Sometimes if you have three different packs of tablets that you're taking you will be saying to yourself oh did I take that one and how many did I take because probably with dementia you might not be able to remember how many you've taken, because there are times if I don't go and look on the dosette box I would not know if I've already taken the evening one, I know I take the morning one, so did I take*

the evening one, I'll go and just check on the pack and it will tell me if I've already taken it. This is Monday and I know I've taken Monday morning and that one is evening, so I know I take it there and that one is finished from there when it was started it was started here. I have forgotten, but it was only once. If I forget to take it or when they changed the doses there was one left, so I could not remember the details if that's how it happened, but I know there was always one left over'.

Researcher: *'It sounds like you have to always check and check for everything'.*

Edward: *'Yes'.*

Researcher: *'Because you were saying when you go out if you've forgotten about the door you have to come back and check'.*

Edward- *'Yes, and also I have something on the door, a symbol on there so when I'm walking out of the door I look at the symbols. If you look at the door you will see it there'. (See Appendix 29 Memory Aide)*

Destiny coped through her religious belief and faith activities as she describes below, a theme which is discussed more fully in Section 4.7:

'You know first I had to try and understand this dementia, to say my God is this what is happening to me, I just told myself that I need God's help. My hope is built on nothing less than Jesus blood and his righteousness. It took time ...but at the end I said this is God's will, I really didn't know what else to do...there are days when I don't what to do and you start to think a lot of things...then I forget some things and that has upset me.'.

The participants' daily life or views of coping with daily challenges represents individual progress and a promising approach to understanding the adaptation process of living with dementia.

4.6.3 A sense of independence: All participants maintained a sense of independence and valued being able to do things for themselves. They all lived in their own homes. The participants were 'hard workers' as discussed previously in section 4.4.4; being independent as much as possible was also a coping strategy of living with dementia and gave them a sense of joy, as Beverley explained:

Researcher: *'Do you find it important to do things yourself?'*

Beverley: *'Yes, it is important to get things done for yourself if you can manage. You shouldn't let somebody force you to do anything but sometimes you are not so well. But I get dressed and I go to the bathroom'.*

Researcher: *'How does it make you feel when you do things for yourself?'*

Beverley: *'Oh yes, it's good. When my granddaughter is here she says, show me how you can do it. And we laugh at that. And the helper, I can show her what to do but I don't go down on my knees and do anything anymore. They help me out.'*

Destiny also confirmed this:

Researcher: *'Do you find it important to do things yourself?'*

Destiny: *'Yes, it is important to get things done for yourself, I used to be this very independent person, I worked so hard to raise the children, in my country we say that water that has been begged for does not quench the thirst... you know we all work at home and I liked my work, my children went to school they had what they needed, it was so hard, but I managed, you can't just sit down then what next?'*

Researcher: *'How does it make you feel when you do things for yourself now?'*

Destiny: *'I'm happy'.*

Edward was very determined and strived to maintain his independence:

Researcher: *'It sounds like you really want to get on with it'.*

Edward: *'I do my best, I'm not saying that I will be able to reach the end of the journey, but I do my best to be able to stand up. If I can't walk, I start crawling for me to reach the point where I'm going'.*

The participants identified that the ability to perform activities of daily living and maintaining a sense of independence contributed to their quality of life. With the concept of hard work and resilience already instilled in them due to their backgrounds and childhood, keeping independent as far as possible, assisted in preserving day-to-day functioning and promoted participation in appropriate and meaningful activities. Dementia-related activities are discussed in the next section.

4.6.4 Dementia related activities: When participants were advised of the dementia diagnosis, engaging in dementia-related activities was common for all participants. These activities enabled them to continue activities they enjoyed, that was meaningful to them and helped them to keep positive about life, whilst socialising with other people living with dementia. Alice attended Singing for the Brain, an activity she enjoyed:

Alice: *'We go singing for the brain. So, it's a club you go to and they sing?'*

Alice's Husband: *'They sing to get your brain focused'.*

Alice: *'And have a cup of tea when you've finished, and the people are nice'.*

Researcher: *'And you find they're very supportive?'*

Alice: *'Yes, I find these people they are ever so nice, and they come and kiss you'.*

Alice enjoyed singing and Singing for the Brain was a relaxed setting for her, which helped her to enhance her communication skills. Beverley attended a sewing group and re-gained skills she had forgotten:

Beverley: *'...sewing group'.*

Researcher: *'Tell me a bit about that.'*

Beverley: *'If you sit there just for a minute I can show you'.*

Researcher: *'You made this? This is crochet, isn't it?'*

Beverley: *'Yes'.*

Researcher: *'That's very nice. Did you learn this at the group?'*

Beverley: *'I just go to start to knit'.*

Beverley's daughter: *'Mum used to do it before, but she seemed to have forgotten how to do it but now she has regained'.*

Researcher: *'So when did you start going to this group then?'*

Beverley: *'It's not very long...January I think...I just do it. I see somebody knitting and it just come in my head and I start to knit it as well. It was very hard the first time to get along with it. What was hard...To knit, to remember'.*

This group has been very beneficial for Beverly and helped her maintain her functional skills for longer. Catherine attended a cultural day centre three times a week specifically for individuals of Black ethnicity living with dementia, where she took part in various activities. This was explained by her consultee, her daughter:

Catherine's daughter: *'you know services to meet our needs, because mum really likes to sing, and she likes knitting and sewing, she goes to the centre three times a week, one day she is with me on Fridays, and the other three days she is at home, with the carers coming in. but there isn't much else, she did try another day centre but she did not get on with the people there, this centre...'*

Catherine's daughter: *'Yes she likes it there and is happy going there she does the exercises when she is well...yes, mum. They also have the pastor come in for service...Or she can just watch TV and watch old films and listen to church music... mum likes to sing, but it took a long time to find this centre, and mum misses home'.*

Destiny attended the Dementia Café. This was a way for her of keeping connected with other people living with dementia as well as access to dementia education, information and support:

Researcher: *'What do you do at the group?'*

Destiny: *'Yes, I go to the Monthly Dementia Café it's for people with dementia, their families and carers, it's once a month and you also get a nice lunch and there are different speakers and activities'.*

Destiny's daughter: *'She also attends the day clubs, the nurse helped her to access The Dementia Support day clubs for people with dementia. A hot meal and social activities are provided at the club, she goes from 10.00am-2.30pm and a small charge is made to cover lunch. The club is at XX House on Monday or Wednesday, transport picks her up. The Support workers from the dementia support team run free afternoon clubs with social activities for people with dementia, she likes the reading and singing! She can also watch films and listen to audio books, she has one friend there who also goes to church, so it is working out ok.'*

Francis attended a similar day centre and Cafe:

Francis: *'I get ready to be picked up the transport comes at 10am, I go on Monday and I have my lunch there ...I go to the centre, where I do some Quizzes & Puzzles, I see my friend there, and we have a chat....'*

Researcher: *'Is that the only place you go...?'*

Francis: *'No no on Tuesdays once a month I go to Café and we sing songs different activities, like the craft, different speakers and a lunch'*

On gaining a dementia diagnosis, Edward realised his passion for helping other people living with dementia. He became quite involved with Dementia Associations taking part in dementia-related interview panels, meeting the Prime Minister and participating in computer lessons. He did not wish to be pitied, instead:

'I don't say I have dementia and you look after me and all these things, I like to look after myself and if I'm not capable of handling myself I will say to myself what's the point of being here really, if you try, you try again and if you cannot succeed you have to give up, but I don't like to give up, I am always determined to carry on'.

Researcher: *'It sounds like you're living quite well with dementia, you've found ways to cope, little ways to help you cope, but you are very active, trying to keep yourself busy'.*

Edward: *'The activities of myself, I believe that's what keeps me going because as I mentioned in the past, when I was still young, the NHS wanted to put me on disabled and I turned it down and I went on exercise and I went back to work and earned wages without having to live with subsidies and things like that.....as I've mentioned I am determined to carry on, the dementia is a big obstacle, if you are determined you will not be able to reach there, but you will go halfway'.*

The participants in this study were recruited via dementia-related groups and activities. As such, they were participants who positively engaged with dementia support services. Therefore, it is important to acknowledge that not all individuals of Black ethnicity engage with these activities; however, for this group of participants this was a coping mechanism and helped the participants understand their lives with dementia.

4.6.5 Importance of immediate family support: Family was often not only important to the participants who took part in this study, but also gave meaning to the participants' whole existence. Participants appeared to have very good family support with minimum carer input; they spoke about their families in a positive way.

Researcher: *"Do you feel you have good support to help you manage the problems like being forgetful? You have got the carers to help you and you have got family, do you feel you have good support?"*

Beverley: *"It is sometimes but my children are good support. I don't know about other people, I don't deal with other people so long as I have my family"*

That was also the case with Alice where she had no formal package of care:

Researcher: *'So do you get any service, any help, carers or not really?'*

Alice: *'No, carers don't come here'.*

Researcher: *'So your husband helps you a lot? Do you help each other really?'*

Alice: *'Yes he does'.*

It was noted that only close family members were aware of the participant's dementia diagnosis. As Destiny explained, it was not necessary to inform the extended family:

Destiny: *'There was no need to tell everyone back home, it was not helpful for them also I was aware that they may not understand or know what dementia is, there is no word back home for dementia, that I know...also it is not something that I will go singing and telling the world. I am fine I have help from my family...'*

Researcher: *'So do you get any service, any help, carers or not really?'*

Destiny: *'No, carers don't come here'.*

Researcher: *'So your daughter helps you a lot?'*

Destiny: *'Yes she does, I am not dying I need a bit of help with some few things...I really try to do as much...'*

Edward also agreed that only his close family was aware:

Researcher: *'So is it only your close family that knows?'*

Edward: *'Yes,*

Researcher: *'How do you think for the family or friends who do know that you've got dementia, how do you think they see you?'*

Edward: *'Some of them may look with pity on me and in certain ways I'm not saying no, but I'm not giving them the impression that I'm on my knees, can you give me a helping hand to stand up, I will look for a prop or something, so I can stand up before I do it'.*

Therefore, it was not necessary to inform the wider family, when the close family was aware and provided the necessary support. This may have been related to how perhaps extended

family may view 'dementia'; however, this aspect was not further explored during the interviews.

4.7 God and Religion

The interlinking theme '*God and Religion*' forms a significant part of the participants' lives, throughout their different stages of life, from '*Life before Dementia*', in the '*Journey to Diagnosis*' and finally '*Living with Dementia*'. In the context of this study, the researcher categorised the theme '*God and Religion*' by the participants' use of religious specific language, for example: words including 'belief', 'healing', 'pray', 'prayer', 'faith', 'God', 'church' or by reference to religious scriptures, religious practices or religious beliefs. The participants in this study were all of the Christian faith.

For the participants, who were finding meaning in their lives as they coped with the day-to-day difficulties of memory loss, the presence of '*God and Religion*' was noted to be a constant during the interviews. When participants spoke about their early memories of childhood, '*Life before Dementia*'; their memories of their belief in God and religious activities were very clear and they described these in detail during the interviews. All the participants had memories of early church attendance; this was part of the usual family life for this group of individuals of Black ethnicity despite differences in countries of origin, as discussed below by all participants:

Catherine: '*We went to church every Sunday*'.

Edward: '*I grew up as a child in St Lucia going to church with my family, different members of my family had various beliefs and we all respected that*'.

Francis: '*Yes, everybody went to church*'.

Researcher: '*Do you go to church now?*'

Francis: '*Yes, we go together every week, I remember as a boy being rushed to make sure we got to church on time...*'

They described early memories of Sunday school attendance and of community support through the church in the early days:

Researcher: '*When you were living in Dudley were you going to church as the children were growing?*'

Francis: '*As the community grew, we had a church develop that was for our community and we used to take the children, we enjoyed it...my wife loved the church and singing...she got me hooked and enjoyed church songs reminded me of being at home*'.

Participants also described how from a young age, they were taught to pray. Alice explained as follows:

Alice: *'yes I went to church... I grew up praying when my father was saying prayers all of us had to kneel there'.*

In conversation with Beverley she described how she went to church at a young age and that she also raised her children in the same manner:

Researcher: *'Did you go to church at all?'*

Beverley: *'I went to church every Sunday. I didn't go to church every day, I try but when you have children you want to send them to Sunday School'.*

Going to church was an important event, she was raised to wear her *'Sunday best'* to church, in a way giving the best to God;

Researcher: *'Tell me a bit more about church'.*

Beverley: *'Well you get some money and they help with the bathroom, the bathing, comb their hair and put on the nice dresses. White socks, Sunday best! On Sunday, we go to church and praise God'.*

As the participants grew older, in the *'Journey to Diagnosis'* the concept of *'God and Religion'*, gave them a sense of structure and purpose; and was a way to understand the presenting symptoms as Beverley explained:

Beverley: *'There is so much, and it comes to a time that you can't even make it up ...and you just pray to God to help and he helps....'*

Those participants who were long-term church attendees could describe how their faith and relationship with God had impacted on their lives in general, and how they derived strength and meaning from their relationships with God:

Destiny: *'I'm not sure how I can explain this, like I said before when I was growing up we always went to church and my family way of life-based on belief in God, I don't know any other way of life, like at times I feel God's presence I know that he is listening and helps me get through hard times, it's hard but I have to just keep going and keep faithful'.*

The findings suggest that for the participants in this study living with dementia, faith continues throughout the dementia experience. Participants identified that faith and belief in God gave them most meaning to their lives. They were able to understand their current situations through the eyes of faith. Despite the challenges faced by the emerging symptoms and the medical dementia diagnosis; meaning in their lives came through faith, that constant belief of things hoped for. Destiny and Alice were observed to display stronger faith than the other four participants. This was noted in their use of scripture from the Bible and description of experiences. The following interchange with Destiny reflects this:

Researcher: *'Okay. Are you quite religious, would you describe yourself as religious?'*

Destiny: *'Yes I am, because I go to church every Sunday, I pray to God every day, so yes, my spiritual life is quite important to me. Well, you know, without God nothing is possible, and for me going to the church helps me to keep things in perspective and, you know, to keep focused, because there are so many problems in the world today, but focusing on God, it helps'.*

Researcher: *'Do you find it helps to pray when you are a bit low, does it help you a little bit?'*

Destiny: *'Oh yes, yes. I just pray and ask for help'.*

Researcher: *'How do you feel now that you have been through all of this?'*

Destiny: *'I still think that it is only by faith in God that I am here today. I am a fighter.... I am thankful for this day God has granted another day of life, for many did not make it....one of my favourite scriptures is, "This is the day that the Lord has made. Let us be glad and rejoice in it'.*

Strong faith in God was in this study perceived as assisting with acceptance of dementia and coping with dementia in their daily lives. For Alice, her hope included healing, a practice that is commonly found in Evangelical churches:

Researcher: *'So you believe that God can heal you then?'*

Alice: *'We don't believe, we know that.... Yes, and I think with dementia, even in Jamaica.... No, but I'm telling you first, he'll heal me'.*

This is something she believed with much conviction. Alice's background was religiously based, this gave her comfort, a previous healing experience, known as a - *visitation of the Holy Spirit* - was the basis of her strong beliefs regarding healing:

Alice: *'I go to my bed to sleep because where I was so feeling sick, I went to my bed and in my dream, I saw this big person, really fat and head down and praying. The person was praying, and they were praying and praying. I open my eyes, I don't see anybody really and I jump off the bed. I was walking around the bed and I was saying, because I didn't really get into this Christianity that much, I was in it, but I didn't understand. I get up myself because I couldn't walk, the foot, and I walked around my bed and I said, because I never see anything like this before and I'm walking around the bed and I said, I didn't even really recognise that it was Christ until after, realise it was the Lord that heals me'.*

Whilst this healing experience was personal to Alice, the concept of healing and prayers when unwell was discussed by other participants. When participants are unwell they prayed, their families prayed, their church communities prayed:

Researcher: *"I also wanted to talk a bit about the church. I know you said to me that the church, very supportive. I just wanted to understand a bit more how are they supportive, prayer, what prayer means to you?"*

Beverley: *"Prayer. They come here to pray. If something happens to you, they come, they comfort you. They pray. Yes, if anything happens to you. They're very good. They comfort everything, marriage and all these things. Everything, blood pressure. Illness, prayer. Prosperity, everything. God hear me."*

This raises the point, as to why participants and their families may not necessarily seek professional help when they experience early signs and symptoms of dementia, as they may first pray:

Alice: *'Yes, and other people, when you don't know go and they know you're sick, all the people pray for you. God is good, God can do great things. The thing about it is belief. You've got to believe. Just believe. in yourself, God will heal you, and you pray about it'.*

I also did question whether there was a correlation between the strength of one's faith and the tendency to access services. The findings in this study identified that the perceptions of dementia were informed by religious beliefs, which potentially had a negative influence on accessing dementia services. Participants accessed religious services or support before accessing health services.

The researcher sensed that faith and belief in God for a few participants was more than just prayer, it was a way of life. When *'Living with Dementia'* it was a source of strength and the unintended consequence is that it was a coping mechanism:

Researcher: *'So what would you say is very important in your life now, what are the most important things for you in your life at the moment?'*

Alice: *'My church is very important to me because I like to go and it's very jolly'.*

Researcher: *'Do you think that going to church helps you cope?'*

Alice: *'Yes it does'.*

The church provided a stable source of support and kinship. The participants, despite cognitive impairment, could draw some comfort from religious activities, as described by Destiny:

'I enjoy reading my Bible and spending time with God. I go to church. There I find peace, Yes, the church members are my community, also they give me support and help, the church members pray for me and it helps as there are also church activities helping me to get out at times'

Researcher: *'Oh, it sounds like they're supportive. So, the church friends, they come and visit you, you go out with them?'*

Destiny: *'We go out together, yes, that's right. Yes, the priest.... Yes, he does, he prays for us, we make prayer requests with him, he does visits at home. church members visit me if I don't go to church'*

Participants outlined how dementia impacted on the ability to perform religious rituals such as praying. The challenge with memory loss was that the participants sometimes were not able to remember to pray:

Catherine: *'Well I am. No, I don't really pray, I used to but I'm not sure what happen why I stopped'*

For Beverley, it was still possible to pray when she remembered to:

Researcher: *'Do you pray every day or try to?'*

Beverley: *'You try to, but you don't pray every day. You pray at night or before you go to work.... sometimes I forget.'*

Participants described how they prayed every day despite challenges and they felt that their religious activities remained important. Catherine's daughter did find it important to try and continue taking her mother to church:

Catherine's daughter: *'mum and I go to church on Sundays, but not every week and we don't stay long because mum sometimes will be wanting to come home as she is worried about leaving dad alone also sometimes mum gets upset and we have to leave I try to go when her carer is with us as she can help if anything happens, mum. Things have changed you know she is not how she used to be'*

For several participants, the church was still an important part of their community lives and provided a sense of community cohesion. Participants explained how the church was key to maintaining relationships with friends and other church members; in addition, the church was part of their community life supporting them in their day to day life. This experience dates from a time when they were growing up going to church:

Researcher: *'So, the church is really great then?'*

Francis: *'Oh, yes the church is good, and my pastor is supportive'.*

Researcher: *'What about praying, do you pray much?'*

Francis: *'I pray every day, I pray I pray'*

Researcher: *'Do you get help from the church?'*

Francis: *'Yes if I don't go to church, the pastor will come look for me, that church is my life when Mary passed on the church really helped me, they visit me every day'.*

Similarly, Destiny explained:

Researcher: *'So what would you say is very important in your life now, what are the most important things for you in your life at the moment?'*

Destiny: *'My church is very important to me because I like to go, and I pray, I pray a lot, it doesn't matter if I forget what I prayed for, I still pray, I feel that God listens, I can*

explain it, I just know that within me it will be ok, I feel it. I like singing a lot and I sing and pray'.

Researcher: *'Do you think that going to church helps you cope?'*

Destiny: *'Yes it does...I go to church...Yes, do a lot of community work which is part of the church. So, we grew up in the church, just part of the community. Well it's important to me because it helps me cope with difficult situations or things that I don't understand, and it also helps, you know, to keep me occupied and busy, so it's been good... Well because I get involved in a lot of the community work that we do with the church, because I don't work anymore it helps to get me out of the house, and people come to visit me from the church as well, I go to prayer groups'.*

For the participants living with dementia, attending church also provided a strong sense of ethnic social connection. As with other community members in their ethnic group, the church was an accepted part of their lives, through every stage of life, even more so towards the end of life. Francis had faced many challenges when he had been unwell in hospital:

Francis's Daughter: *'Yes dad was not very well and in hospital not too long ago and the family was very supportive, the church members even had a rota to visit him and brought him homemade food to eat and sang with him and brought him some church songs to listen to, I think this really keeps him going...at one stage he was so low when mum died but it was also around the time of the stroke'.*

Francis: *'Well I'm ok, much better, if I'm not well I tell my daughter and she calls the GP and our pastor. He visits and sits with me prays and reads as we sing. I have to keep going, I get up and get myself ready every day and wait for the carer'.*

Even through ill health, personal loss and bereavement, God and the church helped him to find a way to cope with life:

Francis: *'They helped me get by, I miss her so much'.*

Francis's daughter: *'mum passed away five years ago...the church was very good, they helped us with organising everything, and they visited every day because mum was an active church member, she was in the choir and helped with many activities. They were going to the church for 15 years and it was very difficult, but they have been very helpful, if he doesn't go they come and check if he is well and if I am out of the country they make sure he is ok'.*

Edward was the only participant who did not display the same level of faith or engagement in religious or church-related activities; he explains:

'But for me personally, I did not feel a deep religious need, I don't know whether it is the fact that I grew up in a poor background. I believe in hard work. I am just not one that is going for religion. I believe I do as much as I can in what I believe, but when it comes to religion I have not been prayerful or very religious, I follow all religions with

some interest, but I am not a regular church-goer. Religious-wise there were people in the family that have been in different religious ways, but I am not one that is going for religion. I believe I do as much as I can in what I believe, but when it comes to religion I have not been biased against one to the other one, or what I'm caring for is if somebody cares for me and then I can care for somebody else and I will do the same for them.....Well this is my whole feeling, it was not somebody that taught me what to do and what not to do, but within myself I know I grew up in a poor background, so I followed the poor to the rich and the rich to the poor and I follow all religions equally, and I respect everybody like they respect me. This is my way religious-wise'.

This section has discussed how the subtheme of 'God and Religion' influenced the participants' lives from childhood to the onset of dementia symptoms, gaining a diagnosis and their lives post-diagnosis. The reliance on faith and belief in God, religious services or activities may have delayed or hindered access to dementia care services for some of the participants. However, for most participants, faith and belief in God proved to be beneficial and positive in bringing solace, summarised eloquently by Beverley:

'...there is a joy in my soul, peace and gladness in my heart'.

4.8 Summary of chapter

In this chapter, I have provided the findings of this study. The interpretation of the phenomenon of living with dementia as an individual of Black ethnicity is my own interpretation, as I understood the experience from the participants who took part in this study. The chapter presented the findings in three main themes:

- Life before Dementia
- Journey to Diagnosis
- Living with Dementia

The inter-linking theme 'God and Religion' was noted to be significant in all three overarching themes and as such the discussion regarding 'God and Religion' is presented individually. I then put forward that the lived experience of dementia as an individual of Black ethnicity was a continuum greatly influenced by the participants' background, family support and religious beliefs. The participants made sense and found meaning in their present lives, and hopes for their future, through an awareness of the influences of their past, their culture, and their heritage. Although memory is affected, the findings show that the ability to live life, having a sense of independence, and participating in dementia-related activities provided a sense of being for the participants of Black ethnicity living with dementia. For the participants living with dementia, recent events may have disappeared from their memories, but older memories of

childhood and their countries of origin remained intact and continued to shape their lives post dementia diagnosis. The next chapter will present a discussion of the findings in the context of the reviewed literature.

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This chapter presents the discussion of the findings relevant to the phenomenon- ‘the lived experience of dementia as an individual of Black ethnicity’ as detailed in Chapter Four and in relation to the literature reviewed in Chapter Two. In this chapter, I develop links between the research findings, the evidence and theoretical arguments presented in the literature review together with evidence from additional literature, relevant to the findings.

According to Heidegger (1962), phenomenology’s task it to question what it is to be in the everyday world. In seeking an understanding of the lived experience of dementia, I had to understand the participants’ worlds. The findings from this study identified the following three overarching themes, with subthemes as detailed in Figure 3.3:

- Life before Dementia
- Journey to Diagnosis
- Living with Dementia

Again, the interlinking theme, ‘*God and Religion*’ was noted to be significant in all three overarching themes and as such the discussion regarding the inter-linking theme, ‘*God and Religion*’ presented individually in section 5.5.

This discussion revisits key sources already cited in Chapter Two. As there is a scarcity of research which specifically addresses the experience of Black people living with dementia in the UK, this chapter also discusses the findings in relation to additional literature not included in the literature review chapter. For context, it was important the findings were discussed in relation to other studies investigating the lived experience of long-term conditions within ethnic minority groups, where cultural backgrounds and religious beliefs were found to be influential. For example, as revealed by the literature review there were no UK studies that specifically considered the impact of God and religion for people living with dementia of Black ethnicity. I specifically sought studies that considered the impact of religion and long-term conditions with Black people living in the UK; for example, this resulted in the review of Moorley *et al.* 2016, which focused on the experience of African-Caribbean women living in the UK after a stroke. The additional literature introduced in the discussion chapter contributed to interpreting the findings from this study.

5.2 Life before Dementia

In this study, the participant's country of birth was an important factor influencing dementia knowledge, attitudes and health-seeking behaviours. All the participants who took part in this study were not born in the UK. This study adopted a qualitative approach where all participants were of Black ethnicity, were living with dementia and were not born in the UK. No other study has exclusively researched participants of one ethnic group where all participants are first generation Black African/Caribbean participants and shared the immigration experience of relocating to the UK as adults of working age. The study sample (one Black African participant plus five Black Caribbean participants) is representative of the immigration patterns to England and Wales, as discussed in Chapter Two section 2.2.4; Black African migration to the UK started later than that of the Caribbean and Asian people.

This study highlights that the influences of the past, growing up in their countries of origin, emerged as a starting point for the participants. This was noted as a sense-making mechanism, by which the participants understood themselves and constructed their worlds. The findings in this study show that all participants grew up with family support and cohesion; instilled in the participants was discipline and hard work. Research on Caribbean families has described their parenting style, as strict, with expectations of obedience, hard work, respect, manners; as well as educational and social competence (e.g. Durbrow, 1999; Wilson *et al.* 2003; Griffith and Grolinick, 2014). This study suggests that there may be a correlation in how the participants were raised and how they coped with settling in the UK and later in life when living with dementia. This is discussed further later in this section.

In this study, the participants were first generation Black African/Caribbean and they were more familiar with other high-profile diseases, such as HIV/AIDS and cancer, which were more prevalent with public health campaigns in their countries of origin than the participants migrated from. Consequently, as a result, *dementia* often had no meaning for them. They had no personal/community experience of dementia. They were not aware of friends or family members who had dementia. This finding is consistent with work by Berwald *et al.* (2016) where they noted that in their study Black Africans repeatedly mentioned not having to consider dementia in their home country nor did they remember having a structure in place to handle it. However, the question here is whether personal stories of dementia providing illustrative examples of experiences from individuals of the same ethnicity would have affected the way the participants constructed their worlds, pre-and post-diagnosis of dementia, as well as the decision-making process such as seeking early support from health services. Other studies have found that providing information within personal stories affects how people

understand and conceptualise that information, and consequently, the choices they make, in contrast to facts presented in non-narrative style (see Entwistle *et al.* 2011; Bekker *et al.* 2013).

The reality is that dementia does exist in the participants' countries of origin; for example, Waldron, *et al.*'s (2015) study in Jamaica examined the prevalence of cognitive impairment in community-dwelling older adults. Whilst in the Ugandan clinical setting, Namuli (2015) highlights that, in addition to Alzheimer's disease and Vascular dementia, the other most common causes of dementia include: infections (commonly HIV and Syphilis), substance abuse (alcohol), trauma (road traffic accidents) and nutritional deficiencies (vitamin B-12). Dementia figures in Uganda are expected to rise; the epidemiological data may not follow expected trends notably due to the prevalence of HIV/AIDS (Namuli, 2015; WHO, 2016).

Consistent with previous studies (see Seabrooke and Milne 2003; Azam, 2007; Giebel *et al.* 2014; Johl *et al.* 2014), the findings in this study note that there are also linguistic differences to take into consideration. All participants expressed that there was no word for 'dementia' in their countries of origin. Whilst the participants spoke English, they also spoke vernacular forms of English and one participant spoke Swahili.

This study found that forgetfulness, memory or cognitive decline, were expected from older people and as such, they were perceived to be a normal part of ageing. The participants did not view the symptoms of dementia as a potential illness, therefore they did not seek help. Evidence from the literature review in Chapter Two highlighted that not all cultures view dementia as a disease (see Berwarld *et al.* 2016), and that cognitive impairment may be regarded as a natural and an expected consequence of ageing (Jolley *et al.* 2009; Botsford *et al.* 2011; Berwarld *et al.* 2016). The inability to recognise symptoms of mental illness has been noted in BME communities and was found to be a key barrier to accessing health services, particularly for people who had grown up in their countries of origin (Memon *et al.* 2016). As a consequence of this, the findings from the current study are that the participants presented at a later stage to health services, when their dementia had progressed.

In this study participants described how the symptoms of dementia were relabelled negatively as 'crazy' or 'lose his mind' in their native countries. The stigma associated with dementia in BME communities is well recorded in literature (e.g. Mackenzie *et al.* 2003; Seabrooke and Milne, 2004; St John, 2004; Azam, 2007; La Fontaine *et al.* 2007; Moriarty *et al.* 2011; Mukadam *et al.* 2011; Botsford *et al.* 2012; Mukadam *et al.* 2015); this study also confirmed that indeed the stigma still exists even in the participants' countries of origin, however, there was no evidence it was a barrier to seeking help for the participants in this study.

This study puts forward that immigration experience, from the initial motivation to immigrate, the employment experience, cultural differences and racial consciousness, had an impact on the overall dementia coping experience. The participants in this study were immigrants of colour, and their ethnic identity had defined and shaped their lives. Despite adversity, for example, difficulty in managing childcare and cultural difference in the UK, they had a sense of resilience and optimism instilled in them from childhood. The concept of resilience is introduced in this section and is discussed further in this chapter; however, it is noted that across the life course, the experience of resilience will vary (Windle, 2011), and being resilient was noted in the participants' stories in this early part of life, their lives before dementia. This finding is similar to Botsford *et al.*'s (2011) work, which identified a concept of resilience held by carers from BME communities; this was due to the carer having overcome important challenges and obstacles during the immigration experience while settling into a new country of residence. Thus, the carers had already developed ways of coping and adapting to the situation which came into play in their present situation of caring for a family member with dementia (Botsford *et al.* 2011).

In the UK, there is a growing body of research focusing on resilience, ageing and mental health (see Netuveli *et al.* 2008; Angus and Bowen-Osborne, 2014;). There is a plethora of research on resilience and the capacity to cope in the context of forced migration on Mexican immigrants to the USA (Berger Cardoso and Thompson, 2010; Hagelskamp, Suarez-Orozco, and Hughes, 2010; American Psychological Association[APA], 2012; Valdez, Valentinté and Padilla, 2013). Just like Mexican immigrants in the previously mentioned studies, the participants in this study had a deep commitment for hard work instilled from their childhood, with hope for a better life in the UK. All participants in this study had immigrated to the UK as adult to work. This study suggests that this determination enhanced their ability to cope with persistent stress and to manage difficult situations such as living with dementia.

5.3 Journey to Diagnosis

It is notable that in this study, all the participants and their friend/or relative were unaware of the importance of early diagnosis and did not have any knowledge of the signs or symptoms of dementia. They were aware of personal changes but did not know that they were indicative of cognitive impairment. The literature review has already highlighted that BME participants in other qualitative studies have often been found to lack knowledge with regards to the signs and symptoms of dementia (e.g. Parveen *et al.* 2017). Purandare *et al.* (2007) also noted in their quantitative study where the participants were Indian older people in Manchester (UK),

they did not have sufficient knowledge about dementia, which may be one of the reasons for their relative absence in the local dementia treatment clinics. Indian older participants in this study showed significantly less knowledge about dementia and were less aware of the impact of dementia on personality, reasoning, and speech compared to Caucasian-White British older people.

What is more interesting is that participants in this study who lacked knowledge regarding dementia, did not conceptualise dementia as having a biological cause (i.e. death of brain cells), but rather as a result of other factors or events (e.g. a fall, a seizure). This is similar to other studies where the participants were also immigrants; for example, Iranian immigrants in Sweden associated developing dementia to their life challenges and difficulties, and this was their way of finding a meaning and understanding the disease (Mazaheri *et al.* 2014). Jutlla (2015) in her work also found that migration experiences and migration identities had an impact on understanding participants' experiences of services.

By providing an explanation for dementia, participants in this study distanced themselves from having dementia, which was a way to minimize the effects of forgetfulness, and to explain their forgetfulness (Mazaheri *et al.* 2014). Explanatory models of illness have been noted in literature to refer to a person's views about the nature of their problem, its cause, severity, prognosis and treatment (McCabe and Priebe, 2004). Downs, Clare and Mackenzie, (2006) in their work discuss explanatory models of dementia. In their work, they note four explanatory models, which include dementia as a *neurological condition*; dementia as a *neuro-psychiatric condition*; dementia as a *normal part of ageing*; and seeing dementia from a person-centred perspective. This finding, therefore, suggests that what people believe about their illness influences their experience of and access to health services. Therefore, the participants in this study had a distorted understanding of dementia, which did, delay diagnosis and influence the decision to seek treatment (Mukadam *et al.* 2011). This is again consistent with other studies, where participants thought that support from a GP was only for serious persistent problems, resulting in delaying accessing health services until crisis point (Zhan, 2004; Papastavrou *et al.* 2007; Berwald *et al.* 2016). This was also the case in this study, where help was only sought after a significant event (e.g. a fall, a seizure). Therefore, what is evident in this study is that the participants in this study held a cultural view of dementia and that this affected the way in which the participants sought, understood and received treatment and care.

In determining the threshold at which the individuals of Black ethnicity accessed services, the findings in this study indicate that the participants and the family only accessed services or

support from GP after a specific event that was significant (e.g. a fall/seizure), therefore indicating a particularly high threshold in seeking help for this group of participants. Reported barriers to accessing services, such as family support and, accommodating the changes and delay seeking help until they cannot cope, were found to be similar to those reported by Lawrence *et al.* (2008) and Mukadam *et al.* (2011). However, this was in contrast to the indigenous White British population (Parveen *et al.* 2016).

Hailstone *et al.* (2017) found in their study exploring attitudes of people from ethnic minorities to accessing dementia services, that the strongest predictor of willingness to seek help was perceived social pressure from significant others; this again was related to beliefs about the views of family members and embarrassment around seeking help. Their study noted that a willingness to seek help was also strongly associated with attitudes about the benefits of seeing a doctor for memory problems and how they would help (Hailstone *et al.* 2017). In this study, when the participants did access services, they had a negative experience of the health service and difficulties in navigating health services. Negative experiences of healthcare services by minority ethnic groups are suggested to be a major contributory factor in a late presentation to specialist dementia services (Mukadam *et al.* 2011).

5.4 Living with Dementia

Post-diagnosis, the unwillingness to accept a diagnosis of dementia was found as a key barrier to accessing support from health services for the participants who had grown up in their native countries. Like Berwald *et al.* (2016), findings in this study indicate that the participants did not think dementia was found in Black communities. In this study participants did not think dementia would happen to them. This again was related to their backgrounds and low awareness of dementia. In this study, the use of language was found to influence their understanding of the concept of dementia, disease progression, its impact on day to day life and the future. Studies have found that where ethnic differences were a factor in the overall experience of adult acute mental health care, it was mainly due to language (Weich *et al.* 2012; Memon *et al.* 2016). Stokes *et al.* (2014) describe in their work how lack of information impacted on personal understanding of dementia and had implications for adjustment and making sense of the dementia diagnosis.

In this study, ethnic background and identity defined acceptable responses to dementia and appropriate coping mechanisms. Again, the concept of resilience is relevant -i.e. although living with dementia was 'hard', they had to cope - coping was expected from their communities as Black people during this stage of life. Windle (2011) in her work described

resilience as the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. In this study, it is about how the participants coped through the various stages of their lives pre-diagnosis (as discussed in section 5.2) and post-diagnosis in the face of adversity, managing the challenges of day to day living with dementia, as individuals of Black ethnicity. Memon *et al.* (2016) note in their study, that in relation to coping with mental health issues, within BME communities, individuals were expected to 'deal with it'.

This study found that the participants had a sense of independence; which was also was a coping mechanism in their daily lives. Living with cognitive impairment, the participants in this study were actively engaged in re-constructing their sense of self-independence, using a variety of coping strategies, such as attendance at dementia-related activities, close relationships with family and the church community, which was a focal point for socialisation. The stigma attached to dementia in this study meant that dementia was often concealed from the wider family, a finding which is similar to Parveen *et al.*'s (2016) findings with the BME community. Family support and care in this study were key to helping the individual cope with day to day life post-diagnosis, as has been found in other studies relating to BME groups and the experience of dementia (Adamson and Donovan 2005; Botsford *et al.* 2011; Giebel *et al.* 2014).

5.5 God and Religion

If the concept of God, spirituality and religion is fundamental to personhood, then it must also be as integral to the life of a person living with dementia as it is, to any other person (Kevern, 2015). The definitions of spirituality and religion are often debated; however, in this thesis, religion is viewed as the faith tradition that includes the beliefs, rituals, and ethical values accepted by a community and transmitted over time (Nelson-Becker and Canda, 2008; Canda and Furman, 2010). Spirituality is linked to both religion and culture and is often viewed as more subjective and personal (Nelson-Becker, 2011). Spirituality in this work is understood to be the ways individuals seek meaning and purpose (Chow and Nelson-Becker, 2010).

The impact of religion on general care is well documented in the literature. For example, Jehovah's Witnesses decline allogenic blood transfusion for reasons of religious faith (Bodnaruk *et al.* 2004; Hoffman, 2014), even if the consequence of this is death (Griffith, 2014; West, 2014). The New King James Version of the Holy Bible asserts that *faith... "Now faith is the substance of things hoped for, the evidence of things not seen"* (Hebrews 11, verse 1). Therefore, it was essential to explore the influence of God and Religion, the impact of faith, of

things, hoped for but not seen, in relation to the lived experience of dementia and Black ethnicity.

The study findings suggest that religious beliefs and practices instilled from childhood, influence a person's daily life and continue to influence a person's daily life from childhood to the onset of dementia and post-diagnosis life. In this study, like the findings of the systematic review by Regan *et al.* (2013), which focused on religion and its impact on dementia care pathways in BME communities; religious beliefs or rituals such as praying, healing etc. influenced the disease experience, including symptom identification and appraisal, decision to seek care and to contact health services such as the GP. This study found that religious belief most influenced the decision-making process related to accessing services. Religious participants (for example Alice), were less likely to initially seek support on the onset of dementia symptoms or when she was unwell. Rather the participants would pray or seek help from religious leaders. Even when symptoms persisted, the participants in this study did not immediately seek help from NHS health services. They could cope with family or religious support and prayer. In understanding this I reflected that The New King James Version of the Holy Bible does advise in James 5, verse 14-15 that *"Is any sick among you? Let him call for the elders of the church and let them pray over himand the prayer of the faith shall save the sick"*. Therefore, I understood the participants perspective.

These findings were similar to Islam *et al.*'s (2015) study looking at BME service users and access to early intervention psychosis services; they noted that for many BME service users, involved support from faith/spiritual healers, before seeking medical intervention and that this behaviour may have led to treatment delays. They recognised in their study the value of proactively including service user's religious and spiritual perspectives in the initial assessment and care planned (Islam *et al.* 2015). However, clinicians in this study acknowledged that they had limited spiritual/religious or cultural awareness training (Islam *et al.* 2015). Moorley *et al.* (2014) also noted in their work exploring why Nigerian women present with breast cancer to health services at advanced stages; found that some of their participants preferred alternative medicine as a treatment option for breast cancer and that these beliefs may have been directly linked to cultural, family or religious belief

As religion is an important component of any cultural heritage, further research is required to explore this further in the UK. Moorley *et al.* (2016) write that people often look to spiritualism for the restoration of health, guidance and hope. In this study, one interpretation may be that a stronger faith (which was evident in two participants) is associated with a less frequent access to healthcare services. Ark *et al.*'s (2006) study found that White Christian women

were more likely to access health services than Christian women from African American communities, who showed a strong reliance on God and religion. Similarly, African American women who regularly attended religious services were less likely to attend breast cancer screening services (Aaron *et al.* 2003), whilst Kretchy *et al.* (2013) found in their work that in hypertensive patients, where there were strong religious beliefs and spirituality; there was a correlation with nonadherence to medication.

I observed that in my study, that religious organisations did not provide healthcare support by signposting participants to attend healthcare services, rather they engaged in religious activities such as prayer or healing. Another factor which impacted service access was the notion that the dementia was God's will. It is worth noting that in this study, the participants did not state a preference for religious and spiritual intervention, over and above support from healthcare services, rather religious intervention or activities provided the initial support.

Finally, religion, in this study, was noted to be beneficial for individuals in coping with dementia in their daily lives. Moorley *et al.* (2016) in their study looking at African Caribbean women's subjective accounts of stroke recognised that religiosity and spirituality offered important coping mechanisms. The participants in this study could draw strength from their faith through prayer, to find meaning and courage in facing the challenges of memory or cognitive impairment. These findings are similar to a study by Beusher and Beck (2008), in which the BME participants were also living with early-stage Alzheimer's disease; through personal faith, prayer, connection to church, enhanced the ability of the participants to keep a positive attitude as they faced living with Alzheimer's disease (Beuscher and Beck 2008).

5.6 Summary of chapter

In conclusion, this discussion has considered the findings in relation to migration experiences and life history of the participants who took part in this study. This approach has demonstrated how these have an impact on understanding the participants' concept of dementia, the journey to diagnosis and living with dementia. The findings in this study, highlight the need to understand life histories when considering the overall lived experience of dementia. Following these discussions, the final chapter of this thesis is presented next as a conclusion to the thesis. In the next chapter, I provide a summary of my research outlining what I did and what I found, highlighting the original contribution made by this study, with some concluding comments. I highlight possible areas of further research within this field and make recommendations for policy and practice. The final Chapter provides my concluding remarks regarding this remarkable journey.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

This study was completed to gain an understanding of dementia from the perspective of individuals of Black ethnicity through their unique experiences. In this chapter, I revisit the original research questions as well as the study's strengths and limitations. This chapter, therefore, ends the thesis by reflecting on the study findings and conclusions. The significance of the findings for policy and practice in the future will be explored. This final chapter also provides my concluding remarks regarding my research journey.

6.2 Revisiting the research questions

Hermeneutic phenomenology is concerned with human experience as it is lived: the lifeworld. Its focus is on revealing details, often seemingly unimportant, with the goal being to create meaning and achieve understanding. Heidegger (1962) in his work, maintained that interpretation is crucial. He proposed that *to be human is to interpret* (Heidegger, 1962). Heidegger (1962) writes that the '*ordinary*', lived through the experience, tends to become quite extraordinary when we lift it up from our daily existence and hold it with our phenomenological gaze. The aim of this study was to gain an understanding of dementia from the perspective of the individuals of Black ethnicity, through their unique experiences.

This study had the following aims:

1. To explore how individuals of Black ethnicity living with dementia see themselves.
2. To understand how they cope with the day-to-day reality of living with dementia.
3. To understand the participants' perspective: how that meaning is constructed in the differing perspectives of living with dementia as an individual of Black ethnicity.

The initial questions informing this study were:

1. What is the lived experience of the individual of Black ethnicity living with dementia?
2. How does the individual of Black ethnicity living with dementia describe their experience and everyday lives?

In the next section, I revisit each of my research questions, discussing my key interpretations and the implications of these in relation to the study aims and objectives.

6.2.1 What is the lived experience of the individual of Black ethnicity living with dementia?

Heidegger in his work discusses how one's world, it is assumed, is based on something previously known or a *priori* (Heidegger, 1962). The data from this phenomenological study led to the identification of three overarching themes that summed up the experiences of the participants. The role of '*God and Religion*' was an interlinking theme across the life experience of the participants in this study. In this study, I have considered the stories that the participants had related and the findings that arose from the data analysis and then sought an appropriate means of interpreting what their lived experience really meant to the participants themselves. The participants who took part in this study were not born in the United Kingdom. The 'world' that they found themselves in at the point of the interviews, had a historical structure, that commenced in a different 'world' (i.e. their country of origin).

In exploring the lived experience of dementia, this work recognised the need to understand the participant's individual story, their experience of life before dementia, their journey to gaining a dementia diagnosis and their life experience after receiving a dementia diagnosis. Researchers have emphasised that an important starting point in achieving personalised approaches to dementia services, is the need to pay greater attention to the diversity and complexity that exists across the life experience of people living with dementia (Jutlla and Moreland, 2009). This is because the way people have structured their lives and identities during their life will influence their experiences of dementia. Therefore, participants in this study were to some extent able to construct a narrative, based on their life history –that is, '*life before dementia*'; and this construction enabled them to preserve aspects of their self-identity when they gained their dementia diagnosis- '*journey to diagnosis*', and even how they experienced '*living with dementia*'.

Heidegger (1962) maintained that time must be used as the horizon for the understanding of being. It is only within the concept of time can any understanding of being be reached. Heidegger (1962) used the term 'historicality' for the authentic conception of history. Also, used by some writers is 'historicity'. Historicity is a defining characteristic of *Da-sein* and concerns an individual's history or background (Heidegger, 1962). It includes what a person's culture gives them from birth and what is handed down. It presents individuals with ways of understanding the world (Laverty, 2003). Heidegger regarded this consciousness as woven together and shaped by historically lived experience. He insisted that a person's background and understanding influence their responses always, which means that nothing could be encountered without reference to it (Merleau-Ponty, 1962). In addition, Heidegger in a 1996

translation (p.350) notes that *"Factically Da-sein always has its history, and it can have something of the sort because the being of this being is constituted by Historicity"*. Heidegger (1962) explains that nothing can be encountered without reference to a person's background understanding. Therefore, my understanding is that we are historical beings, and so are the participants who took part in this study.

The influence of cultural and ethnic factors should be considered when trying to understand the subjective lived experiences of heterogeneous groups of people (Downs, 2000). Few of the current generation of older people of Black ethnicity have been born in the UK, as has been demonstrated in this study, and there are aspects of their life history, that may need specific consideration when planning care. Interpretation is critical to this process of understanding of their lived experience of dementia. Heidegger (1962) wrote that to be human was to interpret, therefore that interpretation is influenced by an individual's background or historicity. This study has considered the country of birth, country of origin, migration route, reasons for migration, age at migration, the cultural experiences of individuals and has touched upon the participants' lives in the UK, to understand their current lived experience of dementia. Family support was found to be crucial. Through this approach of understanding the participant's life history and experience, understanding is gained from interpreting links back to pre-history and structure. Their life history, even with fading memories, still existed and cannot be bracketed out. It is through the lens of their own history, culture, beliefs and language that the participants in this study viewed and understood the nature of their lived experience (Lavery, 2003). Therefore, the lived experience of dementia is a continuum of life, one that is impacted on by the factors discussed in this section. Meaning is constructed through their life history; God and Religion offered an alternative meaning and a way of coping. Strength and solace were found in prayer and faith throughout the dementia journey.

6.2.2 How does the individual of Black ethnicity living with dementia describe their experience and everyday lives?

Heidegger's (1962) concept of truth was important for this work as the philosophical base on which this study was built. It was important to establish the truth of what it was like to live with dementia, to hear this from the participants of Black ethnicity, through their experiences, beliefs and perceptions. The truth in this sense is subjective but nevertheless vital in understanding the participant perspective, through their individual stories.

The participants described their experience of dementia and everyday life through the concept

of resilience. Windle (2011) developed a theoretical framework that helps to understand the factors that impact on resilience building. Windle (2011, p. 163) defines “*Resilience as the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. It is about how the participants coped through the various stages of their lives pre-and post-diagnosis in the face of adversity*”.

For the study participants, resilience appeared to be a process of self-maintenance, in that they felt that their resilience was related to a degree of continuity between life before and after the diagnosis of dementia. Even though their lives had changed following diagnosis, most participants noted that a sense of normalcy and similarity to their life prior to the diagnosis of dementia, that was central to a view of resilience and to their positive adaptation or coping. The participants in this study migrated to the UK as adults and faced challenges when settling in the UK; they had to be resilient and cope with the difficulties they faced. Their daily lives and engagement in dementia-related activities of the participants served as evidence to them of their continued independence and resilience but were also recognised as contributors to their resilience. What changed for most participants in this study to a certain extent was how they did these activities, rather than what they did. They still had the same interests, they had a continued sense of independence and tried to carry as much as possible with activities of daily living such as personal care, and they found ways to regain lost skills.

Windle’s (2011) theoretical exploration of the concept of resilience highlights how interlaced with normal, everyday life resilience is, reflecting its multi-disciplinary roots. Like the factors that impact on one’s ability to be resilient as demonstrated by Windle (2011), the participants in this study through the different phases of life, from childhood, to immigrating and then settling in the UK, then developing dementia; had faced challenges/adversity, had developed the ability to manage the effects of adversity through for example family support or their continued belief in God and religion, resulting in a somewhat positive adaptation through coping mechanisms. Consistent with this finding, Bailey *et al.* (2013) suggested that resilience for individuals with dementia “*can encompass the ability to continue with established roles and activities that (re)affirm a sense of self and build on a lifelong accumulation of social, knowledge, psychological, and material assets*” (p. 394), an emphasis on the importance of continuity between life before and after dementia, as identified in this study in Chapter Four.

6.3 Original Contribution to knowledge

In this section, I highlight the contribution that my findings have made to the current knowledge and evidence base, as well as indicating where my research may have made a distinct

contribution. The contribution of this study is methodological and theoretical. The contribution of this study to new knowledge is that it uses a phenomenological approach to understand the experiences of people living with dementia as individuals of Black ethnicity who emigrated to the UK as adults. The Heideggerian approach focused on the participants' experiences and the processes they chose to cope with living with dementia. It enables a better understanding of the patient journey and the choices this group of participants made.

This study also contributes to knowledge in that it provides a guide to assist other researchers conducting qualitative interviews with individuals living with dementia from ethnic minority groups. This study highlights that challenges to recruiting participants of ethnic minority backgrounds can be overcome if the sampling strategy focuses on recruiting participants via religious groups or faith networks as this study has established that for this group of participants – religion plays a central role in their lives.

Through the data collection process, this study contributes to knowledge by providing a detailed explanation of the methods (interview process and techniques e.g. the need to gain ongoing consent on each visit and the use of constant prompting during interviews) used to collect data. This study has demonstrated that when seeking to understand the experiences of people living with dementia, it is important that the researcher understands policies regarding safeguarding vulnerable adults and an awareness of the Mental Capacity Act and has completed mental capacity assessment training.

This study has discussed the use of Consultees when interviewing participants who may be of limited mental capacity. This study has shown that it is possible to interview individuals living with dementia, with the support of a Consultee; and still ensuring that the story of the study participants is not overshadowed by the Consultee contribution. In addition, the literature review in Chapter Two highlighted that often research has mainly captured the views of carers and family members, a key finding in my work and contribution to knowledge is that both carers and the individuals living with dementia often share the same views and beliefs, in relation to awareness and knowledge about dementia, family support and in particular- God and Religion.

I cannot claim that this study captured all the factors influencing the lived experiences of people of Black ethnicity and dementia. Instead, I can offer a perspective that may be common among some who are already marginalised due to their ethnicity and diagnosis of dementia. This study provides insights into the life experiences of a group of people who have experienced immigration to another country in addition to experiencing the development of dementia and living with it. These findings have not previously been revealed within the

population of individuals of Black ethnicity who migrated to the UK as adults and are now living with dementia.

6.4 The strengths and limitations of the study

This section acknowledges methodological strengths and limitations and offers some discussion on how this influenced this study and its findings.

6.4.1 Strengths

My existing knowledge of the literature on dementia and BME groups proved to be a strength and enabled me to complete interviews with some confidence. I did not bracket my existing knowledge, instead, I used it. This study is the only qualitative study to consider the lived experience of dementia specifically from the perspective of individuals of Black ethnicity living in the four North East London boroughs; who migrated as adults to the UK. The study considered their heritage, migration stories as well as their journey to diagnosis. Although this was a relatively small qualitative study, sampling was purposive; the overlap with previously identified findings to help-seeking in dementia in minority ethnic groups suggests transferability of the findings. The research that was undertaken for this thesis employed methodology based on Heideggerian phenomenology (Heidegger, 1927/1962). This study using a qualitative approach was carried out in an area where little is known, focusing on the lived experience of dementia of individuals of Black ethnicity living in four boroughs in North East London. The interpretive aims have been made clear, as has the objective to present depth rather than breadth of experience.

Incorporating a phenomenological methodology was a strength of my study when exploring factors impacting on the individual experience of dementia. Ultimately, having fewer participants in this study, albeit this was not my original intention, was crucial in developing relationships with participants. During interviews, I took extra care to ensure I developed a rapport with the participants. As a person of black ethnicity, myself, I was respectful towards the participants, which greatly assisted in building rapport and I noted this to be a key strength during the interview process and gaining continued access for the remaining 2 interviews. I was aware of principles regarding safeguarding vulnerable adults and as required by the NHS Research Authority Ethics Committee (see section 3.7.3), I had completed mental capacity assessment training on how to assess capacity, as I had to be confident that the participants, the person living with dementia had the capacity to consent both at the beginning of the research process and ongoing consent at all further points when they participate during the

interviews. This study has demonstrated that when seeking to understand the experiences of people living with dementia, it is important that the researcher understands policies regarding safeguarding vulnerable adults and an awareness of the Mental Capacity Act and has completed mental capacity assessment training.

It was essential to have three interviews to help to fully understand the participants' experiences and this was recognised as a strength of the study design. I could build up a relationship informally and flexibly with each participant during the 3 interviews and each interview helped me gain further understanding of the participant's story. I observed that with the third participant who did not complete the process, it was more difficult to tell her story indicating that one interview was insufficient to gain an understanding of her experience. During the interviews, due to cognitive impairment, my clinical experience as a nurse, was a strength as I realised the need for constant prompting with the participants to encourage them to tell their story.

6.4.2 Limitations

The study obtained a small sample from a specific geographical area, that is 4 London boroughs in North East London. Considering the diversity of Black ethnicity, the participants in this study represented a small subsection of this population, therefore, they do not represent the views/perceptions of all strata of the Black population living with dementia in the UK particularly as all participants were from a specific part of North East London. Therefore, the findings may not be representative of other individuals of Black ethnicity living with dementia in London or the UK. Whilst the findings cannot be considered generalizable to other populations, it is important to note that this was not the aim of the study, however, has the potential for transferability. The aims of this study were to capture the uniqueness and diversity of the experiences of the individuals living with dementia who took part in the study

6.4.3 Suggestions for further research

This study presented one interpretation of the phenomenon '*the lived experience of dementia within individuals of Black ethnicity*' about which little was previously known. There is further research potential here, as the perspective provided in this work is my interpretation of the phenomenon; there is a strong likelihood that other interpretations may still exist that need further exploration. Further research is suggested with larger samples focusing on specific

Black ethnicity groups such as Black Africans, including key family members, carers as well as religious groups.

This work does not address the diversity within and across Black communities in London or the UK when considering their experiences of dementia. This study accepts that even within the Black ethnicity groups there are differences. A more detailed examination of the differences between, for example, Black Africans and African Caribbean individuals living in the UK; exploring their lived experiences of dementia, is worthy of consideration particularly in the light of differences in countries of origin, personal histories and migration experiences. Again, such research would further the understanding of the diversity within Black communities and how this might impact on their experiences of living with dementia. The notion that a person's religious beliefs and practices are influential throughout the dementia experience, is introduced by the existing literature and this study but requires a more focused, critical examination in future research.

There is also scope for work exploring the impact of understandings or perspectives of dementia between different generations within Black UK communities and how dementia is experienced or perceived by the later generations. The participants in this study were all original migrants to the UK. Their children who are second generation British (born in the UK) may have an entirely different understanding of dementia that may or may not be influenced, for example, by their Caribbean or African origins.

6.5 Recommendations for policy and practice

This section discusses the recommendations for policy and practice in relation to commissioning of dementia services and clinical practice.

6.5.1 Recommendations for Commissioners

NHS England has committed to improving the quality of services for people with dementia by placing patient experience and personalisation at the heart of the commissioning process (NHS England, 2017c). In addition to the above, there is a clear recognition that the commissioning process gives regard to the need to reduce inequalities between patients in access to, and outcomes from dementia healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities (NHS England, 2017c)

This study developed from a need for a better understanding of the lived experience of dementia, from the perspectives of individuals of Black ethnicity. The findings demonstrated that key aspects such as family support, awareness of dementia, and use of language about dementia had an impact when accessing services. By incorporating these findings into the commissioning of dementia services and the pathway re-design process it will enable health and social care professionals to engage more effectively with patients, looking at ways of engaging them in accessing and developing services. This study suggests that commissioners of dementia services, local authorities, healthcare services and voluntary community groups need to play a role in collating and disseminating dementia information/public health promotion advertisements or interventions in accessible languages, where relevant to their local area, as these are currently lacking. More recently the Alzheimer's Society has produced resources that include translated dementia information and videos as examples (Alzheimer's Society 2017).

6.5.2 Recommendations for Practitioners

Key Dementia campaigns such as the Alzheimer's Society United Against Dementia campaign launched 24 April 2017, calls for the new UK Government to continue to invest in addressing dementia care and improving the lives of people living with dementia as a priority. The previous Government's key aspirations previously outlined in the Prime Minister Challenge (DH, 2015) are that by 2020 every person diagnosed with dementia is having '*meaningful*' care following their diagnosis, which supports them and those around them, with '*meaningful*' care and support being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. NICE explains that "*meaningful and culturally appropriate activities should include creative and leisure activities, exercise, self-care and community access activities (where appropriate). Activities should be facilitated by appropriately trained health or social care professionals*" (NICE, 2011 p.42).

Health and social care professionals can help improve the care that is delivered to this group of patients by having an understanding into their perceptions of their disease progression; and their beliefs of the outcomes, prior to and following diagnosis of dementia. The findings in this study provide some insight into the experience of living with dementia for this group of participants. In providing personalised care, and through the process of ongoing care planning, the findings in this study are useful to practitioners in providing every person diagnosed with dementia with '*meaningful care*' following their diagnosis (NHS England, 2017b). This study provides a basis for service development for providing '*meaningful*' person-centred care and support, delivered through person-centered care planning for the

individuals of Black ethnicity, with consideration of personal histories and different cultural contexts. This is a study that is based on the real-life experiences of individuals who are living with dementia. This study through its exploration of meanings, explores the experiences of the participants, interpreting those meanings to develop an understanding of their overall experience. This study can inform practice from a qualitative perspective. It also gives an insight into the feelings and beliefs that matter to individuals who have accessed services at a later stage, despite the progression of their symptoms. This insight can assist policy developers and service redesign for future care provision, with an opportunity to co-produce services.

6.6 Dissemination of findings

It is planned that findings from this study will be submitted for publication in relevant professional and peer-reviewed Journals. Knowledge from the study has already been disseminated at conferences, as below:

- XX Foundation Trust – Guest speaker Research Conference 2014
- Presentation: '*The Lived Experience of Dementia within Individuals of Black ethnicity: the methodological challenges*'- Royal College of Nursing International Research Conference- Nottingham 2015
- Poster presentation-30th International Conference of Alzheimer's Disease Perth Australia 2015
- Poster Presentation - Alzheimer's Association International Conference-17 July 2017

6.7 Summary of thesis

This thesis offered a perspective of how some individuals of Black ethnicity experience living with dementia. My curiosity concerning this patient group had developed through my clinical and personal experience along with the realisation that there was a paucity of published literature. I formulated the research question to gain an understanding of their lived experiences, as described in Chapter One. A review of the literature subsequently undertaken was reported in Chapter Two. This exercise highlighted a limited number of papers relevant to the lived experience of dementia as an individual of Black ethnicity. Chapter Three describes the Method and Methodology adopted in this study. Heidegger's (1927) phenomenological approach influenced the design and implementation of the study. The participants in this study were recruited purposively for their appropriateness to the inquiry and their willingness to share their experience, using the criteria as described in Chapter Three.

This study recruited six participants and interviewed them, seeking to answer: *‘What is the lived experience of dementia as an individual of Black ethnicity?’*. The analysis of the findings in Chapter Four explained my interpretation of their lived experiences presented by three overarching themes:

- Life before Dementia
- Journey to Diagnosis
- Living with Dementia

The themes were portrayed in text using quotes from the participants. The interlinking theme *‘God and Religion’* was noted to be significant in all three overarching themes and as such was individually presented. In the Discussion Chapter, Chapter Five, the Findings were discussed in relation to the reviewed literature. It was evident that there is a clear need for commissioners and practitioners to consider the complexities that people living with dementia of Black ethnicity experience, and to ensure that services are co-produced with them. This study has contributed to the body of knowledge by further endorsing what was already known about living with dementia within ethnic minority groups generally, but with a focus specifically on Black ethnicity groups. As generalisation of the findings was not the intention, this work also offers a different interpretation of this phenomenon, using qualitative interviews to explore the experience of dementia of a defined population; that is individuals of Black ethnic minority who have migrated to the UK as adults.

6.8 Chapter conclusions

In conclusion, I reflect on my research journey. As I studied the lived experience of the participants; completing the thesis was accompanied by challenges and personal satisfaction. My aim was to share the truth; as I understood it. I had a story to tell. At this point, I cannot help but return my thoughts to Gilroy’s (1994) sentiment which has struck a resonance with me as I face my own reality of growing old in Britain:

“Some white old people face old age with resentment. They are however part of the dominant tribe, and when push turns to shove they will assuredly be taken care of against all corners...And when the years pass and everyone else has succumbed to mindless change.... we shall be the same. Black” (Gilroy 1994 p.129/134).

This study aimed to inform professionals regarding the lived experience of dementia from a Black person’s perspective, not born in the UK but migrated as adults. It is hoped that the findings of this study will influence service provision to improve the care that is provided to not

only individuals of Black ethnicity living with dementia, but myself as I age in the UK. Finally, I would also like to think that this work contributes to the growing body of literature that represents a generation of female migrant Black African Nurse Researchers to which I belong, immersed in a song of a new leaf - telling our stories.

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APPENDICES

Appendix 01: Example application of CASP tool

	Adams 2001 Awareness of understanding of dementia	Pridemore 2003 Awareness of understanding of dementia
1) What is the aim of the research?	Aims: Objective was to explore awareness, recognition and understanding of dementia in South Asian African Caribbean (SAC) communities. Little attention has been paid to understanding South Asian female by African / Caribbean and South Asian female by African / Caribbean for the provision and ability to cope with dementia.	Aims: To examine the views and experiences of dementia among South Asian older people. Research on service provision is limited.
2) Is a qualitative methodology appropriate?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.
3) Was the research design appropriate for the aim?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.
4) Was the recruitment strategy appropriate?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.
5) Was data collected in a way that addressed the research question?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.
6) Was the data analysis appropriate?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.
7) Was the research ethical?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.
8) Was the research valid?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.
9) Was the research reliable?	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 30 cases of people with dementia South Asian / African / Caribbean. 18 African / Caribbean, 12 South Asian. 10 1st generation, 20 2nd generation, 10 3rd generation. 20 < 40 years, 10 > 40 years. M = 6, F = 24.	Yes - aim was to explore the experience of dementia in the community. Has researcher used appropriate sampling and appropriate sampling not over-represented? Also used snowballing sampling and appropriate sampling not over-represented? How were participants selected? 11 professionals, 4 case studies (3F, 1M). Small study - limitation. From GPs, BME health projects, voluntary providers.

Appendix 02: NHS Research and Development Access Letter



Date: 17/04/14

Dear Tiritega Mawaka,

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with the [redacted] NHS Foundation Trust. We are satisfied that such checks as are necessary have been carried out by your employer. This letter confirms your right of access to conduct research through the [redacted] NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 17/04/14 and ends on 31/10/14 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct activities associated with such projects as you have received authorisation confirmed in writing from the Research and Development Director of the [redacted] NHS Foundation Trust. Please note that you cannot start the research until the Chief Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to the [redacted] NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this Trust, in particular that of an employee.

While undertaking research through the [redacted] NHS Foundation Trust, you will remain accountable to your employer [redacted] Clinical Commissioning Group but you are required to follow the reasonable instructions of your nominated manager [redacted] in this Trust or those given on his behalf in relation to the terms of this right of access.

You must act in accordance with the [redacted] NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer [redacted] Clinical Commissioning Group is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

You are required to co-operate with the [redacted] NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other

health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998.

Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

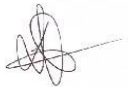
The [REDACTED] NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the [REDACTED] NHS Foundation Trust in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Please also ensure that while on the premises you wear your NHS ID badge at all times, or are able to prove your identity if challenged. Please note that this Trust accepts no responsibility for damage to or loss of personal property.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your employer through its normal procedures. You must also inform the Research and Development Department and your nominated manager in [REDACTED] NHS Foundation Trust.

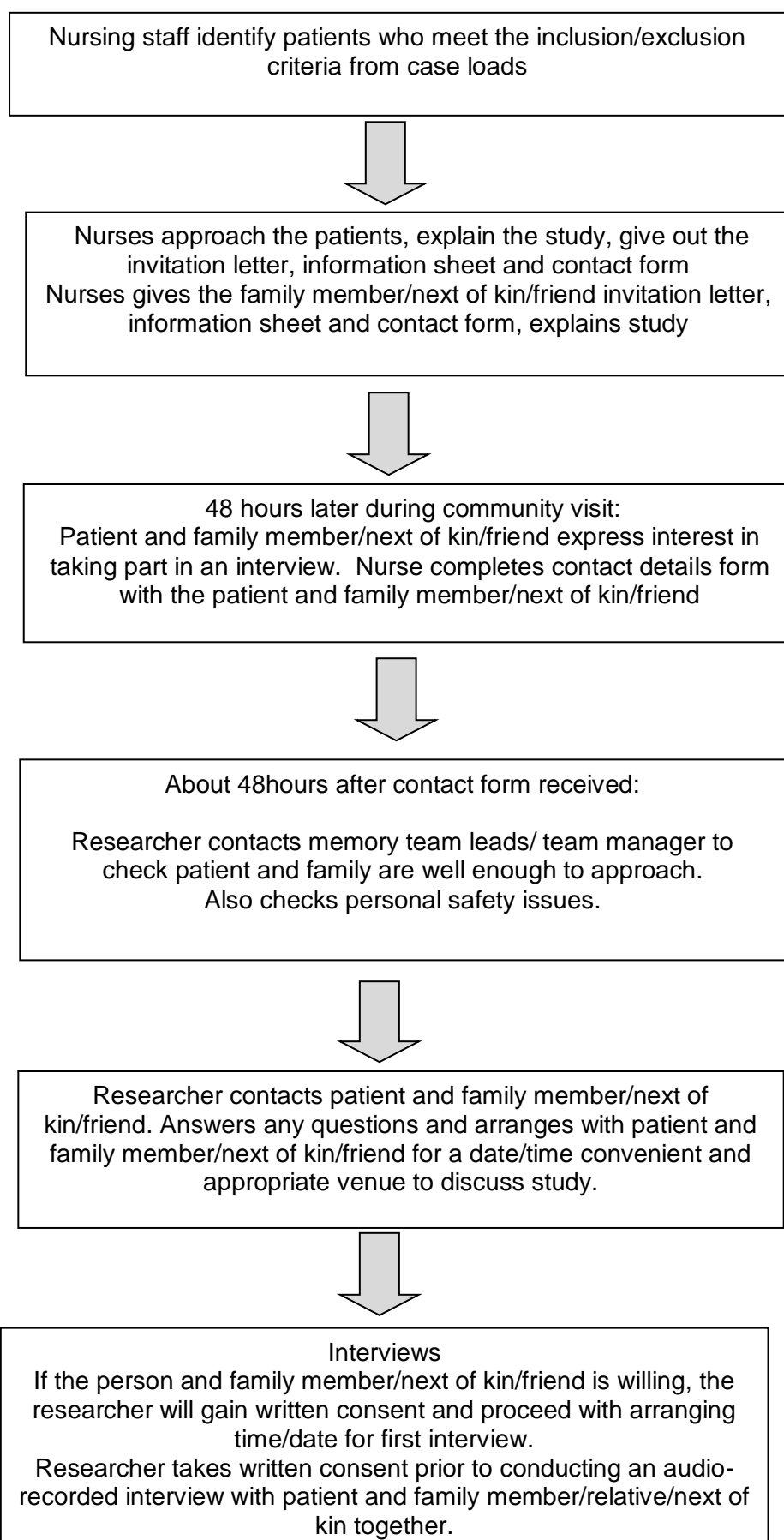
Yours sincerely



[REDACTED]

[REDACTED] London NHS Foundation Trust

Appendix 03: Recruitment and consent example process for patients and consultees who are under the care of the Collaborative Care Team and Community Treatment Team



Appendix 04: NHS Research Authority Ethical Approval Letter


Health Research Authority
NRES Committee London - Queen Square
HRA Head Office
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 7972 2584
Facsimile: 020 7972 2592

30 July 2013

Miss Tiritega Perfect Mawaka
[Redacted]

Dear Miss Mawaka

Study title: Exploring the lived experience of the individual of black ethnicity living with dementia: A phenomenological study

REC reference: 13/LO/0994
IRAS project ID: 122167

The Research Ethics Committee reviewed the above application at the meeting held on 18 July 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator [Redacted] NRESCommittee.London-QueenSquare@nhs.net.

Ethical opinion

The Committee reviewed the above study.

In discussion, the Committee noted the following ethical issues:

- The Committee noted this is a student study for a PhD qualification. This is a qualitative study using semi structured interviews. The aim of the study is to understand the lived experience of black people living with dementia and the impact of the disease on their daily lives. The Researcher will recruit 10 participants to the study.

The Chief Investigator and Student on the project, Miss Tiritega Perfect Mawaka and Prof [REDACTED], Academic Supervisor, attended the review of the application.

The Chair introduced the Observers and advised the Researchers of the procedure regarding the Observer's responsibility to maintain the confidentiality of the meeting. The Chair also advised the Researchers that the Observer would leave the meeting if they wished. The Researchers agreed for the Observers to remain in the meeting.

Discussion took place as follows:

- The applicant gave an overview of the study. She confirmed the interviews will be audio taped and will be transcribed by the IPA service. The applicant informed the Committee that the tapes will be destroyed in line with the data protection act and that all data will be anonymised. The applicant went on to say that if a participant loses capacity or deteriorates, the friend / relative will be asked if the data can be used.
- The applicant confirmed the initial approach will be completed by a member of the participant's clinical team and that person will say whether the person is appropriate to join the study. The applicant stated she will only approach people who have been assessed as having capacity.
- The applicant confirmed she intends to take consent at each interview. The Chair informed the Researcher that there was no reason for her to re-consent as consent is only required once. The Chair asked the Researcher to confirm how consent will be taken in light of this.
- When asked about her experience, the applicant informed the Committee that she has a Masters Degree and has clinical experience as a Nurse.
- The Committee asked the applicant what procedure was in place to deal with participants who become distressed. The Researcher explained the procedure and the Committee asked that this information be added to the Information Sheet.
- The Committee recommend to the applicant to complete the training on how to identify capacity.
- The applicant confirmed the mobile number listed in the application is a work number.
- The applicant confirmed that black people referred to in the application specifically referred to people from African, Caribbean and Other black people as defined by them. The Researcher went on to say the majority of this group will generally speak English.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

- The Committee notes that the initial approach will be made by a member of the participant's clinical team and an Information Sheet will be given at that time.
- The Committee notes there will be three sets of interviews lasting between 30 – 40 minutes.
- The Committee notes that the interviews will be recorded and that a friend or relative can be present. In addition, the Committee noted that IPA will analyse the data. The Committee seeks further information on how the data will be stored and disposed of.
- The Committee notes a mobile number is listed in the application and seeks clarity as to whether this is a personal or work number.
- The Committee noted that if a participant loses capacity, their data will be used.
- The Committee noted that there will be a separate consent for the relative / friend.
- The Committee notes the consent times varies from 48 hours to one week and seeks clarification on this.
- The Committee stated the application was unclear as to whether adults lacking capacity will be included in the study.
- The Committee notes that recruitment will be from various NHS sites, memory clinics, community hospital inpatient wards, older persons day centres, collaborative care teams and community treatment teams.
- The Committee seeks clarity on the student's level of experience in dealing with this group of people.
- The Committee notes the applicant will take consent at each interview and believes this is unnecessary.
- The Committee notes there will be no payments made to participants.
- The Community notes that non English speakers will be excluded from the study.
- The Committee notes that the participant's GP will not be informed.
- The Committee notes from the application that the interviews may cause some distress, but notes the applicant has systems in place to support the participant should there be any distress.
- The Committee notes the applicant may visit participants' home to complete the interviews and seeks clarity on the Researcher's method for managing this risk.
- The Committee notes the indemnity expires on 31 July 2013.
- The Committee notes that the risk benefit ratio seems favourable.

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

The Committee discussed the Researcher's responses further and felt that a Favourable Opinion with Conditions should be given to the study on receipt of the following information been received by the Committee:

- i. The Chair informed the Researcher that there was no reason for her to re-consent as consent is only required once. The Chair asked the Researcher to confirm how consent will be taken in light of this.
- ii. The Committee asks to applicant to confirm what procedure is in place to deal with participants who become distress.
- iii. The Committee seeks clarification on who will be assessing the capacity of the patient with regards to the MCA, and will this be done at every new interaction?

Decision: Favourable Opinion with Conditions

The Committee concluded that a Favourable Opinion with Conditions be given to the study, subject to receipt of further information/clarification set out above.

The REC nominated the Co-ordinator to be the point of contact should further clarification be sought from the application upon receipt of the decision letter.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought

from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		10 June 2013
Evidence of insurance or indemnity		27 June 2012
Interview Schedules/Topic Guides	5	10 June 2013
Letter from Sponsor		25 March 2013
Letter of invitation to participant	6	10 June 2013
Other: CV: Tiritega Perfect Mawaka		
Other: CV: [REDACTED]		
Other: CV: [REDACTED]		
Other: Participant Contact Sheet	4	10 June 2013
Other: Letter to Consultee	5	10 June 2013
Other: Peer Review: Dr [REDACTED]		
Participant Consent Form	6	10 June 2013
Participant Consent Form: Relative/Friends	7	10 June 2013
Participant Information Sheet	10	10 June 2013
Participant Information Sheet: Relative/Friends	9	10 June 2013
Protocol	6	10 June 2013
REC application	122167/4627 33/1/67	10 June 2013
Summary/Synopsis	3	10 June 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/0994

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Pp

Chair

Email: NRESCommittee.London-QueenSquare@nhs.net


Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers" [SL-AR2]

Copy to:

Professor [redacted] NHS Foundation Trust

Appendix 05: NHS Research and Development Approval Letter

[REDACTED] 
NHS Foundation Trust
Research and Development Office
[REDACTED]

Date: 30th August 2013

Dear Miss Tiritega Mawaka,

Re: R&D ref no 2338 – Exploring the lived experience of the individual of black ethnicity living with dementia: A phenomenological study

I am pleased to inform you that the above named study has been granted approval and indemnity by Professor [REDACTED] Director of Research and Development [REDACTED] NHS Foundation Trust. You must act in accordance with the [REDACTED] NHS Foundation Trust's policies and procedures, which are available to you upon request, and the Research Governance Framework. Should any untoward events occur, it is **essential** that you contact your Trust supervisor and the Research and Development Office immediately. If patients or staff are involved in an incident, you should also contact the Governance and Assurance department, in [REDACTED] and complete the Incident and Reporting Form, namely the IR1 form.

You must inform the Research and Development Office if your project is amended and you need to re-submit it to the ethics committee or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records.

You are also required to inform the Research and Development Office of any changes to the research team membership, or any changes in the circumstances of investigators that may have an impact on their suitability to conduct research.

Yours sincerely,



[REDACTED]
[REDACTED] London NHS Foundation Trust

2338 R&D Approval letter – Exploring the lived experience of the individual of black ethnicity living with dementia: A phenomenological study

1 of 2

Appendix 06: NHS Research Authority Ethical Approval Response Letter

Inpatient Services

XX XX Hospital

XX XX

XX XX

XX XX

XXXX XXX

Telephone: XXXXXXXXXXXX

Email: XXXXXX.XXXXXX@nhs.net

5 August 2013

Dr XX XX

Chair

NRES Committee London - Queen Square

HRA Head Office

Skipton House

80 London Road

London

SE1 6LH

Telephone: 020 7972 2584

Facsimile: 020 7972 2592

Dear Sir

Study title: Exploring the lived experience of the individual of
Black ethnicity living with dementia:
A phenomenological study

REC reference: 13/LO/0994

IRAS project ID: 122167

Thank you for your response regarding the above-mentioned study. I note that a Favourable Opinion with Conditions was given to the study and that further information was requested. In relation to the requested information, I can confirm the following:

- i. The Chair informed the Researcher that there was no reason for her to re-consent as consent is only required once. The Chair asked the Researcher to confirm how consent will be taken in light of this. - As advised by the committee the study protocol (version7, page13 -14) has been amended and written consent will only be obtained once. The researcher will discuss the study and go through the information sheet with both the participant and relative/friend and will answer any questions they may have. If the participant decides to take part in the study the researcher will ask the participant to sign the consent form to record that he/she has agreed to take part. This will take place before the first interview. With regards to the relative/friend, if the relative/friend advises that the participant would be willing and able to take part, the researcher will then ask the relative/friend to sign a declaration form. This will take place before the first interview. Before each interview starts, the researcher will check whether the participant and their relative/friend has any questions and whether they are comfortable to continue.
- ii. The Committee asks the applicant to confirm what procedure is in place to deal with participants who become distressed - Through experience, the researcher understands that talking about the experience of living with dementia may cause distress; the researcher will offer support and will do her best to ensure that participants are not put under stress. If this should occur, data collection would stop

at once and the researcher would offer reassurance and comfort. The relative/friend will also be present during and after interviews to provide additional support. If appropriate, and with the participant's consent, if the participant becomes distressed the researcher could rearrange to continue the interview for another time. Where necessary, with the participant's consent, additional support can be arranged through referral to other health professionals. This information is included in the participant information sheet (version 11, page 3) and relative/friend information sheet (version 10, page 3)

- iii. The Committee seeks clarification on who will be assessing the capacity of the patient with regards to the MCA, and will this be done at every new interaction? The initial approach to potential study participants will be completed by a member of the participant's clinical team. The nursing and multidisciplinary clinical staff will be provided with the inclusion/exclusion criteria. The staff will be asked to identify individuals of Black ethnicity with a diagnosis of dementia, who have been assessed by the staff to have the capacity to understand the information sheet and who are competent to give informed consent. The researcher will only approach people who have been assessed as having capacity by the clinical team. This is outlined in the study protocol (version 7 pages 10-11). As recommended by the Committee, the researcher has now completed the online training on how to identify capacity and has fully taken into account the XX XX NHS Trust Procedure for Assessment of Mental Capacity (December 2010) and the XX XX NHS Trust Mental Capacity Assessment Form (December 2010).

I have included the following amended documents reflecting the above changes for your consideration:

Document	Version	Date
Participant Information Sheet	11	5 August 2013
Participant Information Sheet: Relative/Friends	10	5 August 2013
Protocol	7	5 August 2013

I hope to hear from you soon.

Yours sincerely

Tiritega Perfect Mawaka
RGN, BSC(Hons) MSC

Appendix 07: NHS Research Authority Ethics Substantial Amendment Letter

XX XX

XX XX

XX XX

XXXX XXX

Telephone: XXXXXXXXXXXX

Email: XXXXXX.XXXXXXX@nhs.net

16 July 2014

Dr XX XX
Chair
NRES Committee London - Queen Square
HRA Head Office
Skipton House
80 London Road
London
SE1 6LH
Telephone: 020 7972 2584
Facsimile: 020 7972 2592

Dear Sir

Study title:	Exploring the lived experience of the individual of Black ethnicity living with dementia: A phenomenological study
REC reference:	13/LO/0994
IRAS project ID:	122167

With regards to the above-mentioned study please see attached the substantial amendment form and revised documents for your consideration.

Despite my efforts, I have had serious difficulties in recruiting participants and I would like to widen out the recruitment process to include the local branches of Alzheimer's Society who support clients of Black ethnicity living with dementia and may not necessarily be active patients on the NHS trust caseloads. There is no change to the recruitment inclusion/exclusion criteria, the information sheets and consent forms.

I hope to hear from you soon.

Yours sincerely

Tiritega Perfect Mawaka
RGN, BSC(Hons) MSC

Appendix 08: NHS Research Authority Ethics Substantial Amendment Response



National Research Ethics Service

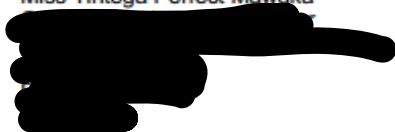
NRES Committee London - Queen Square

HRA NRES Centre Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7821
Fax: 0161 625 7299

13 August 2014

Miss Tiritega Perfect Mawaka



Dear Miss Mawaka

Study title:	Exploring the lived experience of the individual of black ethnicity living with dementia: A phenomenological study
REC reference:	13/LO/0994
Amendment number:	One
Amendment date:	16 July 2014
IRAS project ID:	122167

The Substantial Amendment proposed:

1. To widen the recruitment process to include the local branches of Alzheimer's Society who support clients of the Black ethnicity living with dementia and may not necessarily be active patients on the NHS Trust caseloads and include a revised Protocol to reflect this
2. To include a letter of access to continue participant recruitment.

The above amendment was reviewed on 12 August 2014 by the Sub-Committee in correspondence.

Ethical opinion

No ethical issues were raised.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

A Research Ethics Committee established by the Health Research Authority

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper		16 July 2014
Notice of Substantial Amendment (non-CTIMP)	One	16 July 2014
Other [Consultee Information Sheet]	11.0	01 July 2014
Other [Consultee Declaration Form]	8.0	01 July 2014
Other [Participant Contact Form]	5.0	01 July 2014
Participant consent form	7.0	01 July 2014
Participant information sheet (PIS)	12.0	01 July 2014
Research protocol or project proposal [Research Protocol]	8.0	01 July 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/LO/0994:	Please quote this number on all correspondence
--------------------	---

Yours sincerely



Signed on behalf of:

Chair

E-mail: nrescommittee.london-queenssquare@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: [Redacted] NHS Foundation Trust

Professor [Redacted]

Appendix 09: Interview Topic Guide

The participant will be asked an open question with prompts. If the participant wishes they may show the researcher any pictures or objects of significance.

First interview: The first interview will be about getting to know the person and their life history as that is important for understanding their experiences of dementia. The initial interview will explore values and personal beliefs, childhood experiences as well as information relating to:

- Age/Gender/Occupational status
- Marital status/ family size
- Geographical movements/Immigration history over the years
- Date of dementia diagnosis and type of dementia

Identity and social location: Tell me about your background

Prompts:

- Birthplace
- Ethnic ancestry
- Cultural traditions
- Growing up
- Immigration
- Relationships, marriages, births, deaths
- Family, friends
- Neighbourhood, community

Second Interview: The second interview will explore the present; that is living with dementia now. The interview will focus on adulthood experiences, the demands and difficulties or opportunities of living with dementia as well as the services and support received.

- Tell me about how the lifestyle you've described change over the years, up to the point you started having problems with your memory?

Prompts:

- Words to describe you as a person
- Lifelike before you started having memory problems
- Everyday life
- Pictures of you
- How do you think others see you?
- What 'walk of life' would you say you come from
- Groups of people do you identify with
- Happiness, joy
- Important things about your life now

Third Interview: Questions to be determined by themes identified in first and second interviews. On completion of each of the first and second interviews, the collected data was reviewed to ensure that the interview process had covered all areas as identified in the topic guide. Any areas that were not fully discussed would be explored in the third interview as well as any other areas the participant wished to discuss.

Appendix 10: Sample notes after interview

Emotional Labour of interview

② social experience
dementia in Jamaica - losing mind, mad
discussed journey to dementia
- 2 different perspectives of
how this comes about
participant - fall
returner - 2 years of symptoms
+/- 3 months of not recognising
husband
think exhaustion cause dementia
how sad despite information from
nurses - crying

church - belief in God
healing power of prayer
experiences of friends
participant personal experience of
healing

unable to separate facts scientific /
religion/beliefs diff between me and her
independence - important to her
forgot my name but can cook
well
used to bake
read bible

Separation, the saying goodbye
hard ~~hard~~ ~~hard~~ ~~hard~~
and left too late but I had
to be understood

Key Points interview ②

presentation to service - when she did not
know
+/- 2 years 3 months to diagnosis
diagnosis - leads to support services
knowledge, information
late diagnosis leads to /
results in inequalities
renew ~~leaving~~ in relative - can make financial decisions etc
tiredly to their situation

Religion
Church
prayer
healing

part of day to day life
pray, read bible
believe God will
lead
Coping mechanism
called me "child of God"

culture
different culture
culture shock on arrival

Exposure dementia
versus with Caribbean origin
immigration history → Jamaica
no dementia
kept as secret
'madness'
'lost mind'

Appendix 11: Sample Participant 3rd-Interview transcript

...I remember last week you said that sometimes you have ups and downs, but you still have to carry on, you get up and you get going. Do you remember that?

Yes, I am tired for a while but if you want to go home I got to my aunty. That is me, I don't know. I spend some days or weeks at my auntie and then I can go back home any time you are ready. You are not staying too long with them.

How does it make you feel if you have been feeling a bit low, but you manage to get up and get going and you do your little bits and pieces?

I do my bits and pieces. In some houses, you have to go for water, but we had to get a bucket of water that we can use it. We get along good. If I want to leave this family and go and cry ... I manage somehow..with help.

Okay, last time we spoke about growing up back home...Can you tell me a bit about your mother, please?

Oh dear.

How was she?

Mum was kind but she was quick to beat us if you understand. She's okay, it's only just a few years ago that mum died.

She died when she was 90 something. A few years ago.

Oh okay. Did she have memory problems at all, was she quite forgetful?

(Consultee) She had dementia

Oh okay, so who was looking after her?

She come over here before. She come over here with her children, she was working all the while.

(Consultee) She lived in XX.

Then she got sick and died.

Was she living at home or in a nursing home?

(Consultee) She was at home for a good number of years then her care changed, and they put her in a home and she died in that home, I think it was the change and the lack of care really.

I have been back to Jamaica, she wanted to settle down in her last days, but she didn't have anything, and she just died.

(Consultee) Mum was in Jamaica when she died.

Okay.

I was in Jamaica. If I could take her room at home with me. She never wait, she just died. What is the name of the hospital?

XX?

And the other one?

XX.

Mum was in hospital at XX

And just a little bit about your dad?

I don't know what to tell you, he come to hospital in Jamaica.

(Consultee) He died a few years before my mum's mum. He also had memory problems. I'm not sure what he died of but I think he had memory problems as well.

Is there anyone else in the family who has had memory problems at all that you know of?

Like me.

(Consultee) I've got memory problems! Nothing diagnosed or anything but one of my uncles had mental health issues but not necessarily memory problems and I don't really know anybody else. Mum is the second oldest I think in the family.

Who is the eldest then?

Mum has a sister.

Does she live here as well?

I have four or five sisters here.

And you are the second eldest and your elder sister, is she well, in good health?

She's all right.

We haven't heard anything to the contrary.

And no memory problems that you are aware of?

I don't think so. Not serious memory problems.

That's really good to know a bit more about your family because we didn't really discuss that much when we first had a chat and I thought it would be good to complete the picture really. Is there anything else you'd want to share with me, this is the last time we'll meet?

Appendix 12: Participant Consent Form

Centre Number:

Study Number:

Participant Identification Number for this study:

Consent Form for Participants

Exploring the Experiences of People of Black Ethnicity Living with Dementia.

Name of Participant:.....

Name of Researcher.....

Please initial box

I confirm that I have read and understand the information sheet dated [to add] (version XX) for the above study. I have had the opportunity to consider the information and ask questions and I have had these answered satisfactorily.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any effect on my care.

☐

I understand that the interview will be recorded on an audio recording device. I give permission for this.

☐

I understand that direct quotations from the interview will be used in the research report, publications and presentations arising from the study. I understand that the quotations will be anonymous with no person, workplace or NHS Trust identifiable.

☐

I understand that data collected during the study may be looked at by individuals from involved organisations, for the purposes of monitoring and auditing the conduct of the research. I give permission for these individuals to access the data.

☐

I agree to take part in the above study.

☐

Name of participant:

Date:

Signature:

Name of researcher:

Date:

Signature:

When completed: 1 copy for participant, 1 copy for researcher

Appendix 13: Friend/Relative Declaration Form

Centre Number:

Study

Number:

Participant Identification Number for this study:

Relative/Friend Declaration Form

Exploring the Experiences of People of Black Ethnicity Living with Dementia.

Name of

Relative/Friend:.....

Name of Researcher.....

Please initial box

I [name of relative/friend] have been consulted about [name of potential participant's participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.

☐

In my opinion, he/she would have no objection to taking part in the above study.

☐

I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected.

☐

I agree to their GP or other care professional being informed of their participation in the study

☐

Name of Relative/Friend:

Date:

Signature:

Relationship to participant:

Name of researcher:

Date:

Signature:

When completed: 1 copy for Relative/Friend; 1 copy for researcher site file

Appendix 14: Participant Interview Record

Name	Date and time of interview	Gender	Present at interview	Venue of interview	Interview length in minutes
Alice	1 st interview 11/11/2013	Female	Consultee and participant	Participant house	27mins:36s
	2 nd interview 13/11/2013		Consultee and participant	Participant house	18mins:53s
	3 rd interview 25/11/2013		Consultee and participant	Participant house	29mins:31s
Beverley	1 st interview 22/04/2014	Female	Consultee and participant	Participant house	13mins:01s
	2 nd interview 06/05/2014		Consultee and participant	Participant house	19mins:57s & 7mins:24s
	3 rd interview 13/05/2014		Consultee and participant	Participant house	20mins:57s
Catherine	1 st interview 10 April 2015(rearranged to 24 April 2015)	Female	Consultee and participant	Participant house	Non-applicable- declined to be recorded
	2 nd interview		Declined to continue with the interview process	Non-applicable	Non-applicable
	3 rd interview		Declined to continue with the interview process	Non-applicable	Non-applicable
Destiny	1 st interview 11 December 2015	Female	Consultee and participant	Participant house	34mins:00s
	2 nd interview 17 December 2015		Consultee and participant	Participant house	58mins.30s
	3 rd interview 21 December 2015		Consultee and participant	Participant house	13mins:46s
Edward	1 st interview 12 April 2016	Male	Consultee and participant	Participant house	30mins:00s
	2 nd interview 19 April 2016		Consultee and participant	Participant house	42mins.01s
	3 rd interview 22 April 2016		Consultee and participant	Participant house	10mins.20s

Francis	1 st interview 19 August 2016	Male	Consultee and participant	Participant house	23mins:32s
	2 nd interview 28 September 2016		Consultee and participant	Participant house	20mins:15s
	3 rd interview 14 October 2016		Consultee and participant	Participant house	23mins: 51s

Appendix 15: Sample Transcript

Interviewer

Female Respondent

Male Respondent

So, thank you again for meeting with me today. Today we're going to look at a few things we touched on before. So, feel free to say what you want to say and if you feel you don't really want to talk about that ...

There is nothing to worry about because it's just an illness. You come to recognise it as an illness, you cope with it, simple as that.

Last time we touched upon back home in Jamaica, I was asking about dementia, had you ever heard of dementia?

No. We never hear about dementia, we never hear about prostate, we never hear about cancer. Never hear about none of those things. Just for the last few years these just zoom. Never hear about those.

So, in your community at home, there were old people, weren't they?

Yes.

Did they not have dementia?

No, they were old, then they were dead!

When they're old they just die, we never hear about dementia.

That's what I'm saying, this problem just popped up. Genetic food! No, seriously we never hear.

I hear about cancer and also, I know about cancer.

Now that you're living here, do you know any people in Jamaica with dementia?

No.

No.

When we went back, they wouldn't have really seen it as dementia. We saw them with thyroid problem and things like that.

Do you think there is no dementia in Jamaica then?

I think it's there, but they don't recognise it.

They recognise it, but I don't think it's ...

I don't think they recognise it, XX

Yes, they know but I don't think people ...

Appendix 16: University Ethics Application Letter

Inpatient Services

XX XX Hospital

XX XX

XX XX

XX XX

XXXX XXX

Telephone: XXXXXXXXXXXX

Email: XXXXXX.XXXXXX@nhs.net

19 August 2013

Professor XX XX
University Research Ethics Committee
London South Bank University
106 Borough Road
London
SE1 0AA

Dear Sir/Madam

Study: Exploring the lived experience of the individual of Black ethnicity living with dementia:
A phenomenological study

With regards to the study mentioned above, please see the enclosed NHS Research Ethics Committee approval letters for your consideration. I look forward to hearing from you.

Yours sincerely

Tiritega Perfect Mawaka
LSBU Student Number:XXXXXXX

Appendix 17: University Ethics Response Email

From: Governance: Administration of Research Ethics Committee <ethics@lsbu.ac.uk>

Sent: 21 August 2013 16:55

To: Mawaka, Tiritega

Cc: XXXXX, XXXX; XXXX, XXXXXX

Subject: RE: University Research Ethic Committee application: Exploring the lived experience of the individual of Black ethnicity living with dementia: A phenomenological study (UREC 1344)

Dear Tiritega,

Thank you for submitting all of the documents for the NHS approved study entitled: Exploring the lived experience of the individual of Black ethnicity living with dementia: A phenomenological study. NHS REC Reference: 13/LO/0994 (UREC number 1344).

I can uphold the decisions of the NRES Committee London - Queens Square REC for approval of the study, subject to a few very minor corrections:

1. Please ensure that the LSBU UREC number and the study title appear on all pages of the participant/consultee information sheets and other relevant documents that will be sent out.
2. Please add the contact email for the University Research Ethics Committee: ethics@lsbu.ac.uk on the participant/consultee information sheets in the section entitled 'Who do I approach if I wish to complain about the study?'

Please send in the updated documents and let us know if you require a formal letter of approval in addition to this email.

I wish you well in an interesting research study.

Regards

XXXXX

Professor XXX XXXXX

University Research Ethics Committee

London South Bank University

106 Borough Road

LONDON SE1 0AA

Appendix 18: University Ethics Response Letter

Inpatient Services
XX XX Hospital
XX XX
XX XX
XX XX
XXXX XXX
Telephone: XXXXXXXXXXXX
Email: XXXXXX.XXXXXX@nhs.net
22 August 2013

Professor XX XX
University Research Ethics Committee
London South Bank University
106 Borough Road
London
SE1 0AA

Email: ethics@lsbu.ac.uk

Dear Madam

Study title: Exploring the lived experience of the individual of Black ethnicity living with dementia: A phenomenological study
REC reference: 13/LO/0994
UREC number: 1344

Thank you for your response regarding the above-mentioned study. I note that you are able to uphold the Favourable opinion of the NHS Research Ethics Committee London - Queens Square and that minor changes to the study documents are requested. I am able to confirm the following:

1. The LSBU UREC number and the study title appear on all pages of the participant/consultee information sheets, consent forms and participant invitation letters.
2. The contact email for the University Research Ethics Committee: ethics@lsbu.ac.uk has been added on the participant/consultee information sheets in the section entitled 'Who do I approach if I wish to complain about the study?'

I have enclosed the amended documents reflecting the above changes for your consideration. Kindly forward a formal letter confirming your favourable opinion. I hope to hear from you soon.

Yours sincerely

Tiritega Perfect Mawaka
Student Number:XXXXXXX

Appendix 19: University Ethics Approval Letter

London South Bank
University

Direct line: 020-7815 6025
E-mail: [REDACTED]@lsbu.ac.uk
Ref: UREC 1344

Tiritega Mawaka
[REDACTED]
[REDACTED]
[REDACTED]

Friday, August 23, 2013

Dear Tiritega,

Re: Exploring the lived experience of the individual of black ethnicity living with dementia: A phenomenological study

Thank you for submitting this proposal and for your response to the reviewers' comments.

I am pleased to inform you that Full Chair's Approval has been given by Chair on behalf of the University Research Ethics Committee.

I wish you every success with your research.

Yours sincerely,

W Mitchell

[REDACTED]

Secretary, LSBU Research Ethics Committee

cc:

[REDACTED]

Chair, LSBU Research Ethics Committee

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Appendix 20: Relative/Friend Information Sheet

Information for Relatives/Friends **Exploring the Experiences of People of Black Ethnicity Living with Dementia.**

Introduction

The purpose of the project is to explore the lived experiences of people of Black ethnicity living with dementia. We want to explore their day to day reality and how they make sense of this and how they feel about living with dementia. We would like to invite your relative/friend to take part in our research study. We feel your relative/friend maybe unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we would like to ask your opinion about whether they would want to be involved. We are asking you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take priority.

If you decide that your relative/friend would be willing to take part we will ask you to read, this information sheet and discuss the study with the researcher. If you decide that your relative or friend would be happy to take part in the study, we will ask you to sign the declaration form enclosed. We will then give you a copy to keep. During the study, you are invited to be present at all interviews to support your relative/friend during and after the interviews. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should withdraw from the study. If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking this role, you may seek independent advice. We will understand if you do not want to take on this responsibility. The following information is the same as would have been provided to your relative/friend.

Exploring the Experiences of People of Black Ethnicity Living with Dementia.

We would like to invite your friend/relative to take part in our research study. Before you advise us, we would like you to understand why the research is being done and what it would involve for your friend/relative. Please read the following information and feel free to discuss it with others. The researcher will go through the information sheet with you and answer any questions you have. The researcher's contact details are at the bottom of this information sheet. Please do not hesitate to make contact with any enquiries you may have.

What is the research about?

The purpose of the project is to explore the experiences of people of Black ethnicity living with dementia. We want to explore their day to day reality and how they make sense of this and how they feel about living with dementia.

Why is the research being undertaken?

There hasn't been a lot of research looking at the lives of Black people who have dementia and this is what we aim to do

Why has your friend/relative been chosen?

We are particularly interested in talking with people with a diagnosis of dementia and of Black ethnicity. Your friend/relative has been chosen because they have been identified as an individual of Black ethnicity living with dementia and we would like to hear about their views and experiences.

Do they have to take part?

Their participation in the study is entirely voluntary. We are asking for your view about whether you feel your friend/relative would be willing and able to take part. We will describe the study and go through this information sheet. Their care will not be affected if you advise that they should not take part in the study. If you advise that they would be willing and able to take part, we will then ask you to sign a declaration form. You are free to advise the researcher of their withdrawal from the study at any time, without giving a reason.

What will happen if they take part?

If you advise that your friend/relative may be interested in taking part, the researcher will contact you and ask if you have any questions about the research. If you advise that your friend/relative is willing to participate the researcher will arrange a time that is convenient for both of you and visit at the place and time you have requested; that is most comfortable to you both. The researcher will be wearing an identity badge. The researcher will then discuss the purpose of the study and go through the information sheet.

If you and your relative/friend decide that your relative / friend would be happy to take part in the study, we will ask you to sign the declaration form enclosed. We will then give you a copy to keep. There will be 3 interviews. The interviews will last approximately 30 minutes to 40 minutes and will be held on dates and times that are suitable for you both. During the study, you are invited to be present at all interviews to support you during and after the interviews.

During the interviews, the researcher will ask your relative/friend questions about their thoughts and feelings about living with dementia. The first interview will be about getting to know your relative/friend, their life history as this is important for us to understand their experience of dementia. The second interview will ask your relative/friend about their life now. For example, we may ask your relative/friend if services and the care received met their needs. Is there anything about the care received that was inappropriate or that your relative/friend did not like? The third interview will explore issues or things that we talked about in the first two interviews. We are interested in hearing your views and experiences and you only need to answer questions if you want to.

If your relative/friend agrees, the researcher would like to record the interview, so she has an accurate record. Your relative/friend can ask for the recorder to be switched off at any time. Your relative/friend need only answer the questions he/she want to, and your relative/friend can ask for the interview to stop at any point. If your relative/friend decides not to take part, that is fine, and the researcher will stop the interview immediately.

What will happen to the audio-recording of the interview?

After the interview, the recording will be written out by a professional transcribing service. The researcher will transfer the recording to a protected computer which can only be accessed by the transcriber. The recording will then be deleted from the recorder. The transcriber will not include any information which could identify you or your relative/friend. The transcriber will send the written-out interview to the researcher who will keep it securely on a password-protected computer. When the analysis is completed, and the research report is written, the interview will be deleted.

What are the potential benefits or advantages of taking part?

It is unlikely that your friend/relative will gain any personal benefit from taking part in the research although they may find it helpful to talk about their experience of living with dementia. The information they share will be very valuable as the findings will help improve services for people of Black ethnicity living with dementia in the future. We hope that this will lead to better experiences for patients and families.

Are there any risks or disadvantages of taking part?

There are no risks or disadvantages, but the interviews will take up some of your time (about 30-40 minutes each interview). You are invited to be present during interviews and after the interview for support. If talking about the experience of living with dementia causes your friend/relative any distress the researcher will offer support. We understand that sometimes experiencing memory problems can be distressing or frustrating. We will do our best to ensure that your friend/relative is not put under stress. If this should occur, we would stop at once and offer reassurance and comfort. If appropriate, and with your relative/friend consent, we could re-arrange for another time to continue the interview. Where necessary, with your relative/friend consent, we can arrange for additional support by referral to other health professionals.

Can he/she withdraw from the study?

Your friend/relative can decide to withdraw from the study at any time without giving a reason. If your relative/friend were unable to continue with the second or third interview due to illness, we would like to include the information your relative/friend has given us, unless you or your friend/relative inform us that you do not wish it to be used.

Will the information be kept confidential?

Your friend/relative will not be asked to give any personal details during the interview and their contact details will be destroyed after the interview is completed. All information we collect will be kept confidential and will only be read by the research team. The only exception would be if, as a result of the interview, you or your friend/relative ask the researcher to take up with the healthcare provider an aspect of care they felt unhappy about. The researcher will in this Instance only use your friend/relative's name if you have given permission. The report, publications and presentations based on the research will include short quotations from interviews, but these will be used anonymously as being from 'a patient' and will not include any information that could identify you or your family.

Where will the information be kept and who will have access to it?

All the information will be stored in a locked filing cabinet and on password-protected computers. Only the research team will have access to the information. The information will be kept until the study has been completed and the necessary reports have been written.

What will happen to the results of the research?

The study's results will form the researcher's doctoral thesis. A summary of the findings will be shared with you and/or your friend/relative on request. The research results will also be presented at conferences and submitted for publication in journals for healthcare professionals.

Who is funding the study?

The research is being carried out and self-funded by a registered nurse. She is employed by XXXX XXXX XXXX and is studying part-time for a Professional Doctorate with London South Bank University.

Who has approved the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect the interests of people participating in research. This study has been reviewed and given a favourable opinion by XX XX London Research Ethics Committee. The Trust's Research and Development Office has also approved the study.

What do I do now?

If you feel that your friend/relative may be interested in taking part, please advise the nurse on your ward, clinic or department. Please complete the form with your details and put it in the envelope provided. Please give it to the nurse. They will contact the researcher with your friend/relatives' details.

Who can I contact if I have any concerns or questions?

If you have any questions or queries, please feel free to contact me:

Researcher:

Tiritega Mawaka (Telephone: XXXXXXXXX Email: XXXXX.XXXXX@nhs.net)

Research Supervisors:

Professor XXXXX XXXXX(Telephone: XXX XXX XXXX Email: XXXX@XXX.ac.uk)

Professor XXXXX XXXXX(Telephone: XXX XXX XXXX Email: XXXX@XXX.ac.uk)

Who do I approach if I wish to complain about the study?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and have any complaints about the way you have been dealt with during the study or any other concerns, please contact the Academic supervisors for this study mentioned above. Finally, if you wish to complain formally, you can do this by contacting:

Chair of the University Research Ethics Committee
London South Bank University
Research Ethics Committee
Room 1B13 Technopark
103 Borough Road
London
SE1 0AA
Telephone: 0207 815 6024
Email: ethics@lsbu.ac.uk

Thank you very much for reading this information sheet.

Appendix 21: Participant Information Sheet

Participant Information sheet

Exploring the Experiences of People of Black Ethnicity Living with Dementia.

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please read the following information and feel free to discuss it with others. The researcher will go through the information sheet with you and answer any questions you have. All the information we collect during the study will be kept confidential and will only be read by the research team. The researcher's contact details are at the bottom of this information sheet. Please do not hesitate to make contact with any queries you may have.

What is the research about?

The purpose of the project is to explore the experiences of people of Black ethnicity living with dementia. We want to explore the day to day experience of living with dementia and how you make sense of this and how you feel about living with dementia.

Why is the research being undertaken?

There hasn't been a lot of research looking at the lives of Black people who have dementia and this is what we aim to do

Why have I been chosen?

You have been chosen because you have been identified as an individual of Black ethnicity living with dementia and we would like to hear about your views and experiences.

Do I have to take part?

To help you decide we will describe the study and go through the information sheet. It is up to you to decide if you want to take part in this study. Your care will not be affected if you decide not to take part in the study. If you decide to take part in the study, we will ask you to sign a form to record that you have agreed to take part. You are free to leave the study at any time, without giving a reason.

What will happen to me if I take part?

If you are interested in taking part, the researcher will contact you and your relative/friend to ask if you have any questions about the research. If you are willing to take part the researcher will arrange a time that is convenient for you and your relative/friend and visit you at the place and time you have requested; that is most comfortable to you. The researcher will be wearing an identity badge. The researcher will then discuss the purpose of the study and go through the information sheet with you.

If you decide to take part in the study, we will ask you to sign a form to record that you have agreed to take part. There will be 3 interviews. The form to record that you have agreed to take part in the study will be signed at every interview. The interviews will last approximately 30 minutes to 40 minutes and will be held on dates and times that are suitable for you. During the study your relative/friend is invited to be present at all interviews to support you during and after the interviews.

During the interviews, the researcher will ask you questions about your thoughts and feelings about living with dementia. The first interview will be about getting to know you, your life history as this is important for us to understand your experience of dementia. The second interview will ask you about your life now. For example, we may ask you if services and the care received met your needs. Is there anything about the care received that was inappropriate or that you did not like? The third interview will explore issues or things that we talked about in the first two interviews. We are interested in hearing your views and experiences and you only need to answer questions if you want to.

If you agree, the researcher would like to record the interview, so she has an accurate record. She will only record the interview if you agree, and you can ask for the recorder to be switched off at any time. You need only answer the questions you want to, and you can ask for the interview to stop at any point. If you decide not to take part, that is fine, and the researcher will stop the interview immediately.

What will happen to the recording of the interview?

After the interview, the recording will be written out by a professional transcribing service. The researcher will transfer the recording to a protected computer which can only be accessed by the transcriber. The recording will then be deleted from the recorder. The transcriber will not include any information which could identify you or your relative/friend. The transcriber will send the written-out interview to the researcher who will keep it securely on a password-protected computer. When the analysis is completed, and the research report is written, the interview will be deleted.

What are the potential benefits or advantages of taking part?

It is unlikely that you will gain any personal benefit from taking part in the research although you may find it helpful to talk about your experience of living with dementia. The information you share will be very valuable as the findings will help improve services for people of Black ethnicity living with dementia in the future. We hope that this will lead to better experiences for patients and families.

Are there any risks or disadvantages to taking part?

There are no risks or disadvantages, but the interviews will take up some of your time (about 30-40 minutes each interview). If talking about your experience of living with dementia causes you any distress the researcher will offer you support. We understand that sometimes experiencing memory problems can be distressing or frustrating. We will do our best to ensure that you are not put under stress. If this should occur, we would stop at once and offer reassurance and comfort. Your relative/friend will also be present during interviews and after the interview for support. If appropriate, and with your consent, we could re-arrange for another time to continue the interview. Where necessary, with your consent, we can arrange for additional support by referral to other health professionals.

Can I withdraw from the study?

If you decide to take part, you can withdraw from the study at any time without giving a reason. If you were unable to continue with the second or third interview due to illness, we would like to include the information you have given us, unless you or your friend/relative inform us that you do not wish it to be used.

Will the information I give be kept confidential?

You will not be asked to give any personal details during the interview and your contact details will be destroyed after the interviews are completed. All information we collect will be kept confidential and will only be read by the research team. The only exception would be if, as a result of the interview, you ask the researcher to take up with your healthcare provider an aspect of your care you felt unhappy about. The researcher will in this instance only use your name if you have given permission. The report, publications and presentations based on the research will include short quotations from interviews, but these will be used anonymously as being from 'a patient' and will not include any information that could identify you or your family.

Where will the information be kept and who will have access to it?

All the information will be stored in a locked filing cabinet and on password-protected computers. Only the research team will have access to the information. The information will be kept until the study has been completed and the necessary reports have been written.

What will happen to the results of the research?

The study's results will form the researcher's doctoral thesis. A summary of the findings will be shared with you should you request it. The research results will also be presented at conferences and submitted for publication in journals for healthcare professionals.

Who is funding the study?

The research is being carried out and self-funded by a registered nurse. She is employed by XXXXX XXXXX XXXX and is studying part-time for a Professional Doctorate with London South Bank University.

Who has approved the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by XXXXXX London Research Ethics Committee. The Trust's Research and Development Office has also approved the study.

What do I do now?

If you are interested in taking part, please advise the nurse on your ward, clinic or department. Please complete the form with your details and put it in the envelope provided. Please give it to the nurse. They will contact the researcher with your details.

Who can I contact if I have any concerns or questions?

If you have any questions or queries, please feel free to contact me:

Researcher:

Tiritega Perfect Mawaka (Telephone: XXXXXX Email: XXXX.XXXXXX@nhs.net)

Research Supervisors:

Professor XXXX XXXX (Telephone: XXXXXX Email: XXXX@XXXX.ac.uk)

Professor XXXX XXXX (Telephone: XXXXXX Email: XXXXX@lsbu.ac.uk)

Who do I approach if I wish to complain about the study?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and have any complaints about the way you have been dealt with during the study or any other concerns

please contact the Academic supervisors for this study mentioned above. Finally, if you wish to complain formally, you can do this by contacting:

Chair of the University Research Ethics Committee

London South Bank University

Research Ethics Committee

Room 1B13 Technopark

103 Borough Road

London

SE1 0AA

Telephone: 0207 815 6024

Email: ethics@lsbu.ac.uk

Thank you very much for reading this information sheet.

Appendix 22: Consultation Responses Consultation responses from the Alzheimer's Society Research Network

Tiritega Consultation Responses May 2013

1. Participant information sheet

The explanation of what will happen to the recording is too detailed and could lead to confusion of the participant. Simplify and abbreviate.
Too long- attention will dwindle- bullet points?
<p>I think this does contain all the information although it could do with some rewording in places as I think it's longer than it needs to be that may just be my personal preference. I'm happy to go through it and make suggestions but I don't know if you want that much of a response from us. However, this form contains all the important facts that a patient would need.</p> <p>I'm glad there is a separate form for people who are responsible for patients who would not be able to read or understand the form easily this is really good and often overlooked.</p>
There is no clear explanation of who is the required participant- a person with dementia or carer? Sometimes people living with dementia are referred to in the document as 'people living with a diagnosis'- this could be clearer.
<p>(a) Although issues of confidentiality are often referred to later in the text I think it should be placed at the commencement of the whole document so that, right from the start, the participant is aware of the fact they cannot be identified, etc.</p> <p>(b) So far, the text has referred to the interview subject in person, i.e. using the word 'you' e.g. 'if <i>you</i> are willing to take part...'. But at p.2 para 2 the script goes into 3rd person e.g. 'The ... interview will be about getting to know <i>the person</i> and <i>their life history</i> as that is important for understanding <i>their</i> experiences' It would be clearer if the text were all in the same 1st person singular.</p> <p>(c) p.4 Para. headed 'What do I do now' The potential participant is asked to speak to the nurse at the 'ward, clinic or department' and, having completed the form 'give it to the nurse'. From experience, I know that once diagnosed, most people with dementia do not go to the hospital, clinics, etc. but stay at home where they are cared for. Is it the intention of the researcher to only those who are admitted to the hospital, etc?</p>
To make clear that recruitment is not in Community Setting
In paragraph 1 should 'enquiries' read 'queries'?
<p>1 Whilst the info is mainly clear my first impression was there is far too much info. Can it not be condensed into a couple of pages? People with dementia may not be able to absorb all the info. I found parts repetitive. I may be out-of-touch with ethics committee requirements, but I think this could be more succinct.</p> <p>2 "Lived experiences" – what is wrong with just "experiences?"</p> <p>3 "Risks or disadvantages" TO not OF (sorry, the teacher and pedant coming out in me there!)</p>

4 As a psycholinguist, I believe research shows it is not good practice to right justify paragraphs as it disrupts the reading process.

2. Personal Consultee Information Sheet

The sheet is good, but it may be worth also interviewing the consultee about the participant's experience.

Too long- attention will dwindle- bullet points?

This seems clear enough to me

1. A small point but is the person reading the texts a 'participant' as shown in the heading of document 1 or a 'consultee' as given in this document? Or is it intended for the Carer? It's not too clear. Consistency might be important.

2. Might the presence of the carer during the interviews affect the way the participant answers the questions. E.g. if the participant was not happy with a particular aspect of their care, might they be reluctant to say so in the presence of the carer?

For both the person with dementia and the consultee the reference to 'day to day reality' could better be expressed as 'day to day living experience' especially for PwD, insight of reality may not be there and for the consultee in his/her observation on PwD how the patient and the Consultee cope with the daily situation due to reduced abilities of PwD.

There is an implication that a carer can be present at and take some part in the interviews, but I feel it may be better if it were explicit. many carers can feel very protective in these situations and those living with dementia a little vulnerable. Mum was very able to speak for herself but felt happier knowing I was there to prompt when needed or sometimes to add my input which would then help her to form some new directions in her thoughts. She often found it difficult to initiate ideas.

Again, too much info I think.

3. Participant Consent Form

Add the name of consultee to form.

Simple and straightforward

Too much emphasis on the ability of the person with dementia to make rational decisions

(a) The final sentence does not make sense as it stands. It might be better to add in the word 'copy' and 'the', e.g. When completed: 1 copy for the participant, 1 copy for the researcher.

(b) Should not a copy be kept also in the care file?

The text is clear enough to understand, however depending on the severity of person with dementia, the researcher may need to read and explain then help sign the boxes and the

form to alleviate the distress. If the PwD is confused, then s/he may not be included in the study.

Is it necessary for the participant to know which version of the info sheet they are referring to? Surely by this stage, they will see the final version?

4. Consultee Consent Form

Simple and straightforward

At p.2 there's reference to a 'Person undertaking consultation (if different from researcher)'. It is not clear as to who is being referred to here as there's no mention yet of any other person taking part in the consultation.

If the consultee is a family carer/member/significant other/friend of the patient, need to explain the process of the study with its protocol may arise where research ethics is not aware of. Whereas paid carers or clinicians following the guidelines of a research study would not need further explanation.

This seems fine

5. Invitation letter to participant

OK but could be shortened

This looks fine to me

This expects far too much ability of a person with dementia to make decisions.

- (a) 'Dear Sir/Madam' – seems very impersonal. Would it not be more friendly to refer to the addressee by name?
- (b) If the person contacted has questions to ask of the researcher is the address given a full address? It may be that some would prefer to complete the info. at home and send it on to the researcher.
- (c) In the Invitation ... health professionals full tel. nos. are given – could they not also be given to the participant? For some it's much easier to talk on the phone than to write esp. if they have a visual impairment or problems holding a pen, etc.

Heading- say it in embolden text "Invitation letter to Participant" then continue the study.....

At the second paragraph in the penultimate sentence to add "in particular discuss with your GP or Consultant."

The fourth paragraph should mention that "during an interview at any of three sessions planned to carry out, should you become distressed at any session the researcher will stop immediately and would not proceed any further at the current session and any other sessions left.

This seems fine

6. Invitation letter to health professionals

Perhaps the letter could mention what any possible benefits might arise from participating?
Short and sweet- perfect
I wonder whether the person to whom the letter is addressed might know if the participant would be best interviewed without the carer being present? Would they be given the opportunity to say so?
The letter is clear for health professionals. The insertion of 'service provision and general care' needs to explain whether at an institution or in a communal setting? Does this also indicate that the researcher is collecting further data set for types service and care standard at the chosen setting for further statistical analysis addressing these issues?
This seems fine

7. Participant details contact form

Possibly add name of consultee or another person able to arrange visit
Seems good to me
This is fine- simple and basic
I have concerns about the wording here. I may have misunderstood, but it implies that the person approached accepts that they have dementia and is not in denial. Is it only this group of patients which will be approached? If so, then there's quite a large proportion of the people suffering from dementia who will not contribute to the findings.

8. Project summary

It may be of interest to know in what way the experience of an individual of Black ethnicity differs from the general and if there are difficulties due to cultural differences.
"I think it is very interesting. What is 'Black ethnicity' I guess from the references it is people of Afro Caribbean descent. Will only people whose ethnicity originates from Africa be included? I have in the past known people from the Asian community, and from Turkey and Cyprus too, insist that they are Black. I think that whilst the expression 'exploring the lived experiences of the individual of Black ethnicity living with dementia', for those who work in the field is fine but it is likely that a significant number in the general population will be bemused by it.

At one point, you talk of the day to day reality and how they make sense of this and yet you are actually writing to them.

Just need to tidy up the pronouns. (page 2 second paragraph. letter to would-be respondents)

I think 10 and possibly 8 is a very small sample. What do you hope to do with your results? How much validity will there, for your doctoral thesis? Is this a trial run for furthermore detailed research? I would like to know more explicitly the purpose of this research if it more than for a PhD.

I think 5 full sheets is possibly too many for the respondents to ponder and would suggest that the content be condensed. I would question too other terminology e.g. 'professional transcript service', 'doctoral thesis', 'consultee', Will these mean much to the participants? These are not everyday expressions.

There is always tension between what the researcher wants to know and how he/she should express their ideas and how they should formulate their question sand the level of literacy and understanding of those invited to participate in the study. The skill is to get the balance right, I know with only 10 you aim to recruit people able to respond adequately which necessarily means selection. However, you really need a cross-section of respondents and those need to be of a range of intelligence and educational background at the very least. With so few participants I do wonder how you will be able to generalise from this number or are you simply looking for narratives?

Is it right to assume this group is 'marginalised'?

I thought the project summary very useful and clear. I wish you well."

This is good. Is this aimed at only early-stage patients as a lot of patients would not be able to answer these questions?

Easy to understand and concise document, however.

This sets out the parameters of the research well – but shows the need for obtaining meaningful answers from patients already showing the confusions of dementia.

- a) Would ten participants be sufficient? The researcher suggests that for understandable reasons only 7 or 8 might 'complete the course' and this would make the sample even smaller. Would it be prudent therefore to aim at 15?
- b) Not all people with dementia go the Day Centres, A & E, etc. During the sample and selection recruitment process I feel that GP surgeries in the area described should be approached about people listed in their registers who have dementia.
- c) The summary gives detail about the process and describes the methodology. But it does not define what constitutes 'Black ethnicity'. Does it involve people of Afro-Caribbean origins, of African or middle-eastern origin?

It is stated that Recruitment is concentrated for patients living within the outer NE

London (not specifying whether in the community setting or in a clinical setting) which appears to contradict with actual recruitments which are in the clinical settings. The protocol needs to be clear about it.

If the recruitment is in the community there should be an investigation of what PwD's experience on accessing social care, healthcare services from commissioners and service providers and support received from the charity in the area.

A clearer statement of inclusion/exclusion criteria of the study.

It appears to be that the sample size is too small for statistical significance for reliability and validity of the findings and for service providers to discuss in the study paper.

A significant sample size of the present study is desirable unless the proposed one is a pilot study (which is not stated).

Homogeneity of Black community ethnicity would be compromised for concentrating in recruiting in one geographical area of London i.e. excluding other Black community ethnic background groups in wider London area.

It is not clear whether the researcher intends to extrapolate the results of the current study for later further research study(ies) required with different Black ethnic background participants for homogeneity/comparison between different groups/ results to fulfil and complete her PhD thesis.

I really do support the need to understand the experience from the perspective of a minority group member but wonder if there should be some 'control' group members from the same areas of London.

It may be that the experiences lived by the minority groups are sometimes geographical and due to the health care provision rather than their ethnicity. Should there not be some attempt to look at the experiences of non-ethnic people in tandem to rule this out?

- 1 Whilst I understand the time involved in this project, am not sure a sample size of 10 is sufficient. It will be difficult to extrapolate from such a small sample size to the population being targeted for improved care. (Refer to your potential outcomes.)
- 2 On p3, under Recruitment Process, "BY building relationships with staff" would be clearer. Could also add in "raising awareness of dementia (in general)".
- 3 The following paragraph "Appendix 1" is duplicated.
- 4 Appendix 1 appears to be mainly missing at the bottom of page 4.
- 5 The info provided in Appendix 4 does not match what participants have been told in info sheet. They are told, "the researcher will ask you questions about your thoughts and feelings" But there are no such q's in the first interview.

Appendix 23: Sample Annotations

Annotations

- ¹ her perception of dementia that the dementia was caused by the fall
- ² still believes the fall resulted in her dementia coming out more/ developing
- ³ Husband very clear that the fall had nothing to do with her dementia diagnosis
- ⁴ self-perception - participant believes it does
- ⁵ Question to husband- asked to help obtain a true account of events which is useful, however, the contrast between the two is interesting his perception and her self-perception and perhaps understanding of journey to dementia diagnosis different, also time since dementia diagnosis
- ⁶ self-perception of dementia - is this a coping mechanism for her, this is how she understands her world, she was ok- it was not two years I was all right
- ⁷ asserts her view quite strongly- asserting her independence, her self-perceptions- she tells the research-LISTEN TO ME, I'm the one that have it. She describes her experience of how she believes/understands that dementia developed. interesting.
- ⁸ participant view of how she got dementia diagnosis and how dementia developed
- ⁹ participants view that if she had not had the fall dementia would not have developed so quick, her understanding is that post her fall she developed a bump which didn't bleed, blood circulates into the make and dementia then developed-'make it a big thing'.
- ¹⁰? cultural behaviour to keep things secret- as in not sharing your family affairs outside the family home
- ¹¹ clearly the researcher's assumption on reflection would have been better to let the participant state this
- ¹² not clear what the participant meant by this,
- ¹³ not sure what she means about how her life is different
- ¹⁴ a coping mechanism
- ¹⁵ Participant did not understand and realise she had developed dementia, however she was aware that she was really sick and kept being seen by her doctor
- ¹⁶ just close family are aware of dementia diagnosis
- ¹⁷ participant referring to parents- confused.
mentions doctors are very secretive, perhaps when she was growing up that was the case- and they tell their parents, but not tell you- secretive culture
- ¹⁸ no care package in place care provided by husband
- ¹⁹ Physical day to day challenges of post her fall- pain in neck
- ²⁰ day to day challenges of dementia at times causes tension in their relationship- 'dementia which she blames'.
- ²¹ husband from his perspectives see's that her understanding of her diagnosis and her current situation is limited
- ²² Husband coping - by accepting the situations, he recognises the day to day challenges, the difficulties, her getting lost

- 23 dementia symptoms began before her fall.
- 24 this is how the participants understands is the cause of her dementia- the fall leading to her bump on her head.
- 25 husbands coping mechanism- 'I've just got to low with her'
- 26 enjoys her independence
- 27 day to day challenges
- 28 day to day challenges
- 29 I could sense her frustration at him not trusting her in her tone
- 30 sense of acceptance of the diagnosis
- 31 sense of openness about the diagnosis as she is not the only person with dementia in the church
- 32 church is jolly- uplifting for participant
- 33 important to note that she still has a sense of normality despite living with dementia- i.e. living well with dementia
- 34 again a sense of normality- from her perspective, she is still the same and expects other to see her in that way
- 35 Husbands perspective is that her life has changed completely. But participant can't recognise this...
- 36 husband describes the day to day challenges of living with memory problems
- 37 participant fighting back- highlighting her sense of independence and holding onto it...through this bus example...she knows where bus XXX goes
- 38 participant getting a bit angry noted in tone.
- 39 participant still arguing her case, regarding the bus number, sense of holding to her independence. being able to get a bus on her own and knowing where the bus is going (small side note-.the fact is 252 does not go to Hornchurch and husband is correct, I did not say anything though)
- 40 length of time taken to get a diagnosis
- 41 husband seems to have an understanding of dementia and progression

Appendix 24: Data analysis example- Parent Codes

Nodes - Saved

File Home Insert Draw Page Layout Formulas Data Review View Help Tell me what you want to do

Paste Cut Copy Format Painter Clipboard

Calibri 11 A⁺ A⁻ B I U Font

Wrap Text Alignment Merge & Center

General Number

Conditional Formatting Table

AutoSave On

N269

	A	D	E	F	G	H	I	J	K	L	M	N
1	Name											
2	ACCEPTANCE OF DEMENTIA											
5	ACTIVITIES THAT PARTICIPANTS ENJOY											
23	BAD THINGS											
25	BEFORE DEMENTIA DIAGNOSIS											
27	CANCER											
30	CARE IN OWN HOME											
32	CARERS											
39	CHILDREN											
44	CONCEPT OF CULTURE											
52	COPING WITH DEMENTIA											
57	COUNTRY OF BIRTH											
65	DEATH											
68	DEMENTIA DIAGNOSIS											
75	DEMENTIA DIFFICULTIES IN GOING OUT											
79	DEMENTIA DISEASE DEVELOPMENT											
88	DEMENTIA EMOTIONS											
98	DEMENTIA FAMILY											
100	DEMENTIA GROUPS											
108	DEMENTIA ILLNESS											
116	DEMENTIA IN COUNTRY OF ORIGIN											
120	DEMENTIA MENTAL HEALTH SERVICE											
124	DEMENTIA NOT DISCUSSED											
129	DEMENTIA NOT RECOGNISED											
134	DEMENTIA PARTICIPANTS PERCEPTION											
143	DEMENTIA PARTICIPANTS EXPERIENCE											
161	EMPLOYMENT											
175	ENGLAND											
218	ENGLISH PEOPLE BEING NICE AFFECTIONATE											
222	ETHNICITY											
226	FAITH IN GOD											
233	FAMILY											
257	FOOD											
260	FRIENDS											
263	GENERAL PRACTITIONER											
268	GOD											
269	GREED											
270	HOSPITAL											
273	JAMAICA											
297	KINDNESS											
298	NATURE											
300	NURSING HOMES											
302	PARTICIPANT ACTIVITIES											
312	PARTICIPANT BEING INDEPENDENT											
321	PARTICIPANT DREAM											
322	PARTICIPANT KNOWING ABOUT DEMENTIA											
328	PARTICIPANT LISTENED TO											
330	PRAYER											
332	RELIGION											
338	ROLE OF THE CHURCH											
353	THE EXPERIENCE OF BEING CONFUSED											
358	TRAVEL TO ENGLAND											
543												

Sheet1

Ready

Type here to search

Windows taskbar icons: File Explorer, Microsoft Edge, Google Chrome, Word, PowerPoint, etc.

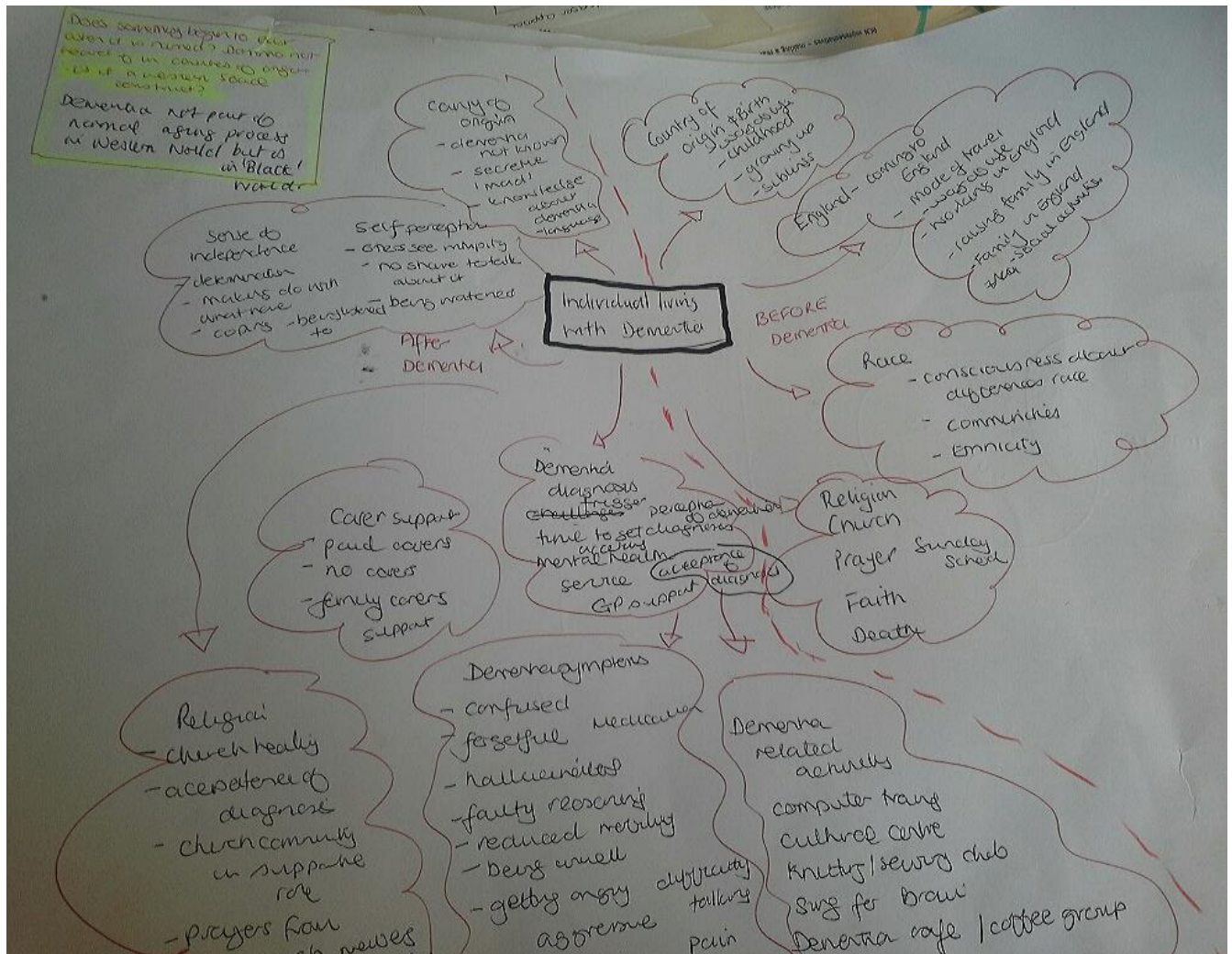
Appendix 25: Data analysis example- Word Cloud



Appendix 26: Data analysis example- Thematic map sample



Appendix 27: Data analysis example-Theme development



STOP

Do you have your keys with you?



Is the cooker off?



Purse?



Taps turned off?



Appendix 29: Participant Memory Aide



Take phone

Pull bell cord

