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END OF LIFE CARE AND DEMENTIA: A HERMENEUTIC PHENOMENOLOGICAL EXPLORATION OF COMMUNITY-DWELLING BLACK AFRICAN-CARIBBEAN OLDER PEOPLE LIVING WITH DEMENTIA AND FAMILY CARERS

THEMBA DLAMINI

A thesis submitted to the University of Huddersfield in partial fulfilment of the requirements for the degree of Doctor of Philosophy

The University of Huddersfield

February 2021

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ABSTRACT

Background: Dementia is a public health issue and a life-limiting condition. Compared to patients with other life-limiting diseases such as cancer, people living with dementia (PLWD) generally receive poor care at the end of life (EoL). Person-centred and culturally responsive end of life care (EoLC) supports individuals to die well and helps their families and carers. Currently, there is no cure for dementia, and most recent evidence suggests increasing prevalence within UK black, Asian and minority ethnic (BAME) groups. Despite this, there is little current UK-based evidence on EoLC for BAME communities with dementia. Within the wider UK BAME community, the voice of black African and black Caribbean PLWD and their families is rarely heard in EoLC research in the context of dementia.
Aim: To explore EoLC among community-dwelling older people from black African and black Caribbean backgrounds who are living with dementia.

Methods: Three, inter-related, qualitative studies were conducted, guided by van Manen's hermeneutic phenomenological approach. The first study involved two focus groups with older African-Caribbean PLWD (n=13) in ascertaining what, if any, would be significant at the EoL, drawing on their lived experiences. The second and third studies involved in-depth phenomenological interviews with bereaved family caregivers (n=6) and family carers (n=7). All participants (n=7 African and n=19 Caribbean) identified as African-Caribbean.

The recruitment strategy involved establishing trust with 'gatekeepers' and prospective participants. Purposive sampling was used in all studies. Template Analysis was applied alongside van Manen's phenomenological data analysis approach to make sense of participants' experiential material.

Findings: Three core themes and subthemes emerged from the analysis:

- **'I don't want to die in old people's home'**: Negotiating preparedness for the EoL, A journey through the undergrowth; Yearning for quality of life at the EoL.
- **Making sense of unfolding events by faith to God*:* '**living in fear of making wrong EoLC decisions'; Two sides of the coin.
- **Living with uncertainty and continuous change: '**God knows what He is doing'; Suffering in silence; Anticipatory loss; At the crossroads.

PLWD and family carers drew extensively on their religious and cultural understandings of dementia and EoLC. For all the participants, their Christian faith formed the basis on which understandings, perceptions, hopes and wishes concerning EoLC were made. There was a shared understanding that it is God who gives and takes life, so planning was not perceived as necessary. There was a lack of understanding of how dementia progresses as an illness, and reluctance to recognise signs of early dementia appeared to be associated with lost opportunities for early discussions regarding future care needs. For many, religion was not merely a set of beliefs or common faith in God, but rather, it was a phenomenon embedded within their everyday living practices**.**

Methodologically, the study demonstrates the potential of van Manen's hermeneutic phenomenological approach in psychological healthcare research. It also reinforces focus groups as a suitable data collection approach in research involving PLWD.

Conclusion: The research programme highlights a need to avoid being dissuaded by the term 'hard to reach' but to develop appropriate research methodologies for BAME groups. When working with BAME groups, considerations of their religious and cultural beliefs could help

to encourage them to access dementia and EoLC services. More UK based research on EoLC is urgently needed to ascertain what if any would be significant for minority ethnic PLWD.

Glossary & list of abbreviations

- **ACP:** Advance Care Planning/Future Care Planning
- **AFRICAN-CARIBBEAN:** refers to participants in this study who self-identified as being of black African - Caribbean ethnicity**.**
- **BAME:** the acronym denotes to Black, Asian, and Minority Ethnic. In this thesis, it is used to refer to all minority groups, including Asian groups.
- **CULTURE:** defined 'as the complex interplay of meanings that represent and shape individual and collective lives of people' (Con 2007, p.vii)**.** I also use the term interchangeably with BAME (cultural groups), as a way of inclusively refer to people of diverse ethnic backgrounds.
- **EoLC:** End of life care
- **EoL:** End of life
- **FAMILY CAREGIVER/S:** In this thesis, a family carer is a person (relative or not) who takes on the responsibility of looking after a person/s with dementia during the illness and at the EoL.
- **MINORITY ETHNIC:** Preference is made to use 'minority ethnic' as an alternative to 'ethnic minority' as the use of later would imply that everyone fits in to an ethnic group instead of an ethnic group's minority status.
- **PLWD:** People living with dementia. The choice was made in respect how those with the condition prefers to be referred to as shown by the Dementia Engagement and Empowerment Project (DEEP).
- **PCC:** Person-Centred Care
- **SCIE:** Social Care Institute for Excellence
- **NICE:** National Institute for Health and Care Excellence
- **ONS:** Office for National Statistics
- **DoH: UK** Department of Health
- **WHO:** World Health Organisation
- **MDT:** Multidisciplinary team
- **DRRHTT:** Dementia Rapid Response & Home Treatment Team
- **EAPC:** European Association for Palliative Care

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Dedications

I dedicate this work to my late father Enock Bhalwa Mpofu, who sadly died during the 1st year of my pursuit of this research degree.

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My academic biography and esteem

Oral Presentations and dissemination of findings

Dlamini, T (2015). Why should we involve people with dementia in the end-of-life care research? Paper presented at the *University of Huddersfield Research Festival*

Dlamini T: (July 2017). End of life care for ethnic minority people with dementia: the perspectives of caregivers (Invited by the Older People's Services Commissioning Board Greater Huddersfield CCG) July 2017.

Dlamini, T. (2017). Raising dementia awareness among the police: a contribution to the K.E.Y. (Keep Educating Yourself): Paper presented to West Yorkshire Police, Huddersfield,

Dlamini T (July 2018). End of life care for people dying with/from dementia: exploring the lived experience of African/Caribbean caregivers. PsyPAG 2018 Conference, University of Huddersfield.

Publication

Dlamini, T. (November 2016). End of life care in dementia: exploring the experiences of community-dwelling Black African and Caribbean people with dementia and their family carers in the North of England. *Celebrating the work of postgraduate researchers in the School of Human and Health Sciences* (published abstract)

CHAPTER 1: BACKGROUND TO THE RESEARCH PROJECT

1.1. Introduction

In this chapter, I introduce the thesis. I begin the chapter by detailing my interest in the phenomenon of end-of-life care (EoLC) for minority ethnic people living with dementia (PLWD). I move on to present the background information to the research, including an overview of minority ethnic people and dementia in the United Kingdom (UK). Critical concepts in the thesis are also discussed. The rationale of the research project, its significance, aims, and objectives are presented. I conclude the chapter by looking at the layout of the whole thesis.

1.1.1. My interest in the phenomenon

There is always a beginning of everything in our lives. The beginning of my interest in EoLC for minority ethnic PLWD stemmed from working as a community specialist dementia care support worker within a multidisciplinary team. I encountered PLWD and their family caregivers. Although these family caregivers and PLWD were from various backgrounds within their community, they all shared an experience of proving care to a relative and an experience of living with dementia. It is from my work with PLWD and their caregivers that I regularly listened to their caregiving or care receiving experiences. Because of each person with dementia experiences and journeys through with the condition their way and face various challenges and threats to their 'personhood' (Kitwood (1997). I learnt that families were confronted with the unpredictability of behavioural and psychological manifestations of dementia on a day-to-day basis. This made providing care to a relative with dementia at home a challenge to others and a satisfying endeavour to others. My role with a multidisciplinary team context involved visiting PLWD who were experiencing some crisis at home to offer support and to talk to family caregivers about their caregiving experience to provide support or signpost them to relevant services. I remember visiting Peter (not his real name), a former healthcare professional who had developed Alzheimer's disease years after his retirement. Over time, Peter and I established a good rapport. During many of my visits to monitor the

progress of his care, he would often reflect on his career in healthcare while his favourite song 'Sweet Child' by *Pentangle* was playing. Peter would repeatedly talk about his life experiences and his travel around the world and would summarise his narration with his wish to have 'a good death'. Over my ten years plus of regular contact with PLWD and their families, I heard various accounts focussed around EoLC.

Despite taking great pleasure and satisfaction in making a difference to PLWD and their family carers during crisis times, there were times when things went in the wrong direction. Some people I had seen for a considerable period would often die and would leave me questioning whether they had a good or bad EoLC experience. Even at this stage of my research, I do not doubt that times like that not only defined the lowest experience in my job but also made me realise that the end of life (EoL) of PLWD was not often a priority in our practice. Yet, for people like Peter, that was an essential part of their lives. I recall something featuring in my mind: how are people dying with dementia cared for in the community, and why do we not ever talk about EoLC? How do people experience living with dementia? How do family carers make sense of their role given the impact that dementia has on their relative and them? How do PLWD like to be cared for at the EoL? What is quality care from the caregivers' point of view, and how can we get to know this? The above questions prompted me to consult some literature on dementia care and related EoLC research to acquaint myself with 'what is going on'. My immediate realisation was the abundance of research on caregiver experiences compared to the limited literature on the lived experience of PLWD in general.

Indeed, Berwald et al. (2016) in their recent study here in the UK found that many of their ethnic minority participants believed dementia was a 'white man's disease' with some saying, 'we do not do dementia'. These perceptions of dementia, in my view, are a serious cause of concern given that the current estimated 25,000 PLWD who are from ethnic minority groups is expected to reach 172000 by 2025 as these groups are aging (All-Party Parliamentary Group on Dementia, 2013). Based on my observations during my community work and engagement with people from ethnic minority backgrounds, there is, more than at any given time, an increasing need to work closely with these groups to enhance their understanding of dementia, improve their access and use of available dementia services. Despite the UK's diverse and aging population (Ahmed, Egal, & Mohammed, 2016), there is minimal local evidence which reflects the needs of various minority groups. From my practice-based experiences and literature, I realised the need for research on EoLC for PLWD from UK minority ethnic groups.

Many researchers have made calls for urgent inquiry given that many people from ethnic minority groups with dementia are going to require EoLC (e.g., Connolly et al., 2012; Koffman, 2018). As quality healthcare requires to be evidence-based, UK based research evidence is crucial to ensure the needs of minority ethnic groups are met. While the use of research evidence from elsewhere is equally important, there is a danger of representation, given various contextual differences in the experience of minority ethnic groups. The EoLC for minority ethnic groups has not been explored rigorously to understand for the improvement of their care.

I wanted my research to explore what if anything is essential to black African/Caribbean PLWD at the EoL. To develop a dependable understanding, it was clear to me that understanding the lived experience of family carers who provide care to their relative with dementia would be extremely helpful. My motivation for undertaking this research project is to enable the voice of minority ethnic PLWD and their carers to be heard in something that directly affects them. I believe that by listening to their first-hand stories, my research would develop a deepened understanding of the meanings they ascribe to their experiences. Their voice as 'experts by the experience' of living dementia and caregiving would be valuable in the understanding EoLC from their perspectives.

I hope this research will contribute to filling the current gap of EoLC research evidence for minority ethnic groups and trigger further research interests around the topic. Having said all the above, I can agree with Sullivan and Sargeant's (2011, p.449) assertion that 'good research follows from a reasonable starting point'. From here, I move on to explore the EoLC from the perspectives of African/Caribbean PLWD and their family caregivers.

1.2. Structure of the thesis

Table 1 summarises the structure of the whole thesis

Table 1: Structure of the thesis

Chapter	Description
Chapter 1	Introduces my interest in the phenomenon and provides the background information to the research project. The chapter sets the scene for the work by providing an overview of dementia as a life-limiting condition and what is currently understood about palliative and EoLC for PLWD. Key

	concepts within the thesis are discussed and aims and objectives of the research projects are outlined in detail.
Chapter 2	Presents the review of the literature which seeks to identify the gap in the current knowledge base to justify the current research
Chapter 3	Presents the methodology which guided the research project. The chapter also details the theoretical and philosophical principles of the research. A case for a qualitative approach is made, and phenomenology is introduced through the work of Husserl and Heidegger. The justification for choosing an interpretive phenomenological approach over the descriptive one is detailed.
Chapter 4	Presents the methods of the study. It introduces van Manen's (1990, 2014) hermeneutic phenomenological research approach and its six steps. The chapter covers all the 'nuts and bolts' and research activities, which includes, ethical considerations, the recruitment strategy and justifications of chosen research techniques. The chapter concludes with a reflexivity section which covers my insider/outsider position
Chapter 5	Presents thematic findings from the focus group interviews study with older African-Caribbean PLWD.
Chapter 6	Presents thematic findings of current caregiver interviews study of the research project
Chapter 7	presents thematic findings of the Bereaved Caregivers' interviews study of the research project
Chapter 8	Presents the discussion, which is aimed at contextualising the key thematic findings reported in Chapter 5, 6 and 7 in relation to existing theoretical concepts highlighted in the review of the literature (Chapter 2). The contribution to knowledge made by this research is also presented in this chapter.
Chapter 9	In this chapter, I reflect on the overall study. Issues about inclusion and representation and concern around the homogeneity of the sample are discussed. I also reflect on my insider/outsider position and suggest some strategies of engaging with the so-called 'hard to reach' groups in research. Based on the research findings, I suggest future research directions and present the limitations of the exploration

1.3. Dementia in the United Kingdom (UK)

Globally and at national level, dementia is an increasing public health concern and a health and social care challenge for societies across the world (Koffman, 2018). Currently, it is estimated that there are 850 000 PLWD in the UK, of which 25 000 are from Black, Asian, and ethnic minority (BAME) groups (Lakey, Chandaria, Quince, Kane, & Saunders, 2012). Because the UK's population is also aging, reflecting the current global population trends, it is currently projected that the number of PLWD in the UK will reach one million by 2025 (Nichols et al., 2019). Although there are evidence-based treatments to halt the progression of the illness, there is currently no cure for it. In the UK, diagnosis rates continue to improve. Having people diagnosed at the earliest stage of the illness trajectory is a crucial policy agenda (Department of Health, 2009). A diagnosis of dementia can bring various changes to the person and their family, but it enables those diagnosed to access the care and support they need, including opportunities to plan for their future. Despite this, a substantial number of people with suspected dementia processes remain undiagnosed, especially those who are from ethnic minority groups.

The phrase 'dementia' depicts a constellation of symptoms which consist of a decline in memory, communication, orientation and problem-solving. Although various dementia subtypes exist, Alzheimer's Disease, Vascular Dementia, Lewy Bodies Dementia, Frontotemporal Dementia and Mixed Dementias are more common (Livingston et al., 2017). These symptoms are neurodegenerative and progressive, which means they cannot be reversed. Despite being recognised as one of the leading causes of death (ONS,2016), compared to patients with other life-limiting illnesses such as cancer, PLWD and their families often receive suboptimal EoLC (Sampson, 2010).

Improving and delivering quality care for PLWD has been an overarching priority advocated by UK government institutions and related bodies (e.g., DoH, 2009; National Audit Office, 2007) and has become a health care priority (Froggatt & Keady, 2010). The need to improve care for PLWD led to the formulation of England's first National Dementia Strategy (DoH, 2009) followed the establishment of memory clinics across the UK to ensure early interventions and early diagnoses (Alzheimer's Society 2014). Despite all this, a wealth of previous literature

continues to show that people with the condition die badly due to poor and mostly disjointed EoLC compared to other patient group dying from life-limiting diseases (Sampson, 2010).

1.3.1. BAME experiences of migration

The Windrush era (Walters, 2004), is known to be the first large scale phase of migration of people from BAME communities into the UK. This large-scale migration occurred from around 1948, a few years after the second world war. Those who arrived largely participated in rebuilding the country, working in various industries across the UK (Byrne, Alexander, Khan, Nazroo & Shankley, 2020). Amongst the arrivals after the war were people from African-Caribbean and Asian communities, with people from the African continent migrating to the UK in the later years (Braham, Rattansi & Skellington, 1992). On their arrival in the UK, most of them experienced various forms of discrimination and racism, which impacted on the process of integration into society (APPG, 2013). The differences in cultural practices between the immigrants and the host society were affected by how they went through the process of acculturation and integration, including the extent to which they maintained their cultural identity (Burholt, Dobbs & Victor, 2018).

According to a report by the Runnymede trust, a thinktank specialising in research on race equality and race relations (Lievesley, 2010), the immigration of people from BAME backgrounds into the UK has long been identified as an influential factor in socio-demographic variation. Although the extent to which different BAME groups experienced discrimination and racism is often overlooked, what is more evident about their experiences is that most were disadvantaged socially and economically leading to inequalities and healthcare disparities (Lievesley, 2010). As hinted above, these experiences impacted on the process of integration, and prohibited individuals from BAME communities from actively seeking help, accessing and using mainstream healthcare services (Butt and O'Neil, 2004). In addition to the above issues, the difference between and within BAME groups adds more complexity with regards to terms of access and use of healthcare services. Hickman and Walter (1997) argue that without reference to the experiences of discrimination and racisms described above, understanding the current social and health care needs of BAME people can be challenging.

A report on older migrants in Yorkshire by Integration up North (2015) observed that most of older BAME individuals struggled to make sense of illness such as dementia, as they would have not witnessed their own older relatives suffering such conditions in their country of origin due to migrating to the UK in their younger age. In addition to stigmatisation of mental illness

and culturally and religiously rooted beliefs, conditions such as dementia and their causes and impact is less understood (Brownfoot, 1998). Cultural and religious issues as well as experiences of discrimination or mistreatment have been associated with mistrust of services resulting in an array of barriers to access and use of public services (Calanzani, Koffman & Higginson, 2013). Although there are some similarities about how dementia is experienced between BAME groups and their White British counterparts such stigma, part of problems that maintains these challenges are precise to BAME people and therefore must be approached differently (APPG, 2013). For instance, the Social Services Inspectorate (1998) warned that stereotypical beliefs that ethnic minority families 'look after their own' works as a barrier to reaching out to these communities and extends the health inequality gap.

More recent evidence suggests that people from BAME communities are ageing and more likely going to develop conditions such as dementia, including other life-limiting illness (Calanzani et al., 2013), there is need to understand how people from these communities make sense of these illnesses to improve their access and use of services.

1.4. Dementia among minority ethnic people in the UK

In the UK, there is an estimated 25,000 ethnic minority PLWD, although this number is projected to double by 2026 (Lakey et al.,2012). These figures may not be definitive for minority ethnic groups due to problems associated with diagnosing dementia, especially at the early phases of the condition. People from these groups currently make up nearly 14% of the UK population but vary in their cultural diversity based on their geographical origins (All-Party Parliamentary Group on Dementia, [APPG] 2013). Based on the 2011 census, the past decade has seen the whole UK increasingly become diverse culturally and ethnically, with people from these communities evident across the entire UK. England has had an increase across all people who are nested under the Black, Asian and Minority Ethnic (BAME) umbrella (Office for National Statistics, 2012). According to the report published by the Race Equality Foundation (Koffman, 2018), compared to over half a million in 2001, by 2026, an estimated 1.3 million people will be from BAME communities who are over the aged of 65 years and by 2026, those over 70 years will be nearly half a million. Within all BAME communities, the White Irish community are likely to have more individuals aged 65 and over, thus 35.9% of this group's population projected to be older). People Black Caribbean are expected to increase, with 13.4% of their population being over 65, Other White 10.7%, Indian 10.6%, and Other Asian 9.6% (Koffman, 2018).

Most UK ethnic minority groups generally have an uneasy relationship with healthcare and do not aften engage with the available dementia care services resulting in underrepresentation (Mukadam, Cooper, Basit & Livingston, 2013). The proportion of older people among minority groups are on the rise as those who migrated to the UK around the 1950s are reaching their seventies and eighties according to the report by the Runnymede Trust (Lievesley, 2010). This means there would be a surge in dementia cases among minority ethnic groups from now onwards. Therefore, there is a need to ensure people from these groups people to access and dementia services, including palliative and EoLC (Care Quality Commission, 2016; Kenning, Daker-White, Blakemore, Panagioti & Waheed, 2017). A most recent study exploring dementia diagnosis trends from analysis of primary care data among UK minority groups reported a higher incidence of dementia among people from black backgrounds (Pharm et al., 2018).

People from BAME backgrounds are generally under-represented in dementia services and face many barriers when it comes to accessing services, such as language problems and limited knowledge of how to access the services they need within the broader healthcare service systems (Daker-White, Beattie, Gilliard & Means, 2002). This means despite the UK now being home to an ageing and culturally diverse population, inequalities in healthcare still exist and must be confronted (Ahmed, Egal, & Mohammed, 2016).

The prevalence of dementia is thought to be higher among BAME communities when contrasted with the majority White UK population (Adelman et al., 2011); however, these estimates are drawn from small sample localised studies (Dementia UK, 2007). Because evidence suggests people from UK ethnic minority groups often present to services late (Mukadam et al., 2013), they do not receive timely diagnoses as recommended by the current UK Dementia Strategy (Department of Health, 2009). When they access dementias services, Cooper et al. (2010) reported that it is when their dementia has become severe. Having a diagnosis is crucial as it unlocks access to support services for the person and their family and enables one to access the available treatments, which are thought to help halt the natural progression of the illness when the person is diagnosed at the earliest phases of their illness (Department of Health, 2009, NICE/SCIE, 2007). More inadequate diagnosis of dementia among minority people could be the reason why ACP is not prioritised.

The process by which a definite diagnosis of dementia is reached can be challenging, and in for ethnic minority groups, this remains a challenge due to factors such as lack of cultural competence skills among primary care staff, which is further hindered by several complex

cultural beliefs about the illness (Kenning et al., 2017). Nonetheless, due to the existence of dementia-specific risk factors such as diabetes, hypertension, strokes, and heart diseases among these groups (APPG, 2013), overall, 22 % of those with vascular dementia are thought to be people from BAME communities (Moriarty et al., 2011). However, as also noted by Dementia UK (2014), epidemiological evidence remains sparse. Dementia does not see ethnic or cultural boundaries (Forbat, 2003); it affects people from all various cultural, ethnic, socio-economic backgrounds and does not discriminate (APPG, 2013). Estimates of dementia prevalence among individual ethnic groups have not fully been analysed (Alzheimer's Society, 2014), but an assessment of demographic trends indicates that migration is the main reason and driver of change in the UK's population.

1.4.1. Minority ethnic family caregivers and their role

Family carers occupy an ambiguous place, being both providers and possibly receivers of care (Payne & Grande, 2013). Two-thirds of PLWD reside in the community (Johl, Patterson & Pearson, 2014), and are frequently cared for by their family members (Adams, 2006). Besides challenges resulting from the demands of caregiving, family caregivers face difficulties of witnessing the EoL of the person they look after, which can subject them to vicarious distress and suffering (Payne & Grande, 2013). Previous studies exploring caregiving experiences among ethnic minority groups have found that irrespective of ethnic group, family carers provide most care to their relative with dementia (Koffman, & Higginson, 2003); however, their input is often overlooked (Carers UK, 2013).

While family caregiving has attracted research in the past decade, a careful look at the literature shows that little attention has been paid to minority ethnic family caregivers' experiences within the UK in general, and less so about EoLC (Johl et al., 2014). Most of the previous work on minority ethnic groups originate from the USA and Australia and has primarily focused on the physical, psychological, financial, and relational impact of family caregiving for dementia. However, due to differences associated with migration experiences and structure of health and social care systems, using such evidence to inform services for BAME people living in the UK is questionable (Johl et al., 2014, Calanzani et al., 2013, Connolly et al., 2012). Given that available evidence suggests more BAME people could be living dementia in the UK (Adelman, 2011), and the underrepresentation of this group in dementia care services (Darker-White et al., 2002), it is likely that BAME family carers provide more care for their relatives with dementia compared to other groups. Despite this, generally, there is limited literature to date

that has explored family caregivers' views about the EoLC (Davies et al., 2014; Hennings, Froggatt & Keady, 2010).

1.4.2. Culture

In light of the effects of migration, culture has been recognised as an essential aspect in EoLC, (Gysels et al., 2012). Culture, defined in terms of people's values, norms, and beliefs, often shape people's perceptions about illness and the responses they take when exposed to specific symptoms (Cox, 2007). For instance, persistent forgetfulness and confusion may be viewed as the expected presentation of an older person and may not be considered as a cause for concern requiring any investigation. The intercourse between culture and ethnicity is a strong one; however, the latter is not fixed as this can change depending on context and all influences how people perceive illnesses such as dementia (Cox, 2007). The Department of Health (2009) notes that dementia can affect anyone in society. While research on BAME dementia in the UK is generally limited (Moriarty et al., 2012, Dementia UK, 2007) research on EoLC for this group remains severely inadequate (Connolly et al., 2012; Calanzani et al., 2013, CQC, 2016).

When one considers the ongoing migration and demographic changes in UK communities, one can therefore argue that the paucity of research evidence on minority ethnic groups is a failure to fully reflect the UK's increasing cultural diversity within its communities including the health and social care challenges that comes with it (Ahmed, Yates-Bolton & Collier, 2014). With dementia set to increase among BAME groups, 'it is essential that their needs be met by accessible and responsive services (Dementia UK, 2014, p.89). While across the UK, in general, there is limited research that has explored the views of minority ethnic PLWD in the context of EoLC (Koffman, 2018; Mathie et al., 2011; Godwin & Waters, 2009), no studies to date that have sought to investigate and understand EoLC from the perspective of minority ethnic PLWD, with the available evidence being limited to exploring barriers to use of services (Kenning et al., 2017). In this research programme, I use the term culture loosely to refer to a unified pattern of actions, including but not bound to thoughts, communication, languages, beliefs, values, and practices.

1.4.3. Ethnicity

Ethnicity has been defined in terms of 'shared origins or social background; shared culture and traditions that are distinctive, maintained between generations, and lead to a sense of identity

and group; and a common language or religious tradition' (Senior & Bhopal, 1994, p.327), and it is not in the scope of this thesis to encroach into a debate surrounding the notion of ethnicity. As outlined above, 14% of the UK's total populations is made by ethnic minority groups and remains on the increase (Office for National Statistics, 2016). However, ethnicity has a profound influence on people's attitudes to accessing dementia care services and on how they use those services once they decide to access them (Cox, 2007), including satisfaction with those services Greenwood, Habibi, Smith, & Manthorpe, 2015), and has long been at the centre of a debate (Bhopal, 1997).

From a cultural and ethnic viewpoint, in a review of the literature to explore pathways to care, Mukadam et al. (2011) found that people from BAME communities are often reluctant to present to dementia care services. If they did access the services, it was when dementia had become more severe. However, the concept of ethnicity appears to be a tricky one to define without being entangled in the historical debate attached to it. Debating these concepts in more detail falls outside the focus of this work. Thus, for this research, I adopt a more simplistic definition provided by Helman (2000) who describes ethnicity regarding a shared culture, tradition, religion, language, and origin. In doing so, it is essential to highlight the danger associated with the misuse and application of this concept in research. This is mainly due to its fluidity, which, according to Iliffe and Manthorpe (2004), can lead to a 'category fallacy' (p.289) that is often overshadowed by many other variables that change over time. For example, people acculturate to the host population following migration, therefore, attributing people's responses to an assumed stable ethnic identity might lead to it suffering cohort effects that are limited to one or two generations of that given ethnic group only (Iliffe & Manthorpe, 2004).

Furthermore, Iliffe and Manthorpe (2004), in their paper debating the use of 'ethnicity' in dementia care services, point out that the 'intra-ethnic group variation is greater than interethnic group variation', which supports 'the view that ethnicity as a category may not have great explanatory power and may foster a category fallacy' (p.283). Consequently, it is not in the interest of this work to make a case about the differences between the black African-Caribbean PLWD and their carers. Thus, I use the term black African-Caribbean to refer to the participants in general. This does not necessarily ignore the differences embedded in people's cultural and religious beliefs, including their shared understandings of meanings that they ascribe to given experiences. As argued by Iliffe and Manthorpe (2004), a rigid emphasis on ethnicity alone could encourage misconstruction and can obstruct the way for culturally responsive services for BAME communities. Ethnicity refers to how people identify themselves from a cultural

perspective, which is fluid and context-specific (Ford & Kelly, 2005). It is not within the scope of this research to dig deeper into the debate surrounding ethnicity. Therefore, the above overview is only meant to establish the basis and context of the study.

1.4.4. Religion among UK minority groups

Religion is a subjective, self-defined concept which is meaning to an individual (ONS, 2011). Although the UK has a long history of being a Christian country (ONS,2001), the 2011 census indicated a drop in people who identified themselves as Christians, from 41 million in 2001, to 33.2 million in the 2011 census (ONS, 2011). Based on the 2011 census, of the 56 million England and Wales residents, 59% stated that they were Christian, 5% were Muslim, 0.4% were 'other' religion and 25% were not affiliated to ant religion (ONS, 2011). With regards to minority ethnic groups' religion, the ONS (2011) data analysis indicated that almost half of the individuals born outside the UK stated that they were Christian (48%), with the majority of black African and black Caribbean identifying themselves as being affiliated to religion (Christian). The projected increase of dementia among minority ethnic groups poses even a more significant challenge, as understanding the needs of an ethically and religiously diverse population whose conceptualisation of health and illness may be different from the majority (Department of Health, 2010).

1.4.5. Cultural competence in dementia and EoLC

The notion of cultural competence has been defined in several ways in literature, though all seem to concur on that it relates to the way which people and organisations respond dutifully and effectively to persons who are from different cultural and ethnic backgrounds. This includes recognising the diversity of people's beliefs (culture and religious) and values in a fashion which enables them to feel their dignity is being respected (Mackenzie, Bartlett & Downs, 2005; Kim, 2011). As the UK is becoming culturally diverse, cultural competence in healthcare has become an area of increasing interest and debates (Department of Health 2001). Despite its complex nature, there is no doubt that there is a need for healthcare professionals to be equipped with such competence if they are to deliver health and social care services to a culturally diverse population. (Nyatanga, 2008). Dementia affects people from all walks of life, and various people approach and take unique ways to EoL (Dlamini, 2016). This makes cultural competence more relevant to EoLC to ensure those who work with individuals from a different

cultural background gain the trust that further encourages them to engage with the available services (Mackenzie, Bartlett & Downs, 2005; Kim, 2011).

Unlike in the UK, in the USA, cultural competence has been integrated into the design of services as a prerequisite and cornerstone of providing culturally sensitive dementia care for minority groups (e.g. Pachana & Gallagher-Thompson, 2018; Clarke et al., 2018). It is not unforeseen that despite its diverse population, the UK has limited research evidence relating to how cultural competence can be integrated into the formulation and delivery of healthcare, including EoLC. This does not mean that the importance of cultural competence is unknown (Koffman, 2018), but there appears to be a lack of effort to recognise the impact that culture has on people's use and access of healthcare services. Still, it is the issue of embedding the notion of cultural competence into practice such that confidence levels of cultural groups in using services such as palliative and EoLC are enhanced (Nicol & Nyatanga, 2017).

The limited evidence of cultural competence within the UK would appear an oversight, and somewhat at loggerheads with the current population projections, considering that BAME groups makeup 17.5% of the UK's population and are ageing (ONS, 2011; Lievesley, 2010). The predictions cover various groups that are nested under the BAME acronym, who have multiple cultures and perceptions of health and use of formal care support services. Meeting the needs of the diverse population will require understandings of their cultural attitudes to ensure services are designed or delivered with that in mind. When it is embedded in the philosophy of care delivery, Mendes (2015) observes that cultural competence can be crucial element which enables the provision of culturally responsive high-quality care. Although challenging in terms of training staff in palliative care, cultural competence has been found to enable healthcare providers to offer care services that acknowledges the cultural needs of patient (Payne et al., 2007).

Across Europe, understanding people's culture has been recognised as a critical component to EoLC research as identified by the Positive diveRsities of European prIorities for reSearch and Measurement in end-of-life cAre (PRISMA), a panel of 30 experts from across Europe, who met in Spain in May 2010. In the UK, culture and its influence in dementia care have recently been acknowledged by national bodies and highlighted in government strategies (e.g., NICE, 2006; The Scottish Government, 2011), though its importance appears to have taken a back seat in both research and practice. Research has indicated that developing cultural competency enriches the care providers' aptitudes in building a trusting connection with the community

that uses the available services (Kim et al., 2006). However, Owens and Randhawa (2004) in their exploration of palliative care provision for the South Asian community in Luton (UK) found a lack of cultural sensitivity of care as being a barrier to access and use of available palliative care services. Individuals are multifaceted, and culture can be challenging to conceptualise as it changes over time.

1.5. Dementia as a life limiting condition

Dementia has been recognised as one of the challenges that face today's society (WHO, 2012). Data shows that dementia has overtaken cardiovascular disease and cancer to becoming a leading cause of death in England and Wales (ONS, 2015). Despite being recognised as a leading cause of death, dementia continues not to be consistently recognised as a terminal condition (Mitchell et al., 2009). A prospective cohort study investigated the survival of community-dwelling older people and found that even a minor impairment of an individual's cognition strongly predicted mortality (Sampson, Bulpitt & Fletcher, 2009). This was after controlling for critical health and social mortality predicting factors for older people.

There is a growing understanding that dementia ought to be recognised as a life-limiting illness with no current known cure, as doing so is crucial to improving the currently widely recognised as poor care for people dying with and from dementia (Sampson, 2010; van Der Steen et al., 2014). As a life-limiting condition, dementia generally has a prolonged and unpredictable illness trajectory, which is often characterised by a progressive decline and has a similar prognosis to that of other life-limiting conditions like cancer (Sampson, 2010). Evidence suggests it is often difficult to tell whether a person with dementia is nearing the EoL, especially at the advanced stage of the condition. Due to this, PLWD do not always receive appropriate palliative care, whose aim is to enhance the comfort of terminally ill patients, yet towards the EoL, individuals with advanced dementia experience distressing symptoms as that experienced by people dying from cancer (Davies, Rait, Maio & Iliffe, 2017). One of the problems associated with dementia is that it is not continuously recognised as a life-limiting and incurable condition (Middleton-Green, Chatterjee, Russell & Downs, 2017). A possible explanation for this relates to the current health care model's emphasis on the cure of illness; as such, healthcare professionals may be reluctant to focus on the incurability aspect of the condition as opposed to concentrating on how care and treatment pathways can be put in place

(Middleton-Green et al., 2017). Such hesitancy on redefining dementia as incurable and as a life-limiting condition may need to change to ensure PLWD receive quality care EoLC.

Dementia is often not acknowledged as a terminal illness, requiring palliative and EoLC. The slow progression of the condition throughout several years and its unpredictable prognosis differentiate it from other terminal diseases. Identifying the terminal phase in advanced dementia is very important in the provision of EoLC. However, the nature of dementia poses a significant problem. For example, a person's symptoms may indicate he or she is approaching the EoL, but they may live for years. Despite its progressive nature, and its impact on communication, PLWD and their families do not often discuss future care needs in advance before the person's ability to communicate, and the condition impacts decisional capacity. This has significant implications on the 'person-centeredness' of the care, as the person's needs may not be known. For BAME groups, the consequences are even more significant as poor dementia as awareness often leads to this group presenting late to dementia services when the condition has deteriorated (Mukadam et al., 2011).

1.5.1. Palliative care and dementia

Palliative care has been described as both a philosophy and practice applied to individuals who have a terminal illness (WHO, 2014). The primary purpose of palliative care is to promote and maximise an individual's comfort and quality of life from using a holistic approach to intervention and a need for healthcare professionals to work collaboratively. Pain and other sources of discomfort are usually identified, treated, and managed while being sensitive to the person's emotional, social, and psychological well-being. A considerable evidence base shows poor recognition of dementia as a terminal condition as being the primary barrier to this type of care (e.g., Lillyman & Bruce, 2016; Mitchell et al., 2012; Ryan et al., 2012).

Dementia is an incurable and progressive illness, which means the care needs of the person with the condition increases by time. According to Sampson (2010), people with end-stage dementia have a similar prognosis as other terminal illnesses but do not always receive optimal EoLC. Overtime, palliation of symptoms becomes the primary goal of care. However, due to the illness's long and unpredictable trajectory, there are difficulties in separating the EoL phase from the advanced stage of dementia. One explanation for this is that as a condition, dementia affects each person differently, which leads to variations in survival rates and difficulties in predicting the end phase. Brodaty et al. (2012) reported that the duration from the point of

diagnosis to death vary significantly between PLWD but averages from one and a half to eight and a half years. However, others have reported that for some people, it may even be much longer (Mitchell et al., 2009). Due to this, a joint report by Marie Curie and Alzheimer's Society (2014) has recommended that 'dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death' (p.11). Although there is a need to adapt palliative care to dementia (van Der Steen et al, 2014), it is highly evident that PLWD can benefit from it as those with advanced dementia are susceptible to pneumonia due to problems with swallowing and are commonly bedbound and unable to mobilise.

It can prove challenging to diagnose disease in its earlier stages in people with communication difficulties (McDanel & Carnahan, 2016). Downs et al. (2017) trace the origins of hospice and palliative care from Dame Cicely Saunders's work and her establishment of St Christopher's Hospice in 1967. In its inception, palliative care was commenced in response to the poorer EoL experiences that were common for people with life-limiting conditions around the 1960s (Clark, 2007). It is thought that the work of Kubler Ross (1960) on death and dying further contributed to the globalisation of palliative care. Recently, there has been a heightening emphasis on the importance of extending palliative care to all individuals with chronic illness and their families regardless of diagnosis.

Palliative care is defined by WHO (2014, p.5) in inclusive terms (see Table 2). It is 'an approach that improves the quality of life of patients and their families facing the problem associated with a life-threatening illness, through the prevention and relief of suffering using early identification and impeccable assessment and treatment of pain and other issues, physical, psychosocial and spiritual'.

Table 2: WHO (2014) definition of palliative care

▪ provides relief from pain and other distressing symptoms;
▪ affirms life and regards dying as a normal process;
▪ intends neither to hasten or postpone death;
▪ integrates the psychological and spiritual aspects of patient care;
▪ offers a support system to help patients live as actively as possible until death;
▪ offers a support system to help the family cope during the patient's illness and in their bereavement;

▪ uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
▪ will enhance the quality of life, and may also positively influence the course of illness;
▪ Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to understand better and manage distressing clinical complications.

(WHO 2014, p 5.).

Based on its terminal nature, people with dementia should ideally benefit from a palliative care approach; however, as stated above, the first requirement for the care to be implemented is to identify it as a terminal illness. Due to the increasing recognition of poor care received by PLWD and their families at the EoL, a recent White Paper by the European Association for Palliative Care developed from a Delphi framework, (van der Steen et al., 2014) has made recommendations specific to dementia. The National Institute for Health and Care Excellence (2006) recommends that palliative care should be introduced at the point of diagnosis while other researchers, for example McCarron et al. (2011) questions the implications this can have, given that most people are receiving their diagnosis early while they are cognitively functioning well.

Because palliative care was initially designed for cancer, whose prognosis is less problematic compared to dementia's unpredictable and long trajectory, its applicability to dementia can be challenging. PLWD are rarely referred to palliative care services (e.g., see Afzal, Buhagiar, Flood & Cosgrave 2010; Huang, Hsieh, Hsieh & Wang 2017). This may be a reason why people dying from/with dementia do not regularly use hospice services (e.g., Miller, Lima, & Mitchell, 2010). There is, however, adequate evidence that suggests hospice care is equally helpful in improving the quality of life of this patient group (Miller, Gorzalo & Mor, 2001).

1.5.2. EoLC and dementia

EoLC is described as care which supports patients to die in peace, comfort, and dignity and focuses on patients with a life-limiting condition and a life expectancy of 6 to 12 months (Connor, & Bermedo, 2014; Gold Standards Framework, 2011). Despite being recognised as one of the leading causes of death, compared to patients with other life-limiting conditions such as cancer, PLWD and their families often receive suboptimal EoLC. Nakanishi et al. (2015)

have pointed out that in research, policy, and practice, EoLC for PLWD has been a neglected area. A need to extend palliative care to other life-limiting conditions other than cancer, including dementia, has been strongly expressed in literature and continues to draw considerable debates (Nakanishi et al., 2015). However, recent research continues to identify the poorer EoL experiences for both people dying from dementia and those close to them (e.g., van Der Steen, 2010; Denning, Jones & Sampson, 2013; Hennings, Froggatt & Keady, 2010).

While these studies and reports highlight a need for the improvement of the EoLC for PLWD and their families, they rarely identify the needs of BAME people, despite the well-documented underrepresentation of these groups in healthcare, including the lack of their voice in research (Moriarty et al., 2012). As dementia is thought to be higher in prevalence among this group (Alderman et al., 2011), there is evidence suggesting BAME groups understand and experience dementia differently, including caregiving (Lawrence et al., 2008). However, despite the difference in experiences of dementia, there is lack of understanding of how this relates to EoLC. Nevertheless, what is essential is that at the EoL, people with advanced dementia – a life-limiting condition, should have equal access, and be provided with individualised EoLC that meets their needs for respect, dignity, and physical comfort, regardless of their ethnicity (Calanzani et al., 2013).

1.5.3. Advance care planning (ACP)

ACP involves a process by which individuals discuss and record their EoL wishes, preferences or choices in anticipation that decisional capacity will be lost at some point (Robinson, Dickinson, Bamford, Exley, & Hughes, 2011). In palliative and EoLC literature, ACP has been associated with promoting self-determination and enabling individuals to have some control in how one prefers to be looked after at the end of their life. While previous evidence shows that when implemented early ACP, can help ensure the delivery of personalised care at the EoL (Denning et al., 2011). However, there is limited evidence available on ACP among UK ethnic minorities in the context of dementia. The purpose of ACP[1] is to assist healthcare professionals to consider the wishes of the dying person when it gets to the point that they are not able to make their needs known. As dementia is progressive, meaning people will deteriorate by time, having the conversations early is vital to allow, the person to express their wishes or assign a

[1] In this thesis, the term 'future care planning' is used interchangeably with advance care planning.

Power of Attorney, usually an entrusted person who can be legally consulted by health and social care professionals to make decisions.

As a process, ACP involves an individual who, upon anticipating a loss of decisional capacity in the future, initiates early discussions about his or her future care preferences or choices including the EoL wishes, that is, how the individual wants to be cared for in the future and having their wishes documented. In dementia, it is crucial to note the significance of timing in implementing the discussions as failure to do so may mean a person, whose dementia may have gotten to the advanced stage, is no longer able to discuss their needs due to the decline in their cognitive abilities and communication (Poppe, Burleigh, & Banerjee, 2013). Previous research has shown that BAME people often present late to services, usually when their dementia has advanced; therefore, the implementation of ACP may be difficult as a result. There is minimal evidence on the effectiveness of ACP for ethnic minority people, although indications from the USA suggest minority groups often to do not have ACP in place compared to their white counterparts.

In a review of the literature to elucidate racial or ethnic diversity concerning decision making at the EoL, Kwak & Haley (2005) found dissimilarities within racial groups existed which were mainly in keeping with cultural values, demographic characteristics, acculturation, and familiarity with treatments options art EoL. One reason cited by many studies relates to lack of trust and reluctance to undertake such conversations with a relative with dementia. On the other hand, as ACP is based on understanding the impact the illness would typically have in the future, it may be difficult for those around the person to accept a diagnosis of dementia. This would best appear to be the case with BAME groups where normalisation of dementia symptoms takes most of the time that could have been used to discuss future care needs, assuming an early diagnosis would have been given. For example, a recent study exploring ACP among Korean Americans concluded that participants' understandings of Alzheimer's disease were the single primary factor, which was associated with discussing and implementing ACP (Hong, Casado, Lee, & Pruchno, 2018).

Poor understanding of dementia shown in UK studies researching BAME groups suggests BAME people may not be able to contemplate the progression of the condition - which is the basis for implementing the discussions. Thus, consideration of ACP may not be feasible. Some previous work as also indicated that having ACP in place would make it easier for the family and professionals to make EoLC decisions based on their relative's values and preferences at

the EoL. Kwak and Haley's review of literature mentioned above also found that at the EoL, African Americans prefer the use of life support while Asians and Hispanics favour family-centred decision-making compared to other racial or ethnic groups (Kwak & Haley, 2005). In conjunction with dementia, research evidence in this area is very limited within the UK context, though the value of having ACP have been shown by many recent studies. In their study, Badrakalimuthu and Barclay (2013) found that where there no ACP for PLWD, and EoLC decisions were often shouldered by family members who acted as surrogates along with healthcare professionals rather than the patients themselves, and the care delivered my not reflect the needs of the dying person. Even though some examples of good practice do exist, in a recent study that examined the views of healthcare professionals, PLWD and their family carers about ACP, Robinson, Dickinson, Bamford, Exley, & Hughes (2011) found that ACP was not embedded within dementia care services as a matter of routine. The study further found that ACP dialogues were often initiated late along the illness trajectory, which led to decision-making being done by proxies.

As stated above, as dementia advances a person with the condition would often increasingly find it problematic to communicate. In conjunction with the person-centeredness of care at the EoL, planning allows the voice of the person with dementia in the formulation of their care (Robinson et al., 2011). Indeed, family members may have some ideas of what their loved one would have preferred at the EoL. However, difficulties arise when they face potentially challenging EoLC decisions such as withdrawing life support intervention and discontinuation of treatments.

Studies in this area have found that such decision often impacts on already distressed family members, feeling as if they have not made the right decisions, though their (Nuffield Council on Bioethics 2009). ACP has been found to assist with reducing unnecessary emergency hospital admissions and the commencement of ineffective treatments. Referring to palliative care for PLWD, Meller, Squires, Chan, and Willett (2006) has emphasised the value of transparent discussions with family carers concerning a typical dementia trajectory, the potential complications of dementia and the inadequacy of treatment options available to promote a high degree of understanding and thus promote the implementation of ACP.

1.6. Rationale and significance of this research project

Evidence that informs policy and care for BAME groups with dementia in the UK mainly originates from studies conducted on African Americans in the USA and other multi-cultural countries such as Canada and Australia. For example, a comprehensive review of literature on EoLC for minority PLWD did not find any UK based study, with nineteen of the twenty reviewed studies originating from the USA (Connolly et al., 2012). Transferability and use of such evidence within the UK can be debatable in terms of relevance because the USA context is different in many ways, including the design of the healthcare system, the experience of minority ethnic groups and health and social care policy. Concerning the EoLC for minority PLWD, there is currently very limited UK based research (Koffman, 2018, Connolly et al., 2012). This paucity for UK based evidence is emphasised by the UK national dementia strategy (Department of Health, 2009, p.97) which states 'end of life care for people with dementia is an under-developed area which requires specific attention'. Experiential focused research is further limited.

The lack of UK based evidence in the context of an increasing number of older BAME PLWD in the UK is a critical issue, especially considering that dementia is uncurable, meaning many people will require EoLC services (Moriarty et al., 2011). Of importance, and even enshrined within the UK's Dementia Strategy (DoH, 2009), is that regardless of cultural background, geographical place or socio-economic status, dementia EoLC should not only meet the needs of individuals with dementia but should also ensure family caregivers needs and experiences are considered (APPG, 2013). While there has been growing research interests in family caregiving in general (e.g., Payne and Grande, 2013; Carers UK,2013) within the UK, the dearth of research exploring the experience of older BAME PLWD and family caregivers of this group in relation to EoLC has been identified in many recent papers, however, research evidence remains limited (Connolly et al,.2012).

After a introductory review of the literature at the early stages of my research journey, the necessity of this research project was emphasised on the 17th of January 2016 when Professor Alistair Burns, NHS England's National Clinical Director for Dementia and Older Peoples and Professor Bee Wee, National Clinical Director for End of Life Care for NHS England, appealed for a debate on EoLC for PLWD after reviewing national EoLC intelligence network briefing on dementia in which poor care for people dying from dementia was highlighted.

Their NHS England appeal blog for a debate stated:

> *'We know that people with dementia do poorly regarding the EoLC but have many of the same symptoms in their last days of life. An issue is people in care homes – the majority of whom have dementia – being admitted to the hospital for the last few hours or days of their life… [Furthermore] there is a fear that people in the later stages of dementia lack capacity and so there is reluctance in staff to be more proactive. It is precise because people with dementia will ultimately lose capacity that the opportunity to offer advanced care planning at an earlier stage must not be lost'.*
>
> ***(NHS England, 2017: Call to debate EoLC for people with dementia)***

Given the current projected increase in prevalence of dementia, palliative care for PLWD individuals has become a critical research area (Roger, 2006). Despite two-thirds of PLWD residing in their own homes, previous research examining the palliative and EoLC has focussed on care home environments (Goodman et al., 2010). There is a need for research on EoLC to explore the needs of community dwelling minority ethnic PLWD.

Good EoLC should also support family members of the dying person and ensure their needs are met. The overall aim of palliative care is the achievement of a 'good death'; however, what entails a good death would perhaps be understood better from a subjective point of view this is unfeasible. The notion of dying well has mainly been discussed in terms of how people's EoL wishes are considered by those who provide care (DoH, 2009). This extends to meeting the person's preferred place to die and support to maintain comfort and symptom management at the EoL. Previous research has shown that there is a need to attend to the physical, emotional, social and spiritual needs of both the individual who is dying and his/her family, most of the research on EoLC for BAME PLWD and their family carers is limited. EoLC can be received or delivered at home, in a care home, hospice, or hospital but most research exploring the needs of people with dementia has mainly focussed on care home settings, despite two-thirds of PLWD in the UK living in their own homes.

More recent UK policy such as the National Dementia Strategy (Department of Health, [DoH] 2009) and the End of Life Care Strategy *'delivering high-quality care for adults at the end of life* (DoH, 2009).

1.6.1. Developing the research question

The need for improvements in EoLC for people with dementia who are from UK minority ethnic groups influenced this research. Additionally, my work experience in dementia care and awareness of developments around palliative and EoLC for people with dementia helped in the formulation of the research question. Furthermore, the research question is strongly supported by the literature reviewed in Chapter 2. Moreover, the gap in the literature on EoLC for minority ethnic people with dementia within the UK was identified, and the lack of experientially based studies was illuminated.

In general, the 'voice' of BAME PLWD and their family caregivers has not been a heard in matters that directly affect them. While other subgroups that are nested within the BAME community have been researched, there is minimal literature on black African and Caribbean communities compared to other groups. To date, there little is known about the lived dementia care experiences and EoLC needs for BAME people with dementia. However, with regards, there is minimal existing evidence on EoLC for PLWD of African-Caribbean background and UK minority ethnic groups in general. For example, a review of the literature exploring EoLC for PLWD found no UK papers Conolly et al. (2012). More recently, Koffman (2018) has called for more research as most evidence that informs UK policy is often extrapolated from studies from outside where the experience of minority ethnic groups is different. Therefore, there is a need for UK based EoLC research from the perspective of BAME PLWD and family caregivers.

1.6.1.1. Research questions

To maintain a strong orientation to the phenomenon of interest, these questions guided the study:

- Concerning care at the EoL, how do community-dwelling African-Caribbean PLWD experience dementia?
- In the context of EoLC, what meanings do African-Caribbean PLWD and family caregivers attach to their experience of dementia?
- From the lived experience of bereaved African-Caribbean family caregivers, what is good EoLC?
- What is the experience of current family caregivers who are providing care to an African-Caribbean with dementia, and what are their needs?
- From the lifeworld of older African-Caribbean people with dementia, what cultural approaches underpin their views, hopes and perceptions of EoLC?

1.7. Aim

To explore the lived experiences of dementia care and perceptions of related EoLC

1.7.1. Objectives

- Explore literature on EoLC in dementia for BAME groups within the UK and understand how they experience living with dementia in the context of EoLC.
- Promote participation in research by allowing a research-neglected voice of older African-Caribbean PLWD and their family caregivers to be heard in an issue that affects them.
- Encourage an open dialogue on EoLC among this group of people and establish the best approach to having effective communications about the EoL and care issues.
- Explore any similarities/differences amongst a group of older African-Caribbean to illuminate unmet needs and potential barriers to EoLC support.
- Explore the experiences and perceptions of ACP to identify facilitators and barriers to accessing good quality EoLC among African-Caribbean PLWD.
- What meanings do African-Caribbean PLWD and the family caregivers ascribe to their lived dementia experience in the context of preparing for future care at the EoL?
- To explore the lived experiences of dementia care and perceptions of related EoLC amongst community-dwelling older African-Caribbean PLWD and family caregivers.
- Explore what constitutes quality EoLC from the lifeworld of older African-Caribbean PLWD and family caregivers

1.8. Summary of Chapter

This chapter presented my interest in the phenomenon of EoLC and introduced the purpose of the study, its aims, and objectives. The chapter also provided background information to the research and looked at essential concepts. The chapter concluded with the layout of the whole thesis. The next section reviews the literature to identify the gap/s in current knowledge to support further the aims and rationale of the research presented in this chapter.

CHAPTER 2: REVIEW OF THE LITERATURE

2.1. Introduction

This chapter presents the literature review and its aims.

2.1.1. Aims of the review of the literature

The purpose of this literature review was to determine what is known about EoLC for minority ethnic PLWD in general and people of African/Caribbean background. The principal rationale was to identify a gap in the current knowledge base to contextualise the current research question within the existing knowledge base regarding the perceptions, attitudes, views, understandings, and beliefs associated with EoLC for PLWD, thus necessitating this research project. In addition to this, reviewing the literature was essential to position the research methods employed in this project in relation to methods presented in previous primary studies, thus enabling not only an understanding of how knowledge has been negotiated but also identifying future methodological options for research on EoLC. The above aims were achieved by adopting a scoping review approach to synthesize the existing research evidence on EoLC for minority ethnic PLWD.

2.2. Method: Scoping review

A scoping literature review method was chosen over other approaches to reviewing literature due to its suitability to determine the scope of existing research literature available about a given subject area. Arksey and O'Malley (2005) define a scoping review approach as one which aims to map critical concepts of a research area, enabling primary studies and exploration of the type of available evidence. A systematic approach to reviewing literature was initially considered but rejected due to the relatively shared consensus about the lack of EoLC research evidence for minority ethnic people in the context of dementia. Pharm et al. (2014, p.2) explains that a scoping review method "can be of particular use when the topic has not yet been extensively reviewed or is of a complex or heterogeneous nature".

2.2.1. Literature Search Strategy

Because EoLC for people with dementia is currently an under-researched and not a well-defined area in the United Kingdom (UK), I decided to broaden the initial literature search by casting the net wider devoid of rigid search parameters in the hope to reach out to literature on EoLC in dementia. Arksey and O'Malley (2005) suggest that the method for identifying literature in a scoping review 'needs to achieve in-depth and broad results' (p.8) and should locate studies on a topic without being tied to particular study design. One major challenge was that there was minimal peer-reviewed literature explicitly focusing on EoLC for black African and black Caribbean PLWD, with the available research on minority ethnic groups being tending to be small-localised studies/reports (also noted in Moriarty, Rutter, Ross & Holmes, 2012). This challenge was addressed by applying key search terms gleaned from palliative and EoLC literature loosely to dementia without restricting the search to UK based research.

2.2.1.1. Search Terms

'End of life care' OR 'Palliative care' OR 'Terminal care' OR 'Hospice care' OR 'supportive care' AND 'dementia' OR 'Alzheimer's disease OR 'Cognitive impairment' OR 'memory problem' OR 'neurodegenerative disease' NOT 'Cancer' NOT 'Diabetes' AND 'minority ethnic' OR 'ethnic minority community' OR 'Black and Minority Ethnic' OR 'BME' OR 'BAME' OR 'Black African' OR 'African-Caribbean' OR 'Black Caribbean' were used to search for literature. A combination of the above terms was applied to suit each electronic database. The searched databases include MEDLINE, Embase, PsycINFO, Scopus and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The use of Boolean search operators 'AND' 'OR' 'NOT' assisted in narrowing or expanding the literature search.

2.2.1.2. Broadening the scope of the search

Due to lack of literature specific to African/Caribbean with dementia using the above terms, I decided to consult specialist libraries such as the Alzheimer's Society, Social Care Institute for Excellence (SCIE) and National Institute for Health and Care Excellence (NICE). Where literature on a subject area is limited, Greenhalgh and Peacock (2005) suggest a need to consider other approaches to help identify required evidence. In addition to this, I hand searched the reference lists of identified papers to help locate papers/reports on the subject (Armstrong, Jackson, Doyle, Waters & Howes, 2005).

2.2.1.3. Inclusion criteria

The BAME inclusion criterion and search terms outlined above were used for the initial literature search which resulted in the retrieval of very limited data on the subject matter. To broaden the scope of the search, a decision was made to loosen the BAME inclusion criteria and search more widely for literature that would help set the wider context of EoLC and dementia. This decision enabled a comprehensive search of the literature on the subject, and tallies with Petticrew's (2015) recommendation that 'individual studies should be sought and included on the basis that they can add conceptually to the review' (p.3).

- Research papers and reports focusing on dementia care, palliative and EoLC for minority ethnic groups were initially considered.
- Research papers and reports on dementia care, palliative or EoLC and were then considered for the review.
- There was no time limit set and studies/reports needed to be written in English.

2.2.1.4. Exclusion criteria

- Studies/reports were excluded if they were not written in English.

2.2.1.5. Data management

The EndNote library was used to store and organise results from the search and to identify and remove duplicates.

2.2.2. Reviewing the literature

The search aimed to synthesise a wide range of texts covering scientific papers, grey literature, stakeholder websites, and practice related literature and reports. First, the retrieved articles were initially scanned by their title and extracted in full if identified as relevant using the inclusion and exclusion criteria. Following this, the abstracts of each paper were scanned through as a first selection step and inputted into EndNote to allow for further scrutiny. Once an article or report was identified as relevant for the review, the third stage was to examine the paper in its entirety for the appraisal (Aveyard, 2014). Literature from elsewhere was initially skimmed for its relevance before being scrutinised in full. However, there are essential

limitations in these studies, which relates to context, design and structure of the health and social care system including differences in cultural norms, beliefs, and experiences (Darker-White et al., 2000; Milne & Chryssanthopoulou, 2005).

2.3.1. Appraisal of papers

Aveyard's (2014, p.90) guiding questions were useful to make sense of the literature:

- Is the research relevant to my review?
- Have I identified literature at the top of my hierarchy of evidence?
- Is this literature of high quality to include in my review?

The papers considered relevant were critically examined for their relevance and methodological strengths and limitation.

2.2.3. Summary of literature search results

Despite the growing research interest on EoLC for PLWD in general, the literature search generated minimal papers focusing on the EoLC for minority ethnic PLWD in the United Kingdom and no evidence on people of black African/Caribbean background. This lack of UK based research evidence on EoLC for minority ethnic PLWD has been reported in previous literature reviews (e.g., Connolly et al., 2012), and more recently, given the projected prevalence of dementia among this group, and lack of research evidence, a research briefing paper by Koffman (2018) has called for urgent research as 'the absence of UK-based research cannot continue' (p.3). As reported by Connolly et al. (2012), most studies generated during the search were conducted in the USA, a problem identified by many previous papers (e.g., Calanzani et al., 2013, Connolly et al., 2013). Research conducted in the UK papers mainly focused on minority ethnic people's perceptions of dementia, barriers to accessing services and few on caregiving experiences and care decision making. There was a higher number of UK papers on 'minority ethnic groups' but only researching South Asian communities. USA papers principally explored hospice use by African Americans with advanced dementia while some examined caregivers' views on artificial feeding, and EoLC interventions and decision-making.

2.3. Presentation of the review

I present the review in a thematic narrative approach informed by Green, Johnson, and Adams (2006) suggestion of writing narrative literature reviews.

2.3.1. Global perspectives about EoLC for PLWD

Dementia remains a major growing public health challenge internationally, causing a significant impact on health and social care services. This challenge is likely to worsen over time, as the world's population continues to age rapidly (WHO, 2012). This which means the number of PLWD will increase exponentially and thus many people will die from the illness as there is currently no cure available (van der Steen et al., 2014). Despite dementia presently being recognised as the 7th leading cause of death worldwide, international evidence suggests that when compared to people affected by life limiting diseases, people dying from dementia often do not receive quality EoLC (WHO Global Dementia Observatory, 2017).

Globally, EoLC for people dying from dementia has consistently been found to be inadequate and disjointed compared to people with other life-limiting condition (Mitchell et al., 2009). Reasons for this include a historical lack of recognition of the illness as a terminal condition and prognostication problems caused by its unpredictable long illness trajectory (van der Steen et al., 2014). There is a growing evidence base suggesting that access to palliative and EoLC should be made available for everyone with a life-limiting condition. Lack of international consensus on whether dementia is a terminal illness appears to be the main barrier to extending palliative care to people dying with dementia. There are, however, indications of expanding research interests in this area catapulted by a global recognition of the poorer EoL experiences for this group of patients (WHO, 2011). Despite this, evidence on EoLC for people with dementia remains comparably thin.

2.3.2. United Kingdom perspectives about EoLC for PLWD

Individuals from UK minority ethnic communities are significantly under-represented in the take-up of dementia services (Parveen, Peltier, & Oyebode, 2017). Data from the Office of National Statistics (ONS, 2015) revealed that the period between 2014 -2015 dementia surpassed coronary heart disease to become the most common cause of death in England and Wales with slightly over 60 000 people recorded to have died from the condition (Alzheimer's Society, 2017; BBC news 14 November 2016).

Research exploring EoLC for PLWD has consistently shown that poor care is common for many people dying with or from the condition (e.g., Sampson, 2010; Koffman 2018; Pope et al., 2013). One theme highlighted in research has been inadequate communication (the person may no longer be able to make their needs, choices or preferences known) and failure to reliably recognise when an individual with advanced dementia may be nearing the EoL (Moriarty et al., 2011). Despite the Department of Health (DoH, 2010, p.7) stating that by 2014 individuals living with dementia in England ought to approve the statement, "I am confident my EoL wishes will be respected. I can expect a good death" there are indications that people with dementia are still receiving mostly suboptimal care at the EoL (Sampson et al., 2011).

It is estimated that 850 000 PLWD in the UK and are supported by 540 000 family caregivers (Prince et al., 2014), and over the coming years, this number will increase (ONS, 2016). In the UK, the National Dementia Strategy (Department of Health, 2009) set out the impetus for dementia care, including diagnosis. Indeed, there has been a notable improvement in the past few years, with many people being diagnosed early (Robinson, Tang & Taylor, 2015). There is a paucity of research on EoLC for PLWD in the UK (Moriarty et al., 2012). However, the agenda of dying well with dementia has recently gathered some recognition. For example, in January 2017, Professors Alistair Burns (NHS England National Clinical Director for Dementia & Older People's Mental Health) and Bee Wee (National Clinical Director for End-of-Life Care for NHS England) called for a debate on EoLC for people with dementia, an indication of increasing recognition of an understanding of this care. Responding to this call, one of the many blog participants responded:

> *'A debate about end-of-life care for people with dementia is long overdue. My mother died recently from dementia. She died at home, in pain and highly agitated. Palliative nursing teams lacked the relevant experience to care properly for her and administer pain relief appropriately. A request to the local Hospice was denied as the staff did not have the necessary experience to care properly for her, yet...death from end-stage dementia is no different to that of death from some forms of cancer. The fact that many hospices do not accept dementia patients is in itself worth a debate. There are so many issues wrapped up in this subject that need to be addressed.'*

(NHS England 2017: Call to debate EoLC for people with dementia)

This quotation highlights the poor care for people with dementia

With two-thirds of PLWD, living in their own homes (Alzheimer's Society, 2007), and a projected increase of dementia among BAME groups (APPG, 2013), it is time to focus on community-dwelling individuals. The available literature in this area has mainly explored perceptions of dementia (Berwald et al., 2016), and barriers to accessing services (Mukadam et al., 2010). Findings from these studies have revealed reasons behind poor dementia awareness, lack of information regarding impacting care service uptake by most minority ethnic groups with very little attention to on the EoLC for BAME PLWD. Sampson Burns and Richard (2011) found that quality EoLC was a significant concern for family members of individuals with advanced dementia. Sampson et al.'s findings appear to be supported by Robinson, Hughes, Daley, Keady, Ballard and Volicer (2005) who found that most complaints made by families within the NHS were around EoLC for a relative.

The issue around the experience of BAME people with dementia was brought forward by the All-Party Parliamentary Group (APPG, 2013) in which they requested Public Health England to ensure dementia awareness among ethnic minority groups was prioritised. Although the APPG found some examples of reasonable care, they concluded that dementia-related stigma and social isolation was prevalent among BAME communities. The APPG did not make an emphasis on the care for people nearing the EoL. This could be an oversight, given the importance of dying well with dementia enshrined within the National Dementia Strategy (DoH, 2009).

2.4. Ethnic minority people and dementia in the UK

An approximated 25,000 people of BAME background live with dementia in the UK – a number projected to treble by 2051 (Baghirathan et al., 2018). Ethnicity is a multidimensional concept with numerous links to health. Individuals from UK minority ethnic groups are thought to be ageing as the majority of them migrated to the UK in the early 1950s to rebuild the UK after the destruction caused by the World Wars (Lievesley, 2010). Due to their ageing population, evidence suggests dementia may be higher among minority groups (Adelman, 2011). Despite this, many studies have reported that individuals from these groups do not always access dementia care services. They also encounter dementia in a significantly dissimilar way to their white British colleagues (Lawrence et al.,2008). For example, evidence indicates that they often receive their diagnosis at an advanced stage of dementia and help-seeking often happens during a crisis (Mukadam et al., 2013). Cultural appropriateness of services such as EoLC has been identified as fundamental to addressing the long-standing

disparities of access to healthcare services among ethnic minority groups (Scheppers, Dongen, Dekker & Geertzen, 2006). Botsford et al. (2015) note that the UK's BAME population is increasingly diverse yet growing steadfastly as mirrored by an increase of older BAME people between the 2001 and the 2011 census. Mohammed (2017) points out that the rise 'presents challenges for providers of dementia services if they have not worked with these groups previously or if their commissioning process does not consider the major shifts in demographics...' (p.7).

Despite dementia being recognised as a public health priority (WHO 2012), and evidence suggesting a higher prevalence of dementia among minority ethnic groups (e.g., Alderman, Blanchard & Livingston, 2009; Alderman, Blanchard, Rait & Leavey, 2011), there is still minimal knowledge of how BAME people experience dementia within the UK. The needs of various ethnic minority community groups must be understood to ensure health care services are designed to meet the increasing demand of this culturally diverse society (Ahmed, Wilding, Howarth-Lomax & McCaughan, 2017).

Previous studies focusing on South Asian communities found no word for dementia, and many authors argue this impinges on awareness (Mackenzie, 2006; Jutla & Moreland, 2007) and works as a barrier to accessing services (Lawrence, Samsi, Banerjee, Morgan & Murray, 2011). On reviewing the literature, there appears to be a complex cyclical interrelationship between poor understandings of dementia by most BAME communities, barriers to accessing dementia care and related services (including palliative and EoLC) and early diagnosis. The 'cycle' often hinders on ACP which has significant implications on the person-centeredness of EoLC. In regard to Jolly et al. (2009), they found that the lack of understanding of dementia often leads to it being seen as a natural decline concomitant with old age, which further complicates early access to diagnosis and treatment options, a theme that emerged in Mukadam et al. 's (2011) study.

In a recent qualitative study, Berwald et al. (2016) used a vignette portraying an individual with classic dementia symptoms. The researchers then completed semi-structured interviews with fifty participants of black African and black Caribbean ethnicity to explore awareness and barriers to help-seeking for memory related problems and found that most participants thought it was unnecessary to consult a doctor for minor issues such as forgetfulness, despite nearly all the participants' indicating some knowledge of the term dementia. Furthermore, Berwald et al. found that most of the participants conceptualised dementia as a 'white person's illness' a view

that the authors attributed to the existence of stereotypical views rooted in cultural norms and beliefs. Similar beliefs of dementia being a 'white man' illness were reported in Mkhonto and Hanssen (2017) qualitative interview study with white and black South African nurses and carers of people with dementia. Therefore, these views are not uncommon and validate culture as the lens by which people make sense of their illness experiences.

A recent meta-synthesis of qualitative studies by Kenning, Darker-White, Blakemore, Panagioti and Waheed (2017) explored barriers and facilitators among ethnic minority groups' access to dementia care and related services. The authors found that 19 of the 55 papers included in the review reported inadequacies as expressed by carers and general community members about information relating to the causes, symptoms, and prognosis. The theme 'cultural habitus' - a conceptual framework drawn from Bourdieu's (2000) work was used by authors to describe how deep-rooted cultural norms guided behaviour and thinking among the participants. The study highlighted that cultural norms not only influenced care decisions but also influenced ethnic minority group perceptions of Western medicine, resulting in the stigmatisation of dementia.

Kenning et al. (2017) further found that cultural norms and community expectations on caregiving not only played a pervasive role as a barrier to accessing formal dementia service (reported in 10 papers) but also 'put increased pressure on family members' (p.9), often leading to 'concealment and denial' of dementia and carer stress due to fear of community responses. Regarding the acceptance of home care, many qualitative studies indicated families' reluctance about allowing 'outsiders' to come into their homes to provide care. However, Kenning et al. (2017) poignantly point out that the notion of 'outsiders' was mainly expressed in conjunction with trust-related problems.

Berwald et al's (2016) findings confirm previous findings by Mukdam et al. (2011) in which normalisation of early indications of dementia by the participants was found to be a contributory factor of why most BAME people present late to dementia services. Participants in Berwald et al. (2016) also commented that their 'culture was secretive and highly valued privacy and personal affairs' (p.1), with many opposed to discussing private and potentially stigmatising issues with their doctor and others expressing some concerns around 'compulsory institutionalisation' and medication-induced harm. Again, these findings exemplify a more reliable link between help-seeking behaviours and attitudes towards care but appear to be underscored by a lack of understanding of dementia and reluctance around open discussions

regarding mental health problems due to stigma (Kenning et al.,2017). Studies conducted in Sub-Saharan Africa has shown culturally shaped beliefs which are attributed to dementia, with many believing witchcraft to be the cause (e.g., Mkhonto & Hanssen, 2017; Mushi et al., 2014; Agyeman et al., 2017). In Mkhonto and Hanssen's (2017) study, dementia was attributed to witchcraft rather than to disease, leading to the stigmatisation of people with dementia, including beatings, stoning, and even killings. It is likely that when people migrate to Western Countries, they take with them their belief systems (Bhugra, 2004) and such beliefs as uncovered in Berwarld et al. (2016) could reflect the upkeep of such views over time.

One limitation noted in studies focusing on BAME groups in the UK is an inadequate appreciation of differences between minority ethnic groups. Although previous authors (e.g., Jutla, 2010) have called for researchers and healthcare practitioners to appreciate the diversity between and within BAME groups, the problem has not been addressed in the literature. The danger of categorising BAME groups as a homogeneous group is itself a barrier to mainstream care services and research participation (Salway et al., 2009); while notoriously masking unique variations, for instance, people from South Asia, are referred to as 'South Asians' in literature, often without delineating that they are not homogeneous (La Fontaine, Ahuja, Bradbury, Phillips & Oyebode, 2007). Gerrish (2000) has maintained that continuance of failure in research to account for these differences may render a study meaningless due to lack of representation and is one factor justifying this enquiry.

Ahmed et al. used both interviews and focus groups with representatives from BAME and stakeholders to explore how access to dementia services could be improved for BAME people in the Salford area and found that imperfect knowledge of dementia, including the existence of negative conceptualisation of the condition such as seeing it as a form of 'madness' existed.

Bullock (2011) found that EoLC preferences among USA minority ethnic groups were primarily influenced by one's culture and ethnic background. While it is essential to understand that lived experiences of minority ethnic groups in the USA would more likely be different from ethnic minority groups in the UK, based on various aspects, for instance, migration experiences, Bhopal (2012) cautions researchers around the use of terminology about ethnicity as context and societal values often shape people's preferences. Similarly, a wealth of evidence (e.g., Evans & Ume, 2012; Braun, Beyth, Ford et al., 2008; Carr, 2011) has shown that Hispanics, Asian and African Americans rarely document or discuss preferences for EoLC and do not often prioritise planning even when severely ill. Lackan, Eschbach, Stimpson et al.

(2011) found that most ethnic minority people in the US continue to be reluctant to access hospice care. At the EoL, many who also have an underlying belief that suffering is a normal part of life often prioritise aggressive treatments, and nothing can be done other than seeking resilience through religiosity.

Despite national and international calls for the improvement of EoLC for PLWD (e.g. the European Association for Palliative Care white paper [EAPC] 2014; UK's Department of Health (2009) End of Life Care Strategy and recently, the National Institute for Health and Care Excellence (NICE) guidance for care of the dying adults in the last days of life, research has shown that BAME PLWD remains underrepresented in services, including palliative and EoLC services (Daker-White Beattie, Gillard & Means, 2002). However, a Social Care Institute for Excellence research briefing (Moriarty, Sharif & Robinson, 2011) found that many BAME groups' knowledge of dementia and related services remains low which does not fit in well with the National Dementia Strategy (Department of Health, 2009) recognition of early diagnosis which helps to implement treatment pathways early and maintain people's functional skills longer.

Additionally, a review of the literature by Mukadam, Cooper and Livingstone (2010) revealed barriers to help-seeking, resulting in most BAME people presenting to memory services at late and at a crisis point when dementia has reached the advanced stage. Mukadam et al. also found that beliefs associated with dementia, denial, communication barriers perceived discrimination and a view that nothing can be done compounded access to services and could help explain low service uptake by many BAME communities. For similar reasons, Chin et al. (2011) also found delays in receiving dementia care among Hispanic and African American groups.

In 2013, the All-Party Parliamentary Group for dementia (APPG)'s report *'dementia does not discriminate'* put the agenda of understanding the experience of BAME PLWD at the core. The report called for services to be made available and to consider how people from UK minority groups experience dementia to meet their needs. Highlighted in the APPG report (2013) was a need to understand the relationship between people's culture, ethnicity, and dementia. Botsford and Harrison Denning (2015, p.9) assert 'there is growing evidence that ethnicity and cultural backgrounds are significant with regards to how both individuals and communities deal with the onset of the cognitive changes associated with dementia'.

Despite targeted campaigns (dementia friends' campaign, dementia-friendly environments, and National Dementia Strategy etc.); these findings show the existence of the poor understanding

of dementia by most people from minority ethnic groups, which have a significant implication on early diagnosis and future care planning. While some studies have explored the usefulness of future care planning or ACP concerning EoLC for PLWD, questions regarding how African/Caribbean PLWD and their carers make use of future care planning has not been fully explored. An issue relating reluctance in discussing issues related to death and dying are barriers to future care planning (Seymour, Gott, Bellamy, Ahmedzai and Clark, 2004); yet a broad evidence base shows that for PLWD and their families, having these often tricky discussions about the future can be helpful in EoLC decision-making process (Harrison-Denning, King, Jones, Vickestaff & Sampson, 2016), thus helping to ensure quality person-centred EoLC is given.

The person-centeredness of EoLC should be the extent to which the recipient of the care is involved and how the care meets the needs of that person, and his or her family is a measure of its quality. Nyatanga (2001) argues that the notion of quality care 'is culturally subjective, and it is important that quality is achieved with the patients in mind' (p.245). Concerning this, the SCIE report further called for understanding around cultural stereotypes based on the assumption that view service providers needed to be sensitive to cultural stereotypes that mean some communities are assumed to 'look after their own', which often results in services failing to reach out to BAME communities.

A recent report *'A different ending addressing inequalities in end-of-life care'* by the Care Quality Commission (CQC, 2016) found that people from BAME continue to have negative experiences towards the end of their lives often leading to inadequate care experiences. There has also been an increasing politicisation of dementia care in the UK, for example, the Prime Minister' Dementia Challenge 2020 seems to have set a strong political impetus including an increase in research and funding. While the PM's challenge calls explicitly for 'culturally competent' care for BAME PLWD, less has since been done to improve the experience of minority ethnic groups with dementia (Truswell, 2013), no UK studies have explored the EoLC for BAME people with dementia (Koffman, 2018).

Calanzani, Koffman and Higginson (2013) on behalf of Marie Curie and Public Health England concluded that despite a growing evidence base, which indicates that ethnic and cultural differences can contribute to people's illness experiences and their behaviours around illness, there, was very little covered about the experience of PLWD and their family carers concerning EoLC. However, most research on BAME groups tend to focus on exploring barriers to

accessing care, treatments, and diagnosis (e.g., Hashmi & Seabrooke, 2009; Mukadam et al., 2011), and have highlighted that people from these backgrounds face barriers in health and social care, though less has been explored in the context of EoLC.

Much of the research discussed above has helped examine barriers to and inequalities in health and social care, which includes underrepresentation of BAME groups in services and low uptake of formal dementia care. Findings from these studies have provided some insights into the interwoven nature of culture, ethnicity, and stigma. Most importantly, how all these relate not only to access services but also, to how people understand and make meanings to their experiences with dementia.

2.4.1. Culturally motivated perceptions of dementia

The influence of culture on how people perceive, and experience dementia has been reported in many previous studies (e.g., Lawrence et al., 2006; Clarke et al., 2017) and thus cannot be overlooked if dementia care, including EoLC for BAME people, is to take a new direction towards being culturally relevant. Most BAME groups perceive dementia as a natural process of ageing (Lawrence, Murray, Samsi, & Banerjee, 2008) while scribing various meanings to explain its existence, such as punishment from God (Samsi et al., 2010) and even witchcraft (Mkhonto & Hanssen, 2018). Available evidence suggests that cultural beliefs and norms inform people's understandings of their health and illness (e.g., Dilworth-Anderson et al., 2002, Mukadam et al., 2011, LaFontein et al., 2007). Therefore, it is through the lens of culture that people negotiate and attach meanings to the symptoms that define a condition like dementia. Recognising the implications of people's perception and the related ascriptions and meanings should be a fundamental consideration in formulating services for minority groups (Mackenzie, Bartlett & Downs, 2005).

Samsi, Banerjee, Morgan, and Murray (2010) so rightly point out 'the profound effect of culture and ethnicity on caregiving underlines the imperative of addressing the cultural context of the person with dementia's experience' (p.40). Lawrence et al. (2010) conducted a grounded theory guided qualitative study with PLWD to examine the experience of living with dementia among the black Caribbean (n=11 South Asian (n=9) and White British (n=10) and theme 'threat to valued elements of life' emerged from a thematic analysis of interviews. The theme highlighted the view that dementia poses a threat to people's abilities to live autonomously.

This threat to valued elements of life has been reflected in Kitwood's work, who has emphasized that the experience of dementia is socially embedded, where the person with a neurological impairment interacts with his/her immediate social environment (Lawrence et al., 2010), which also brings at the fore a need to understand the cultural context in which dementia is being experienced - the notion of 'personhood'. Downs (2000) maintains that understanding cultural meanings not only helps us to the lived experiences of PLWD but also assists in mapping individuals' response to living with the condition. Despite this recognition of the effects of culture on meanings attached to dementia, in the UK, Lawrence et al. (2010) note 'most striking is the stark absence of research with minority ethnic groups' (Lawrence et al., 2010, p.40). The lack of research focusing on BAME people and their experiences of dementia and related care has contributed to poor care experiences and lack of confidence on healthcare professionals regarding how best to provide care to this group of people. For example, a qualitative study by Kai et al., (2007) found that lack of knowledge about the care needs of BAME groups increased lack of confidence and uncertainty among staff, often resulting in inadequate and discriminatory care

To explore issues of ethnicity and culture in EoLC among nursing homes in the UK, Badger, Clarke, Pomphrey, and Clifford (2009) conducted a mixed-method study using surveys and qualitative interviews with care home nurse managers. The authors found that the delivery of culturally sensitive care varied. Some homes were found to be responsive to residents' diversity, while others responded to culturally relevant care issues on an 'as-required' approach (Badger et al., 2009, p.1726). Some home managers who participated in the study reported that they faced difficulties with meeting BAME dietary requirements, although, overall, the approach to providing EoLC and meeting people's needs was found to be of some quality. There was an emphasis on enhancing care staff's understandings of different cultural and religious needs of older people nearing the end of their life.

Previous studies have also highlighted a need for cultural knowledge to be embedded within service formulation and delivery to prevent discriminatory care and narrow the lack of trust and under usage of services (Mackenzie et al. 2006). All this supports a need for a deepened understanding of the experience of care from the perspectives of those receiving it and their families. It also reinforces a debate regarding a necessity for those who provide services to acquire cultural competence to engage well with various UK ethnic minority groups (Smedly et al., 2003).

2.4.2.Dementia related experiences among BAME communities

Dementia in people from BAME groups can be described as 'hidden' as there are suggestions that prevalence could be higher yet diagnoses and help-seeking remain low. However, literature also tends to depict people from BAME as 'hidden' and 'hard to reach' which, while true, can further hinder efforts to reach out to these communities, mainly when brought together with some widely held views such as the belief that BAME looks after their own (Department of Health, DoH 1998; Cheston et al., 2017). Being 'hidden' may depict that BAME PLWD and their carers do not receive the care and support. 'Hard to reach' as a term, should not be used nowadays as it blames the people, further feeding into the negative discourse that expands, rather than narrow the current disparities. For example, Ahmed, Wilding, Haworth-Lomax & McCaughan (2017) conducted a piece of qualitative work which aimed to explore people's lived experiences about dementia, access to services and support in Salford area and found that care for PLWD was primarily family-based and dementia service awareness was shallow. Ahmed et al. also found that because care was family-based, this led to low service uptake, which then fed onto the view that 'they look after their own'- a belief which can become a barrier if used without caution (Cheston et al, 2017). This assertion also fails to account for changes in family caregiving between the older and younger BAME generation.

Given that caregiving is a family-based entity in most BAME communities regarding EoLC Nyatanga (2002, p.243) has warned that 'professionals may wrongly deduce that they do not need to provide care to these patients and their families'. Each person experiences dementia differently; however, people from ethnic minority groups may experience living with the illness differently due to culturally substantiated views, ethnic status and stigmatisation of dementia, which is higher in these groups (Mukadam et al. 2011). Policy on dementia care and previous studies have emphasised the notion of 'living well with dementia' (DoH, 2009). However, there is limited available research evidence on what 'living well with dementia' is about from the perspectives of BAME PLWD as their voice in research is seldom heard. The little available research has mainly focused on South Asian communities, caregiver's experiences, and professionals. One Norwegian study examined the lived experience of minority ethnic nurses and found that they were motivated to acculturate to the host population norms to provide quality care to PLWD (Egede-Nissen, Sellevold, Jakobsen, & Sørlie, 2017). The dementia strategy (Department of Health, 2009) acknowledges that dementia has no racial barriers. It affects everyone, and it does not discriminate (APPG, 2013), however reaching out to most

minority ethnic groups to address health care inequalities remains a question that has yielded short answers in research (Moriarty & Butt, 2004).

Inequalities in health and social care are not a new phenomenon, early reports by the Brownfoot Associates (1998) and the Department of Health (2001) pointed out that BAME people face stigma related to mental health problems and dementia. Research by Daker-White et al. (2002) also found that BAME groups often did not know what services were available and were more likely to perceive the available services untrustworthy. However, a closer look at the related literature shows evidence that these inequalities seem to have been around the 'hard to reach' discourse (Flanagan & Hancock, 2010), a narrative which deters service providers from exploring options of engaging with BAME communities (Cheston et al., 2017). While these epithets make us understand the barriers to reaching out to some groups within our communities, using them with no caution can inadvertently perpetuate the existing disparities. Similarly, embedding the 'hard to reach' into discourse may have severe implications from care providers' position. For instance, Ahmed et al. found that stakeholder assumptions that most people from BAME receive care from their family acted as the barrier to accessing dementia services. Inequalities in healthcare may no longer be conceptualised around these notions, given how the UK is increasingly becoming diverse, ethnically, and culturally. Moriarty and Butt used a cross-sectional survey to investigate disparities in quality of life among older people from various groups and found a relationship between inequalities in healthcare and people's income. Presenting late to services such as memory clinics may mean opportunities for early diagnostic work are constrained and family caregivers may have provided care with minimal resources potentially affecting their health and wellbeing (Bowes & Wilkinson, 2004).

The effect that culture and ethnicity have on caregiving, according to Lawrence, Samsi, Barnerjee, Morgan & Murray (2010) underlines the imperative of exploring the cultural context of BAME PLWD. A wealth of evidence shows that future care planning can improve the quality of life of PLWD at the EoL as it helps care providers to use the person's preferences to deliver personalised care (e.g., Hospice UK, 2014; WHO, 2011). The importance of time in implementing early discussions regarding future care preferences is crucial. However, as highlighted earlier, minority ethnic people present late in services, which means that families may no longer be able to discuss future care needs with their relative with dementia due to loss of decisional capacity (Mukadam et al., 2010), thus impacting on for future care choices and preferences. For these reasons, early diagnosis is highly recommended to allow PLWD to plan

(Samsi & Manthorpe, 2011). Families and healthcare professionals may have to make decisions on assumptions, which may not represent the person's choice and preferences.

2.4.3. Dementia related experiences of BAME family caregivers

Johl, Patterson and Pearson (2014) define a family carer as 'an individual helping a relative who is experiencing difficulties due to physical, emotional or cognitive impairments, often without financial compensation' (p.4). As discussed earlier, two-thirds of PLWD live in the community, and family caregivers provide most the care. Previous research conducted with caregivers of BAME PLWD has reinforced that cultural norms and beliefs have an impact the meanings that individuals attach to symptoms of dementia and the nature of care (Dilworth-Anderson, Williams, & Gibson, 2002). However, these studies research have mainly channelled their focus on caregiver burden. Lawton, Rajagopal, Brody and Kleban, (1992) studied 127 black American caregivers of PLWD and found lower caregiver burden levels when compared a sample of 472 American White caregivers. Cultural meanings attached to caregiving and the underlying caregiving ideology was attributed to caregiving satisfaction. Similarly, Dilworth-Anderson and Gibson (2002) qualitatively studied 121 caregivers (predominantly African-Americans) of PLWD to examine the relationship between meanings assigned to dementia and cultural values, norms, and beliefs and found that family caregiving and help-seeking were influenced by the family members' definitions attached to dementia. These findings suggest that cultural norms and expectations underscore the caregiving role, while meanings attached to dementia influence help-seeking behaviour.

Some researchers in this area, such as Janevic and Connell (2001) and Yeo (1996), though USA based, have argued that assumptions about dementia caregiving experience drawn on research evidence using samples of White American caregivers may not reflect an accurate picture for other groups based on factors such as socioeconomic status and approaches to caregiving hence, the delivery of care services based on such assumptions may be as unfitting. This is particularly relevant in the UK, especially considering the lack of research evidence on EoLC for BAME PLWD and their families. End of life caregiving for PLWD is a highly demanding role for family caregivers (Alzheimer's Society, 2017; Pinquart & Sorenson, 2005). While it has been extensively researched, less attention has been paid to family caregivers' experience towards the EoL of the care recipient. Less attention has also been directed on how bereaved caregivers make sense of their experiences of EoLC received by their relative.

Insights into the nature of family caregiving towards and following the death of a relative with dementia were highlighted by Schulz et al. (2003) who as part of the REACH (Resources for Enhancing Alzheimer's Caregiver Health) used structured interviews and standardised instruments to examine the type of care and experiences of 217 family caregivers through the year before the patient's death and following the bereavement of the care recipient. Schulz and his colleagues found higher depressive symptoms during caregiving before the death of a family member with dementia, which subsided following the death. In the space of 3 months following the death of the relative, caregivers' depressive symptoms declined significantly, and in a year, the levels of symptoms subsided markedly lower compared to the level reported while active caregiving. The authors found that 72% per cent of family carers stated that the death of their relative with dementia was a relief for them, whereas 90 % of the carers thought the death was a relief for the care recipient. The authors concluded that when death is preceded by a long period of caregiving as typified by the long and dwindling illness trajectory, which is often punctuated by infections and the associated unpredictability, all this can lead to a significant stressful period for caregivers. When their relative *finally*[2] dies, it can be experienced as both a loss and a relief.

Despite their caregiving experiences as in Schulz et al. (2003), Greenwood, Habibi, Smith and Manthorpe, (2015) points out those family caregivers of people with long-term conditions are rarely acknowledged in the literature. Research on caregiving in dementia has mainly been looked at through Lazarus and Folkman (1984) Stress and Coping model and guided by the caregiver Stress Process Model established by Pearlin, Mullan, Semple & Skaff (1990). While these theoretical models have helped identify essential structures of dementia caregiving across minority ethnic groups, EoL caregiving in the context of dementia remains relatively less researched and has suffered from lack of qualitative research interest (Lawrence et al., 2010).

Several studies have highlighted the notion of intergenerational reciprocity as a mediating factor fundamental to the maintenance of familial ties and most crucially, as a way of preserving the family's dignity and sense of honour (Mahoney, Cloutterbuck, Neary & Zhan, 2005; Sun, Ong & Burnette, 2012). Consequently, this has been thought to create an imbalance of care, unfulfilled expectations, which further generate stigma and resentment to those

[2] I use the word '*finally*' to delineate this period from anticipatory loss that the relatives of a person with dementia may experience along the course of the illness as reported in Garner (1997)

providing the care, mainly due to dearth of awareness of dementia as an illness and its impact to the person (Berwald et al., 2016).

Carers UK (2011) notes that in the United Kingdom (UK), BAME family carers often provide more care than majority groups. One possible explanation for this could be the existence of traditional caregiving attitudes and a sense of 'duty' in providing care reported by Ahmed & Rees-Jones (2008) in their secondary analysis of qualitative data that explored caregiving among Bangladeshi family caregivers. Similarly, Parveen, Morrison and Robinson (2011) qualitatively explored the variations in caregiver role between carers of South Asian (SA) background and white British and found that familism or sense of obligation/duty was common and often led to SA caregivers being extrinsically motivated while white British carers were intrinsically motivated (relationship with care recipient). Yeandle, Bennett, Buckner, Fry and Price (2007) used a survey and semi-structured interview across the UK to explore carer's needs and found that carers from minority ethnic background stated that they were not aware of services due to the unavailability of information. Yeandle et al. found minority ethnic carers reported that the available facilities/services were unresponsive to their needs. Similarly, Gunta et al. (2004) in their telephone interview with minority ethnic caregivers in the USA and found that cultural values and beliefs influenced both the caregiving context while it also impacted their attitudes towards service uptake. These studies highlight the interwoven nature of culture, approach and philosophy to caregiving and use of care services.

Family carers play a vital role in supporting PLWD throughout their journey with dementia and at the EoL (Greenwood et al. 2015); therefore, their experience can be a valuable source from which understandings of both their own needs and those they care for can be developed. In the context of the EoLC for PLWD, there are very limited UK based studies which explores family caregiving (Koffman, 2018). However, research has revealed that perceptions of dementia among BAME communities can influence both diagnoses, care experience. For example, Patel, Mizra, Lindblad, Amastrup and Samoli, (1998) found that South Asian caregivers attributed signs of a dementia process to normal ageing or "an act of God," while stigmatisation of the condition was common.

The impact that dementia has on people extends far beyond the person with the condition (Wattis& Curran, 2011). At the onset of dementia, families often readily provide care to their relative; however, as dementia progresses, carers are often continuously expected to adapt to their relative's changing needs. Prigerson (2003) notes that due to the condition's trajectory,

which is usually long and unpredictable, caregiving to PLWD can be a demanding role but can also be a fulfilling one for family members. About decision making at the EoL, the family carers would have known the wishes of their relative with dementia during their caregiving journey, and thus are best be placed to make decisions that reflect the aspirations of their relative once decisional capacity is impacted by dementia in its advanced stage. Research has found that at the EoL, family carers may ensure the person's wishes are prioritised and respected. Vickrey et al. (2007) conducted six focus groups with 47 caregivers of PLWD from African-American, Chinese-American, Euro-American, and Hispanic-American communities to examine ethnic variations in dementia caregiving experiences and found that differing conceptualisation of dementia-specific stigmatization, use of spirituality and religion to cope with the burden of caregiving, language issues and discrimination. These findings advocate that narrowing the disparities in EoLC for PLWD necessitates a need to appreciate these variations that underscore caregiving (Vickrey et al., 2007).

Many studies suggest that at the EoL, family carers may experience grief and loss before the death of their relative with dementia. This often affects the psychological well-being of carers, and when coupled with the increasing care needs, family carers may experience significant carer stress. However, the caregiving journey is subjective; therefore, family caregivers will respond differently (Brodaty & Donkin 2009). The stigmatisation of mental health, including dementia, has also been explored among BAME communities. For example, a qualitative study by Mackenzie (2006) completed semi-structured interviews with 18 carers from Eastern European and South Asian communities in the north of England and found that many carers commented on experiencing stigma when caring for their relative with dementia. The findings of this study highlight that both cultures experience shame about having a diagnosis of dementia or having a family member who is living with dementia. For example, some carers revealed that experiencing stigma from people from their community made them avoid seeking help from other members of their community while some had to ‘cover-up' things despite facing significant carer stress. Brought together, these findings show that some BAME groups possess various perceptions of dementia ageing and caregiving can be a barrier to help-seeking. The term ‘tribal stigma’ is used by Liu, Hinton, Tran, Hinton, & Barker (2008) to illustrate the nature of humiliating feelings that a family holding filial piety responsibilities can experience when an older person, who is expected to fill a particular role, fails due to dementia.

There is an issue of culture and ethnicity being highlighted in many studies; however, this has been examined from a service delivery perspective rather than from a meaning-making lens.

For example, Mukadam et al. (2011) found that cultural pressure, such as seeing caregiving as family-based and concerns about criticism by relatives and friends surfaced as a barrier to help-seeking. While these findings have triggered a debate around cultural responsiveness of services, it is unclear how cultural beliefs relate to EoLC for BAME PLWD and their family caregivers. In Giunta et al.'s (2004) study, authors found that cultural values and beliefs not only influenced the context of caregiving but also influenced service uptake and family caregiving caring role duties. There is a strong orientation to the importance of understanding cultural norms, as caregiving among BAME groups appear to draw extensively on cultural expectations.

Johl et al. (2016) found that fear of stigma led to carers being isolated; however, from the caregiver lived experience perspective, 'covering up' was a technique of avoiding the stigma. Mackenzie's (2006) study provides an understanding of the impact stigma has to family caregivers and care recipients, the study has a limitation in that there was a lack recognition of the inherent differences culturally between and amongst different South Asian community subgroups. It is crucial to understand these differences among BAME communities when researching ethnic minority groups (Bhopal, 2006).

Similarly, in their findings from a qualitative study with eighteen carers which aimed to examine why older people from UK minority ethnic groups present late to dementia care services, Mukadam et al. (2011) found that fear of stigma was a barrier to accessing services. Mukadam and her colleagues also found that four White caregivers who participated in their study did not express that they feared stigma.

A person with dementia may still be cared for at home and carers may have to adjust to continuous changes at home such as having to deal with various professionals who may visit the dying relative at home. However, research has shown that such adjustment may not be easy for BAME family caregivers due to both community stigma and cultural views of caregiving. Schultz et al. (2003) found that dealing with communication with professionals, together with the psychological impact of providing care resulted in carer burnout. Towards the EoL, family caregivers may develop poor sleep patterns, feel exhausted, and changes such as incontinence problems may become difficult to deal with.

Studies (e.g., Brodaty & Donkin, 2009) found that family carers experienced a poor physical and increased risk of psychological ill-health. Despite caregiving to a person with dementia being a round-the-clock task, Lawrence (2008) found that caregivers from BAME background

were often unwilling to access support services resulting in poorer healthcare experiences. However, there remains a dearth of research evidence explicitly looking at family caregiver experience, including what it means to be an African/Caribbean family caregiver to a relative with dementia. Using a grounded theory approach and in-depth interviews to explore attitudes and support needs between ten black Caribbean, ten South Asian and twelve white British carers (n=32), Lawrence (2008) found that carers' attitude revolved around a 'traditional' or 'non-traditional' principle. These caregiver attitudes further shaped how most of them understood their role (e.g., natural, expected, or virtuous) and informed caregiver attitudes towards services. Similar findings have been echoed on many studies; for example, Ahmed & Rees-Jones (2008) concluded that religious beliefs often fueled the notions of 'caregiving duty' particularly in most Asian groups. In conjunction with dementia, many authors such as Javenic and Connell (2001) have reported that cultural norms vary regarding the stigma and meanings associated with living with dementia, which often has implications on how minority ethnic groups interact with dementia care service systems.

It has been asserted that BAME family caregivers face similar challenges as other carers; however, the literature suggests that they face additional barriers underscored by cultural barriers, stereotypes, and language. While the findings show that, there is a cultural dimension in carers' attitudes towards care; it is unclear how their cultural views influence meanings associated with caregiving in dementia care. A study by Townsend and Godfrey (2001) revealed that caregiving underpinned by filial responsibility existed among minority ethnic groups and stereotypes around gender were at the core of caregiving responsibility. Within the UK's diverse population, each community have specific and different dementia-related needs, and thus BAME communities should not be viewed as a single homogenous group. These differences demand a need to work closely with various groups to understand their needs and ensure care and support services are presented in conducts that are culturally appropriate for each group (Bhattacharyya, Benbow, & Kar, 2012).

Seabrooke and Milne (2004) found that BAME carers tend to care unaided and in isolation, though to date, research has explored issues pertinent to caregivers of BAME with dementia at the EoL mainly from carers or from studies that do not recognise the diversity and differences with one ethnic minority group. In qualitative research guided by a grounded theory approach in which Adamson and Donovan (2005) interviewed twenty-one African/Caribbean and fifteen South Asian family carers of PLWD, issues related to filial responsibility as reported in Mackenzie and Godfrey (2001) emerged. These findings may suggest approaches taken by

various ethnic minority groups to EoL and could reflect expectations related to caregiving. For instance, Greek Cypriots expected their daughters to provide care while there was no emphasis on a similar expectation by African/Caribbean carers in a study by Botsford et al. (2011).

Some studies have found that caregiving among BAME groups can be perceived as a duty. This was demonstrated by a qualitative study by Parveen et al. (2011) aimed to delineate between extrinsic and intrinsic motivations for caring and found that South Asian caregivers were mostly extrinsically motivated. The authors found that motivation stemmed from perceiving their role as an obligation or duty. It is, however, unclear how caregiving motivation is experienced at the EoL. Although a systematic review of pathways to care in dementia by Mukadam et al. (2011) found various barriers among BAME groups such as not recognising dementia as an illness and seeing caring as personal or family responsibility and as well as stigmatisation of dementia, this has not been explored in relation to the EoLC.

Lawrence, Murray, Samsi and Banerjee (2008) in their qualitative study which compared the caregiving experiences of African Caribbean, White and South Asian family carers conducted in-depth individual interviews with thirty-two carers, aged between 33 and 87 years around London and their study, found similar views as in Adamson and Donovan study; for instance, many perceived caring as a role which was an addition to their active responsibility as family members. Interestingly, the researchers maintained that the carers who held a 'traditional caregiver ideology' perceived giving care as a natural response that can be expected from a family member, for example, African Caribbean family carers born in the UK, predominantly 2nd or 3rd generation) did not have similar traditional caregiving views as held by older 1st generation carers. The further study highlighted that carers' religious beliefs had a significant impact on the nature of the caregiving role, for example, South Asian daughter and son carers mainly drew extensively on religious beliefs and saw caring as not only a cultural norm but also as a time to give back to their parents for what they have done for them (looking after them).

These findings offer insights on differences in views about caregiving between older and younger BAME people, which suggest possible effects on caring due to current demographic changes (Nyatanga, 2002). Due to participants being from London area, Lawrence et al. (2008) study findings are limited to the participants who participated in the study and not representative of the broader UK BME community.

A rich evidence base suggests the existence of variations in caregiving experiences that reflects ethnic and cultural differences in society. For example, African American caregivers have been found to experience lower levels of burden and often view their role from a positive standpoint when compared to White American caregivers (Dilworth-Anderson et al., 2002). Also reported in Lawrence et al.'s study, some scholars in this area have asserted that likely explanations could be possible cultural differences in stress appraisal, coping strategies, nature of support networks, and intrinsic attitudes and meanings attached to caregiving (Aranda & Knight, 1997, Parveen et al., 2011).

2.5. EoLC related experiences among BAME communities

> *How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services*

(Department of Health, 2008, p.10)

Despite the above quote, people dying from dementia, who are a vulnerable group, continue to die badly (Sampson, 2010). As providing excellent care is a 'litmus test' and an indicator of how well health and social care services are delivering essential services to those nearing the end of their life, it is, therefore, reasonable to say EoLC services are failing the 'litmus test' given the poor and suboptimal EoLC that people with advanced dementia continue to receive. Previous research has revealed various potential barriers to accessing palliative care services for BAME people. Key themes identified included lack of cultural and religious sensitivity in how services are delivered, perceived and structural discrimination, language barriers, cultural underpinned views in relation to death, and as previously discussed, some assumptions that BAME people look after their own. However, much research USA based, and the use of such evidence in the UK raises questions of relevance (Connolly et al., 2012). This literature review has identified paucity in studies focusing on the experience of BAME people with dementia in the context of the EoLC within the UK despite the projected increase in the prevalence of dementia among these groups.

Connolly et al. (2012) completed a comprehensive review of the literature on EoLC for minority ethnic groups in the UK and found that all 20 studies that met the criteria for the report were conducted outside the UK. Nineteen studies of the twenty identified adopted quantitative

methodologies, with only one being qualitative. The review found the existence of disparities in EoLC for PLWD from ethnic minority groups, which they argued, might be due to difficulties posed by living with dementia and ethnic minority status. Although the review reported EoLC experiences for minority groups with dementia, there are problems of context, given that most of the research was completed with African-Americans, Asian groups and Hispanics whose experiences are different from UK minority groups. A common theme found by Connolly et al. was that most African Americans preferred not to make decisions to withhold treatments while artificial feeding and life-sustaining procedures were more frequently applied. These preferences have been attributed to historical events that incited a lack of trust and suspicions on medical interventions such as the Tuskegee Study (Gamble, 1998). There is also some evidence suggesting that caregivers' experiences differ between ethnic groups, although the level of strain that these carers face in their role appears to be the same (e.g. Dilworth-Anderson, Williamson & Gibson, 2002, Parveen et al., 2011), though there is limited evidence of these experience in relation to family caregiving in dementia at the EoL. Connolly et al. (2012) is the one vital evidence which shows limited availability of EoLC research for PLWD in the UK.

Generally, research evidence exploring EoLC experiences, as noted by Burt (2012), has been constrained by dependence on retrospective data, mainly gathered from proxy respondents, for example, bereaved family members. While these studies have contributed towards the provision of care to PLWD and understandings of lived caregiver experiences, they lack the subjective voice of PLWD. Personal stories told by PLWD may reveal the meaning of what it means to be a minority ethnic person living with dementia and what is essential at the EoL. Calanzani et al. (2013) found that BAME people had more unmet EoLC needs compared to people from white a background. In addition to this, barriers to access the available services further exacerbates their unmet needs. Most studies related to the experience of minority ethnic people with dementia in the context of the EOLC has mainly been conducted in the United States and primarily utilise quantitative approaches that do not capture in-depth subjective experiences.

One study; Parveen et al. (2016), used a 'scoping exercise' (roadshow discussions) to explore perceptions of dementia and use of related services by minority ethnic communities and found differences in responses, for instance, African and Caribbean PLWD and their carers viewed dementia as being caused by 'dying of brain cells' while Indian groups referred to dementia as 'brain confusion'. This lack of understanding may explain why BAME people mainly get their

diagnosis late resulting in poorer care experiences and 'missing opportunities' of discussing future care needs before decisional capacity is affected by the progression of dementia.

In his report: A *Fragmented Pathway Experiences of the South Asian Community and the Dementia Care Pathway: A Care Giver's Journey*, Mohammed (2017), who wrote about his caregiving experience for his mother who had dementia and received EoLC at home, reflects on the impact that a dementia diagnosis and a person's minority ethnic status often have. Mohammed talks about 'a triple discrimination' when referring to the contribution that language, ethnicity, and dementia had to the difficulties he encountered in navigating the [fragmented] dementia care pathway although he reveals that his mother received excellent care in the hospital before he requested her to be transferred home following a prognostication of EoL:

> *I made it clear to everyone that I wanted mum at home with my immediate family and me; the response from the nurse who I spoke to was amazing. She said that now that I had decided that we wanted mum at home she could start the process of transfer almost immediately.…'*

(Mohammed, 2017, p.24)

Once home, Mohammed writes that the transfer of his mother's care from hospital to the community was not smooth, for example, the discharge doctor had not signed off prescriptions from the hospital, and the district nurses who visited had not brought the syringe driver, though the error was corrected the following day. He goes on to describe the Hospice at Home team who visited his mother as 'very professional and took charge straightaway' (p.26). However, the main problem was making sense of various professionals from various services that immediately got involved in his mother's last few days, such as hospice nurses, district nurses and Occupational Therapists. Similar experiences such as Mohammed's have been reported in research. Mohammed's experience following his mother's discharge from hospital highlights a need for collaborative working across various services, for instance, a review of literature on partnership working by Gardiner, Gott, & Ingleton (2012) found that excellent communication between specialist and generalist palliative care providers, including clarity of roles and responsibilities among professionals, facilitated the delivery of coordinated care.

Calanzani et al. (2013) synthesised findings from 45 literature reviews on EoLC for minority ethnic groups, and they found that PLWD often receives suboptimal and mostly disjointed care

at the EoL. As most studies in Calanzani et al. review were conducted in the USA (as noted in Connolly et al. 2012), they did not fully reveal about the UK situation. However, there are indications of poor end of care experiences specifically for PLWD within the UK (Robinson et al., 2006; Thune-Boyle et al., 2010), and more so in minority ethnic groups due to specific barriers such as lack of service awareness and stigmatisation of dementia (Connolly et al., 2012).

Gysels et al. (2012) suggest culture is a crucial component and vehicle towards an understanding of appropriate care for people nearing the EoL as identified by their expert panel study. The thirty experts on EoLC who participated in panel identified of a need for research to explore concepts of culture and cultural competence; and called for a definition of EoLC in the context of social and cultural diversity (Gysels et al., 2012). At the EoL, family members and those close to the person with dementia often find it challenging to come to terms with the situation.

Previous studies have reported that family carers begin grieving while the person is alive (Chan, Livingston, Jones & Sampson, 2013; Herbet, Dang & Schulz, 2006). One reason is caused by a long-protracted illness trajectory that mainly typifies dementia in which the person's skills of daily living are impacted (Blandin & Pepin, 2016), which often affects caregivers' health (Holley & Mast, 2009). Dupuis (2002) interviewed adult daughters and sons who were providing care to their parents (38 and 23 respectively) to explore the experience of ambiguous loss and found that caregivers went through phases of experiencing anticipatory loss, which changed as the care recipient deteriorated. Givens et al. (2011) reported that elevated pre-death grief was a reliable indicator of difficulties among caregivers following the death of the recipient of care and support.

These findings would appear to support evidence that caregivers of PLWD often develop severe mental and physical health problems (Kiely, Priggerson & Mitchell, 2008). Witnessing the changes as the person journeys with dementia often triggers a sense of loss, which can further be strained by limited communication at the advanced stage of dementia (Chan et al., 2013). A review of literature exploring dementia among ethnic minority groups (Kumar, Spilker, Sagbakken, & Price, 2004) reported that during the caregiving journey, the progressive loss of the care recipient's physical, mental, and social capabilities caused by dementia positioned family caregivers in a challenging situation punctuated with uncertainty. A large body of research (e.g., Schulz & Martire, 2004) has exhaustively examined the harmful effects

on the health and wellbeing of the caregivers caused by this unpredictability, including the challenges brought by a need to make the right decisions at the EoL.

2.5.1. Decision making in the context of EoLC

As already indicated above, the number of BAME PLWD is expected to increase, and family members provide most care. Where ACP has not been done, family caregivers are expected to make difficult EoLC decisions, but evidence on ACP for minority ethnic PLWD is limited (Badger et al., 2009). Botsford et al. (2011) stress that an individual's ethnic background status represents who they are, and attention to their culture is therefore crucial when seeking to understand or provide dementia related support and care. EoL decision making can be a challenging task for family carers, including healthcare professionals (Denning et al., 2011). If in place, ACP can help family carers to make decisions based on their knowledge of the person, who may have lost the mental capacity to make their own choices, however, both the person with dementia and their family carers need to understand the progressive nature of dementia and initiate early conversations about the future (Denning et al.,2011). As an individual with dementia nears the end of their life, various challenging decisions often require to be made about their care (Alzheimer's Society, 2017; Blank, 2019). In a USA study that used a hypothetical scenario to explore the EoLC decision making by family caregivers, Allen-Burge and Haley (1997) found that African-American caregivers of PLWD were likely to make decisions in favour of cardiopulmonary resuscitation (CPR), choose artificial feeding compared to Caucasian caregivers. However, the issue of artificial nutrition has been found to be sensitive topic area and professionals and relatives often find making EoLC related decisions challenging. These decisions include pain treatments, the use of CPR, and tube feeding.

Diwan, Hougham & Sachs, (2004) conducted face to face structured interviews with 150 community-dwelling, patient-caregiver African Americans dyads as part of the PEACE study to examine the experiences of caregivers of PLWD at the EoL and found no difference in caregiver role strain, subjective and emotional strain between African-American family caregivers of PLWD and white carers. When PLWD have had opportunities to discuss and make their future wishes and preferences known (advance care planning), family carers may find it easier to make decisions based on the desires expressed (Poppe et al., 2013). In a quantitative study of 63 bereaved caregivers which aimed to explore the experiences of caregivers of PLWD at the EoL, Owen, Goode, Haley (2001) found that African-American caregivers were less likely to think of the events before and after their relative's death, less

likely to experience loss before the relative's death, and less likely to make funeral plans before death. The researchers concluded that life-sustaining treatment decisions and reactions to death were influenced by ethnicity. This finding suggests that carers' ethnicity influences EoLC choices and decisions but making the right decision at the EoL can be challenging for family carers (Kenning et al., 2017).

Decisions regarding whether to continue or withdraw treatments for a person nearing the EoL is a challenge for medical staff and families (General Medical Council, 2010). A review of literature examining decision making among minority groups found that cultural and religious norms have a significant influence (Regan et al., 2013). Implementing ACP can be challenging for people from BAME communities due several barriers. For instance, there is evidence that BAME communities often perceive or understand dementia from a cultural and religious standpoint which delays early help seeking, resulting in late diagnosis often when dementia has advanced (Mukadam et al, 2013). Opportunities for early discussion would have been lost, and thus ACP may not be feasible to put in place due to loss of decisional capacity due to advanced dementia, which then negatively impacts on the EoLC decision making for carers and healthcare professionals (Con, 2007). However, participants in the focus group study exploring older people's views about the role of advance statements in EoLC decisions in Seymour, Gott, Bellamy, Ahmedzai and Clark (2004) reported concerns and difficulties about thinking ahead about death and discussing issues around dying. Seymour et al. concluded that it might be useful to avoid having more emphasis on completing advance statements but to conceptualise ACP as a process of discussion between healthcare professionals' patients and their families.

2.5.2. The Impact of lack of knowledge of services

Concerning dementia care services and BAME communities, apparent from this literature review is low service uptake (Moriarty et al., 2011). Another issue identified is the assumptions that BAME groups look after their own often inadvertently work as a barrier as care and service providers may feel reluctant to reach out to BAME communities under the obscurity of this stereotypical view. The 'they look after their own' assumption fails to recognise the changing demographics; for example, first-generation BAME people and those born in the UK may have different views and expectations. The need for services to be culturally responsive is not a newly identified problem, for instance, the 1998 *inspection of community care services for black and ethnic minority older people* (DoH 1998) inspected and evaluated community

services and found that services inappropriately addressed the needs of BAME older people. The inspectorate concluded that the 'needs of black elders are the same as those for other older people, but sometimes these needs should be met in specific and different ways' (DoH, 1998, p.10). The report found that some service providers took the view that BAME people 'they look after their own' (DoH, 1998, p.31), which has recently been cited by many studies as a barrier to care service delivery

There is a substantial evidence base, which has illuminated negative experiences of services in healthcare. However, communication and language difficulties are evident in literature; for example, Randhawa et al. (2003) found that language - failure to speak English was an obstacle to both access and use of palliative care services. Lack of knowledge of services and reluctance to access them is further compounded by the existence of cultural taboos and meanings that many BAME communities attach to mental health, dementia included, often resulting in reluctance towards help-seeking, despite a need for support (Mukadam et al., 2011).

Again, as indicated earlier, a report by CQC (2016) on which focus groups and semi-structured interviews were carried out, highlighted that of the lack of knowledge and awareness about EoLC services and support was not only evident but was also a barrier to good and individualised quality care for BAME communities, including place of care at the EoL. Furthermore, participants in the CQC report revealed that they did not understand palliative care. This may indicate that some BAME groups are unacquainted of the importance of palliative care and its aims, an issue that when added to the stigmatisation that many BAME groups attached to dementia, may impact on access to quality EoLC.

A key finding raised by a focus group by the CQC was that most participants commented that up until a family member received the EoLC, they did not know anything about it. Some stated that they lacked confidence in navigating the health and social care system and were not aware of services and how and where to seek help. Some authors have recognised the relationship between lack of awareness and lack of information about facilities, and how this can influence access to and satisfaction with services (APPG, 2013). A good example is a study by Bowes and Wilkinson (2003) who found that BAME older people lacked both awareness of available services and lacked knowledge of procedures to reach out to services, and for those who accepted services, many were dissatisfied.

Awareness of dementia feeds into the perception of services. For example, a small study by Purandare, Luthra, Swarbrick and Burns (2006) with people of Indian background in

Manchester (UK) found that lack of knowledge about dementia among caregivers appeared to be one of the principal reasons of the sparse presence of this group in dementia treatment clinics. Nyatanga's (2002) paper 'Why do minority ethnic groups, not access palliative care' explores how cultural groups in most Western Society including the UK have a low palliative and EoLC service uptake. He argues that there are challenges associated with providing culturally sensitive care; however, such problems should not be viewed as challenges per se but as opportunities for understanding the needs of various cultural groups within the UK's multicultural context. A pertinent issue to draw on here is that people's culture shapes how they perceive their health and illness (Neuberger, 1994). However, the term culture itself presents contextual meanings for different people, making it a sophisticated and fluid phenomenon to comprehend (Nyatanga, 2002).

Given that dementia is perceived instead as a natural part of ageing, one can argue that the poor EoLC service uptake by BAME groups may be explained from this perspective. Indeed, Nyatanga (1997) goes on to say there is a healthy relationship between people's cultural perceptions of their illness and how, for instance, they seek treatments; adhere to treatment regimens and negotiate a sense of control regarding their situations. Again, Jutla (2011) warns that it is essential that service providers and researchers alike to be sympathetic of cultural diversity and to have an awareness that there are some differences within cultural groups as well as between those cultures.

The standards mentioned above were suggested over a decade ago (DoH, 2001), 17 years later, literature does not sufficiently indicate whether the standards have been achieved. However, there are indications of renewed efforts in the wake of increasing cultural diversity and the projected increase of dementia. As a result, the current discourse suggests a shift towards the cultural responsiveness of care and an emphasis on cultural competence in practice (La Fontaine, Ahuja, Bradbury, Phillips & Oyebode, 2007) as a way of addressing barriers to dementia care services for minority ethnic PLWD and their families. However, evidence documenting the experience of these groups and their family carers in the community is limited.

2.5.3. Recognising the end of their life

A vast majority of studies indicates that it is often problematic to tell whether a person with advanced dementia is nearing the EoL. For example, in their clinical evidence review paper of illness trajectories and palliative care, Murray, Kendall, Boyd and Sheikh (2005) found that

compared to cancer's relatively predictable illness trajectory, PLWD has an unpredictable trajectory. The path is characterised by prolonged dwindling often punctuated with hospital admissions, despite this, identification of the EoL phase remains difficult, even with tools such as the Gold Standards Framework Prognostic Indicator Guide (Thomas, 2010). The Gold Standards Framework (GSF) has been found to facilitate joined-up high-quality community palliative care. For example, a study by King, Thomas, Martin, Bell, and Farrell (2005) explored general practitioners' (GPs) viewpoints on the GSF following its national roll-out through semi-structured telephone interviews with 68 GPs and found that most GPs felt using GSF facilitated consistency of care, including a reduction of patients being lost on the broader healthcare system.

Given that appropriate timing and prognostication lie at the core of palliative care, there is limited evidence suggesting whether the NICE QS 9 is being achieved. Another critical related issue has been the under-recognition of dementia as a terminal illness (Lillyman & Bruce, 2016), including inconsistency of recordings of it being a cause of death (Nazarko, 2014). The significance of explicit recognition of dementia as a terminal condition would allow people to opportunities to plan for their future care at the earliest stages, thus help preparedness and the provision of care that meets people needs and wishes (van der Steen et al., 2014; Ryan et al., 2012; Nazarko, 2014; Mitchell et al., 2012).

However, things are changing; the terminal nature of dementia is increasingly being recognised (Dempsy, 2010). Given that research continues to find that BAME generally conceptualises dementia as a natural symptom concomitant with old age. Therefore, this group of people may not see it as a terminal condition, further impacting on both access to and understandings of EoLC. Another critical aspect of EoLC for PLWD, though challenging, is to ascertain they are nearing the end of their life to facilitate a time assessment of their care needs. Because of the complicated illness trajectory concomitant to dementia, verifying the end phase continues to be recognised as a barrier to quality EoLC for people dying with/from dementia (Lillyman & Bruce 2016) The uncertainty about the end phase of a relative with dementia not only has a significant impact on the family but makes it difficult for professionals to provide EoLC.

2.6. Cultural/religious influences on preferences at the EoL

In their narrative review of research on EoLC decision making in minority ethnic groups, Kwak and Haley (2005) state 'individuals from ethnic minority backgrounds may be especially likely

to turn to their traditional norms and practices at the EoL because religious, cultural beliefs and norms can provide them with meaning for their illness' (p. 634). Similarly, Milne and Chrysssanthopoulou (2005) stress that culture and ethnicity play a role not only on influencing and patterning of caregiving for PLWD, but also in shaping the meanings attached to the illness. However, most of the literature in this area often do not make a dissection between culture and religion, yet they are two distinct but interwoven concepts (Regan, 2014). Mukadam et al. (2010) found that religion was a basis from which most BAME PLWD sought meaning, hope and purpose in their everyday lives but also influenced help-seeking. Similar findings were reported in a USA qualitative study by Levkoff, Levy and Weitzman (1999) who conducted in-depth interviews with 40 caregivers from four USA minority ethnic groups to explore help-seeking of minority family caregivers of PLWD and the role of religion and ethnicity and found that religiosity and factors related to ethnicity can either facilitate or impede on the help-seeking behaviour. The study findings are commendable, notably that most participants stated they used prayer to cope with their everyday caregiving duties.

Such findings highlight the importance of religion/culture for minority ethnic groups, although this does not mean all ethnic minority groups are religious. While previous research (e.g., King et al. 1995, Ross 1997) has reported that older people have higher spiritual and religious needs, a more recent paper (Regan, 2014), reported that his is often ignored. For example, in the USA, Winston, Leshner, Kramer and Allen (2005) found that the complexity of meanings for most African Americans was shaped by both historical and contemporary events such as the experience of discrimination, oppression and religiosity. Langdon, Eagle, and Warner's (2007) qualitative study examining the subjective experience of dementia revealed how individuals with dementia attempt to preserve their autonomy through turning to spirituality in search for the meaning of life. While these findings offer insights into the interrelationship between cultural, religious and life experiences in influencing people's perceptions on illness and care for the dying, there are specific limitations inherent in using such evidence in the UK.

One limitation is about the contextual difference, for instance, differences in historical migration experiences between minority ethnic groups among UK and USA ethnic minorities could be a factor which determines how they access and make use of healthcare services (Connolly et al.,2012). In addition to this, the differences in the structure of the healthcare systems and how countries deal with issues of ethnicity and associated disparities could lead to incongruence in experiences between UK and USA minority groups (Burchett, Mayhew,

Lavis & Dobrow, 2012a). Therefore, the applicability and transferability of such research findings drawn out of the experience of USA minority ethnic groups to UK minority ethnic groups renders itself to scrutiny of both its representation and usefulness (Bucherrett et al., 2012b). The context from whom the evidence emanates is vital in the transferability of health care research collated evidence (Hanney & González-Block, 2017); this is because it underscores the intercourse between people's cultural beliefs, health and meanings of living with long term ill health that are often compounded by many factors that bring the broader community into the arena, for example, a mixed-method study commissioned by the Joseph Rowntree Foundation, Salway, Platt, Chowbey, Harris and Bliss (2007) stress that 'for many minority ethnic respondents, the 'community' emerged as a somewhat oppressive presence in their lives, monitoring and judging behaviour, while at the same time being the primary potential source of support. Furthermore, Salway et al. found that religion was an essential dimension of belonging to a community for many BAME groups as it provided the basis from which explanation for expected behaviours, norms and 'avenues to social contact and emotional sustenance' was negotiated (p.22).

A qualitative study by Katsuno (2003) found that religiosity enhanced the perceived quality of life for the 23 people with early-stage dementia who participated in semi-structured interviews. A key finding of this study was that religion was used as a means of coping with the everyday challenges of living with dementia, while some used it to negotiate meaning and purpose in their lives. Similarly, Jolley et al. (2010) conducted a study in the West Midlands (UK) using the Royal Free Interview for Religious and Spiritual Beliefs, to examine the spirituality of PLWD and their carers. The study reported that in the earlier stages of dementia process, there was no discernible reduction of spiritual awareness amongst PLWD compared with those caring for them. The authors called for providers of services to cover issues related to spirituality and faith into routine assessments and ensure care plans accommodate people's spiritual needs.

Religion has a significant influence on some minority ethnic people's everyday life. As expressed by many people in this study, EoLC should pay attention to how issues of faith influences individuals' EoL wish. Johnson, Albert-Avila and Tulsky (2005) conducted a research review and found that religion worked as a basis from whom wishes, and preferences related to EoLC were made by African-Americans. They further found that religiosity made

African Americans see life-limiting interventions to be hastening death, which they perceived as against God's will.

Regan et al. (2013) completed a systematic review of religion and dementia-care pathways for BAME PLWD and only located two USA relevant papers. The study found that religion hindered access to the traditional health care pathways and helped individuals to cope with their circumstances by accepting and reflecting on their situations. About culture and religion, Calanzani et al. (2013), in their review, concluded that, while there may be cultural - or religiously substantiated preferences, assumptions should be avoided as religious beliefs and cultural beliefs vary across considerably across minority ethnic groups. While these findings shed insights into the importance of meeting people's cultural and religious/spiritual needs, lack of research in this area suggests that BAME people's cultural and religious/spiritual needs are not addressed in services, including EoLC.

2.6.1. Phenomenological literature on EoLC for BAME PLWD

Given the need for health and social care services to provide the best care informed by people's needs, it is not surprising that various studies have drawn on the phenomenological methodology to understand people's experiences of living with dementia and their perceptions of the care provided to them. Research has also explored caregivers' experiences in conjunction with the EoLC of those they care for (e.g. Schulz et al., 2003). One US study; Lewis (2014) conducted a descriptive phenomenological study to explore the experiences of primary caregivers of PLWD who were actively seeking hospice care. From completing in-depth interviews with eleven primary caregivers, the study revealed that the EoL was a period of loss and disappointment and a time by which caregivers battled to adjust mentally from seeking curative therapies and opting of life-prolonging treatments. Dementia has a prolonged illness trajectory; people can live with the condition for years. This time is often punctuated with feelings of loss, anger, grief, and at times, caregiver stress. This was also found in Lewis's study, as many caregivers viewed the death of their relative with dementia was a relief and a blessing. For example, caregivers felt that their relative was finally at peace when they died while it was also the end of caregiving. While this study's findings show the lived experience of caregivers at the EoL, it also demonstrates the value of qualitative approaches to understanding these issues and thus further necessitates experientially focused methodologies.

Phenomenological literature in this area has predominantly explored caregivers' experiences. Although also unclear about the participants' ethnicity, another phenomenological study by Peacock, Duggleby and Koop (2014) investigated the lived experience of family caregivers who provided EoLC to persons with advanced dementia and found that carers valued being there and being with their relatives at the EoL. This study adopted a rigorous methodological approach, interviewing bereaved caregivers (4 wives, three husbands, three adult daughters, and one adult son) two to three times following the death of the relative they looked after and its findings highlights carers' wishes at the EoL, in particular, being physically present to ensure that comfort care is given to their dying relatives who may be no longer able to make their needs and discomforts known at that time. These studies show that the lived experience of dementia varies considerably between individuals and their families.

While findings from these studies are more relevant to the context and to those who participated in the study, they provide a deepened understanding of the complexity of family caregiver's lived experience at the EoL of their relative dying with/from dementia.

2.6.2. Knowledge gap

The literature reviewed above shows that there is a paucity of research focusing on EoLC for UK minority ethnic groups in general. As far as the review shows, there is very limited studies that have explored EoLC for PLWD who are from BAME communities within the UK. Calls for UK based research on EoLC for minority people with dementia has been echoed by Koffman (2018), Connolly et al. (2012) and Calanzani et al. (2013). Most of the qualitative evidence has mainly explored barriers to formal service uptake, while issues related to race and family caregiving in dementia have been mostly quantitatively examined. The difference in methodological approaches perhaps mirror the nature and quality of the evidence but necessitates a need for more experiential-based research. The review has identified that people's cultural backgrounds often shape their experience with dementia and influence their attitudes towards care and support services. However, as most studies on this area have predominantly focused on perceptions of dementia and understandings barriers to accessing services, it is unclear how culture relates to EoLC and the approach taken by this group to the EoL.

To deliver appropriate EoLC which is culturally sensitive, it is imperative for health care professionals to be culturally aware or competent (Con, 2007). Because early signs of a

dementia such as memory loss are often viewed as a normal process of ageing, individuals from BAME groups often receive their dementia diagnosis late, usually when decisional capacity has been affected. This has implications on the use of ACP (Poppe et al., 2013). Many studies continue to report that dementia remains highly stigmatised among BAME communities which impacts on help-seeking, ACP, and access and use of services (Mukadam et al., 2013).

Among minority groups, there is evidence that family caregivers often try to provide care for their relative with dementia in fear of stigma and shame (Kenning et al., 2017). However, the implication of this in relation to EoLC for minority ethnic groups has not been fully explored. Based on the limited research evidence, it is, therefore, plausible to assert that stigmatisation of dementia and the normalisation of early signs of a dementia process may contribute to poor care at the EoL, as opportunities for ACP may be lost. EoLC decision making often falls onto the family members, who may make EoLC decisions based on what they previously know about their relatives, rather than what the person may have wished at that time, thus affecting the person-centeredness of the end of EoLC. Awareness of dementia lies at the first stage while EoLC is at the end of the Dementia Care Pathway. It is clear from the literature review that most research has neglected the end part of the pathway of dementia care, yet current policy has highlighted a need to improve the EoL experiences of people dying from dementia. The review has further revealed the existence of culturally underpinned misconceptions about dementia among some BAME groups as well as a view that care for a relative with dementia is a family business. While caregiving is meaningful to the family and the care recipient, when brought together, this creates a situation whereby BAME communities are reluctant to access services while further feeding into the 'hard to reach' narrative.

One knowledge gap in the current literature concerns the lack of research on the experiences, attitudes and needs of both BAME PLWD and family caregivers about EoLC, (given that care is mainly family orientated). The apparent reluctance in the use of dementia care services may further explain why the research community has overlooked this area but may also be the reason why researchers have not been confident to conduct more research. Two-thirds of PLWD in the UK dwell in the community and are mainly supported by their families (Wattis & Curan, 2011). Therefore, there is a need for research to focus on community-dwelling BAME PLWD and their family carers. As most studies are descriptive, an interpretive approach to research that draws on BAME PLWD and family caregiver experiences can offer new insights, reveal meanings attached to experiences, illuminate the basis of attitudes, hope, and wishes and

the approach taken by this group to EoL. Research on the EoLC experiences appears to suffer from a range of general methodological shortfalls, principally linked with the challenges of reaching out and recruiting minority ethnic groups as participants and completing primary research with PLWD.

Burt et al. (2017) argue that essential first-hand meanings attached to the people's experience of living with dementia are commonly absent from retrospective data. Thus, people's attitudes, preferences, beliefs, hopes and wishes about their future care have often been overlooked in research. Gibson, Timlin, Curran and Wattis (2004) suggest that qualitative methods have contributed to our knowledge of the experiences of PLWD and their family caregivers. The review shows that current knowledge about EoLC care for PLWD in the UK is devoid of the perspectives of minority ethnic communities. This is not only reflected by the lack of research in this area but also by the absence of this group's voice in the current EoLC.

In terms of research with minority groups Fang, Sixsmith, Sinclair, & Horst, (2016) explains that despite a lack of research on minority groups, qualitative methods, are useful in producing culturally sensitive understandings of EoLC.The scarcity of literature further necessitates a need for an exploration of how this group of people living with dementia, construct meanings, perceive future EoLC and make sense of their situation.

2.7. Summary of chapter

This chapter has reviewed and presented the literature. The review has identified no primary studies specifically exploring the EoLC for PLWD who are from minority communities within the UK. There are — however, reports and reviews identifying the problem and offering directions for future research. For example, the absence of UK based research on minority ethnic groups about dementia EoLC has been noted by Calanzani et al., (2013) Connolly et al. (2012) and Koffman (2018). There is a substantial evidence base on research exploring perceptions of dementia, family caregiver experiences, barriers to and disparities in health and social care. Most of these studies appear to be focusing on South Asian communities with minimal research on African, African-Caribbean people, and other minority groups. While cultural and religious influences have been highlighted in papers exploring minority ethnic communities' perceptions of dementia and reasons behind the under usage of formal services, other than USA based evidence, there is minimal UK evidence of this in the context of the EoLC. Another critical issue revealed in the review concerns the absence of the voice of older African/Caribbean PLWD and their family caregivers in dementia EoLC research. There is a clear need for both older black African/Caribbean PLWD and their family carers to tell their stories about their experience of dementia and related care, including EoLC.

CHAPTER 3: METHODOLOGY

3.1. Introduction

In this chapter, I outline the methodological framework that underpins the overall research process. I begin this by detailing the relationship between philosophy, methodology and method before briefly discussing the need for a qualitative study in this area, including a rationale for adopting a hermeneutic phenomenological approach for the research. I also discuss the background history of phenomenology as a philosophical movement, through the work of Husserl, Heidegger, and other existential phenomenologists. An overview of the chosen hermeneutic phenomenological approach, guided by the work of van Manen (1990, 1997 & 2014). In the method section, I aim to outline the specific steps and rationale behind the decisions that I took during the study. I move on to contextualise hermeneutic phenomenology as the most suitable approach which guided the overall process of this research, as well as how the data was analysed, with the support of Template Analysis (King & Brooks, 2017). The chapter concludes by outlining Yardley's 2008 framework for achieving rigour and credibility in the study.

Langdridge (2007) defines the term methodology as one denoting the general manner of researching a topic, whereas method is the specific procedure or technique adopted to research a given topic. A researcher's philosophical position influences the choice of methodology and method (King & Brooks, 2017). Given that various philosophical and theoretical assumptions underpin different methodologies, King and Brooks (2017) advise that it is essential for the researcher to consider the philosophical orientation of a piece of research, as this not only determines the research process but also has real implications with regards to how data are collected and analysed. Demonstrating this can be regarded as a fundamental facet of achieving coherence and enahncing rigour in the exploration (Silverman, 2015).

3.1.1. Philosophical perspectives: ontology and epistemology

As the lens by which we perceive the world, philosophy cannot be overlooked in any research process. Its role in shaping the conduct of the research is noted by Baldwin (2014, p.2) who

states 'the researchers' philosophy or the way they view the world will undoubtedly influence how the study proceeds'. Therefore, as the researcher in this study, my worldview of what constitutes or counts as reality (ontology) and how knowledge is generated (epistemology) has real implications on how I go about designing, conducting and reporting the research findings.

Epistemology is concerned with how we get to know what we know ('how we can obtain this knowledge' (King & Brooks, 2017, p.14), including what can be accepted as knowledge, while ontology considers the nature of the social world and what we understand as real (Seale, 2018). Regardless of whether the researcher's assumptions are presented, every research has epistemological and ontological assumptions, which in turn shape or determine the choices that the researcher makes concerning the formulation of the research question, and how the data is collected, analysed, and reported.

As this research aims to explore a social phenomenon from the perspectives of individuals within their social context, it lends itself to a relativist rather than realist epistemology. Therefore, it is situated within the interpretive and constructivist/relativist paradigms which are concerned with how people make sense of their social world and the belief that, by obtaining their subjective experiences, we can (through interpretations) make sense of meanings embedded in their social world.

3.1.2. My assumptions and values and their implications

As a researcher, I possess my worldview, biases and prejudices that define who I am. I was born in a caring family in which respect for every older person (not relatives alone) was not a negotiable thing, but a must-do. My view on this remains unchanged, and inevitably impacts my approach to the present research. This further determines the design of the research and how I go about conducting it, including the decisions that I make during the study. For example, based on my work experience in specialist dementia services, my understanding is that dementia affects each person differently. Thus, every person's journey with the condition and their knowledge of it will be very different, and families also make sense of their relatives' illness in many ways. Therefore, on approaching this research, I held these assumptions, and my approach to framing the research question and the decisions that I made about the design of the study reflect these assumptions. This research explores a social phenomenon, within a given context, with multiple possible realities that each person (and those who provide care) would have constructed. I assume that by 'tapping' into the subjective realities of PLWD and

family carers, a rich picture of their realities about the topic area would be uncovered. Therefore, I considered the idea that there is a single reality as unfitting, and thus, I rejected quantitative approaches for this reason. As emphasised by King and Brooks (2017) that the researchers' ontological position has a strong influence on the design of the study, therefore, my worldview of what constitutes reality will go on to inform how I designed this research, including all specific steps, which I followed in researching the phenomenon of EoLC.

Epistemologically, this research is guided by an assumption that people's everyday experience actively contributes to knowledge generation and nature of reality, that is, 'our view of reality is only that, a view, something constructed in our heads, invented by us' (Speed, 1991, p.396). By gathering the lived experience descriptions of people with mild dementia and those of family caregivers their everyday experience of living with dementia or providing care to a relative with dementia in the context of EoLC, understanding their 'reality' will be possible. Silverman (2000) argues that choosing a research methodology should not be merely by preference but that it should be determined by the research question/s the study aims to address. Thus, the nature of the problem or phenomenon of interest that the researcher is attempting to investigate leads him/her to the best-suited research approach.

3.1.3. Rationale and justification for a qualitative approach

The aims of the research project are concerned with human experience in its subjective nature that would not be appropriately explored through quantitative methods that are more suitable for testing hypotheses, measurement and investigating relationships between variables. Qualitative methods are situated within the interpretive paradigm and are suitable for the exploration of people's experiences from their viewpoints. Qualitative approaches embrace the understanding of the social world as experienced by people as opposed to providing explanations of the causal relationship between variables that are stressed by hard sciences that underpin quantitative research approaches (King, Horrocks & Brooks, 2019).

In any research, the research question helps to inform which research approach/s (qualitative or quantitative) is most suited to answer it (Silverman, 2015). The aims and objectives of this study outlined in Chapter 1 (sec 1.5), necessitates a qualitative approach that enables participants to tell their stories about their experiences (Pope & Mays,1995). A qualitative approach was, therefore, chosen as the most appropriate, as the subject matter that this research intends to explore a context-specific human experience (Golafshani, 2003). Furthermore, the

study plans to focus on people whose voice is seldom heard in research, or those depicted in literature as 'hard to reach' or 'seldom heard'; one rationale for a qualitative approach is its suitability for enabling people's voices or narratives to be heard.

In healthcare research, qualitative methodologies have the power to reveal people's experiences and meanings about their illness or health, thus producing essential knowledge for healthcare providers (Green & Thorogood, 2018). Therefore, the rationale for a qualitative approach in this study fits its purpose of listening to PLWD and family caregivers' accounts of their experience, to enable a deepened understanding of the meanings they make within the social world they inhabit (King & Brooks, 2017; Creswell, 2007). The aims and objectives are detailed in Chapter 1, section 1.7. Research participants' accounts will be collected from face-to-face interaction with African-Caribbean PLWD and family caregivers in a 'naturally occurring setting'.

As shown in the review of the literature (Chapter 2), many minority ethnic older people will develop dementia and will require person-centred EoLC. However, there is currently a lack of experientially focused research. There is an absence of the voice of minority ethnic PLWD and their families in the context of EoLC in the UK. The gap in knowledge and lack of understanding about the topic area means exploratory research is required. Thus, the use of a qualitative approach suits exploratory will not only address this gap but will allow the voice of this group to be heard in research.

3.2. Phenomenological psychology

Phenomenological psychology has its foundations in the phenomenological philosophy of Edmund Husserl, who is acknowledged as the founding father of phenomenology. As a research method, phenomenology studies phenomena. It enables the meanings that individuals ascribe to the everyday experiences to be illuminated from their viewpoints (Sundler, Lindberg, Nilsson & Palmér, 2019). Phenomenological research offers insights on phenomena as experienced or lived by individuals. Therefore, phenomenological psychology is interested in the (subjective) lived experiences of human beings (Dowling & Cooney, 2012; Norlyk & Harder, 2010).

Many other phenomenological thinkers have developed phenomenology further, for example, Davidsen (2013, p.322) suggests Heidegger introduced 'the existential turn' in phenomenology shifting away from Husserl's 'pure' or transcendental phenomenology to the understanding of

our being in the world (ontology). Phenomenological psychology embraces people's lived experience and recognises human beings as subjective meaning-makers. Because subjectivity is situated at the realms of phenomenological psychology, Giorgi (2009) observes that phenomenological research does not aim to make generalisations but strives to provide detailed descriptions of people's experiences taking the influence of people's culture and history and the intersubjective constructions of knowledge into consideration. Englander (2016) explains that phenomenological psychology continues to evolve; for instance, research approaches inspired by phenomenological theory diverge methodologically based on whose phenomenological philosophy underpins them (Langdridge, 2007). These approaches either make an emphasis on description or interpretation of phenomena based on Husserl or Heidegger's phenomenological philosophy. Therefore, phenomenological psychology relates to the application of phenomenological methods in psychological research to understand the structures of phenomena.

3.3. Introducing Phenomenology

Phenomenology has been described as both a research approach and a philosophical movement (van Manen, 2014). As a research approach, phenomenology primarily centers its focus on people's lived experience or lifeworld and aims to illuminate aspects of people's taken for granted everyday experiences (van Manen, 1997). Lester (1999, p.4) states 'phenomenological approaches are good at surfacing deep issues and making voices heard'. Although there are many critical thinkers within the broader field of phenomenological philosophy, contemporary phenomenological research methods have generally been underpinned by the work of Edmund Husserl and Martin Heidegger. A major debate within the phenomenological research literature is between descriptive (Husserlian) versus interpretive (Heideggerian) phenomenology (Norlyk & Harder, 2010).

3.3.1. Husserlian 'pure' or transcendental phenomenology

Husserl is often regarded as the architect of phenomenology, and from his philosophical position; phenomenology allows us to reach 'true meaning by way of penetrating deeper and deeper into reality (Sloan & Bowe, 2014, p.5). According to Husserl, phenomenology was to be a science of pure phenomena. If we are to negotiate certainty, we need to ignore anything outside our immediate experience (Groenewald, 2004), by 'going back to the things

themselves' (Moustakas, 1994, p.26). Thus, his way of doing philosophy is often conceptualised as a shift from the Cartesian dualism of reality as something 'out there' which was separate from people (Laverty 2003) to understanding the subjective human experience.

Husserl aimed to cultivate a scientific approach with a power of clarifying how objects are experienced rather than being 'out there' and how they manifest in human consciousness (Spinelli, 2005). Human consciousness, according to Husserl, exists through intentionality. In phenomenological terms, the concept of 'intentionality' is perceived as the core element of consciousness relating to "the 'directedness' or 'aboutness' of conscious experiences" (Moran, 2013, p.317), and thus does not relate to a purposive action as one would define the term, but to how the meaning structures of phenomena are presented in our consciousness. Being meaning makers often means our awareness is often directed to something – an object or an experience (Applebaum, 2014). Langridge (2007) and Smith et al. (2009) agree that the identification of the 'life-world' by Husserl remains as one of the fundamental aspects of his work that has influenced phenomenology.

Furthermore, the concept of lifeworlds has become an integral element for subsequent phenomenological developments (Sloan & Bowe, 2014). The basic principle of Husserl's phenomenology its devotion to the notion that experience is to be transcended to discover reality (Kafle, 2011). Therefore, transcendental phenomenology (otherwise termed Husserlian or descriptive phenomenology) emphasises a need for the application of the phenomenological attitude over natural attitude (Kafle, 2011). As opposed to the phenomenological attitude in which we suppress seeing things from our 'habitual' or taken-for-granted position, the natural attitude relates to our everyday understandings of the world around us, our everyday experiences, and the physical objects we encounter – we 'naturally' do not question things, but accept them as they are, and that is our being-in-the-world (Finlay, 2008).

To set aside the natural attitude, one should apply phenomenological reduction, which is achievable through *epoche* or bracketing (Husserl, 1931). As discussed above, this, in part, refers to setting aside the influence of personal prejudices and setting aside one's everyday taken-for-granted assumptions in order to see the phenomenon its appearance to consciousness (Finlay, 2008). Phenomenological reduction from Husserl's point of view requires the researcher to refrain from the 'natural attitude' to avoid looking at a phenomenon with a judgemental attitude (Bradbury-Jones et al., 2008). It is not surprising that thinkers who take from Husserlian phenomenology such as Van Kaam (1966) and Colazizzi (1978) emphasis on

the notion of 'bracketing' which relates to holding back pre-conceived beliefs and ideas about a phenomenon being investigated, which makes it possible to uncover the essence of the experience in its pre-reflective nature (Cohen & Omery, 1994).

Research drawing on Husserl's phenomenological philosophy embraces a belief that the researcher can suspend his or her preconceived knowledge about a phenomenon that is being explored to describe the essential meaning structures of the phenomenon. For example, having worked closely with PLWD and their families, I would have acquired some knowledge about their experience and bracketing would entail avoiding drawing on what I know to 'accurately describe participants life experiences' (Chan, Fung & Chien, 2013, p.2), without the influence of my preconceived knowledge. This method aims to illustrate rather than explain, and research should be devoid of hypotheses.

The notion of bracketing and its application in real-world phenomenological research has attracted debate and remains a controversial but widely misinterpreted issue within phenomenology. Husserl claimed that bracketing off one's natural attitude or how one observes the world around him/her is a fundamental principle of understanding the nature of a phenomenon or the 'things in their appearing' (Langridge, 2007). However, with regards to Husserl's concepts of '*epoche*' many proponents of the phenomenological theory, Heidegger, Sartre and Merleau-Ponty, to name a few, have proposed that because our everyday experience makes us meaning makers and thus becomes embedded in who we are, it would be challenging to dissociate ourselves from those experiences. The overarching point of divergence from Husserl's phenomenological method being that although some aspect of what we represent as meaning makers can be bracketed to an extent, some elements grounded in our being-in-the-world and our view of it may not be easily separated from us and thus we cannot assume a 'view from anywhere' by suppressing what we already know (Ricoeur, 1996). Husserl's philosophy underpins the descriptive phenomenological research methods such as those of Giorgi (2009), Colaizzi, (1978) and Moustakas (1994).

3.3.2. Heideggerian interpretive (hermeneutic) phenomenology

While Husserl's focus was epistemological, Heidegger's interests were ontological – concerned about the 'being' of humans. Heidegger was concerned about the meaning of being human and how through our 'thrownness' or 'Geworfenheit' we make sense of our experiences within the world that we find ourselves thrown into (Seehan, 2015, p.xv). His hermeneutic

phenomenology rests upon the idea of being-in-the-world, that is, what it means to experience things in everyday living. Heidegger's interpretive or hermeneutic phenomenology aims to grasp human experience as it is lived. It is argued that Heidegger was deeply engaged with the thinking of Kant, Kierkegaard, Nietzsche, which is evidenced by 'the turn[3]' in his philosophy (Wheeler, 2013). In his magnum opus *Being and Time* (*Sein und Zeit*), Heidegger writes critically about Husserl's transcendental phenomenology (Östman, 2014). Heidegger argues that phenomenological analysis does not commence from intentionality as proposed by Husserl, but that it begins with the interpretation of the pre-theoretical conditions, from which intentionality stems (Wheeler, 2013).

Heidegger (1926/62) questions what it means to be in the world, which is often referred to as 'Dasein' interpreted as 'the mode of being human' (Laverty, 2003, p.24). Unlike Husserlian descriptive phenomenology, phenomenological approaches informed by the Heideggerian philosophy argue that it is almost impracticable for people to 'bracket' their pre-understandings (Langdridge 2007), because 'pre-understanding is not something a person can step outside of or put aside', (Laverty, 2003, p24). In Heidegger's (1962) view, the starting point of human existence lies within 'being'. Dasein or being in the world is where we start if we need to comprehend the world around us (Heidegger, 1962). Therefore, Heidegger saw no differences between ontology and phenomenology, given that both are orientated on questioning the meaning structures of Being (Kakkori, 2009).

Like Husserl, Heidegger believed in the value of going back to the things as they present themselves as it is through being (Dasein) that as individuals, we make sense of our existence and that of others (Dreyfus, 1991). Heidegger goes on to claim that when we understand our being, our understanding is often based on our experience as we encounter phenomena in our everyday lives (Heidegger, 1962), In the present study, older African-Caribbean PLWD and the family caregiver's 'being' relates to their encounter with dementia or giving care to a person affected by the illness.

Phenomenological research is a dynamic process where the researcher is not passive, but an active ingredient of the meaning-making process (Koch, 1995). According to Laverty (2003), Heidegger believed that mere descriptions of people's experiences without interpretation, were not enough if the aim is to reach a deepened understanding of meaning structures of a

[3] 'The Turn' according to Wheeler (2013) denotes to Heidegger's shift in his thinking in realisation of some issues with his explication in Being and Time

phenomenon. Thus, the researcher's analysis of experiential material should endeavour to go beyond descriptions to interpretation to gain an understanding of the subject matter (Patton, 2002). Heidegger's philosophy and writings (as well as Gadamer) underpins various strands of interpretive approaches within phenomenological research.

3.3.3. Hermeneutics

Hermeneutics initially developed as an approach to interpreting biblical text (Crotty, 2003). Gadamer (1989) philosophical hermeneutics, which underpins van Manen's approach, believed that understanding and interpretation are linked, however, explanation and analysis is an evolving process, which is never definitive (Annells, 1996). To explore people's experience, Heidegger suggested the use of the hermeneutic circle (Heidegger 1950), which Racher and Robison (2003) argue is rooted in the ontological view of lived experience as being an interpretive process. A key aspect of hermeneutics in the interpretation of the human experience is the consideration of the part in the context of the whole and how the whole relates to the part which enhances the depth by which the researcher engages with and understand the embedded meanings in the texts (transcripts). Koch (1996) has argued that Heidegger saw understanding as being a reciprocal activity and thus emphasised the concept of the hermeneutic circle as a way of achieving understanding. In hermeneutic phenomenological research practice, this analytical step is called the hermeneutic circle. When implementing the hermeneutic circle in research, the overarching aim is to illuminate the relationships between the text and context. Thus, it is a 'circle' because during data analysis, understanding of the text hermeneutically requires consideration of the relationship between the entire text (all the transcripts) and parts of it (individual transcripts). Put in another way, understanding of the whole informs understanding of the parts and vice versa. Rather than have a formalised analytical approach, Langdridge (2007) suggests that the phenomenon being explored, and the context dictates the analytical approach for the experiential data.

3.3.4. Influence of personal experience on choosing a research approach

The researcher's personal experiences, worldview and values have an inevitable influence on the research process, and transparency about this is a highly recommended step in demonstrating rigour (Shaw, 2010). This is because in any qualitative research, the researcher is not detached (as in quantitative analysis) but plays an active part in the research process. The

researcher's experience can help or hinder attempts to gather the participants' thoughts and feelings about the subject being investigated. Van Manen (1997) proposes that investigators/researchers should be mindful of their experiences, background, and views as these can affect the overall conduct of the research.

Hans-Georg Gadamer (1989) explains that every reader approaches any given text with underlying prejudices (Gadamer, 1989). Thus, in my interpretation of the text (participants' stories), the outcome would exhibit my underlying prejudices as Gadamer asserts but should at the same time illuminate the meaning units grounded in participants' experiences (Hycner, 1999). However, I must clearly state how I look at the participant's experiential material and ensure there is clarity on how my position relates to the phenomenon being explored.

3.4. The rationale for a phenomenological approach

The review of the literature (chapter 2) showed that there is very limited UK experiential-based research on minority ethnic PLWD in relation to EoLC. In addition to this, the aims and objectives of this research project detailed in Chapter 1 necessitate an approach that enables individuals to tell their stories in order for their voices to be heard. Enabling the voice of the participants is one key objective of this research. Therefore, a phenomenological research approach was considered as it empowers participants to voice their experiences. Phenomenology aims to explicate phenomena and has widely been used in psychological and health research (Matua, 2015). While several phenomenological research approaches exist in the qualitative research literature, Norlyk and Harder (2010) propose that researchers must understand the commonalities and differences inherent in phenomenological research methods. Laverty (2003) states that engaging with hermeneutic phenomenological research requires one to start with self –reflection in order 'to explicitly claim how their position or experience relates to the issued being studied' (p.28). My work experience in community dementia care and years of contact with PLWD and their family caregivers is part of my history that I cannot deny, attempt to 'bracket' or suppress in any manner, as making a difference to PLWD during my work with them has always been meaningful to me as an individual. As Heidegger claims, my experiences are a hallmark of my 'being in the world'. Whenever I meet a person living with dementia, I look back to my previous encounters and use what I already know about dementia to make sense of their everyday life. Therefore, I perceive my preconceived understanding as

an essential feature that would enable me to develop a deepened understanding of participants' experiences and the meanings embedded in those experiences.

For this reason, the idea of bracketing one's pre-understandings emphasised in descriptive phenomenology was rejected. Heidegger's argument that bracketing one's pre-understandings can be difficult was supported. My position necessitates an approach that acknowledges the value of one's preconceived understanding as essential in making sense of research participants experiential narratives. Therefore, a hermeneutic (interpretive) phenomenological approach is chosen because it allows me to take a position from which I will communicate, support, question and make sense of the participant's stories and reveal meanings embedded within their accounts.

3.4.1. Van Manen's hermeneutic phenomenological approach

Van Manen's (1990) hermeneutic phenomenological approach was chosen to guide this research programme because of its ability to enable in-depth descriptions and interpretations of phenomena. It can best be understood as a human science approach, through which meanings attached to human experience can be illuminated. Van Manen suggests that the researcher must apply the 'hermeneutic circle' (discussed below) by analysing a subset of the text (transcripts) and then looking through rest of the transcripts to develop an understanding of the basic structures of the phenomenon embedded within the participants' stories. The 'hermeneutic circle' helps the researcher to discover what is embodied within the text about the aims and objectives of the exploration. To achieve this, Van Manen (2014) suggest that hermeneutic phenomenological research should be driven by 'wonder at what gives itself and how something gives itself' (p.26).

Van Manen's hermeneutic phenomenology approach is more positive about reflective engagement in the research process, which allows the esearcher to draw on his/her experience to make sense of participants' experiences. As a human science approach, van Manen suggests that phenomenological inquiry cannot be formalised into a series of technical procedures (van Manen, 2011). Instead, van Manen sees the researcher's understandings as valuable in bringing the taken for granted essence of experience to the fore. He further makes a strong claim that his approach is "a method of abstemious reflection on the essential structures of the lived experience of human existence" (van Manen, 2014.p26). Abstemious, in the sense that hermeneutic phenomenology enables participants to 'abstain' from drawing on theoretical

assumptions during their lived experience reflections. As an approach to understanding the life worlds of participants Polkinghorne, (1983) and van Manen (1997) place emphasis on how one can apply one's assumptions to clarify the structure of the participants' lived experience using a hermeneutic phenomenological approach. A fundamental aspect of the method is that the researcher should provide the reader with details of their biases, prejudices, and values and how these might have influenced the interpretation of participants accounts. In van Manen's view, hermeneutic phenomenology involves:

> 'being swept away in a spell of wonder about phenomena as they appear, show, present, or give themselves to us…., phenomenology directs its gaze towards the regions where meanings and understandings originate, well up, and percolate through the porous membranes of past sedimentations-then infuse, permeate, infect, touch, stir us, and exercise a formative and affective effect on our being" (van Manen, 2014, p.26).

Furthermore, the choice of this approach was based on its ability to reveal new meanings about the phenomenon being explored or revealing taken for granted everyday experiences into 'visibility' (Harman, 2007, p. 92).

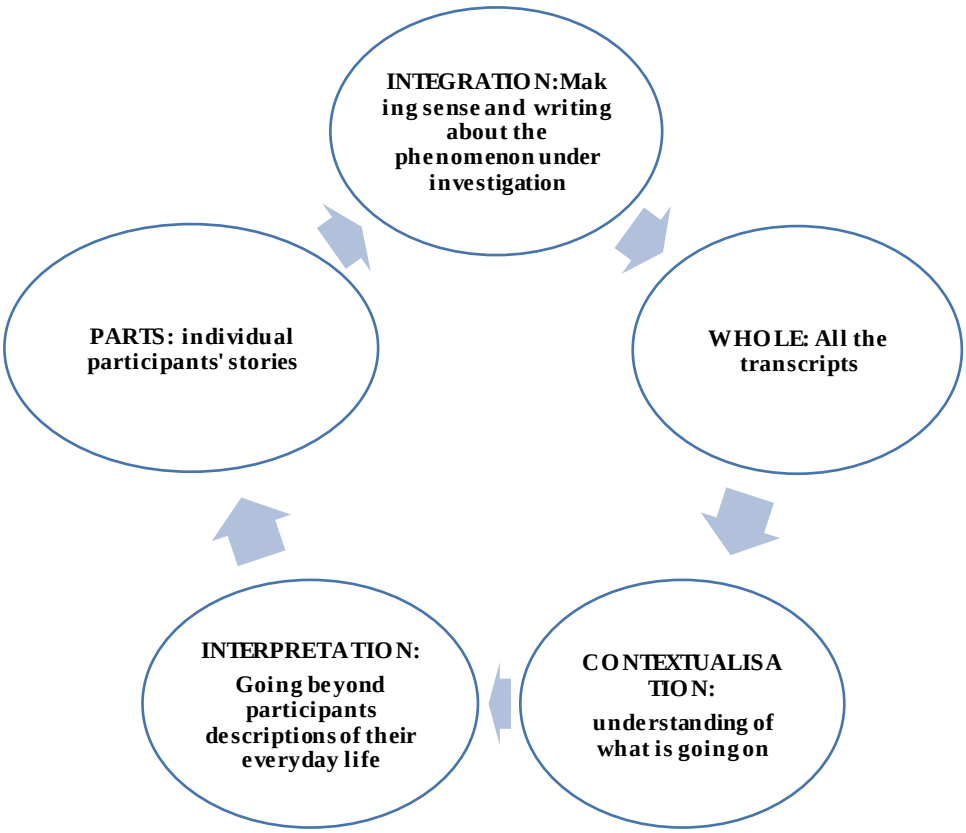

Figure 1:Illustration of the hermeneutic circle

By using the hermeneutic circle (Fig1), making sense of participants' accounts, the research moves from the part to the whole while considering the context from which the experiential reports were collected.

The aim of phenomenological data analysis, according to van Manen (1997, p.36) is to 'transform lived experience into a textual expression of its essence'. The outcome of a phenomenological study should be straightforwardly engaging and simplified in a way that a reader who has experienced the phenomenon can make sense of the themes (Holroyd, 2007). These themes are structures of a given experience, and they represent an aspect being explored (van Manen, 1990). The thematic analysis involves a process of identifying the structures of meanings embodied in human experience embedded within a text (transcripts). From van Manen's (1990) position, the identification of thematic implications of a phenomenon is an activity that requires one to be attentive to subtle issues which when omitted, the phenomenon would not be adequately illuminated in its appearing. van Manen (1990) proposes three approaches by which thematic aspects of an event can be explicated; wholistic approach, in which the whole text is explored, the selective approach, which relates to sections of text being analysed and the comprehensive plan in which every sentence within a transcript is considered in relation to the aim of the study presented in Chapter 1. Regarding thematic analysis, van Manen (1990; 2014) emphasised using lifeworld existentials as an illuminating guide to analysing participants' experiential material thematically. The lifeworld existentials enable the world of lived experience in our everyday life to be grasped in its appearance to our consciousness. These five existentials are universal to all humans whatever their background and are spatiality (lived space), temporality (lived time) corporeality (lived body) and rationality (lived human relation) (van Manen, 2014).

3.4.2. The use of Template Analysis

Template analysis (TeA) can be understood as a style of organising and thematically analysing data and was developed by King (1998), from the earlier work of Crabtree and Miller (1992). Because of its ability to reduce significant amounts of textual data to manageable forms for analysis, TeA has since been used in studies across disciplines of various size and from different epistemological position (Brooks, McCluskey, Turley & King, 2015). TeA is often used to help organise large amounts of data and has been applied in phenomenological studies to facilitate the analysis data analysis process meaningfully. Van Manen suggests that the

process of explicating the meaning structures of a phenomenon should be flexible, TeA allows this flexibility to be achieved the iterative process of devising and refining a template aids reflection and immersion in the data by providing a structure in which to work from. The creation of a template is not the endpoint. Instead, it is a way to expansively consider the data set in relation to the aims of the research, which can then be reflected upon and developed into genuinely phenomenological insights. Among many other forms of data, TeA has mainly been applied on interview transcripts (e.g., Locket et al., 2012); focus groups (e.g., Bassey & Melluish, 2012; Brooks, 2014); semi-structured survey data (e.g., Collins et al., 2018).

A distinctive and critical feature of TeA is the formulation of a thematic, hierarchical coding template. The template allows the researcher to organise emergent themes for interpretation and reporting of findings (King & Brookes, 2017). In this research, the suitability of TeA was based on its ability to organise the vast amounts of data for analysis. Although a study can make use of *a priori* themes to develop an initial template when using TeA (King & Brooks, 2017), the development of following subsequent themes should be grounded in the data. One advantage of applying *a priori* theme/s is that it can help the researcher/s to have a tentative starting position to identify further themes embedded in the transcripts especially where the data set is voluminous (King, 2004). However, a potential limitation of using too many *a priori* or predefined themes is that it can hinder the development of codes that reflect or represent the participants' perspectives about the subject being researched. When using a priori themes in phenomenological research, it is crucial to set one's assumptions aside as failure to do so may become a barrier to identifying new emerging information within the transcripts.

The development of an initial template involves thematically coding a subset of the transcripts and identifying the themes in line with the research question. During this process, parts of the transcript/s, which the researcher considers to be relevant to the aims and objectives of the study are indexed to the designated theme. They are then iteratively revised, defined, redefined, and refined as the analysis continues (Brooks et al., 2015). The process of creating the initial template involves bringing the identified themes together to create some form of structure as work in progress. The remainder of the transcripts is then explored by applying the first template to explore the rest. The conduct is iterative and includes refining and redefining the contents of the template to accommodate further emergent themes within the data (King, 2012).

The presentation of a template in a hierarchical structure does not necessarily designate an order of significance; its purpose is to arrange/organise the data that permits the researcher to

navigate the meanings that are within the text, further allowing an in-depth exploration of the participants' meanings in keeping with the study's methodological framework and, aims and objectives. A critical aspect pointed out by Brooks et al. (2015) is that ideally, one cannot claim to have produced a 'final template' in an absolute sense, as further engagement with the data would more likely further highlight a need for the previously identified themes to be refined. For the development of the central theme, a good rule of thumb is to ensure that there are no critical sections of relevant data left uncorded. Concerning the maintenance of rigour, one main advantage that TeA has is its allowance of an audit trail of how the themes were identified during the analysis stage and how the researcher's thinking evolved (King, 2012). Regarding enhancing the study's trustworthiness, Carcary (2009) has maintained that an 'audit trail enables readers to trace through a researcher's logic and determine whether the study's findings may be relied upon as a platform for further enquiry' (p.11). In this study, an audit trail is shown in (Appendix 16), which provides transparency about how the themes evolved during the application of TeA.

3.4.3. My position as a researcher in hermeneutic phenomenology

From the beginning of developing an interest to undertake this research, I realised that suppressing my existing understanding of dementia was going to be an impossible action. I have spent a significant quantity of my life working closely and interacting with PLWD and their families; this had become part of my life history and background that I cannot dissociate myself from – a point emphasised by Heidegger (1927/1962). From a broader standpoint, I perceive the experience gained from my contact with PLWD and their families as a fundamental aspect of my understanding and development of empathy towards PLWD and their families. As outlined in the methodology section above, an interpretive/ hermeneutic phenomenology was favoured over a descriptive approach, because the latter makes an explicit emphasis on that the researcher should 'suppress' or 'bracket' his/her preconceived understandings of the phenomenon under investigation.

3.4.4. Reaching out and researching 'hard to reach groups'

African-Caribbean PLWD and their family carers are often regarded as 'hidden' or 'hard to reach' (Cheston et al., 2017). 'Hard to reach' is a phrase applied to refer to those sub-groups of the population that have been found to be challenging to recruit or involve in research

(Shaghaghi, Bhopal, & Sheik, 2011). The use of these terms in research and health and social care practice over time appears to have become a barrier to engaging with those who fall under the umbrella of these epithets (Holpit et al. 2012).

For these reasons, throughout the evolution of my curiosity in the phenomenon and the inception of this research programme, I was aware that the success of the exploration would be determined by how well I developed strategies for involving African-Caribbean PLWD and their families. For example, Hussain-Gambles et al. (2004) and Sheikh et al. (2009) emphasised that a researcher's attitude to the population group whose participation in research is requested has implications for the recruitment process. Before attempting to engage in the recruitment process, I needed to avoid perceiving the target population as challenging or 'hard to reach' to recruit in research because that would have shaped how I went about planning the recruitment process.

3.5. Establishing rigour and credibility

As in all good research, the quality of this research should be taken seriously and in line with the chosen research approach (Finlay, 2013). Several qualitative commentators and researchers (e.g., Noble & Smith, 2015; Sandelowski,1993) have questioned the applicability of the term validity, a term associated with quantitative research, into studies employing qualitative methods. However, the idea of having criteria for assessing quality seems to have taken the upper hand over time, given the increasing recognition of qualitative research in evidence-based healthcare. While Yardley's (2008, 2017) criteria to achieve rigour in qualitative psychological research underpinned the quality checks adopted in this study (described in the next section, below), my understanding of rigour in this work was also drawn from van Manen's assertion that quality phenomenological research should attract the reader's curiosity about the phenomenon being explored (van Manen, 2014).

For van Manen (1997), the extent to which the research is orientated to the subject area and its strengths, clarity and depth are critical quality considerations. This resonates with Yardley's recommendations that I used as a guide for this research programme. From his point of view, orientation relates to how the researcher is involved with the research participants and how he/she makes sense of their stories. Strength refers to how the text is convincingly representative of essential features that allow an understanding of the meanings embodied in the accounts given by the participants. From van Manen's viewpoint, the richness can be

achieved by the level of depth in the description of the participants lived experiences in the report (findings). In contrast, the depth and rigorousness of the research can be illustrated by the extent to which text provides a holistic depiction of the participants' feelings and experiences. Given that hermeneutic phenomenology seeks to elucidate the fundamental essential themes as lived by the participants, each identified theme must be substantiated by excerpts taken from their lived experience descriptions to demonstrate rigour of the research and trustworthiness of findings (Morse et al., 2002)

Issues pertaining to establishing reliability and validity of research has long been emphasised as critical to the trustworthiness of findings and thus cannot be overlooked. Without demonstrating this, Morse et al. (2002, p.14) states "research is worthless, becomes fiction, and loses its utility". However, the concepts of validity and reliability are often discussed in relation to quantitative research, with many researchers disputing their compatibility with qualitative research (e.g., Lincoln & Guba, 1985; Morse et al, 2002). This has resulted in various procedures deemed fit for demonstrating the quality and trustworthiness of qualitative research being suggested. For example, Yardley (2008, 2017) suggests that validity of qualitative research findings can be established through four vital but flexible components which are: sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (Yardley, 2017). To demonstrate validity, this research programme was therefore guided by Yardley's (2008, 2017) components detailed above.

3.5.1. Sensitivity to context

Research that demonstrates sensitivity to context should reflect the context or setting, including a clear demonstration of the perspectives of the participants and how the study went about interpreting them (Yardley, 2008,2017). Demonstrating rigour through sensitivity to context also includes avoiding imposing 'preconceived categories' (Yardley, 2017, p.296) but developing them from the participants' accounts. In this thesis, sensitivity to context is reflected by how I provide a clear description of who the participants are and where they were recruited. This research also demonstrates this by giving a substantial number of verbatim extracts from the interviews, giving PLWD and family caregivers a voice as meaning makers in their context but also assisting the reader of this work a scope navigate how the interpretations were derived from the participant's accounts. Furthermore, the thesis provides a review of relevant literature to contextualise the study, including theoretical perspectives of the topic under investigation.

3.5.2. Commitment to allow the voice of PLWD to be heard in research

Firstly, I have demonstrated my commitment to the study by adhering to ethical principles in research involving a potentially vulnerable and less researched group of people. Through a purposeful research design which respects the autonomy of PLWD and their right to participate in the study, commitment to the rigour-the voice of people with dementia is heard, rather than only focussing on professionals as informants. The thesis demonstrates an effort that I have made to understand the epistemological stance of hermeneutic phenomenology, and it is underpinning philosophical assumptions. Regular contact with my three thesis supervisors allowed me to discuss any issues arising from fieldwork and obtaining their constructive feedback on the transcripts helped to ensure the entire research process yielded enough data within ethical boundaries a vital aspect of the rigorous study.

Yardley (2008) asserts that the researcher's consistency during interviewing and throughout the data collection process, and his or her degree of attentiveness towards the participants, demonstrates his or her commitment to, and the rigour of the research project. The transcription of each interview completed was undertaken with an attention to detail approach while using the field journal which helped to ensure the both the participants' and researcher's emotions during the interview process were taken account of, including the full interactions with participants and during the interview. During the process of data analysis, I maintained a systematic approach, and excerpts from the participants' accounts are provided to illustrate and support each theme. In keeping with the principles of hermeneutic phenomenological data analysis, I aimed to offer clarity and depth of interpretation of the data by making use of regular thesis supervisor feedback during the data analysis process. Sensitivity to context is also achieved by evidencing theme development throughout the analytic process using the hermeneutic circle and critical principles of Template Analysis (King & Brooks, 2017).

3.5.3. Transparency and coherence

Transparency refers to the extent to which the reader can clearly follow the research processes that were conducted in a particular study. In this study, transparency was achieved by providing a clear description of the research process from recruitment of participants to undertaking in-depth data analysis (Yardley, 2008). Transparency was also demonstrated through a detailed narrative about the insider/outsider perspective (etic & emic), which can

also help the reader of this research to understand the implications of my position and engagement with the research process.

Coherence in qualitative research refers to the suitability of the research and analytical techniques chosen to explore a research problem. This includes a clear relationship between the philosophical underpinnings of the research and the methodology. Yardley (2008) explains that coherence is enhanced by reporting findings in a manner consistent with the approach adopted. Findings in this study are presented in a way that represents the voice of the participants. After all, it is the study's key objective to allow participants' voice to be heard in EoLC research; for this reason, quotes from participants' stories are used to support each identified theme. Yardley suggests that the coherence of the study is based on its ability to allow the reader to understand what was done and the reasons behind the decisions that the researcher made. In this study, I demonstrate this by showing an audit trail of how the analysis was done from the development of the initial template to the final. As the researcher's position inevitably influences qualitative research (Yardley, 2008), I provide a detailed account of reflexivity on the research process and my position as a partial insider/outsider in the research which enhances transparency and coherence of the study. Thus, the evolution and procedural development regarding data analysis process are demonstrated by an audit trail from the initial coding template to the final one (Appendix 15); which show sensitivity to the interview data throughout the analysis.

All the materials used are found in the appendix, including evidence of the iterative systematic illustration of how the analysis process evolved in keeping with TA and van Manen's approach. Regular discussions (face to face and by email) with my supervisors regarding the development of themes worked as a basis to ensure the story in this thesis was grounded on the data and makes sense in the context of the dementia care and related EoLC. Finally, my aim and motivation of this work have been to provide a coherent argument thread, which informs through the entire thesis, an effort that I reflect on as I write.

3.5.4. Impact and importance

Yardley (2008) explains that a critical test of a piece of research is its degree of usefulness and interest to real-world applications, otherwise 'there is no point in carrying research' (p. 268). As no relevant studies specifically exploring EoLC for minority ethnic groups with dementia and their families in the UK were identified in Chapter 2 (review of literature), it is hoped that

this study will contribute towards an understanding of quality care for African-Caribbean PLWD and their families. My motivation for this research programme is to respond to the calls about a need for EoLC themed research on UK minority ethnic groups with dementia by several researchers in this field (e.g., Koffman, 2018, Connolly et al., 2012, Calanzani et al., 2013). As evidence suggests many people will die with or from dementia as the population ages, the need to fill the existing knowledge base on EoLC for minority ethnic PLWD is more relevant to the context shown by literature review in Chapter 2. I hope that the knowledge generated by the study will be useful to appropriate health professionals and may be used to improve EoLC services. There is also an opportunity that the product of this research programme could necessitate identifying critical areas that further research can be focussed on and may trigger an open dialogue about EoLC for PLWD dementia, and more so for those who are labelled as 'hard to reach', and who are underrepresented in dementia care services despite evidence showing an increase in dementia. Despite the limitation of this research programme due to its focus on a small group of African-Caribbean people within the broader minority ethnic bracket, I hold real hopes that the voice of this small group will be heard in research whose product is relevant to them and the echoes from their experiential narratives may trigger further research currently lacking to improve their EoLC experiences.

3.6. Reflexivity

In qualitative research, reflexivity plays a crucial role in promoting the credibility of findings and thus cannot be overlooked. Although there are many definitions of reflexivity, Shaw (2010, p.4) defines it as 'an evaluation of the self' and suggest it should be embedded in experiential qualitative psychological research to reduce bias. Dowling (2007) refers to it as process of self-critique and continuous self-awareness which the researcher must engage with, to show how his/her values, experiences, opinions influenced the overall design and conduct of the research. In this whole project, I remained self-aware, assessed, and reassessed my position as a researcher. Finlay (2003, p.ix) explains that reflexivity a "thoughtful, self-aware analysis of the intersubjective dynamics between the researcher and the researched". She further elucidates that reflexivity should not only focus on the researcher's personal experience but should also cover the methodology of the study. Despite this, most qualitative research literature tends to depict reflexivity in terms of personal reflexivity; that is the researcher's ability to acknowledge who they are and how their position, values and interests may have had an influence on the overall research process and its output. While this is important, there is need to look at

reflexivity from a broader perspective that covers a critical reflection of the methods or techniques that the research, the decisions that were made along the research process and the researcher's position. Langdridge (2007) have argued that proving the readers with this information helps them to understand the researcher's influence on the inquiry and enhances the validity of the findings as it sheds light into how knowledge was created.

Reflexivity was framed in two ways in this research. Firstly, I considered my position as a black man researching a sensitive topic with older black people who are a vulnerable group of people due to their illness and due to their minority ethnic status. I drew extensively on my partial insider/outsider position and how my value base, understandings of the phenomenon under investigation that I brought into the research could have positively or negatively influenced the process and its outcome. For example, being a younger black African man researching a group of older black people enabled me to connect with them. In addition to this, my experience of working with PLWD and their families helped me to communicate with the participants respectfully and sensitively but was crucial in developing an in-depth understanding their experiences. Being a researcher made me an outsider in that my mission was to collect information for the research programme.

Secondly, reflexivity in this research covers a critical analysis of the methods that were used and the reasons behind some decisions that I made. This is important, given that in hermeneutic phenomenological research, participants are encouraged to engage in a reflective journey of their experiences, and their stories represent the intelligibility of their personal lives (King, Horrocks & Brooks, 2019) - something of importance for approaches that are nested under interpretivism, where the interpretation of human experience and meaning is a central priority. However, developing an understanding of how one's prejudices or presuppositions can have an impact on the research can be challenging. While researchers often fail to provide detailed accounts of this (Spence, 2017), in this research, I have detailed my work experience and outlined how my insider/outsider position could have impacted on the research.

3.7. Summary of Chapter

Chapter 3 presented the philosophical, theoretical, and methodological underpinnings of the research programme. I have also detailed the rationale for a qualitative approach and introduced phenomenology. I have discussed the implications of my personal experiences and how these may have influenced my choices and decisions in designing the research programme. Van Manen's hermeneutic phenomenological approach has been presented as a chosen approach to guide the conduct of the research. TeA has been presented. Strategies for establishing rigour and credibility for the research and reflexivity have been presented. The next chapter covers the methods of the research.

CHAPTER 4: METHODS FOR THE RESEARCH PROJECT

4.1. Introduction

This section describes and explains my application of van Manen's (1990) hermeneutic phenomenology. I used this approach with the support of template analysis (King & Brooks, 2017), to recruit the participants, gather their stories and explicate them phenomenologically to develop a deepened understanding of EoLC from the viewpoints of African-Caribbean PLWD and their family caregivers

The study design involved a focus group interview study with older black African-Caribbean PLWD (exploratory phase) and in-depth phenomenological interviews with current and bereaved BAME caregivers of a relative with dementia. BAME family caregivers provide most of the care to their relatives with dementia (Johl et al., 2014). The assumption was that they could reflect on their caregiving roles and help illuminate the care recipients' experiences and needs.

The overall design and data analysis were mapped out using van Manen's (1990, p.31) six essential steps for undertaking a hermeneutic phenomenological study:

1. Turning to the nature of lived experience
2. Investigating experience as we live it
3. Reflecting on the essential themes which characterise the phenomenon
4. Describing the phenomena in the art of writing and rewriting
5. Maintaining a strong and orientated relation to the phenomenon
6. Considering the parts and the whole.

(van Manen 1990, p.31)

Table 3 summarises how the six steps were applied. Sections 4.1.1- 4.1.6 then provide a more detailed explanation.

Table 3: Van Manen's steps for conducting phenomenological research (van Manen 1990, p.31)

Essential research step	Research related description of step
Turning to the nature of lived experience	The current study aimed to explore perceptions and hopes regarding care at the EoL from the perspectives of Older African-Caribbean PLWD and their carers, with the guiding question being: what is the lived experience of black African-Caribbean PLWD and what is the lived experience of current and believed family caregivers who provide or have provided care to a relative with dementia? Throughout the progression of the research, I reflected on this question continually to ensure that the methodological steps that were implemented remained the most suitable to explore the subject.
Investigating experience as we live it	The approach to data collection aimed to explore the lived experience of older African-Caribbean PLWD and that of family caregivers in the context of future EoLC. To study the experience as lived by PLWD and family caregivers, the use of focus groups, semi-structured in-depth phenomenological interviews allowed them to reveal their experiential accounts about EoLC to be heard, tape-recorded and subsequently verbatim transcribed. These were then turned into phenomenological text on which meaning structures about the phenomenon of interest (which is EoLC) were illuminated. Interviews in all the research phases permitted the participants to contextualise their experiences of living with dementia and what it meant to them and as they re-revealed themselves through phenomenological interviews. Thus, both focus groups and individual carer interviews were used as a tool for giving the voice to participants, capturing their experiences and collection of their stories in relation to the aims and objectives of the study.

Reflecting on the essential themes which characterise the phenomenon	To reflect on the meaning structures depicted in the participants' stories, the first step was to identify the structures of the participants' experience that were prominent in the data. In conducting a phenomenological study, one should adopt a phenomenological attitude as the preamble to carrying out a coherent investigation (Finlay, 2008). For example, during the focus group and carers' interviews, I sought to recognise essences/meaning structures from participants' accounts by looking at individual perspectives within the data and looking at the whole data set. I used the field diary to document my feelings and thoughts and that of the participants during and immediately after the interviews. The fieldwork notes were then used in refining the interview schedule on the following interview sessions. Furthermore, to reflect on the essential themes that characterise dementia EoLC, efforts were made after each interview to ensure the audio-recorded interviews were transcribed at a suitable time while the participants' reactions during the interview process remained vivid in my mind and diary reflection (Polkinghorne, 1983). Delineating the essential themes was accomplished by applying the hermeneutic cycle, which I initiated by acquainting myself with the data and carefully reading and re-reading the transcripts to ensure that I captured the essence of participants' meanings. Through this process, the illumination of essential thematic structures was achieved by moving between transcripts in search for shared meanings that the participants had from their experience. Isolating thematic statements (discussed below) was obtained by selecting relevant comments, remarks, words, and phrases that I felt were important from the reading and re-reading of

	the data. These selected phrases or statements formed the main themes and sub-themes. van Manen (2014) suggest that when conducting a phenomenological analysis, the researcher should avoid concentrating on locating 'sameness or repetitive patterns' in the participants' stories (p.353). According to van Manen, any fundamental idea that may appear less frequently in the experiential material (e.g., transcripts) but has the power to reveal more about the phenomenon under investigation should not be left
Describing the phenomenon in the art of writing and rewriting	In naming the themes, I followed a suggestion by van Manen (2014) that to describe the phenomenon under investigation, (dementia EoLC in this case) one must write poetically, in such a way that describes essences "universal in the experience" (Kendall, 2006, p. 1152). The focus was to 'receive what is given' in the text (transcripts) (Finally, 2008). However, this needed me to be curious while also being mindful of my position and perspective gave my personal, cultural, and historical background (Finlay, 2008). As hermeneutic phenomenology takes both from the philosophical position of hermeneutics and phenomenology, in van Manen's (2014) point of view, a phenomenological text must acquire a questioning mood leading to a sudden realisation of 'the unexpected enigmatic nature of ordinary reality' (p.360). As I compiled drafts of my analysis and interpretations of participants stories, I regularly revised and refined the presentation of the phenomenon. The lived experience descriptions about living with dementia in the context of future EoLC given by PLWD, current and bereaved caregivers that collected during data collection, are included in support of meaning structures (themes) of the EoLC

Maintaining a strong and orientated relation to the phenomenon	Despite the challenges that I faced during fieldwork (e.g., negotiating access to participants, establishing trust and rescheduling interview dates) my quest to gain an understanding of EoLC from the perspectives of African-Caribbean PLWD and their families continued to fuel my motivation to the study. There were times that I found myself immersed in the experiential accounts of the participants in such a way that evoked empathy and deep emotion. To avoid losing focus and direction of the research process, I regularly used a journal on which I made systematically documented my reflections, which I then used as a reminder of maintaining a strong focus on the research question during the analysis process. Furthermore, to ensure orientation to the phenomenon under investigation was retained throughout the research process, I valued and prioritised regular contacts with PhD colleagues within the School of Human and Health Sciences at the University of Huddersfield and used my weekly meetings with my thesis supervisors as a platform to reflect on the research process and the issues I experienced during fieldwork. All these activities were critical in maintaining a strong and orientated focus on the phenomenon while also assisting me in keeping an open mind towards how the world appeared to both older African-Caribbean PLWD and family carers about EoLC.
Considering the parts and the whole	During the process of isolating essential elements of the participants' accounts for revealing new perspectives and understandings from the meanings they attributed concerning EoLC, I constantly reminded myself to question and re-question my existing knowledge, for instance, how do older African-Caribbean PLWD experience living with dementia and what, if any, is crucial to them at the EoL? How do family

	carers of African-Caribbean ethnicity make sense of their role and what, if any, is essential at the EoL? These questions were critical during the hermeneutic circle of understanding. The hermeneutic circle allowed me to search for themes (parts) while considering what was embedded in the 'whole' (the entire data). This process was iterative. The essential themes were isolated to illuminate the taken for granted structures of the phenomenon of interest with the help of Template Analysis (King, 2012) (discussed in section 3.4.2), beginning with the focus group interview data. It was vital to read and reread the interview transcripts to develop a broadened understanding of the participants' experience before going through each transcript. In this way, an understanding of the whole and the parts were made possible, consequently aiding in the development of a deepened knowledge of EoLC for this group of people. I concentrated on writing phenomenologically to illuminate and present the phenomenon under investigation as grounded in the experiential narratives of the participants. The hermeneutic circle was applied through a process of iteratively exploring each transcript in the relation to the entire data and vice versa.

Applying van Manen's six steps when conducting this phenomenological research enabled a deepened description, interpretation and understanding of participants' lived experiences of dementia and perceptions of EoLC. It gave the voice to a 'seldom heard' group of people and allowed the nature and meaning of their lived experiences to be explored and comprehended from their perspectives.

4.2. Accessing and recruiting participants

My opportunities for accessing and recruiting participants depended on good relationships between myself, daycentre staff, service users and family carers. I found that my background,

personal insights, and experiences were invaluable in developing appropriate, sensitive, and effective strategies.

The theoretical underpinnings for the approach to sampling in this study drew on the tradition of pragmatism in research, which favours the selection of the best research methods for addressing the research issue (Tashakkori & Teddlie, 2009). The epistemic contribution of pragmatism to study design is especially relevant to the complexities of real-world health and social research (Long, McDermott & Meadows, 2018) that requires research which is responsive to context and addresses practical problems, as found in this study. Health research methodologists, e.g. Long et al. (2018) and Holtrop and Glasgow (2020) emphasise the value of pragmatism, with its "focus on the practical and achievable, rather than the theoretical or ideal" (Long et al. 2018, p.5). Therefore, the sampling for the present study, with its context of health and social care, is supported by methodological positions found in the literature, and further echoes Long et al's (2018 p. 5) statement that "pragmatists judge the value of knowledge (and our ways of knowing) by its context-dependent, extrinsic usefulness for addressing practical questions of daily life".

4.2.1. Project Setting

This research was carried out in one of the largest ethnically and culturally diverse cities geographically located in the North of England, with people from BAME background occupying 19% of its estimated 575,400 population during the 2011 census (ONS, 2011). The city has large and aging Pakistani, Caribbean, black African, Indian, Bangladeshi, Chinese, Yemeni and Somali communities (Sheffield City Council Knowledge & Research, 2013). Most of the people from these BAME communities moved to the city to work in the by then booming steel industry around the early 1948 during the Windrush era (APPG,2013). In addition to this, Integration up North (2015 p.5) states 'the ageing of the ethnic minority population for Yorkshire and the Humber will raise important issues for policy makers and planners particularly in localities which have a higher ethnic minority concentration such as Bradford, Kirklees, Sheffield and Leeds'.

Therefore, the city's richness in terms of its ethnic and cultural diversity, and a call for a need for research to understand the increasing needs of the city's aging BAME community by its local dementia strategy (Sheffield CCG, 2019) made it a suitable setting for the research.

My role within a specialist dementia care services within the city involved supporting individuals living with dementia and their family carers. This partly involved signposting them to appropriate community services for care and support. My knowledge of the city's services for older BAME people, which I acquired through many years of working in older people's services, was helpful in identifying the setting for the research. For instance, my awareness of adult day-care centres for BAME people helped me to locate an adult day-care centre from whom PLWD and their family caregivers were recruited for the study.

In the UK, adult day care centres provide daytime services (mainly activities and psychosocial interventions) in a supportive, safe, and uplifting environment aimed at promoting the service users' wellbeing. The day centre website from which participants were recruited states that it provides its service to 'enrich lives, build and maintain skills, enhance people's understanding of their condition, nutritional meals and enhance the capabilities and strengths of PLWD'. There are also various in-house activities provided at the day centre, and these include craftwork, musical entertainment, bingo and other games for mental stimulation, gentle group exercises and discussion groups (covering current issues and historical events), local outings and trips and carer support groups.

4.3. Recruitment strategy

The initial recruitment strategy was geared towards building trust and giving my potential participants the chance to get to know me. This involved investing extra time in multiple visits to the participating organisation (day centre), to discuss the research and to answer gatekeepers' and prospective participants' questions about the investigation. It was also an opportunity to outline the approach to maintaining their anonymity and confidentiality, should they consider participating in the study (Ritchie & Lewis, 2003). McKeown et al. (2010) suggest that to involve PLWD in research, substantial groundwork is required before the process of recruiting participants commences, which includes identifying the gatekeepers and building trust to facilitate the recruitment process.

4.3.1. Working with gatekeepers

Particularly at the earliest phase of the research, there were several times when the managers asked me to reschedule visits as they were 'too busy'. Such occasions during the process of

negotiating access to the setting demanded "patience and sensitivity" (Richie & Lewis (2003, p.62)); and again, my familiarity with the city through my work and awareness of dementia day-care providers was helpful. Another step that I found helpful in identifying the gatekeeper was my knowledge of the management structure/hierarchy within the day centre. I designed and distributed jargon-free information sheets (Appendices 4&5) and supplemented them with frequent visits, which were critical for discussing the research process and developing trust. It was crucial to maintain contact with the day centre management. Gasman and Payton-Stewart (2006) suggest reaching out to gatekeepers is vital throughout the study. This included giving brief talks about the purpose of the study, data collection procedure and time, issues related to their confidentiality, inclusion, and exclusion criteria for involvement in the research programme. As discussed above, the first step was to build and establish trust as part of the initial recruitment strategy of a group of people depicted as 'hard to reach'. Having worked directly with PLWD and their families, I was aware of the importance of building trusting relationships; failure to do so often led to poor service outcomes and patient/carer disengagement from our service.

4.3.2. Developing trust with PLWD and family carers

Once trust with gatekeepers was established, and questions surrounding the research had been answered, PLWD and family carers expressed their interest in participating in the research. Knowledge of the population group can be helpful in successfully recruiting minority ethnic people in the research project. For example, it could be taken as a form of disrespect to address an older person by their first name, and so, as noted in my encounter with older PLWD, it was essential to refer to them as, for example, Mr Jones, instead of Peter.

Again, my understanding of working directly with PLWD and their family caregivers, and my knowledge and experience of how to communicate effectively with them, were crucial assets in recruiting and screening potential participants. The process involved being flexible in scheduling appointments, to avoid disturbing the routine within the day centre. For example, one focus group was carried out soon after lunch to fit in with the usual activities of the centre.

The time invested in building rapport and trust was critical in dealing with the potential participants' assumptions about how the findings of the study would directly benefit them. Allowing adequate time for questions, responding sensitively, and my frequent presence within the day centre was vital strategies that I employed to ensure participants were fully informed

about their involvement in the research. As my identity was both as an insider and outsider, I was able to establish the trust necessary to facilitate recruitment and participation (Dwyer and Buckle 2009).

4.3.3. Navigating concerns around capacity and autonomy

Concerns around PLWD's capacity to provide informed consent, and an assumption that a PLWD is unable to voice their experiences, often means that proxy accounts are used to understand the lived experience of PLWD (Bamford & Bruce, 2002; Gove et al., 2017). I considered this to be an over generalisation and disregarding PLWD's autonomy: something which goes against current policy and practice, which emphasises that people should exercise power and influence in matters that have direct resonance with their lives (Tanner, 2012). Groups run by PLWD (e.g., Dementia Engagement and Empowerment Project [DEEP]) have emphasised the importance of understanding their lived experience, which has influenced how dementia studies are designed (Morbey et al., 2019).

Some PLWD have challenged the tendency to overlook their abilities as autonomous individuals by researchers and practitioners, describing it as reductionist (Swaffer, 2014; Bryden, 2005). Clarke and Keady (2005) critiqued the use of proxy accounts to explain the experience of PLWD and argued that, if the experience of living with dementia is to be understood, then there is a need to capture the accounts of those living with the condition. This is because previous studies have shown that family members or caregivers of PLWD often have different views regarding their care and experience to that of PLWD (Dewing, 2002; Groen-van de Ven et al., 2017). Respect is a critical ethical principle is about treating people as autonomous individuals, and those whose autonomy is threatened by conditions like dementia are entitled to protection. As this research was on a marginalised group within society (Tanner, 2012), their participation in study could be a way of challenging marginalisation (Wilkinson, 2002).

In this research, involving older minority ethnic PLWD and their families, their dignity and rights were thoroughly considered. Dignity, from Nordenfelt's (2004) view, recognises the identity, integrity, independence, and background of PLWD. I also felt the importance of using participative approaches to reduce the widespread stigmatisation of dementia by minority ethnic groups. Swaffer (2014), who lives with dementia, argues that researchers could be inadvertently perpetuating stigma attached to dementia by not involving PLWD in research.

She writes, 'it is still very much about people with dementia without them' (p.710). The above reasons and the lack of the voice of minority ethnic PLWD and their families necessitated their involvement in this research. This was further reinforced by the literature review in Chapter 2, which found limited evidence about EoLC for PLWD.

McKeown, Clarke, Ingleton and Repper (2010) noted that obtaining consent is a complicated procedure that requires the researcher to ensure participants are well informed about the research. To ensure informed consent was obtained from participants, I abstained from using unnecessarily complicated research jargon, and all participants were provided with information sheets written in simple terms and presented in short sentences to facilitate understanding about the research programme (Jootun & McGhee, 2011) (Appendices 4&5) detailing the research. They were also encouraged to feel free to contact my PhD supervisors or me should they need further information about the study (Alzheimer Europe, 2012). In any investigation, participants have the right to know what their involvement entails and must be provided with all relevant information about the study. Given the nature of dementia and issues associated with obtaining informed consent, measures were implemented in this study to ensure that gaining approval was a continuous activity, rather than the traditional one-off task before interviews. Dewing's (2007) process consent framework (a widely used approach in this area) guided the conduct for obtaining participants' consent before and at junctures throughout the interview process. Generic consent issues were covered in the consent form (participant consent form, Appendix 6), which was signed by the participants in all the studies.

4.4. Additional considerations for the research programme

This section outlines the ethical considerations that were applied in this study. It also deals with some ethical issues that arose during the research process, which had to be managed to prevent harm to individuals who participated in this study. Research involving PLWD raises unique ethical challenges due to diminishing decisional capacity. However, when conducting this research, my overarching priority was to safeguard all the participants from likely harm as a result of their participation in the research programme. In any investigation, the protection of human rights should be taken as a mandate (Kvale, 1996).

As a researcher, I have a moral obligation to research in such a manner that minimises the likelihood of harm to participants and this research was guided by the principles of respect for

people (the autonomy of the participants), beneficence, and justice (Capron 1989) and was guided by the core principles for involving PLWD in research advocated by the Scottish Dementia Working Group Research Sub-Group (Scottish Dementia Working Group Research Sub-Group, [SDWG] 2014). These principles include the value of involving PLWD in research, recognition of their lived experience as essential to understanding what it means to live with dementia, maintenance of physical and emotional safety during their participation, being given opportunities to discuss or ask questions to decide whether to participate in research (SDWG, 2014). Guidance for involving PLWD in research was also taken from Alzheimer Europe's position on the importance of engaging PLWD in research as participants (Alzheimer Europe, 2011; Gove et al., 2017).

In view of these considerations, adequate and well thought out information about the research programme (appendix 4&5) was provided, to ensure that participation in the study was not only voluntary but also based on understanding. Because older people with dementia are a vulnerable group, my responsibility as a researcher was to ensure that the participants fully understood what was entailed by their participation (King et al., 2019).

4.4.1. Commitment to maintaining participants' safety

The collection of data in this study involved discussing sensitive topics with PLWD and their family caregivers, and this inevitably intruded profoundly on their subjective experiences (Sivell et al., 2019). Attempts were also made to ascertain that the participants understood the potential risks that may arise because of their participation in the research (Alzheimer Europe, 2011). I also drew from my work experience to offer reassurance and to communicate sensitively with participants. Where appropriate, I gave the participants enough time to pause for a break whenever they became emotional. The interview proceeded when the participants who chose to take a break stated that they were ready to continue. Most of the interview meetings were completed at the day centre, where there were trained nursing staff, and a supplementary distress protocol was put in place, including local self-help numbers. After the interviews, participants engaged in their routine day centre activities which allowed enough time to identify any potential psychological harm. All the participants were advised concerning the voluntary nature of their engagement with the research at the onset of the interviews, including the right to withdraw from the research programme without explaining their reasons.

To minimise causing distress to participants at the opening of the interview process, I refrained from sensitive and intrusive questions until a rapport was established and all participants were informed that they were not obliged to answer questions they felt were distressing to them. Again, I used my work experience to look out for any indications of possible distress.

4.4.2. Commitment to maintaining participants' confidentiality and anonymity

The maintenance of participants' confidentiality was a priority of this research. Assurance of confidentiality to participants was discussed as part of the process consent framework. All the data collected from the participants were kept confidential, in keeping with the University of Huddersfield data management policy. Pseudonyms were used to substitute participants' real names and any details that could potentially lead to the identification of participants were removed. Therefore, none of the names used in this thesis is a participant's real name. Focus groups and most of the caregiver interviews were conducted in a secure and private room within the day centre. An extra safeguard to protect participants' confidentiality was adopted when conducting caregiver interviews in their own homes. This involved planning with the participant to make sure they were no visitors for the duration of the interview meeting. Because maintenance of confidentiality can be difficult in focus groups, reminding participants to treat issues discussed as confidential material before and after focus groups was a prioritised strategy (Krueger & Casey, 2000). Overall, throughout the research process, my foremost aim was to maintain and uphold participants' privacy, confidentiality, dignity, rights, and anonymity.

4.4.3. Commitment to maintaining the researcher's safety

As a researcher and a human being, listening to participants' stories often ignited a myriad of emotions, primarily when they reflected about their everyday personal challenges of living with dementia and their EoLC wishes and desires. Despite the participants' emotionally charging lived experience descriptions, I was able to connect with them. Connecting with the participants gave me the opportunity to probe for further details about their experience which enabled depth of data. Because most of the interviews were conducted at the day centre, where there were trained healthcare staff and support facilities, my safety as the researcher was not a concern. However, during the four caregiver interviews which were conducted at their homes, telephone contacts were made with the School of Human and Health Sciences admin staff before and

after each interview session as a safety measure. Pre-interview planning involved having my mobile phone's battery charged fully just in case there was a need to contact the admin staff at the University. In addition to the above commitments for my safety, during fieldwork, I had regular supervision meetings, email and telephone and contacts with my Phd supervisors which offered me an opportunity and space to reflect on my fieldwork experiences and related challenges.

4.4.4. Use of the Process Consent Framework

Dewing's (2007) 'process consent' framework guided the procedure and conduct of obtaining consent from PLWD (study 1). As a framework in dementia care research, process consent has been used successfully in qualitative studies involving PLWD (Tanner, 2012; Helstrom et al., 2007; McKeown et al., 2010; King, Hopkinson & Milton, 2016). Based on this process, obtaining consent is not a one-off activity but a continuous one. The researcher revisits the initial consent during the research process to ensure it remains the same. In this study, participants were asked to confirm their approval before focus group interviews started (McKeown et al., 2010).

Informed consent, according to Alzheimer's Europe (2009) can be considered to have been given if an individual (or his/her legal representative), after having been adequately informed about the research, and having understood the details provided and being able to decide based on that information, freely agrees to participate in the study. In respect to this suggestion, I devoted adequate time to explaining the research and answering any questions that prospective participants had regarding the study. A consent form was signed by all participants at the onset of each focus group and participants were given opportunities to ask any questions they had regarding the study. Allowing enough time was also crucial in easing the atmosphere and encouraging participants to be relaxed and to consider their participation freely (Bamford & Bruce, 2002).

4.5. Ethical approval for the research project

Ethics approval to conduct this study was sought from the University of Huddersfield Human and Health Sciences School Research Ethics Panel (SREP, Appendix 11), before the recruitment of any participants. As already specified, the study did not recruit participants from NHS sites, and there was no infringement of personal data such as clinical records or

confidential documents about NHS treatments. After providing a comprehensive ethics proposal and supporting information, the research plan was endorsed by the Ethics Committee (Appendices 11& 12).

4.6. Sampling approach

Purposive sampling was employed to intentionally select older African-Caribbean PLWD who would provide a rich diversity of accounts related to their lived dementia experiences and be able to share their views about care at the EoL (Munhall, 1994). As the aim of the overall thesis was to gain an understanding of EoLC from the lifeworld of black African-Caribbean PLWD and family caregivers, I believed that their accounts would be appropriate to answer the research question (Polit et al., 2001). For Creswell (1994), an essential requirement in qualitative research is to select information-rich participants who have something to say or share about the subject area. Details of samples are provided under each study write up.

4.6.1. Inclusion criteria for older African-Caribbean PLWD

- Identify themselves as black African-Caribbean by background
- Identify themselves as living with any form of dementia.
- Able to understand the aims and objectives of the research from information sheets provided and to demonstrate competence to provide informed consent
- Be able to participate in a focus group independently and communicate in English
- Not permanent care home residents
- Willing to contribute about their experiences and views in the focus group discussion

People who did not meet the above criteria were excluded from the study. A decision to exclude PLWD with advanced was made. However, this was not because of their level of impairment, but was due to the aims and objectives of the research programme—moreover, the existing group of PLWD comprised of community-dwelling people with mild-moderate dementia.

4.6.2. Recruiting African-Caribbean PLWD

The framing of this study was that of an exploration into what it means to be living with dementia and what those who live with the illness perceive as vital to them at the EoL. Thirteen older African-Caribbean PLWD (mild to moderate dementia) were recruited through a day centre. All the participants self-identified themselves as being from black African-Caribbean background were expected to demonstrate awareness about their diagnosis of dementia. This requirement was aided by the fact that the acceptance criteria for the day centre needed all prospective dementia day centre users to have a diagnosis with dementia. The day centre provides various activities predominantly for black African-Caribbean communities PLWD. The activities offered include bingo, craftwork, music entertainment, 'singing for the brain', reminiscence/discussions and local outings.

The process of obtaining access to research participants was straightforward though this involved regular visits to the day centre during the preliminary stage to negotiate access to participants. For instance, after getting no response to numerous emails sent to the day centre manager to request access to participants, I had to telephone the day centre as an email follow up strategy. Although there was initially a lack of interest about the research, invitations to visit the day centre enabled face to face discussions about the research programme which facilitated the establishment of a rapport and trust with the day centre management. I was granted access to participants, including a confirmation letter in which the management pledged to support the recruitment process for PLWD.

A position paper calling for the involvement of PLWD in research (Gove et al. (2017, p.4) states that 'people with dementia must know what is expected of them before being asked to decide any possible involvement'. Similarly, Alzheimer Europe (2011) encourages researchers to consult with PLWD during the design phase of a study. To achieve this, invitation leaflets (Appendices 2 & 3) were given to day-care users. Individuals who expressed an interest to participate in the focus group interviews were provided with information sheets and encouraged to discuss their participation in the research with their families. To ensure the participants had all the information they needed to decide whether to participate, the manager of the day centre and I arranged a session on which I gave a brief verbal outline of the research process, including a brief synopsis what involves a focus group interview process and face to face carer interviews. Part of the oral discussions also covered a statement of assurance of anonymity and confidentiality as I noticed that this was a significant area of concern for much older African-Caribbean PLWD and family members.

Even though PLWD gave consent, the managers requested that the families of those interested be informed about their family member's interests in the research. Reassurance and explanations were provided to family members who needed to know more about the research process. Some family carers/relatives wanted to know about focus groups and their duration, and such discussions were also used as an opportunity to introduce the current caregiver interview study, thus setting the recruitment process for the recruitment of current caregivers.

4.6.3. Sampling and recruitment of bereaved family caregivers

The recruitment process for bereaved African-Caribbean family caregivers was approached slightly different compared to current caregivers. This was because after the death of the individual with dementia who they cared for, most of the caregivers no longer attended the carer groups within the day centre, which made it difficult to locate them. The breakthrough to bereaved caregiver recruitment came when I visited a local faith centre after being signposted by people who knew some of the bereaved caregivers who were regular attendees.

The faith centre Minister, a social worker by profession, invited me to his office to discuss the research programme. Following our meeting, the Minister who had a leadership position within the church, made firm assurances to help in the recruitment of bereaved carers. He informed the church members in two more local branches about the research on my behalf. Also, the minister recommended that I place the invitation leaflets on the faith centre's 'community events' board for church attendees to see.

A total of six bereaved family caregivers who self-identified as of black African-Caribbean background were recruited. Of the six, three were recruited from the faith centre, two more were identified from another affiliate church branch through the help of the church minister whereas another carer (not a faith centre user) was identified through word of mouth via one of the carers recruited at the main faith centre. They were all provided with information sheets detailing the research programme and were further encouraged to contact my supervisors or me should they require further information about the research.

4.6.4. Inclusion criteria for bereaved family caregivers

- Identify themselves as from African-Caribbean background
- Over 16 years of age
- Provided care to a relative who had dementia towards the end of their life

- Able to communicate verbally in English

Caregivers who did not meet the above criteria were excluded from the study.

4.6.5. Sampling and recruitment of current caregivers

As most of the current carers were relatives of the PLWD recruited for the focus group study, the recruitment process was less challenging. A total of seven current caregivers who self-identified as of black African-Caribbean background were located and recruited through the day centre where PLWD were recruited. The day centre provides social activities, tea/coffee, and cake afternoons for family carers of PLWD and delivers a caring and coping session for family members who are providing care and support to a person living with dementia. Following discussions about the current giver interview part of the research programme with the facilitator of the caring and coping session, I was introduced to a group of current carers who attends the caring and coping session for support and an opportunity to reflect on their caregiving challenges and experiences and learn from each other. The facilitator of the group, a retired psychotherapist, further helped with handing out the study leaflets to current family caregivers during the group session. Carers, who expressed an interest to participate were provided with information sheets. Some carers were already aware of the study through the recruitment of their relative with dementia which facilitated the recruitment process. However, some carers requested further verbal explanations about the research programme before deciding whether to participate.

4.1.1.1. Inclusion criteria for family caregivers

- Identify themselves as from African/Caribbean background
- Over 16 years of age and able to speak in English
- Be a family carer and willing to take part in the research
- At the time of the interview, be actively providing care to a relative person with dementia (unpaid).

4.7. Data collection: PLWD

Data collection was through two focus group interviews (n=6; n=7), which were conducted at the day centre from which participants were recruited. Focus groups are a well-established data

collection approach in healthcare research and have previously been used in qualitative studies involving PLWD (e.g., Sutcliffe, Roe, Jasper, Jolley, & Challis, 2015; Bamford & Bruce, 2002; Stephan et al., 2018 and Casey & Murphy, 2014). The first focus group comprised of six African-Caribbean PLWD and seven contributed in the second group. As in a focus group study involving PLWD (Stephan et al., 2018), limiting the number of participants to manageable sizes helped encourage participants to interact without losing the direction of the discussion. The moderation of the focus groups involved using probing statements to stimulate and promote an open and focused discussion about EoLC. This was achieved by refraining from using complex terms and avoiding long sentences to help participants to understand (Stephan et al., 2018). However, unanticipated logistical difficulties arose at times, such as too few people turning up on the day on which the focus group was to be conducted and some stating they were not feeling well enough to 'sit and talk'. On these occasions, I had to cancel the focus group and rearrange the focus group interview day and time. Finding a suitable day for all the participants proved to be a challenge, so on many occasions, I had to extend the initial agreed date and time planned for fieldwork.

4.7.1. Justification for focus groups

In this study, the African-Caribbean PLWD were day centre users and thus can be considered as an existing group. Holloway and Wheeler (2010) and Palmer, Larkin, de Visser and Fadden (2010), suggest that focus groups are suitable when researching pre-existing groups whose members share some experiences. In this research, the decision to use focus groups with older African-Caribbean PLWD instead of individual interviews was based on their ability to facilitate an in-depth exploration of a topic, collection of many insights about the subject matter and their ability to generate rich data through participant-to-participant discussions (Fallon & Brown, 2002). Having observed a group activity with PLWD being conducted during one of my visits to the day centre, I believed that using focus groups instead of one-to-one interviews allowed a naturalistic feel for participants which I considered an essential aspect for collecting data from PLWD. Thus, the focus groups took a relaxed position and for this reason, concurred with King et al. (2019) who suggest that the nature of the study and whether the focus group is formal or informal. As noted in Harmer and Orrell's (2008) study, focus groups were selected as the most suitable data collection approach based on their potential to activate recall between PLWD, thus facilitating an interaction to flow. Rodriguez, Schwartz, Lahman & Geist (2011) recommends focus groups as a data collection approach for research involving marginalised

groups due to their ability to empower them as a group, thus allowing new insights to be generated.

4.7.2. Conducting the focus groups

The focus group aimed to encourage a discussion amongst participants about what it means to live with dementia as an African-Caribbean older adult and what, in the context of care, matters at the EoL. A loosely framed topic guide, devised from the literature review in chapter two, was used to keep the groups focussed (Morgan, 1998). The guiding principle throughout the focus groups was to ensure that each person with dementia was respected, and their voice heard (Gove et al., 2018). I allowed adequate time to establish a conducive ambience and to set ground rules at the beginning of each focus group (Scottish Dementia Group, 2014). The ground rules included a reminder to all participants to respect each other's confidentiality and to treat the issues discussed as private (King & Horrocks, 2010).

At the onset of the focus groups, I offered participants time to ask any questions they had about the project and their participation. As consent was treated as a continuous activity, participants were asked whether they were happy to continue. They were also reminded of the voluntary nature of their involvement, including their right to withdraw from the focus group discussion at any time without explaining their motives. Proper time management and prior liaison with day centre staff were fundamental to the logistics of the focus group interviews, to ensure that the process of data collection was successful and did not affect the function of the day centre.

Having worked closely with PLWD and their families, I was aware that complex and lengthy sentences could be confusing for PLWD to comprehend (Alzheimer's Society, 2014). For this reason, I used short sentences, devoid of research jargon. As the participants often meet up to play various games and thus were used to sitting as a group, I avoided making the process of data collection appear rigidly formal. This helped to create a relaxed ambience for the participants to share their experiences (Rodriguez et al., 2011).

I ensured the discussion was participant-led by refraining from expressing my assumptions or unnecessarily interrupting the participants (Morgan, 1997). My involvement was merely aimed at stimulating the conversation to encourage and ensure the voice of each participant was heard. My role was to listen to what they were saying during their interactions and to probe for detail and to introduce topic areas for discussion, while carefully encouraging the participants to contribute to the focus group discussion.

In their introductions, participants in the focus groups demonstrated an awareness of their difficulties by either stating they had 'Alzheimer's', 'dementia', a 'memory problem', or 'I have this evil disease of the brain'. This enabled me to start the discussion using a general and less direct question: 'what is it like for you to live with this condition you just said you have? How does it mean to you to live with the condition? What is important to you now?' More general hypothetical stimulus questions (Kitzinger and Barbour, 1999) might be, 'imagine that your doctor says you are too ill to recover, how would you like to be looked after at the EoL? When you hear the words EoLC, what comes to your mind? What are your thoughts about care at the EoL? If you were to mention something about care at the EoL, what would that be? How would you like to be cared for when that time comes? What do you value most at the EoL?'

I aimed to provide older PLWD with the freedom to interact between themselves and to encourage them to share their views. However, at various junctures of the discussion, I had to intervene to encourage other participants to share their opinions when I realised dominance over the interaction by the same participants. I also probed further for detail where an exciting and relevant subject matter was not discussed in detail. Given that lucidity varies among PLWD, there were times when participants struggled to find the right words, resulting in long pauses during their interaction. I used minimum prompts to help the participant to finish their points.

4.8. Data collection: current and bereaved family caregivers

The in-depth, semi-structured phenomenological interview allows experiential material to be explored and gathered and was chosen as a useful way to gather bereaved and current caregivers' lived experience of caregiving to a relative with dementia and at the EoL. The collected experiential accounts were the carers' narratives on the day-to-day caregiving to a person living with dementia or a reflective account of the lived EoL caregiving experiences. These accounts facilitate an enriched understanding of a phenomenon under investigation (van Manen, 2014).

4.8.1. Justification of phenomenological interviews

Interviews are a widely used data collection method in phenomenological studies. Phenomenological research aims to describe an individuals' experience devoid of theory, but in the manner, the person describes their experiences or understands it. Interviews are,

therefore, phenomenological if participants can reflect on their lived experience or express their views about a phenomenon adequately (Bevan, 2014). The open-ended nature of phenomenological interviews provides participants with an opportunity and space to talk about their lived experiences. In-depth phenomenological interviews were used as a mode of eliciting for comprehensive information about the lived experience of current and bereaved carers of African-Caribbean PLWD. I chose in-depth phenomenological interviews based on their ability to allow a 'seldom heard voice' of African-Caribbean family caregivers of PLWD to be heard.

4.8.2. Conducting the interviews

The interview process involved asking the caregivers open-ended questions about what it means to be a black African-Caribbean family caregiver to a relative with dementia. Participants were asked questions about their views on quality EoLC and encouraged to share their opinions (van Manen, 1990, 2014). A loosely framed interview guide (Appendix) was used to ensure the interview covered critical areas about the phenomenon of interest. Open-ended phenomenological questions helped the carers to reflect on their caregiving lived experiences and to describe their values motivations, beliefs, perceptions, understandings, and opinions with minimal interruptions, which gave them a platform to have their voices heard (Byrne, 2004). The interviews were flexible and started by asking the carers relatively broad and open questions 'what does it mean to you to be a carer to a person with dementia? What would you consider essential at the EoL? Can you tell me more about what you refer to as good care? Where appropriate, I encouraged the carers to expand on their answers using probing questions such as 'can you explain what that means to you/how that made you feel?'

4.7.2.1. Using a field diary

I used a field diary to document environmental contexts, participants' non-verbal cues, and impressions during fieldwork, including my reactions to their narratives during or soon after interviews. In part, the diary also worked as a collection of my lived experience journal throughout the research programme and was valuable in providing me with a vivid recollection of useful developments that were not audio-recordable (by Dictaphone) (Sutton & Austin, 2015). My fieldwork reflections (Appendix 10) were a valuable tool during data analysis, which I have described in detail section in the section below.

4.7.2.2. Data preparation for the research

Large amounts of data were generated from focus group discussions with older African-Caribbean PLWD and in-depth individual phenomenological interviews with a current and bereaved caregiver. The transcription of the audio-recorded interviews was completed soon after each meeting, in line with van Manen's (2014) recommendation that it should be completed while the researchers' fieldwork experience is not yet distorted. In addition to early transcription of data, the notes documented in the fieldwork diary worked as a reminder about some useful participants' non-verbal responses which further aided the interpretation of their experiential narratives (as in appendix 10). An essential commitment throughout this research programme was to ensure that participants' confidentiality and anonymity were upheld throughout the research process and to achieve this, I adopted a robust use of pseudonyms and avoided using identifying information that can inadvertently reveal the identity of the research participants. Passcode lockable lockers in a secure office were used to store the participants' consent forms and transcripts, in keeping with the University of Huddersfield policy.

4.9. Data analysis approach for the research project

The conduct and analysis of data were underpinned by van Manen's (1990) phenomenological analysis. The hermeneutic phenomenological analysis aims to illuminate the meaning structures of a phenomenon, accessed through engagement with participants' lived experience descriptions (van Manen, 2016). King and Brooks' (2017) Template Analysis assisted with the organisation of participants' accounts for the analysis and the development of themes. The content of the three data sets was rich in experiential accounts; however, due to the differences in experiential perspectives, I decided to analyse each data set independently and thus develop themes representative of:

1. Focus group interviews with PLWD
2. The current caregiver interview study
3. Bereaved caregiver study

The overall process of data analysis for the three studies involved searching for meaning structures through an iterative activity (hermeneutic circle)

- Familiarising myself with the transcripts

- Preliminary coding
- Clustering the codes to build themes
- Formulating an initial template
- Applying and generating the template
- Making a final interpretation

(King & Brooks, 2017, p.26).

The first step involved reading and re-reading the transcripts to familiarise myself with and immerse myself in the data. As noted by King and Brooks (2017), having transcribed the data, reading, and rereading the transcripts several times helped me to be familiar with what was going on in the text. Also, I referred to the field notes to remind myself about contextual details of the interviews to relive the situation and help make sense of the data. The second step involved preliminary coding of the transcripts. This analytical step entailed documenting brief comments on the right-hand indented margin of the line numbered and paginated transcripts in MS Word (Appendix 15).

The advantage of using the provisions of MS Word was that I was able to apply different colours to highlight segments of the text that I considered relevant to the aim and objectives of the study. The preliminary comments were made as close to participants' own words as possible and were used to define potential themes (King & Brooks, 2017). This process was iterative and not merely linear. The next step involved bringing the ideas that I had identified together in clusters or categories based on how they were related. This enabled the creation of an initial template. I then moved the identified themes around meaningfully until some degree of structure was achieved in the template. The above steps were used to analyse carer interviews. The process of data analysis in carer interviews started by coding a subset of transcripts (3 transcripts of the bereaved and three of the current caregiver interviews). After identifying themes in the subset of the data, I then used them to explore the rest of the transcripts (King & Brooks, 2017). To achieve trustworthiness of data and analysis, during the preliminary phases of the data analysis stage, I requested my three PhD supervisors to independently look at the coded subset of transcripts and the accompanying initial template. As they saw the data 'with new eyes', I drew on their comments to redefine the themes and restructure the template.

4.9.1. Data analysis: PLWD

Some phenomenological studies have used focus groups as a data collection method and have developed their protocols to analyse the data in keeping with phenomenological frameworks (e.g., Bradbury-Jones, Sambrook & Irvine, 2008; Macleod et al., 2002; de Visser & Smith, 2007). In this study, focus groups allowed multiple voices to be heard, and as in Palmer, Grain, Larking & de Visser (2010) elicited, 'more experiential reflection than one-to-one interviews' (p.100).

However, individual participants' accounts can be camouflaged within the discussion, making it difficult to formulate their phenomenological accounts. This necessitated exploration the focus group data to reveal both shared experiences and individual participants' experiences. To achieve this, I looked at the data in its entirety to elicit a shared meaning first and then explored the data from an individual level to capture individual participants' lived experiences, using a protocol of analysing focus group data phenomenologically devised and previously used by Palmer et al. (2010). It was essential to identify each participant's contribution (albeit an arduous task) during the focus groups and by applying a number to help determine each participant and their participation (e.g., Participant 1-13) phenomenological accounts were developed.

4.9.2. Data Analysis: Carers

The transcripts were scrutinised to identify relevant statements that related to EoLC. The aim was to build an understanding of the meaning structures [themes] within the participants' narratives. In keeping the hermeneutic phenomenological data analysis, statements within participants' lived experience descriptions/accounts that I considered relevant to the research question were identified and highlighted on Word. Using Word was particularly helpful in enabling a systematic approach in exploring the entire data set. The process of data analysis was iterative and cyclical in nature. It involved scrutinising and coding the transcripts for meaning structures embedded within the participants' verbatim-transcribed stories and moving back to ensure key information was not omitted. Highlighted phrases which were representative of the caregivers' lived experiences were coded and then clustered meaningfully according to their relationships. These were then used create an initial thematic template (King & Brookes, 2018). A fundamental step in hermeneutic phenomenological research which I followed is to move beyond mere descriptions of participants experiences to interpretation of meanings (van

Manen, 1991). This was achieved through applying the hermeneutic cycle, which entails making sense of the whole (all the transcripts) by reference to individual transcripts and then by considering this in the context of whole text.

4.9.3. Applying the principles of reflexivity in this research

I defined reflexivity and discussed it in more detail in Chapter 3 (Section 3.6). This section focuses on the application of the principles of reflexivity. When undertaking this study, the first step was to maintain a phenomenological attitude (Finlay, 2008). This was about moving away from the natural philosophy of everyday life. For example, it was necessary to avoid making assumptions about participants' experiences based on my knowledge and expertise in dementia care. Finlay (2008) advises that maintaining a phenomenological attitude requires the researcher to secure genuine curiosity and be open to surprises from the participants' accounts. On carrying out interviews, suspending my understandings and awareness of dementia care meant that I was open to new emerging understandings of EoLC from the participants' perspective. Being mindful of the influence that my pre-understanding could have was a critical step to enabling the explication of taken for granted everyday aspects of the phenomenon of interest. In other words, maintaining a level of self-awareness enabled 'the things to present themselves in their appearing' (Langdridge 2007, p.18). More crucially, it facilitated the seldom-heard voice of older black African/Caribbean PLWD and their family carers to be heard – which was one of the principal intentions of this research project.

My pre-understanding of dementia, particularly communication with PLWD was a strength regarding the generation of experiential accounts. For example, I was aware that if I had to communicate effectively with PLWD in a way that was respectful of their autonomy, I had to refrain from using terms they find stigmatising such as 'suffer' or 'demented' (Swaffer, 2014; DEEP, 2012). I also refrained from using research jargon, complicated phrases, or long ambiguous sentences. This was important, although the focus group interview process was mostly participant-to-participant discussion, while my role was to moderate and stir the direction of the interaction.

Sendelowski and Barosso (2002) suggest that reflexivity is the hallmark of quality in qualitative research. Moving on from this idea, my personal experience as a researcher who has worked in dementia care for over ten years brings with it some own influences on the research process. As a black African young man, my value base is built on respect for my elders, as old age is

often understood to reflect wisdom. Given that the participants in this research were older people from African-Caribbean backgrounds, my position during and throughout the study was to ensure that I respected that all the participants were more knowledgeable than I was. Potential danger and drawback of this view were that it could have obscured me from questioning further for detail and depth. Shaw (2010) defines reflexivity as 'hermeneutic reflection' and a guiding principle in experiential qualitative research. As a black man researching a group of black older PLWD and family caregivers, who were initially suspicious of the motives behind my request for their involvement in this research, my experience exemplifies a journey of self-discovery, sensitivity to context and self-awareness, involving the use of a robust reflective approach on my position as a researcher, but also as an 'insider' and above all, a human being.

During data analysis, I regularly referred to the reflective diary in which brief notes about my experiences soon after interviews were written down. Doing so helped me to 're-live' the situation, which was useful during the data analysis and interpretation process. Finlay (2003) believes that qualitative researchers must be engaged in some form of interpretation, because to avoid doing so renders the research pointless, and it may be another piece of "realist repertoire" (p.30). Throughout the research process, I was conscious of how personal prejudices could influence the study, and I regarded the participants as knowledgeable of their unique experiences. To achieve this, I continually reflected on Finlay's (2003: 108) clarification of Gadamer's theory, from which van Manen's approach developed:

"Our understanding of 'other-ness' arises through a process of making ourselves more transparent. Without examining ourselves, we run the risk of letting our elucidated prejudices dominate our research. New understanding emerged from a complex dialectic between the knower and known, between the researcher's past pre-understandings and the present research process, between the self-interpreted co-construction of both participant and researcher. Between and beyond…"

From van Manen's (1990) view, reflective awareness of one's personal experience can help orientate oneself towards the phenomenon. As a researcher, this means acknowledging who I am and what I believe in, including how and why my interest in undertaking this study developed. Lamb and Huttlinger (1989) also observed that self-awareness and an awareness of the relationship between the investigator and the research environment must never be underestimated in qualitative research. As noted by Shaw (2010), being a reflexive researcher

(one who proactively explores him/herself at the onset of the study), helps to navigate the participants' presentation of self as a knower, which then helps revise the researcher's fore conceived understanding and assumptions resulting in new understandings of the phenomenon to develop.

My partial insider (being a black man) and my outsider position as a researcher unknown to participants could have influenced how the participants responded during the interviews. For example, they could have omitted the taken for granted everyday experiences by assuming that as a black man, I was knowledgeable about some of their experiences, thus affecting the depth and soundness of the data. However, my partial insider position could have encouraged participants to consider me as part of them, which could have made them talk more freely about their experiences. While my insider/outsider position could have facilitated the establishment of trust leading to a successful recruitment of a potentially difficult to engage with group of people, the power unevenness between myself as an investigator and those being researched (PLWD & family carers) can affect the conduct of the overall study (Merriam et al., 2001). Respect for the autonomy of the participants was important in this research, and I considered every participant a co-constructor of knowledge about the topic as an 'expert by experience' rich with the information required for the study (Råheim et al.,2016). EoLC and areas related to death and dying are sensitive topics and researching them requires one to be attentive to the wellbeing of the participants. During my interviews, I was conscious of how I presented questions. For example, King and Horrocks (2010) have suggested that it may be useful to refrain from introducing emotionally charged issues initially, waiting until participants feel comfortable enough to reflect on the sensitive parts of their experience about the research topic.

To ensure the participants' psychological well-being was not unduly impacted upon because of their participation, I asked the participants how they felt about their involvement in the study at the completion of the interview process. For example, I asked, 'how did you find the discussion? How do you feel about your contribution?' Carers and the PLWD talked mostly about their thoughts before the interview happened: not seeing the value of participating and their reluctance to do so. They talked further about how their reservations changed to positive feelings after the discussion. Some of the participants stated that they were grateful for the opportunity to talk about what they described as essential issues in their lives that they do not often find it easy to talk about. For example, towards the end of their focus group, Delroy (pseudonym) stated, '…I want to thank you for asking us to talk about this; I think it's important for us (...) I also enjoyed taking part...'

While completing the fieldwork, I prioritised the use of a reflective research fieldwork journal to document not only the participants' feelings, emotions, and responses that I felt were important in helping me to 're-live' the interview process to make sense of their experiences during the analysis, including my feelings following the completion of the interviews. In her study exploring the EoLC experiences of family members of people with dementia, Nunns (2015) cites Clarke's (2009) recommendation of using a field diary as an approach to establish transparency of what is being researched, including the approach to data analysis that the research adopts. For example, most of the participants' frequent mentioning of God, when reflecting or describing their experiences, made me realise how important their beliefs in God were. Without this written in the diary immediately after data collection, the significance of this to the participants could be presented in a superficial manner that does not capture the depth of their belief in God.

Using a field diary aided the process of reflexivity and was a way to recall participants' non-verbal responses that were pertinent in making sense of their lived experience. For example, after each interview, I wrote a short description of how the interview process went, whether I had encountered unexpected difficulties or any issues that I considered useful in relation to the aims of the study. Where participants shared more experiences beyond the scope of the interview (after the Dictaphone has been switched off), the reflective field diary was used to document pertinent and relevant data.

The process of building trust requires a researcher to expose him or herself to the population group from whom data is to be collected. In the current study, I invested time in visiting the research site, explaining the research, and answering questions that had suspicious connotations such as the purpose of research, how much time was required, and concerns regarding confidentiality. Even though participants were provided with jargon-free information sheets (Appendix 4 & 5) visiting the day-care centre in person and discussing the research process and giving the prospective participants space to ask questions appeared to be the basis for the establishment of trust. This demonstrates that exposure (using visiting and answering questions about the research) gradually builds confidence with both the manager (who acted as a gatekeeper) and the prospective participants. It was also imperative to provide an overview of why I was interested in exploring the topic area.

Once trust was established, and questions about the research and the research process answered, people, started to express their interest in participating. Not only does the above strategy

contradict with Sheikh et al. (2009) who reported that community leaders had little awareness about research and its aims, it goes further by suggesting that researchers need to ensure explanation about the study are prioritised as a cornerstone for establishing trusting relationships. Older people from BAME groups expect to be respected by the younger generation, and indeed old age is often discussed in the context of wisdom – my understanding of this from practice and my insider researcher position was useful. Knowledge of the population group can be a helpful tool for establishing trust. For example, it could be taken as a form of disrespect to address an older person as by their first name, and so, as noted in my encounter with older PLWD, it was essential to address them as, for example, Mr Jones, instead of Peter.

As highlighted above, when planning for this research, I came across terms like 'hard to reach,' 'seldom heard' 'hidden groups' 'marginalised groups. This encouraged me to prioritise developing my knowledge about the target population subgroup from whom this research sought to collect experiential material. Even though I considered myself, in part, as an insider (regarding my minority ethnic status) and an outsider (regarding being a researcher) familiarising myself with the culture, history, values and general traditions of the group was influential in establishing the trust. I attribute the successful recruitment of participants in the building of trust. By this, I do not suggest an in-depth understanding of the population group but an overview of the group's general ways of living, which can be a useful tool in negotiating access and throughout the recruitment process including the establishment of the rapport. In recruiting participants, it is also essential to explain why the researcher is interested in this area of research.

Meezan and Martin (2009), suggest that developing an understanding of the population under study can be achieved through immersion, research, or using consultations. As highlighted in the in my interest in the phenomenon at the onset of this thesis, I have experience of working directly with PLWD and their families in their families. Gasman and Payton-Stewart (2006) observed that the researcher's familiarity with the population group being studied increased their awareness of the politics tangled around a research topic area and helped in the overall design of the study. Again, my knowledge (based on work experience & training) of how to communicate effectively with PLWD and their families was an essential asset in recruiting and screening potential participants, including the generation of data. During the participant recruitment process, it was necessary to maintain contacts with the day centre management. Gasman and Payton-Stewart (2006) suggest reaching out to gatekeepers is vital throughout the

study. As hinted above, this included giving brief talks about the purpose of the study, data collection procedure and time, issues related to their confidentiality, inclusion, and exclusion criteria for participation.

4.10. Summary of chapter

Chapter 4 presented the methods section of the research programme. It covered the 'nuts and bolts' of research including the recruitment strategy, collection of data and specific analysis steps. The chapter has discussed my commitment to allow the voice of older African-Caribbean PLWD and their families to be heard in research. The use of the process consent framework to ensure informed consent was continuously negotiated with the participants throughout the research programme has been detailed. Commitments to maintain participants' and my safety as a researcher has been discussed. Finally, the reflexivity section discusses how my position as a partial insider and outsider when undertaking the research might have impacted on the overall research practice, including the choice of methods and decisions that I made when conducting the research.

CHAPTER 5: FINDINGS - FOCUS GROUPS WITH PLWD

5.1. Introduction

In this chapter, I use van Manen's conceptual framework to present findings from two focus group interviews with older black African-Caribbean PLWD. The overarching aim of this study was to explore the lived dementia experiences of black African-Caribbean PLWD in the context of EoLC. The key objectives were to develop a better understanding of what it means to be black African/black Caribbean older person living with dementia in the UK and to allow their voice to be heard in dementia and EoLC research. Thus, the study sought to capture their lived dementia experiences, views, and perceptions about their EoL preferences, choices and what, if any, is crucial to them at the EoL. Table 4 and 5 below presents the 13 older African-Caribbean PLWD who participated in the first focus group.

5.1.1. Participants' characteristics: PLWD

Table 4:Focus group 1 participants

Name	Age & Sex	Ethnic Background	Living arrangements	Dementia Diagnosis
Leroy	56 Male	Black African	Regular day centre user Lives with wife Receives extra support from church friends	Vascular Dementia
Phillip	69 Male	African Caribbean	Regular day centre user	Alzheimer's Disease

			Lives alone Supported by family members	
Winston	73 Male	African Caribbean	Does not use the day centre regularly Lives with his family who support him	Vascular Dementia
Benjamin	78 Male	Black African	Regular day centre user Lives with an older son Also supported by grandchildren	Alzheimer's Disease
Anna	67 Female	African Caribbean	Regular day centre user Lives with husband Supported by her family	Alzheimer's Disease
Jill	68 Female	African Caribbean	Does not use the day centre regularly Recently widowed	Vascular Dementia

			Supported by her family and church friends	

Table 5:Focus group 2 participants

Name	Age & Sex	Ethnic Background	Living arrangements	Diagnosis
Margaret	81 Female	African Caribbean	Regular day centre user Lives with daughter and has a supportive family. Receives extra support from church friends	Alzheimer's Disease
Florence	73 Female	Black African	Regular day centre user Lives alone Supported via a home care package Receives extra support from church friends	Mixed Dementia

Lucas	71 Male	African Caribbean	Regular day centre user Lives alone Has a supportive family	Alzheimer's Disease
Joshua	68 Male	African Caribbean	Does not regularly use day centre Lives with wife Has a supportive family	Alzheimer's Disease
Charles	89 Male	Black African	Regular day centre user. Lives alone. Supported via a home care package Receives extra support from the church	Vascular Dementia
Teddy	87 Male	African Caribbean	Regular day centre user. Lives alone Does not want home care support	Alzheimer's Disease

			Extra support from family and church	
Delroy	82 Male	African Caribbean	Regular day Centre user Lives with his wife who is his primary carer	Vascular Disease

Four core and lower-level themes emerged from data analysis. Table 8 below summarises them prior to the detailed discussion that follows.

Table 6:Summary of core and lower-level themes

CORE THEMATIC AREA	LOWER-LEVEL THEMES
'I DON'T WANT TO DIE IN OLD PEOPLE'S HOME'	• Perceiving being in a care setting as disempowerment • Perceiving care settings as places filled with loneliness • Seeing own home as a 'peaceful place'. • Influence of religious and cultural traditions on EoLC expectations
NEGOTIATING PREPAREDNESS FOR THE EoL	• At the deep end • Respect, privacy, and dignity • God 'gives and takes life.'

	• Acceptance of destiny • Soldiering on • Hoping for the right decision to be made • A journey through the undergrowth
YEARNING FOR QUALITY OF LIFE AT THE EoL	• Setting one's eyes at the end of the road • Searching for solace through prayer • Valuing being 'talked to'

5.2. 'I don't want to die in old people's home'

This theme captures the EoLC preferences expressed by older African/Caribbean PLWD who participated in the focus group interviews. Many expressed a strong wish not to end their lives in care homes or hospital wards. Being placed in a care setting at the EoL was frowned at by almost all the participants for various reasons, including concerns about disempowerment and loneliness. For many, their own homes were peaceful places where one can end his/her life in peace. This view came across as important for the majority of the older PLWS and permeated the focus group discussion. Some reflected on previous negative experiences within hospital wards and nursing home/residential care settings and emphasised their wish to die in their own homes. In the excerpt below, Leroy provides his view that he will die well if he ends his life in his own home and associate hospital wards with noise - something he does not like:

> '… will die well, peacefully, in my home, I don't want to die in older people's home (..) my home means everything to me (..) to my family (..) I hope to remain home until the end, (..) look, I have been in hospital wards many times (..), they are too busy…. I don't like noise at all' (Leroy)

Others associated dignity, privacy and 'being at peace' at the EoL with their own homes than any other place of care. Dying at home can best be understood using the life-world existential

of *spatiality –lived space* (van Manen, 2014) which relates to how humans experience living in each context in relation to the phenomenon under investigation. Participant 3 associates his home with dying 'peacefully' and is sure that his family will respect and provide the dignified care he wishes for at the EoL:

> '…I have lived with this illness for years now, nobody can look after you better in your own house than your own family (..) that's what I think, but I don't think it's me alone who feels like this …many black people still look after their relatives, that's it (..) it is just like that (…) it has always been like that, I think my family can make sure that I die with respect, I die peacefully (..) in my home(..) that's why I do not want to go anywhere else (Winston)

There were strong negative views associated with hospital admissions at the EoL with many seeing this as unnecessary and a likely source of disruption to the care that their family may be providing at home. The existential of *spatiality* asks, how do older African-Caribbean PLWD 'experience the worldly or unworldly moods of certain places? (van Manen, 2014, p.305). Participant 3 offers insight as to why being admitted to the hospital impacted his care at home and further envisioned that this could happen at the end of his life:

> 'I don't want to go up and down in hospitals, why? Its waste of time and I know a friend of mine who never spent much time at home it is not good. I do not want that; it disturbs things at home. When I came back home from [name of hospital], everything was up in the air (..) I am not saying I will not ever go to the hospital; I am trying to say going there [hospital] disturbs everything at home…. this might be the case at the end of my life…' (Winston).

> Those places [hospital wards] are too noisy, and I don't want my life to end in there, it is horrible (Charles)

Others stated that they feared they might end up dying somewhere else, but many trusted that their family[4] would make the right decisions. This trust bestowed to the family can be understood from the lifeworld existential of *relationality* –lived self in the context of others – how do people relate to the phenomenon under investigation in relation to others? Participant 10 reveals his wish:

[4] The word 'family' represents anybody within the extended family context (e.g., children, nephews, wife, grandchildren, etc.)

> ‘Like everyone else, I hope to end it all at home, that’s what I want (..) I have no doubts my family would make sure I stay at home; they know how much that means to me (Joshua)

Humans are ‘beings’ because of being connected to other people within changing circumstance. Dementia appeared to have threatened the autonomy of older PLWD with adverse effects on their being with others and their reliance on others. Trusting one’s family was further echoed here:

> ‘If the time to die has come, let me stay in my house, why should people take me to a hospital ward, I don’t think it’s necessary (..) I also hope my family will make sure I don’t go into old people’s home’ (Teddy)

Older African-Caribbean PLWD described excellent EoLC as care that did not involve being unnecessarily moved from their own home to another place of care. For many, such a situation would impinge on ‘peace’ and tranquillity and perhaps trigger uncertainty due to the perceived absence of family as a source for reassurance. Mistrust of other care environments appeared to be the case when it came moving to a care home or hospital ward environment. Again, looking at this from *lived space,* the phenomenon ‘being at peace’ was not achievable in a hospital setting:

> ‘…Sometimes people are moved to places they do not want to go. I don’t trust older people’s homes (..) we have all seen things on the news. If all goes by me, I will make sure my family know that when the time comes, they must not allow anybody to take me away to a hospital. I need my peace; it is never peaceful in hospitals anymore (...) my concern is that it will distress me if that happens. I just hope it doesn’t happen to me, but you never know…..’(Florence)

Some commented that there were fewer black people in care homes and being in such an environment would lead to social isolation. This view was continually expressed about accessing any care setting other their own homes:

> I can explain how I felt. It was horrible to look around and see nobody who looks like you (Phillip)

Jill talks negatively about her dislike of noisy environments and her tone emphasises her previous admissions as a source to her views. She further reveals how she felt as a black woman at that time:

> ‘My children will not take me into a home [care home]; they know it. I have been in the hospital many times; I know what it is like to be in there…. it’s very noisy……some people look at you as if they have not seen a black woman before, yes (...) that's why I want to stay in my home until the end’ (Jill)

Benjamin also expressed a strong desire not to be placed in care; he saw dying in an unfamiliar place as disrespectful:

> ‘I looked after my family well, why should they let me die in a place that I don’t know? I have told them this, ‘don’t take me in a care home, let me have peace in my house, that’s what I want, to me that is a respectful way to die’ (Benjamin)

One participant repeatedly stated that the quality of care delivered to people with dementia within care homes and hospital wards was suitable to a person who does not have a family to provide care, with many asserting that care staff and nurses often do not have enough time to give the necessary quality of care:

> If I don't have a family, that's fine to go in there [care home] that means I have no choice, but I have six children to take good care of me. Everyone knows that it is very scarce to receive proper care at home especially when you are like us, I do not expect anything good from those places [care homes], but it is fair to say not every home is terrible, some are good. We see it on TV, nurses leaving people in dirty clothes and soiled beds, we see all this. Nurses have many people to look after, how can they give proper care to a person nearing the end, it is not possible (Anna).

Phillip expressed a negative view underpinned by previous experience from visiting friends in care home settings. A wish of ending life at home was strongly expressed. The role of the family in deciding for admission into a care home environment was also articulated:

> I agree that some care homes are excellent and I know from visiting two friends in a home that it’s not a place I would like to end my life in, last week someone came to talk to us here, people with this illness have had their lives change in many ways, mine has changed. Sometimes I do not know whether I am coming or going [laughs]; the sad part of it is that things will never go backwards. Many people end up in a care home without good care and love, as long as I can still talk to my family, there is no way they will put me in a care home, they know it [family], I don’t want to die in a place that I don’t know. I want my family to be with me, to stay with me until I close my eyes [die] (Phillip).

One participant used a famous African proverb: ‘The person who knows the road is one who has used the road in the past’ to describe the level of understanding he had about residential

and nursing home-based care, linking his wish not to be placed into institutional-based care from a conversation with his friend who was placed in care:

> 'A friend of mine is in a nursing home, and sometimes they hide the buzzer, so he cannot call for help when people are there, they look after them with care because relatives may say something, like complain or take their father or mother out of place, but when the family are not there you know they just ignore them, and that means if I go to a nursing home, I will have to deal with that kind of situation, so my friend said to me, now you have Alzheimer's, please do not come to a nursing home, tell your family whatever happens, they must not let you go to a nursing home, its bad, okay, it's not good for us'(Margaret)

Being in one's own home emerged as a critical component of quality care at the EoL because being in a 24hour care setting was perceived as a barrier to having family and friends around, even if the care home prioritised opportunities for families to be around towards the end of life of their relative. There was a definite emphasis on both the importance of the presence of family and friends and being in a familiar place:

> For me to go [die] peacefully, my family and people I have known through my church should be with me; I could not imagine leaving without saying goodbye to my family (Margaret).

> I pray to God to help me go [die] well. I will have peace wherever my spirit will go if I end it all in my home. I do not want to look around and see the wall; I want to see my family that is all I wish, God help us' (Leroy)

Adding to this subtheme 'being with own family in a familiar place' participant 11, further emphasised:

> Dying without your family and friends is like someone who disappears to a foreign land without telling others…they will not have peace in their souls until they know where their relative is. It's true. You must have the final moment with your loved ones, which is how people used to do. I know things have changed, yes, this happens less nowadays. I think my family should see me go, and I must see them beside me, that is how I want to die. They need to pray for me and make sure that I am clean and comfortable' (Charles)

Being with family and friends was a source of comfort, reassurance, and validation. Focus group participants assumed that their families knew about their EoL wishes and preferences, though all participants stated they had not documented their wishes beyond 'discussing' with the family:

> I think I will be more comfy with my family around. I do not think there is anything I can wish for at the end of my life. I have seen people dying in my life, what you need at that time is someone to hold your hand and say, 'it's ok, you are brave'. My wife and my family as whole know that I don't want to go up and down to the hospital, I don't want to die in a home, but it's hard to tell what's going to happen, you never know what the future holds for you (…), it's a sad thing to end up in a care home because, I mean, my wife should be able to tell people what I have always wished for, that's my hope' (Leroy)

There is a sense of desperation in participant 5's tone when explaining that there is nothing one can do when relatives and professionals have decided that placement into a care setting is the only solution:

> With this problem [dementia], I get confused and sometimes wonder how I would manage without them [family]. It would be difficult for me to be comfortable without them around me; it is even hard to imagine it. If I end up in a care home, there is nothing I can do, but if I have my family with me, like when I am about to go [die], I am sure I will be happy. I will know that they will tell people who will be responsible for my care to take good care of me (Anna).

I remember vividly how issues alluding to this theme catapulted a heated dialogue among the participants about their fear of ending up in hospital wards. There were reservations around disempowerment, loss of control and poor care experiences that some participants reflected upon; with many convinced that hospitals and care homes were not places they would wish to end their lives in. The former hospital lived experience appeared to fuel the fear with two participants reflecting on what happened when their relative was in the hospital:

> 'If you find yourself stuck in there, [hospital/care home] you can't do anything about it. You have no idea how it feels to be in a home[5]. I have been, it feels like a prison, you have no control of whatever happens to you. I don't want to ask for help all the times we see it in newspapers that some care homes mistreat people (Florence)

Some expressed their wish to die sooner rather than find themselves permanently placed in care homes or hospital settings:

> 'I want to die at home, that's where I belong. I would rather die tomorrow than find myself locked in a care home or busy and noisy hospital ward' (Anna)

[5] The word 'home' or 'old people's home' is used to refer to both the participants own homes and nursing care homes or residential care homes

> ‘Would you like to be looked after by someone who doesn’t know about you? Perhaps most of us here will say ‘no’. To me, it is disrespectful for little girls [nurses] to help me wash and dress, it is not fair to them too. I prefer everything to happen in my home’ (Winston)

When asked why he felt that way, Anna not only revealed a strong desire to be cared for in his house but illuminated a sense of insecurity and fear of loss of control that was perceived as rampant in care homes and hospitals:

> ‘My home is where I belong. I have been in [name of hospital] many times; I hate it. I hate it, that's all I can say. To die there, no no no [shakes head]. I don't want to lie in that bed, I mean, think about it, just lying on the bed waiting for help, what will be the point?' I don’t even want to set my foot in a care home’ (Anna).

Of the older African-Caribbean people with dementia who had previously experienced hospital care, some were fearful about being hospital admission because they did not want to be away from their families, relatives, and homes:

> ‘I know I have been to the hospital many times. I was terrified by then, and I still think that the hospital is not a peaceful place. When you are taken in, you leave your home and your family, when they visit you in there, umm, that's very nice, but when they leave, you feel the pain, you feel lonely even though the place is always busy. Having said all this, if it wasn't for them [hospital], I might not be living now’ (Charles)

There was a belief that the family provided care at home and other formal support described by one participant, as ‘home help’ was better than the care provided in a hospital setting:

> ‘...well, I think my family and home help is better than the help I got when I last went to the hospital. It's ok to go into hospital and come out but not at the end (…) end of life and that, (..) it’s not. I will rather have people come in to help at home, that's a better option for me’ (Lucas)

Most participants within the two focus groups mentioned poor treatment outcomes experienced by them or by their family member in the hospital, appearing to think that they may receive similar treatment near the end of their lives. Participants also revealed negative experiences, which impacted their perceptions of hospitalisation at the EoL:

> ‘He was left wet, laid on his mess and when I went to see him, (...) Now what does that mean to me, will I be looked after well in the same place, No, I don’t think so’ (Teddy)

> ‘I remember asking one of the young ladies to get me something to drink, but she went and never came back. How would I wish to be looked after in such a place when I am dying?’(Joshua)

> ‘I gave them a lotion for his skin, but nobody applied it onto his skin (..), Believe me, his skin was flaky and rough. I told them over and over, and nobody listened, but they were all nice to me, I know that’ (Lucas)

Participants were fearful that hospital-based care would take away their dignity. In the eyes of the participants, dignity seemed to be more about privacy. This was discussed concerning ‘young nurses’ who were described as less caring and ‘rough’:

> ‘Everything most of us are saying here is true. Hospitals are good but also bad. I refused to be washed by girls at the age of my granddaughter. I mean, it made me feel sick. As an older man, I think it was disrespectful that I had to be seen by young people. Maybe it’s only me, but I was in the hospital for a fall outside my home and couldn’t wash myself, and I tell you this, the young nurses were rough to me. They smiled at me, but when I think about it, they didn't care, they were just doing their job, errr, they were just rushing, everything was quick, you see’(Benjamin).

The care received during previous hospital admissions appeared to influence participant’s perceptions of their future care at the EoL:

> ‘…I could not lift that cup to drink, and nobody had time to help me drink… they [relatives] all know that I had enough of going up and down to the hospital. I never forget all the things, ahhhh it's not a nice place in them hospitals believe me. After all this, there is nothing, I mean nothing, which can change my mind about where I would like to die. Home is the best place for me too’ (Jill)

5.2.1. Perceiving being in a care setting as disempowerment

There was a belief among the participants that institutional care disempowers people as they are ‘locked up’. The expressed fear of disempowerment appeared to be related to concems of leaving one’s own home into other care settings, losing family support and other social networks such as the church community. This led to many expressing a fear of dying away from home, which they linked to poor experiences and an ‘undignified way to go’:

> '...let me die in my home with the people I love around me. I have suffered a lot with this evil disease. I don't need any more problems. I don't want to feel out of place, helpless, confused, and away from my home, my people, my community' (Winston).

This fear was not just that of institutional-based care at the EoL, but that moving from a familiar place away from one's family was disempowering and risked affecting the person's relationship with their family. Participant 11 talks about her experience when she went into respite care and what she believes would happen at the EoL:

> 'I agree with this man here [another participant], I have been through this before. When you are in the hospital for a long time, it's not fair for your family to see you all the times. That's not a good thing. I was in a home for two weeks when my daughter went away; it was the worst experience I have ever gone through. I felt neglected by my family; I didn't know where to find things, toilet. I was not comfortable at all. I don't want to go [die] in a place like that. It's good to go in for a few days but not for a long time. It's not for me that' (Charles)

Older black African/Caribbean PLWD emphasized medical treatment through the course of their illness. While many of the participants commented positively on taking medication as prescribed to them. Some treatments were deemed as unnecessary at the EoL. An exchange of views on medicine demonstrated the participants' concerns about disempowerment relating to medical interventions at the EoL:

> Leroy: 'I take all my tablets, but I don't think it will help me to take a handful of tablets when it is clear I am dying; a glass of water will do me good.'

> Benjamin: 'If I am nearing my time, treat me for aches and pains nothing else. Why should I take tablets that won't treat this dementia I've got when I am dying? The issue is that it won't be up to me anymore, I won't be able to say this and that, though I hope I don't end up taking useless tablets that I don't need.'

> Anna: 'This is a barrier in EoLC and a recent CQC report 'different endings' suggest that people from BAME communities do not often have advance care plans in place. it's good to take everything, everything if the medication is helping. The doctor knows better [laughs], as you have just said, yes, umm, why should I take something when it is no longer helpful? When it's my time, stop giving me 20 tablets that I don't need.'

Contrary to disempowerment, empowerment was described by older African/Caribbean PLWD as the ability to make decisions and maintain a degree of control. However, many continued to express a lived fear of disempowerment in terms of perceived loss of control and independence

at EoL. While many participants showed an understanding of the potential loss of decisional capacity as their condition progresses, there was very little interest in what this entailed at the EoL. What appeared to be known by the participants was that they could ensure those providing the care documented their wishes at the EoL for later reference:

T.D: *'You have talked about your views and feelings about medication, and, interestingly, many of you do not think it will be necessary to take unnecessary medication when you are nearing the end of your life. Have any of you thought about discussing your wishes with your relatives, husband/wives and getting them documented.*

> 'No, it's not fair to talk to your family about things like this. For myself, I don't want to stress them. To be honest, I've never thought that's a possible thing to do. Don't get me wrong, we do have dinner table talks with my family, they know my feelings, but they have never suggested having them documented' (Joshua).

Many expressed feelings of disempowerment about being hospitalised at the EoL. They hoped for their EoLC wishes will be honoured and respected by their carers:

> 'You can't do anything when you are in a care home. They take over everything you know (..)I don't wish to be taken to hospital or care home, I don't.' (Forence)

> 'They [family] know what I want. I have told them never to put me in a home, I hope they don't let me down' (Anna)

Several participants stated that they wished their families to write down details about how they want to be looked after at the EoL:

> 'This is new to me [documentation of wishes], I will be at peace within myself if I know that my wishes will be remembered at the end of my living, I mean, I don't see why I should delay doing this, I think we should all do it' (Jill).

Others described empowerment as being a person - seeing the person before the illness. For example, being told she could not manage aspects of her care evoked a sense of powerlessness to Leroy:

> 'What is important for me, I think it is to be respected as a person, that's right, as a person, not because I have Alzheimer's then can do this, stop that, do that, I don't like that. It makes me feel as if I am no longer living my life but other people's life, that's not how it should' (Leroy).

5.2.2. Perceiving care settings as places filled with loneliness

For the older black African-Caribbean PLWD, who talked about the trust they had in their families and relatives, issues about loneliness and social isolation at the EoL were of concern.

A general perception held by the participants was that 'things have changed nowadays' due to busy lifestyles that families, relatives, and friends face; consequently, having an impact on the amount of time that families had to provide care. Despite participants understanding of this, many had a clear view that their family should go an extra mile to accommodate them at the EoL:

> 'I need my family around me when I am dying. I know they are all busy with their lives, that's understandable, but still, I mean they have to be with me, they need to see what's going on with me' (Teddy)

> 'But we need to realise that good old days are gone, families are now not as close as before, you see, it's a problem' (Florence)

It was felt that approaching EoL 'lonely' would not only be what one participant described as 'a shameful end of everything' but also a bad death. It is not just about the EoL, but the transition and spiritual beliefs post material death that seemed to be the reason behind participants' wishes for their families to be around at the end of their lives:

> '...that's why in the past when a person is unwell, people around that person will spend time with him or her, they will pray, wish him or her good life, if his time is up, he will say goodbye to his people. We know that when a person closes his eyes for the last time, the images of the people around him stay in his eyes. I will be happy if I go this way. Dying alone is a shameful end of everything a person has lived for. It's a shame that this is happening every day now' (Teddy)

Adding to Teddy's views, Participant 8 goes on to say:

> 'It is an awful situation for a person to die alone, after all, he or she has not been living alone, it would be worse than anything bad if I die that way'(Florence)

The focus group discussion revealed the meaning that older African-Caribbean people with dementia had as evidenced by how they strongly valued their community relationships and their homes as familiar to them and as places of comfort. While loneliness was only discussed with institutional care in mind, participants recognised that loneliness can still happen, even if one has people around:

> ‘It’s fair to say I still ask myself many questions, even though my wife is with me all the times. There are times when I just feel as lonely as somebody without family, somebody who lives alone, and this to me can’t change until the end’(Phillip)

While most of the participants felt that accessing institutional care was not what they hoped for at the EoL, one participant stated that many of them might access hospital or residential or care home nursing care in the future and may die there. This comment was confronted with expressions of fear, loneliness, and social isolation:

> ‘If that happens to me, I will not eat anything, so I die quickly; I hate hospitals, they are such a lonely place for me (Benjamin).

> ‘If that is the case, then, so be it. I have been to the hospital so many times. I have lost count. Every time I go, I still feel sad and lonely. Don’t get me wrong though, it is always busy in there’ (Phillip)

While being lonely at the EoL was described as an absence of close relatives and friends, many asserted that their wider community was important because people usually support each other, acting as an extended family for most participants.

> ...well, (..) we are living together as a community, as you can see now (…) you will be surprised that we don’t know each other very well but we care for each other, don’t we? (…) When we get the news that someone is ill, it destroys me, I am sure it does to everyone else (…) when a person we know here dies, our hearts bleeds, it is always saddening to hear things like that…. when I pass on, people I know, here, my community, they will come and say their goodbyes to me (..), it would be a sad day to them and I know that my spirit will hear them’ (Florence).

5.2.3. Seeing own home as a ‘peaceful place’.

As illustrated above, many participants expressed a strong desire to die at their own home. Being at home towards the EoL was associated with being at a ‘peaceful place’. Embedded within this desire was a belief that one’s spirit will be lost in the wilderness’. This was expressed in relation to home being a peaceful place:

> ‘All being well, I prefer my life to end in my own home, I have lived in that house for 47 years you see, I see it as a peaceful place, that’s all I wish’ (Benjamin)

> ‘My spirit will be lost in the wilderness if I don’t die in my house, it won’t find its way back, I like the idea that I will be able to have the people I know around me’ (Winston)

For many participants, dying at home was principally expressed about familiarity with place:

> ‘I don’t want to end up in a care home or any other place; I want to die in my house, (Teddy)

> ‘It's the comfort I want. When I open my eyes in that deathbed, I want to see something I know, I want quietness and the calm, my family home of 54 years provides that' (Joshua)

Most of the participants described their homes as a place they associated with warmth and peace; with others stating the importance of being cared for in a place they “belong” at the EoL:

> ‘Look, I've lived half of my life in that house (…) it’s part of me, it brings warmth and peace if any person wants to make me happy when I am dying, keep me in my home' (Jill)

She offers further insights into the kind of care she would like to receive at the EoL:

> ‘As long as I am clean and covered from the cold, comfortable, with people I know around me, I will be happy’ (Jill)

A fundamental goal for many regarding care at the EoL was, being in a calm, familiar place – their home/s, for as long as possible. Though some felt that their wish might not be met as their families may decide otherwise. For some, it was depressing to think about:

> ‘…like I have said, I do not mind people coming in to help as long as I stay at home. The thing is that it is hard to think about what will happen because some of us will not be able to do anything by ourselves, that, I know. That man said something interesting, what if the very people we trust can no longer manage?’ (Charles)

> ‘If they can't manage things at home, then you and I have no control of what will then happen, some of us will end up in a care home or hospital, it's no brainer really' (Benjamin)

To which Participant 3 responded:

> Thinking about it makes me feel sad; it throws me in the dumps’ (Winston)

Aspects of the home ambience were of importance to the participants. For example, one participant reflected on his previous encounter with the hospital:

> It makes me feel secure to look around and see pictures of my relatives, my friends and some of mine. I know how to open my bedroom window. I didn't get to do this when I was in the hospital; I like fresh air you know' (Leroy)

The view of dying at home, as a first-hand choice and the perceived negativity around accessing hospital or care home-based EoLC was further captured within the focus group discussion:

> **Florence**: ... '*It is ok to go and return home. I would not want to end my life there....'*
>
> ***Joshua****: it is not the hospital, it is the people running it, and they only care if they want. I do not know. I do not see why dying at home is special, it is a personal choice. I will choose to end my life at home. If not, I will be happy to die at the hospital, not in a care home.'*
>
> ***Charles****: You all talk as if we have a choice. Nobody cares if you are black... I don't trust them..... I know why.'*
>
> ***Delroy****: I agree with some of you (...) I mean last time (..) I went to a home for a week. I was the only black person, (...) the only one (..). Even though people were friendly to me, it was uncomfortable. Do not get me wrong (...) everyone was helpful to me. I will choose to die in [name of local hospice] or hospital, though my choice is my home.*

The 'lived hope' that permeated discussions in both the focus groups was that regardless of the care setting in which one receives the EoLC, be it in their own home, hospital, or care home; the environment must be calm, less 'chaotic' and should display a homely feel.

5.2.4. Influence of religious and cultural traditions on EoLC expectations

The narratives of the older African/Caribbean PLWD revealed how they trusted their loved ones to make healthcare decisions on their behalf. The expectation was that God would help their families to make the decisions that represent their EoL wishes. On the one hand, older PLWD expected care to be given to them by their family members 'as it is our tradition'. Overall, the expectations of care appeared to be underscored by cultural and religious beliefs. All the above seemed to be tied onto the view held by many participants that older people deserve looking after by their family members:

> ‘When God says it’s my time to go [die], I do not doubt that my family will do whatever it takes to make sure I am at peace and comfortable, no doubt about that. They [family] know this, you know. The Bible says it all, it’s important they stick to the teaching of the Lord’ (Leroy)

> ‘They know [family] that it is our ways of living for the older people to be looked after well. Everyone will agree with me here, that is how we were all brought up. I looked after my father and mother, and I expect them to do the same to me’ (Charles)

In placing trust in the family as a source of care at the EoL, this also helped to prevent participants from worrying about their care. This was further discussed in the context of religiosity with most of the participants commenting on how they raised their children and that it was their turn to receive care:

> ‘I have six children, two boys and four girls, I do not have a reason to worry about things you know, and I mean if one of them forgets me, I do not think all of them will do that. God says look after your parents and your days will be increased, they all know this because I raised them to be good people’ (Teddy)

Participants identified how older African-Caribbean people with dementia expect younger members of the family to provide care in a reciprocal, obligatory way-something that the bible supports and was of much interest to the older black African-Caribbean PLWD within the focus groups:

> ‘When that time is around the corner, I hope that my family and friends not to forget me, I have done my duty, it’s now their turn’ (Teddy)

> ‘As for me, I thank God for giving me three children and many grandchildren, me and my wife do not doubt that our family will look after us well. We worked hard to bring them up, and now that I have this evil disease, there is no need for me to worry about care, they are looking after me now, what will stop them from looking after me when I am no longer able to do anything by myself?' (Lucas)

While discussing the reciprocal nature of care from their children, two participants described themselves as ‘unfortunate’ for not having children of their own, and hoped their relatives would be well placed to meet their EoLC needs and wishes:

> ‘We were unfortunate not to have children of our own, but I still don't think I’ve any reason to worry, I have many church friends and relatives that I am sure will look after me the way I wish. (Florence)

> ‘I do not think it about being fortunate or not; God does things His own way. For me, I think if whoever will be looking after me knows that my wish is not to die in a care home, hospital, or anywhere else, but my house, then the person is my own relative’(Winston)

Although commenting on how their families have ‘lives to live’, there was less emphasis on the needs of the family. While participants talked about their lived experience of dementia, there was a strong indication of a lack of knowledge and certainty regarding the future should the family fail to provide the expected care. Failure to acknowledge changes in circumstance tended were obscured by the overemphasis on the trust the participants had in their families and friends to give the right care and attention:

> ‘Yeah, that's how things should be, that's our African way of doing things, and it’s our culture. It has always been like that; my children must look after me, it's their role to take good care of me’ (Joshua)

Participants expressed their hope of not becoming a burden at the EoL, although this seemed to be contradictory of the much-emphasised trust and expectations from their family:

> ‘I feel the same with [name], most us here will need to be looked after by others in the next few years or so, but I don’t know what is going to happen, (..), I know we will all die at some point and like everyone else here, I don’t want to be a problem to anyone, even my family, they have lives to live…’ (Jill)

> ‘I agree with what’s being said here when I get poorly, and my doctors tell me that it may be the end of the road for me, I pray not to be a burden to my family, I don’t want them to struggle with me, but at the same time, I don’t want them to put me in a home [care home], that's my main wish’ (Leroy)

Participants appreciated the care they get from their spouses, with many hoping for this to continue to the EoL:

> ‘It may sound silly, but hope my wife will continue to look after me until the end’ (Margaret)

> ‘Marriage is better, and for worse, it has been hard for him [husband], it will bring me happiness if he lives to see me go even though I feel bad to be such a burden to him' (Charles)

Participants seemed to lack some knowledge that palliative and EoLC could be delivered in their own homes. Many believed that to receive such care; one would have to be 'taken away' to either a hospital ward or care home. However, few participants reflected on their lived experience of domiciliary care, their relationship with the carers. While the positive aspects of this kind of care were of less interest to most of the participants, few talked about how home care supported their families to cope:

> 'I hope that when the moment comes, it comes very quick, umm, what I mean by this is that I don't want to suffer a lot, I don't want to be a burden to my relatives ... I don't want to go up and down to hospital…. I don't want a lot of trouble you see; I have had enough trouble' (Florence)

Fostering an environment that allows people enough time with their family and church friends as well as providing choices regarding the place of death, the ambience of the room such as opened windows was key to achieving some degree of dignity and privacy at the EoL.

'I will be smiling to heaven if my church bishop and all the people I know keep me company until I depart. I will forever be grateful wherever I go' (Benjamin)

To some, their culture was not to be ignored, and this appeared to encompass a broad spectrum of spiritual, familial and cultural issues. For example, participants expressed their concerns regarding the type of meals that they eat and that places such as 'dying places' [hospices] were likely not to be able to provide such meals:

> 'The food was…not what I would eat every day. My husband was in a place where people die; the food was not his type. We used to take food for him every day even though they told us to be careful. He was struggling to swallow' (Delroy)

One participant talked about the importance of empathy and a need to be understood as a black person by the people who may be providing the EoLC:

> '…no care home for me, they know, I tell them [family], no care home, no. If it happens to me, I hope when that time comes, whoever will be taking care of me must understand that Mr [name] doesn't like this and that must understand where I come from and that I am an old black man who likes reading his bible...' (Anna)

5.3. **Negotiating preparedness for the EoL**

Most participants regarded preparedness for the EoL as an essential matter to them and their families. While older PLWD appeared to have a general understanding about the progression and potential impact of dementia on their ability to make future care decisions, remaining attached to their faith was regarded as part of preparedness for the EoL. Preparedness was therefore not expressed in the sense of early arrangements or discussions about one's future care but by seeking God and holding on to one's faith until the EoL:

> 'It's important to get closer to God at this time, you know… I am closer to God now than before... I know I have to speak to Him sooner than later' (Teddy)

> 'For me, being closer to God means I am prepared (..), it makes me feel ready for anything…. most people here know what I am talking about'(Margaret)

Regarding future care at the EoL, older African-Caribbean PLWD described their lived experience of preparedness for whatever was going to happen; however, there was generally a lack of interest and understanding of ACP, with many commenting that planning for the future was an ungodly activity that would be viewed as an admission that nothing else can be done:

> 'I have never heard anything like that, we don't do that as believers in Christ, He prepares everything for us (Benjamin)

> '…it will send a message, a wrong message actually (...) it means nothing else can be done because you have said, oh, don't feed me with tubes, don't wake up with a machine when I am gone. I think the person who is ill will see it as giving up and the family will see it as a way of saying that there is nothing else to do' (Benjamin)

Although planning and ensuring one wishes were documented for future reference was not a good idea for the many, their acceptance of the inevitable and awareness about their preferences and choices at the EoL was clearly articulated:

> '…know that my situation will get worse, like worse, so why should I be scared, if it's time to go, let me go, even death knows I am waiting for it, it the way God created us, you see (laughs), yes, as long as I know that I won't have to eat using tubes and pipes (…) tubes everywhere, needles, machines (..) beeping machines everywhere, Peep! Peep! Peep! No (..), not that, I don't want that (..). My wish is never to have things like that; my body is God's temple, yes, yes...' (hymning) (Florence)

Descriptions around the lived experience of preparedness varied across the focus groups with some participants commenting on their initial lack of knowledge of dementia and others reflecting on previously held views:

> 'The first time I was told it was an illness, I said to myself, what is this about, I am 78, what else do you expect? I saw it as part of being old. I never thought I might have this dementia till I go' (Teddy)

The meaning of preparedness, which was described, embodied a sense of fearlessness in the sense that participants talked about the EoLC without showing any uneasiness:

> 'Well, I mean when you have this illness, you move on from asking yourself many questions, I've always been prepared for anything (..), umm, I am no longer afraid of dying as I was back then' (Winston).

> 'This will shock you all, I am pleased with my life right now, and I agree with some people here, I am prepared for anything ahead, God is in control' (Leroy)

Even though there was a general sense of preparedness among the focus group participants commented that it was still problematic to talk openly about death and dying. Several held a strong belief that talking about death would invite it within the family:

> '...even though I see why it can be helpful to talk about these things (…) you will agree with me, we try not to talk about it [death]. It is not something to talk about (…) I think it's not a nice thing to do. The Bible tells us that what you utter with your tongue is bound to happen, talking about it [death] might invite it into the family' (Teddy)

While preparedness was mainly discussed in conjunction with expectation that the EoL was an inevitable event, there was a lack of understanding of preparing for the future such as having early discussions regarding EoLC wishes and preferences. As discussed earlier, the belief held by many was that it was God who knows what will happen in the future, thus capturing the embodiment of temporality. Some participants revealed their understanding and awareness of the shortness of life, and this made them focus more deeply in the near future. Preparedness of EoL appeared to conjure expressions of boldness, and there was a general lack of understanding of the progression of dementia and the potential loss of decisional capacity associated with the illness. While most of the participants expressed a strong desire for their wishes to be respected

at the EoL, trust was mainly placed on the family and God rather than on putting things in place:

> ‘I don't see any need to be talking about what will happen, one of the reasons for me is that it can make them [family] worry, I don't want that' (Benjamin)

> ‘I trust the Almighty God with everything. I don’t have to plan things; He knows what will happen before we know anything’ (Leroy)

As echoed above, a sense of (lack of) preparedness for the end of EoL and related care permeated through the discussion with many emphasising on the inevitability of the EoL phase:

> **Winston:** ‘What I know is that many people at my age know this (..) I mean (…) we know that something could happen (..) at any time, we need to thank God for our lives at this age (..) yes (..) My wife and I are prepared for anything; you know.'
>
> **Margaret:** ‘What are you prepared for?’
>
> **Anna:** ‘To rest, we can't go on forever, can we?'
>
> **Benjamin:** ‘…well, I have been ready for anything for years (...) but I know that I am here because of God’s grace, dementia is nothing’

Although Teddy talks from a subjective point of view, he uses ‘we’ to describe preparedness. Generally, most spoke from a collective standpoint, which suggests an ‘us’-a collectivist way of living, and perhaps a community that these older people have become like a family:

> ‘I think he is like me (..) hmm (…) he is prepared for anything (…) for many of us here, we don’t want to go to, Ummm, (..), we don’t want to be in a home [care home], for me, I want to stay in my house, that’s all I want. God has been kind to me (...) I cannot grumble (…), I can’t, I have had a good life (..) All I wish for now is to be taken [die] before I become a problem to my family’ (Teddy)

5.3.1. At the deep end

The subtheme ‘at the deep end’ encapsulates participants’ feelings of anger, fear and disbelief when they initially received their diagnosis and for some, it initiated a sense of preparedness for the unknown events ahead. Feelings of anger and loss were common in participants’

accounts but were primarily expressed in relation to experiences during the time the initial diagnosis was given:

> 'As you can tell, living with this evil disease is not easy. When I was told I had it [dementia], I was shocked. I felt ashamed about it; It took time for my family and I to understand and believe what was going on though I knew something was not adding up. Nobody in my family has got this [dementia, not my dad or mother. It was a big shock' (Margaret)

Some participants talked about the difficulties they experienced when they realised that the plans they had during retirement 'had gone down the drain':

> '…It's amazing how we all seem to have had similar problems when we were told about it, I felt bitter, and my family went through a lot of trouble of trying to understand what was going on. What hit me hard was that all my plans for retirement went into the drain'(Charles)

Moving away from home to either a residential or nursing home environment at the EoL was frowned at and perceived by many as something that should not happen among black people. Care homes were regarded as 'not for black people' and the thought of dying in care away from one's own home was frightening for many:

> As much as I have come to terms with this dementia, old people's homes are not for black people, we have always looked after our parent and grandparents, it scares me to think that I might end up in a home and even die there'(Lucas)

> '...I am well enough to understand that there is no treatment for this illness(..) There is nothing we can do (…), nothing (..) we just have to face our situation. Thinking about this anger me, it makes me feel unlucky. I mean, cancer is better than this' (Winston)

Although at deep ends, there was a sense of preparedness among the participants. One described how he was 'looking forward to dying.' In his view, life was meaningless because he was aware his situation would deteriorate at some point. He talked about fear of loss of his independence and voiced strong negative feelings about his situation:

> 'I have been looking forward to dying for some time now, I tell you why, look, for us here, things won't get better. I am sure others here feel the same, my fear is knowing, I am afraid of losing everything, I am afraid that one day I will not be able to do things without any other person supporting or helping me, imagine being

helped to the toilet, to wash, to eat. I agree with someone who said he is no longer afraid. I am not too' (Anna)

Many participants made strong comments about their wish to die before they become a burden to their family due to future increase of care needs:

> 'My wish is to be able to say goodbye to my family. I feel angry when I think that I may end up needing to be looked after all the times, I have always said it, I wish to die early, I don't want to suffer, it will be peaceful to go early, that's me'(Florence)

Hoping not to be a burden to their family was described with great depth and emphasis. For many, the thought of being a burden to their families contributed to expressions of sadness, guilt, and despair:

> 'I have this illness (..) I know that (…) umm God help me please, I don't want to trouble my family. I hope it doesn't get there because they don't [family] have to deal with that (Teddy).

> 'My family have done everything for me. I do not wish to disturb them in their busy lives (…) I don't want that to happen (..) if it happens (..) ermm, it will bring sadness to me, I can't bear the thought of it (Delroy)

5.3.2. Respect, privacy, and dignity

Most of the participants' narratives showed that they valued a significant level of autonomy and individuality, and this was discussed in the context of the preparedness for future EoLC:

> 'What is important for me, I think it is to be respected as a person, that's right, as a person' (Leroy)

> 'Yeah, right towards the end I want no issues. I want to be in clean clothes and my church. I will go well that way, that's all I need. I don't want strangers to see me. No, I don't want to go to the hospital, for what, If I am dying, let me die in my home, so why should I go to the hospital, why? I know life gets to a point where we lose it, I mean we have Alzheimer's, but we are not daft you know, that's it (..), you just have to accept it when your time is up. What is important to me is comfort, peace and respect. If I get that in my home, with my family and my friends around me, I think I will be smiling to heaven, believe me [laughs] (Benjamin).

Participants talked about their wish for their choices to be respected at the EoL and this was discussed in relation to the trusting relationship that they had with their families:

> I agree with many people here, sometimes there is nothing you can do about it, I mean this [dementia] will get worse anyway, most of us here won't be able to say anything, so I trust my family more than anybody, they will not let me down, they know what I want, and they respect me. When it's my time to leave when I am lying on my death bed not knowing what will be going off, I have one wish; as long as they look after me well and keep me clean, I will be grateful forever' (Leroy)

For many, compassionate care was being respected and treated with dignity and empathy:

> 'Mmm, yes, I do not doubt this, my family will do anything for me, they will get a doctor for me when I need one, and they [family] will treat me with dignity and love, believe me, if I have to go somewhere else to die there, err, then, I know it would be a place they feel will care for me in a respectful and dignified manner, but I know how things can be in hospital wards, my wife went through hell' (Margaret)

Privacy and dignity were of importance to the participants. For some, dignified care at the EoL was more about a sense of peace brought by a quiet and gentle atmosphere:

> '…I will tell you something, let me die well in my house, it is quiet and peaceful for me, ok, that is what I call respect for the dying person' (Benjamin)

Such a place was, for many, to be able to allow church friends to come in and pray with the dying person, an issue, which many felt, was not achievable in other settings such as hospital wards or nursing home settings. The participants talked about how achieving privacy was more likely to ensure a dignified death. Thus, there was a sense that dignity and privacy complemented each other; therefore, failure to achieve one meant the other was unachievable.

Dignity, to some, was about being clean and not being left undressed. One participant reflected on of seeing her husband subjected to what she described as an undignified treatment of being left undressed and lying on a soiled and wet bed. This reflection further re-enkindled a discussion on the quality of care in hospital wards and nursing home settings with many expressing negative views on such parameters, particularly when they are nearing the end of their lives.

For some, dignity was described in terms of independence:

> 'I think of dying with respect all the time, it's important, but I don't know what God has planned for me. I will die in peace if I am not locked in a nursing home when my day comes' (Margaret)

Participants also talked about their concerns of losing dignity, which many cited issues and fears of being left unclean, and with others describing the loss of dignity in terms of loss of influence and control towards the care, they will be receiving at the EoL. Another participant described how his wife was left shouting for help without anybody attending to her when she was admitted to a hospital ward:

> '…I know this (..), my wife was in [name of hospital], look, I can tell you now that it was the worst thing to see. Before she passed on, I used to spend time with her. It was always busy in that place. So, every time she called for help, it took them a long time to come, it should not be like that. When I became poorly, I couldn't go to see her. There was nobody to ask for help on her behalf. She died like a pig; I can't bear thinking about it [tearful]. Now, you see, (..) you see why I wish never to see myself in a hospital? There is respect for the dying person there (Anna)

The issue raised in the excerpt above is not only about how his wife died in the hospital, but it also reveals how the experience has shaped his views about hospital setting care. To him, the experience means there is no respect for the dying, illuminating anger and grief.

5.3.3. God 'gives and takes life.'

This subtheme captures the participants sense of preparedness for 'God' to take control as He is the one who gives and takes life. There was a frequent reference to God when preparedness was being discussed:

> (...) it's God's will, the giver and taker of life. I am not ashamed to say I have been ready to die for years, but I know I am here because of God's grace, I am here because God wants me to live more days and see the sun, so I am happy about everything, I am so glad to be here and to be with these people here, they are my second family, they know me well and we enjoy being here (Benjamin)

This belief influenced the care that the participants hoped for at the EoL. Planning for future care was less referred to as most of the participants, probably because such plans would have meant overriding the 'powers' that God has regarding what future holds for an individual:

> '…. why would I think about planning things when he [God] knows our tomorrow?' (Teddy)

The dynamics of the focus group further revealed participants lived fear of experiencing suffering at the EoL as opposed to 'being at peace' although the metaphor 'passing through'

embodied a sense of temporality of the being – the experience of dementia; and that the EoL was, therefore, a 'gate' that one has to go through to the other side. Future care at the EoL and the dying process was perceived as redemptive and 'an end' to the sufferings that were mentioned as 'the evils' associated with 'this earth'. While life and living were believed to be God's gift, there was a sense of despair as well as acceptance of the circumstances with other participants voicing that there was nothing that could be done at the EoL other than 'praying to be saved':

> I think when you live with this, you know one-day things will get worse, to be fair, I know I am not going to live long if I do, it's the Lord's gift, that's how I feel (Joshua)

5.3.4. Acceptance of destiny

Many participants expressed a sense of acceptance of their destiny, which overlapped with the theme 'God as the gives and takes life'. A belief shared by many was that 'when God says it's time to go, it's time to go, you just have to take it as it is' (Jill). Most participants held a view that there was nothing that can be done when the end of one's life presents itself but being able to accept the situation was comforting particularly when 'you have prepared things with your God'(Joshua).

> 'there is nothing else to do when it is your time. All you can do is face it...'(Florence)

> 'even very rich people (..) I mean people who are well off, they can't buy time. It's like that you know (…) emm, all I want to say is to be ready all the times' (Phillip).

For others, who were well versed with current treatment options for dementia, acceptance of their situation was not negotiable. One must enjoy life by accepting things as they are:

> 'Most of us here know that there is no cure for this problem. I have been told about it and my wife and I always look out for news on papers and TV, it's that kind of hope, but if you know all this, accepting your situation is not really a problem, it's as tiny as a mustard seed, just ask God to help, He will' (Delroy)

> '…it's the same, I am not really worried about anything… there are no tablets to cure this…. accepting the whole situation means I am ready for anything, we just need to get on with life for now, that's the way forward for us….' (Jill)

The anger was expressed in relation to perceived lost opportunities and fear of loss of control in the future. The subtheme 'acceptance of destiny' further showed participants' understandings of their condition, although it was clear that initially, awareness was poor but attending day-care seemed helpful. There was also a strong emphasis on the presence of family, relatives and friends at the bedside and the need for prayers, with the participants relating this to good care they wished to receive. These ideas embodied religious connotations, such as 'moving on', representing another world where people 'move to' when they die. One key aspect of this subtheme that repeatedly came up from the focus group discussion was a reference to the fearlessness of death:

> I have had enough trouble with this [touches his head], so I want to go peacefully, I have enjoyed my life, been to many places around the world and I am happy about it. I am not scared of dying at all, I have stopped to think about it when you have the lord in you, there is no need to worry about anything, I have no fear at all, (...), yeah, and the lord says do not fear anything I am with you that is it (Florence)

> I think when you live with this, you know one-day things will get worse, to be fair, I know I am not going to live long if I do, it's the Lord's gift, that's how I feel (Joshua)

Most of the participants seemed to describe a level of acceptance that they had dementia; this was echoed in two unique positions. Firstly, because participants felt they could not do anything about their situation (as discussed in theme 'Belief that God is a giver and taker of life'), there was a need to get on with life. Secondly, contentment, along with the wish to die in a familiar place and trust that the majority bestowed upon their families. The participants did not comment on being unhappy with their situation of living with dementia, although the hermeneutic cycle during data analysis uncovered feelings of anger and guilt as discussed above.

> 'We all know that there is no treatment for this Alzheimer's, so that's it, you have to accept it and enjoy life while you still can, do all you can do before everything falls apart, that is my way of seeing things for now' (Lucas)

5.3.5. Soldiering on

Despite the acceptance of destiny by most of the older black African-Caribbean people with dementia, a need to 'soldier on' was voiced. Soldering on as active members of the society was

embedded within the discussions; revealing the extent to which the participants have accepted their situation and negotiated preparedness for the EoL:

> '… [laughs]...well the reality that we all try to avoid is that we are all going to die one day, there is nothing nobody can do to stop that (..), I mean people with a lot of money can't even buy one day more of their life. I have had a good life when my heart stops now; there is nothing I can do. I am happy with that even if I worry about how my family will cope with it' (Florence).

Participants described their initial shock when they received a diagnosis; however, many talked about how they 'accepted' their situation. After acceptance, questioning the future became inevitable. For many, soldiering on with life became the only option as they came to terms with their diagnosis but also realised the temporality of experience in the context of the EoL:

> 'Black folk never give up, giving up is a weakness, as hard as life can be, as hard as we all get in different troubles, it is not wise to give up. I will fight until the end. As we have already discussed this earlier, we all know that no one lives forever, the life I do not like that, it ends, and it stops. As our discussion is about the end part of our lives, my worry is about how and where my life end will. …' (Teddy)

Others described that when their knowledge about the severe nature of their condition improved, they found accepting their situation and soldiering on with life became meaningful to them:

> …. what else can you do? I like what has been said already, it about soldiering on, the journey is long, it has been long for me but what helps me to get on with life is understanding my situation, knowing more about my problems compelled me to talk to my family, to talk about how I feel and also to make sure they understood that, it was not easy, it was hard but worth it. It changed how I get on with things; it made me realise how as people, we forget to thank the Lord as I've said, it's a long, long journey' (Winston)

Moving on from the lived hope of 'soldiering on' with life, living with dementia was, for the many, a journey characterised by 'twists and turns'-a meandering journey through the undergrowth.

5.3.6. Hoping for the right decisions to be made

The theme 'hope for the right decisions' indicates the hopefulness that older African-Caribbean people with dementia had in the context of their EoLC.

EoLC decision-making came across as important to participants, although it was framed as a role largely expected to be played by the family, though some feared that their decision and that of their family were likely to be overridden by the professional's decision. Older African-Caribbean people with dementia revealed that it was their children who they expected to make the right care decisions, including treatment options or discontinuation of treatment. The older people appeared to overlook their role in the decision-making process:

> 'It's true; I don't trust any other person except my family. I am old enough to have seen many things done to black people, so, so, I do not trust anybody. If they decide that, the nurses should stop the machine supporting me to live, which is fine if that decision comes from my family. I do not doubt that they [family] wouldn't do anything to harm me at all' (Leroy).

> …I agree, me too, I have seen it all. I have a large family, between them, they will decide, they will sit and talk to each other. If they decide that I must go to the hospital, I will go. If they decide that I need to take anything to get better, I will do that. I fear that their powers to say this and that may be limited. If you are being treated for something, the doctor's words are final, you know. For now, they know what I want. I do not doubt that my family will make the right decision for me, it's their duty to do that' (Winston)

Few participants stated that their wish was to have control and be able to participate in their care decisions, including EoLC. For many, the role of their family in their care came across as natural, and was associated with making the right care decisions:

> They [family] know what I am like, they know me inside out, so they will say things with that that in mind. Even if I hope that it would still be possible for me to say a few words, I don't see it happening. I remember how my brother [name] at the end of his life, he couldn't join two words, I was in charge of everything, even the nurses and doctors asked me for answers. My family will always do the best for me, (…) they will choose the right things for me and make sure I don't get treated badly' (Leroy)

> 'me too, I wish to be able to say 'yes' or 'no' but then the question is will I still be able to do that. That is why I think my family will decide what is good for me; they will be my voice if that makes any sense' (Anna)

Perceptions and feelings around medical specific decisions varied among participants. While many talked favourably about the importance of taking medication to help optimise comfort at the EoL, others questioned the purpose of taking 'a lot of tablets' if taking them may no longer be helpful at that time. Benjamin sheds some insights into artificial prolongations of life and to him; such a decision is not worth pursuing. He supports his opinion by reflecting on learned

knowledge from previous experience and wonders the reasons of having 'tubes and pipes' at his age, should it be made clear that he is approaching the end of his life. To him, it is not just a medical decision but also something 'disrespectful', an intervention that would temper with his wish to 'go the natural way':

> '...it does not make sense to take a lot of tablets that won't cure anything, especially when it is clear I am dying. The thing is, if my time is up, nothing can be done. This reminds me of what happened to my older sister. Bless her (…), God bless her (…), they put tubes on her arms, pipes through her nose and all sort of things, did she survive? No' (Benjamin)

At this point, another older person asks what if it was the doctors who decided for his older sister to be treated that way, to which participant answers:

> 'I don't know what others think, I respect each person's opinion, and the question is, why should this be allowed? Let me say this, I am 81 years old and have dementia, what else is left for me? I do not want anything like that. (Benjamin)

Issues raised by Benjamin generated a diversity of views, with most of the older people deeply engrossed on this topic area. Most of the participants took great pleasure on exploring their views and wishes, and despite some differing views on dimensions of the EoLC decisions, the surfacing consensus was that once established that a person was at the end of his life, futile interventions were not necessary and perhaps inappropriate. The question held by many was how it could be established that someone is at the end of his or her life and what if the family is agreeable to the suggested treatment plan:

> I've told my wife never to allow this to happen to me, I don't care who decides what, I don't want pipes and tubes, it's awful, I think it's disrespectful. If I am dying, let me have a good death, let me go the natural way' (Benjamin)

With regards to future care decision-making, many participants emphasised a need to be listened to and be supported by their families and caregivers. Involvement of their family in decision-making came across as important for many participants. Previous experiences of being 'left out' during an encounter with professionals and other people, in general, were expressed and revealed threats to empowerment and neglect of the voice of older people in discussions about their care needs. This further appeared to impact on how this group of people participate in the decision-making process, such as involvement in discussions related to their care:

> …I get to my doctors with my wife, the doctors say Mrs [name] how is Mr [name] getting on? Meanwhile, I am at arm's length from where the doctor is sat. How does that make me feel? Well, it made me feel left out, dead. It made me feel that once you have dementia, you are no longer a person' (Leroy)

Some acknowledged that there might be a time when it becomes challenging to be fully involved in discussions about their care. However, a need for full involvement was voiced:

> 'It is not surprising any more. I am aware that it may be difficult to say this and that, but for now, as you can see [laughs], I do not see why I should be left out, not everyone does it though. I don't mind somebody helping me out when I lose my words' (Delroy)

Decision-making was ineffective if it did not encourage a person with dementia to negotiate meaningful choices as part of everyday experience and at the EoL:

> We need people to talk to us. We are not the same, my choice is not his choice, how can you know what I like, or how I would like to be looked after at the end of my life if you don't ask me? As simple as that' (Margaret)

While most of the participants did not see much of value in discussing their future EoLC wishes/preferences with their families due to fears of distressing the family, older people appeared to value their families in the decision-making and their involvement had significant meanings:

> '...at least I know that if it gets to a point where I can't say anything, I trust my children. They will not let bad people look after me (...), they will not (…). They will do something about it, and I have no concerns about what they will decide for me' (Jill)

5.3.7. A journey through the undergrowth

…. 'Has been like walking through a thorny and dark forest….'(Jill).

Living with dementia and thoughts about the EoLC was framed as a journey that one takes through a thorny undergrowth or meandering road; with the destination being the EoL. The discussion around 'destination' shows a degree of preparedness that most participants have negotiated during the journey with dementia. The metaphorical implication of this being the difficulties that one faces at the time by which they receive the diagnosis and during the day-to-day experience of living with dementia and soldiering on with life. This 'journey' was

discussed not only from 'when it all started' but also from where most of the participants, originally came from – the first journey to the UK. This was more relevant to the first-generation participants (those born outside the UK).

Some participants reflected on their arrival in England and the life they have had. Personal reflections revealed the original perceptions about dementia and the journey of trying to make sense of it as an illness revealed how they initially thought their problem was a natural part of ageing, but when this natural part of ageing begun to impact on their everyday life, the majority realised it wasn't a natural part of ageing, but a condition they now live with. For these older people, the beginning of the journey was a revelation, an excursion of discovery through the diagnosis they received. The diagnosis allowed them to know what was going on in their lives, and knowledge brought some closure to them and their families, who may have needed answers:

> '...it has been a long journey for me, I came here [UK] from my country when I was a young man, I mean really you ... and I worked in steel companies for many years. I enjoyed it…., My journey with this illness has been like walking through a thorny and dark forest, very much so, dark and gloomy, you see….and the road has not been smooth for me. It has been hard, and it is still the same, the good thing about being told I have dementia, was hard to take but very helpful in many ways… knowing what was wrong with me, when it all started, brought closure to my family and me. We went through hell. You must take it in and move on. That is what I did. You see a journey. Every day sees things change. It is calming to see that it's not me alone going through this (…), seeing my memory slip away is hard; My only hope, for now, is the end of my journey to be as good as the beginning' (Winston).

The beginning of the journey with dementia influenced participants' hope about what many referred to as the 'ending'. Participants reflected on their lived experience of hope for the future –the ending. For the 'ending' to be good, the beginning was essential. This revealed that participants wanted the end of their life to better than the beginning. In the quotation below, Teddy talks about 'crossing the river well', meaning dying well:

> '…when it all started, I never thought I would need anyone to look after me. It has been a long journey for me too, very, very long. I have had a good life; I have four lovely children, they are good, good people, they look after us [and husband] well, I cannot grumble at all. I hope this journey ends well, it been a long, long journey for me too. I like what somebody said, the journey is full of up and downs, [laughs], I hope to cross the river well, that's all I think about for now' (Teddy)

Florence's account of her 'journey' reveals a degree of satisfaction with her life but also illuminates the difficulties that she has had living with dementia.

> 'I think we need to talk about these things. We need to face them. I have always believed that talking about death brings bad luck [laughs], it is true. I mean think about it, the end will always come, whether I talk about it and this man does not talk about it. I agree I agree, it's been a journey for me too, it's been one thing after another, and I am still following a zigzag road, each day I pray to the Almighty God for this journey to get to the end before it's too late for me' (Florence)

On reflecting on their journeys, many participants referred to dementia as 'an evil illness', and this permeated throughout the two focus group interviews. Unsurprisingly, dementia was, for some, a 'punishment from God':

> …I knew that God was not happy with something, so He struck me with this illness. You have to understand how God works to understand what I mean' (Jill)

While there was a general acceptance of the difficulties associated with living with dementia and the inevitability of the EoL, the journey with the illness depicted a walk through the thorny undergrowth where one was faced with many obstacles. Some commented that it was the 'will of God' that made things to be the way they were for them. The quote below reveals the depth and detail that participant 8 had, not only for dementia the 'evil illness' but what it meant to live and think about the future EoLC:

> As others have said earlier, everything happens for a reason. We all come here because we have one problem, our memory is not good, mine is getting worse, to be honest, for me, it is all God's will. He knows everything. If he wants this journey to end today, He will do it (...), umm; it is up to Him. If I die today, that is the end of my journey. I am prepared; I have been prepared for a long time (Florence)

The meandering part of the 'journey' was embedded in the narratives about living with 'the evil' illness, although two participants emphasised the importance of how the 'journey' would end:

> '…agree with everyone here, I no longer worry much about what is going on in my life, I have this moment where I think about how I would like to be looked after when my time is up. Thinking about it is not easy (..) like, ermm (...) but everyone agrees with me here, I mean, the end will come anyway. For me, this [thinking about the end of life] brings peace, because I have long accepted my situation' (Delroy)

Despite widely held views about issues about death and dying, I vividly remember how many participants used humour and metaphors to describe their lived experience with dementia and future EoLC:

> 'You got to be happy; it's no good to be angry all the times. I used to ask myself many questions, why me, why that, but I have now moved on. Like everyone else in this place, I think and hope that I will be looked after well when I am no longer able to do anything for myself. I have said this already, my son [name] knows what I want and how I want things to be done. There is no secret about it; whether we like it or not, the end will come to us (Leroy)

While the 'end' of the journey with dementia was of some interests to the majority of older African and African-Caribbean PLWD, there was minimal emphasis on the planning for the end of the journey even though there was a general acceptance of the inevitability of the end. When one participant remarked on his thoughts of 'putting things in place', his suggestion was confronted with comments like:

> '...it's just a waste of time, and I think it brings a lot of stress to those who care for us' (Winston)

For some, negativity on planning for the future appeared to be pivoted by a belief that it is not a man who knows his future but God who plans things and who knows what will materialise, when and how? While this view generally tended to be consistent through the two focus groups, participant 9 reveals why he does not think planning is that important to him:

> 'God knows what will happen; there is no reason why I should worry about the end of my life. As an older man, as you can see [laughs], there is one main thing left, only one; and it is dying. For me, it is about how I will die not about why or when [laughs]. After all, my wife is 20 years younger than me. She will take care of that, that's how most black people deal with this' (Lucas).

As stated above, the beginning of the 'journey' appeared to influence participants' views about their future care needs- the 'end of the journey':

> 'I think my family have gone through difficult times already, it will upset them more, I guess. I see why talking about putting things in place and talking about this is important, I see that. I all fairness, in my culture, that is not something we value much, think about it, when I start talking about things like this [future EoLC needs], I think they will believe that I am now dying, it's not worth it really, I don't want to put my family in that situation (Joshua)

Despite lived experience descriptions of what it is like to live with dementia and what it is like to think about the future EoLC needs; and views which echoed culturally and religiously underpinned views, the participants' accounts within the two focus groups revealed that past experiences had an impact on participants' view of the EoL and what matters most to them. For some of the participants, thinking more positively about their situation appeared to be related to the level of trust they held towards their families through their journey with dementia.

5.4. **Yearning for quality of life at the EoL**

Even though the vast majority of the older African-Caribbean PLWD talked more about what they conceptualised as salient issues about the EoL and associated care; such as dying in their own homes, being with their families, approaching the EoL with some degree of preparedness; *yearning for quality of life*[6] *in the moment* was often referred to in conjunction with the desire of living their lives to the best of their ability at the time of the focus groups. For example, Florence, talks about how she often envisions her future care; however, she often struggles to build a clearer picture of her situation, for example, she finds it hard to know what to expect and what could happen at some point when her health deteriorates. It is not surprising that these questions often do not yield any precise answers, leading her (Florence) to consider optimising the quality of her life at the 'here and now' - 'living to the fullest' as she puts it:

> '...well, I sit down and ask myself many questions (...) I am talking about many many questions [LAUGHS], and I get nothing back…. maybe it is only me (…) even if I know this will get worse, it is hard to see what is on the horizon. That's why I try to live my life to the fullest, do what makes me and my children happy now….it makes me feel less worried…' (Florence)

For many, going to the day centre[7] twice a week brought a sense of belonging; a platform from whom loneliness and social isolation were alleviated. Proximity, in the spirit of being with other users of the service; created a communal area in which older African-Caribbean PLWD enjoyed meaningful activities such as a game of dominoes, reminiscence- 'the good old days', music and culturally geared conversations. Most of the older people who described weakened

[6] The definition of Quality of life (QoL) adopted for this thesis is that provided by Felce & Perry (1995), who defines it as 'an elusive concept approachable at varying levels of generality from the assessment of societal or community wellbeing to the specific evaluation of the situations of individuals or groups' (p.51)

[7] The Oxford *living* Dictionary describes a day centre as 'a place providing care and recreation facilities for those who cannot be fully independent'

familial presence in their lives talked about how being with others contributed to their quality of life, termed '*yearning for the quality of life at the EoL'*:

> My life would not be the same if this place were not here (…) I am grateful for this place. I think, we all are. For me, coming here twice a week allows me to be with other people; and we do all sort of things you know. I like playing dominoes (...) I like food and the music. When I am here, everything is ok, I don't worry about anything and I don't feel lonely at all' (Margaret)

In conjunction with *a yearning for the quality of life at the EoL,* many participants stated that being with other people within the day centre made them happy, understood them and bolstered their lives:

> 'Me too, I don't think my life would be the same. I have always been a people's person. I like the company. We all know each other, I know everyone here (...), we talk about the past, things we all know, it's not like 'what is he talking about' [LAUGHS], when I am here, with these people, I don't think about my troubles, I am happy. There are many more reasons why I like to be here.' (Leroy)

Despite the acknowledgement of the benefits brought by attending the day centre, many participants accepted the inevitability of the EoL, acknowledging how this allowed them to focus on things that brought a sense of contentment. As these older people had generally accepted their daily difficulties associated with living with dementia, *yearning for the quality of life in the EoL* was often referred to in terms of how they navigate their journey as people from a minority group in their locality. For many, search for quality of life redirected their orientation towards valuing the time they spend with those close to them:

> … Talking to people at memory clinic helped me, I now know more about dementia than before I had it…...that man just explained how I feel, I now choose to do things that I love more. Because of knowing, I've accepted this [dementia] as part of life ….. I know, I know (…) things won't go backwards [Tearful] Well, I don't know how you all feel (…), talking from how I live my life, I think it is all about trying to get on with life'(Delroy)

5.4.1. Setting one's eyes at the end of the road

Older people with dementia expressed feelings of an intense fear of dying badly. Dying badly was talked about as dying in an unfamiliar setting and facing the EoL alone. Older people described the quality EoLC as one, which meets the unique needs of a dying person such as

being kept clean, comfortable and in a place with a peaceful and serene ambience. On defining the quality EoLC, older people frequently referred to the family and the church as crucial to them. One participant described that failure for him to end his life in his home, surrounded by his family, and would equal loss of purpose and meaning. Many older people with dementia used to active members in their community, they talked in-depth about their premorbid lives, but that they slowly recognised themselves as 'outsiders', with some asserting that they felt living with dementia impacted on their sense of belonging:

> 'When you have this [dementia] you can't keep up with things; sometimes it feels as if nobody wants to listen to me'(Jill)

Another participant commented that approaching the EoL without the right support was like trying to drive a car without the right keys:

> '...to me, you got to know that everything is ok, you don't want to get through that time of your life with things falling apart. If that happens to me, I think (…), I see it as trying to drive a car without the keys, how will you turn the engine on? (Delroy)

For some, quality EoLC was described in relation to compassionate 'warm hands from people taking care of me', which illuminated a need for compassion from those providing care. Issues about food and gender of nurses were raised. Some participants said hospital food was not culturally appropriate and being 'mixed in one room with females' was described in terms of poor care and cited as a reason why many preferred dying in their own homes:

> 'No medication for me, unless it's for the pain, nothing more. Comfort and love from my family and prayers for a peaceful journey home [heaven?]' …they will not allow anybody to shove needles on me, they know that I would not like anything like that, they will say no, leave him alone, don't put all that on him'(Winston)

Many older African-Caribbean people with dementia valued access to high-quality care. However, this was often referred to in the context of the family provided care rather than formal care. It is interesting to note that despite most of these older people's assertion of care as being a family business, there was some acknowledgement of the essential components of good EoLC. For many, quality care at the EoL was envisioned as co-ordinated, and in which they were to be talked to as capable individuals and treated with compassion, dignity, and respect by those providing the care:

> 'If I cannot longer manage my care, I would like to think whoever would be looking after me must be a nice person. We have already talked about how people are treated in care homes, when I see it on TV I feel like vomiting. It's awful. I need to be with warm hearted people who will not treat me like an animal (…) even animals deserve better care. All black people in this country try to look after those who needs looking after, at least the relatives can make sure the person is with someone until they pass on, that's very important'(Benjamin)

Comfort and 'being at peace' came across as important to many, in *yearning for quality care at the EoL*, there was less reference to the management of pain. However, the participants appreciated emotional support and spiritual care:

> '…as an old man, I know that when a person is dying, it is very important to keep them calm, I have seen it all, I have lost many relatives, I know. That is why I said. I pray to God to take me before I lose all my marbles. To me, prayer can move a mountain' (Florence)

5.4.2. Searching for solace through prayer

'Prayer can move a mountain' (Phillip)

Searching for solace through prayer embodies a sense of purpose and hope that older black African-Caribbean PLWD attributed to their everyday life. For many participants, prayer and being with the church community/friends was pivotal at the end of their life. Although not it its broadest sense, prayer – relationship with God, encompasses the spirituality needs that this group of people value. While not all participants talked openly about their religious beliefs, spirituality was presented in many ways - accounts about what it means to live with dementia, valuing the presence of the family, rituals such as having windows open at the EoL, all revealed various dimensions meaning-making through spirituality:

> '…praying is my source of strength; it brings joy to me. I cannot survive without it [prayer]. When I face any problem, I kneel and talk to the Lord. I need to pray to God whenever I feel like doing so, that's why many of us like to come here because we can pray together' (Jill)

Spirituality and religiousness and wish for better care at the EoL were profoundly embedded within the participants lived experience description dementia and appeared to sustain their hope of dying well, and for some, God was in the middle of their view of the self:

> ‘When I pray, I don’t forget to ask the Lord to cover me with his blood until pass on. Jesus died for us so we can have eternal life. I know the Lord is with me all the times, I feel His presence. That’s why I am still walking with my two feet at 86 years of age, isn’t its God’s grace? I know I will rest in peace because He is with me’ (Teddy)

Spirituality and religiousness, for most of the older African-Caribbean people with dementia, was not to be separated from their definition of comfort at the EoL- being ‘at peace’. Thus, ‘without God, there is no peaceful passing on’. During a discussion about artificial feeding at the EoL, participant 4 illuminates’ spiritual comfort that he finds from being part of his church community. His devotion to God and the sense of meaning or purpose that his faith provides insight into his being:

> I pray to God that not to happen [artificial feeding] to me, it is against my belief. My body is God’s temple, and it must be treated in a Godly way, Christians will understand what I mean by this, it’s trying to go against the time that God has given me to live if God be willing, nothing like that will ever happen to me, prayer can move a mountain, you know’(Phillip)

Whereas, meaning and purpose at the EoL were described in terms of one’s proximity to God through prayer and the view of the self as ‘God’s temple’ anticipation of death, or ‘facing it’ which most of the participants talked about, uncovered a continuation in the search for solace:

> ‘Someone earlier said living with this disease is all about suffering every day, to me, if my time is up, I think it would be the end of all this suffering. We have all suffered with this dementia. If it was not for my faith, I would not be talking to you right now, I would not be here, and I have enjoyed my life. …I cannot grumble…, I agree, I feel the same…but if you pray like me, you have no fear of death, there is no need to worry. I see death as getting to the other side of the river (…), I have faith in God, I am strong’ (Joshua)

Anna revisited her long-buried sense of meaning, even if there was no reference to religious faith, revealed similar views:

> ‘I’ve always believed in God. When I think about what would happen in my life, feel happy, I feel less worried than during early days when I was told I had this illness. God has been good to me. I remember 30 years ago when I almost died from a car accident, it was a narrow escape and the Almighty’s mercy. I know that there is no cure for this illness; it means that my time is not far ahead. It makes me strong to know there is nothing that can be done for now’ (Anna)

Searching for solace through prayer revealed participants understanding of what constitutes a bad death. To some, approaching the EoL in a 'confused way' would lead to a meaningless death; or a death where the person has not found inner peace, leading to a profound impact to those remaining:

> 'We have always worshipped our Lord. I don't know how I will see the world if I wasn't born again. Living my life this way makes who I am, and without peace in myself, I don't see how I will pass on peacefully. I think most of us are believers here, we know that people who die badly are those who are confused as to who they are when they are rested in that death bed, you got to have peace in yourself, otherwise dying becomes a life wasted' (Teddy)

The spiritual suffering at the EoL may begin well before the patient is actively dying:

> 'I've gone through many obstacles, sometimes it feels as if I am dead (..) my faith is dead too (..) but then it picks up, I keep going and praying. It's that My family are aware that my spirit will only rest in peace if people from the church and my friends are at the bedside before I close my eyes, that's what I would like, in fact, I would like to thank you for asking us to talk about this, I think it's important for us (Delroy)

Threats to the maintenance of solace were described in terms of lack of privacy in formal care settings, feeding onto the fear that many had with regards to ending their lives elsewhere other than their home, for example, participant 10 talks about the absence of privacy for prayer and meaningful 'last supper' discussions in the hospital ward basing his view on previous experience with his wife. He fears that should he access hospital/care home-based EoLC, communication with his relatives may not be maintained throughout, leading to a bad experience of dying without his family around:

> 'You know it gives your family peace to see you go and it is important to have them around to say goodbye to them (..), the problem is that sometimes people do not get told their relative is dying, it happened to us [and his family]. It is still hard to overcome thoughts of not saying goodbye to her. Because there was no privacy at all, we had to pray in a room with other people. What if more than twenty people from my church want to be at my bedside? That's why I wouldn't like to die at the hospital; sometimes there is no place to pray for many people at once' (Joshua)

5.4.3. Valuing being 'talked to'.

Closely linked to the sub-theme 'hope for the right decision', was the importance of being talked to by healthcare professionals (mainly home care workers) and family. Many focus group participants associated this with respect. Some stated that they valued being spoken to because it gave them the opportunity to know about what the carers or family are doing when providing care and support:

> 'Well, I think it is respectful to talk to me about what is being done and why' (Winston)

> 'It annoys me to see people talking about you while you are with them as if your mouth has been padlocked; I think it is looking down at me as a person' (Jill).

Anna reflected on her lived experience in which, instead of talking to her about her health problems at that time, the healthcare professional ignored her and asked her daughter and son about how she was:

> 'I remember going to [name of hospital] with my son and daughter. I can't remember why, instead of asking me questions, the young woman asked my daughter and son about me. I think it is very important to be talked to; it makes me feel in control of my life.' (Anna)

For some older black African-Caribbean PLWD communication between them, their family and those involved in their care meant more than being respected and valued. Communication was not all about verbal or non-verbal but more about the physical presence of significant others at the EoL. This was perceived as a vehicle by which a dying person can avoid bad death - dying with information that they may have wished to share with relatives:

> 'Think about it, when you are facing death, or realising that things are not going well, the least you want is not to be able to say how you feel, or for those looking after you not to try and ask you how you feel. I think it's bad and I have a feeling many people die with a lot of things in their chest, and that's what I would call a bad death' (Florence)

While this wasn't commented in the context of the EoLC, one participant criticised his son, who agreed for 'home help[8]' to be introduced for him without discussing the decision.

[8] Home help denotes to homecare package. This can be in the form of several home visits by carers to provide support such as medication administration, personal care and meal preparation. It can also be for social reasons.

Although he acknowledged that the support, he was having at home was invaluable, it was regarded as a disrespectful act:

> 'He [son] decided that I needed a little bit of support at home, so, he and some people decided for home help to start, I mean, it was a good decision don't get me wrong, but it made me feel like a little baby, it would have been good to talk to me and see how I felt about it. I am not saying he was wrong to do that' (Phillip)

Care at the EoL was described around family and community relationships[9] and protecting loved ones. Another participant commented that talking about death and related issues, including discussions around future care was something that needs to be practised with caution, as it would mean that there was no more hope for the person:

> 'these discussions need to be done with caution because the [discussion] about how I would like to be taken care of at the end of my life, would tell my family that there is nothing more that can be done, it would mean that the only thing ahead is death, we need to be careful, families would struggle with this' (Joshua)

While discussion around death and dying appeared to be less of a problem to all the participants in the two focus groups, personal uneasiness in talking about death and dying or the perception of death was framed as a taboo and a potential barrier to discussing similar issues:

> 'I agree; there is a need to be cautious. It is not only about me you see; my relatives would find things difficult. Even talking about dying, it was never discussed with young people, not anymore. People need to be careful, you talk about it all the times, and it comes knocking on your door' (Teddy)

Some older people with dementia articulated a need to strike a balance between making their EoLC needs to be known and protecting their family from dealing with 'painful' information about their personal feelings. This appeared to reveal a need for sensitivity around discussing the EoLC issues.

Regarding effective communication, older African-Caribbean people with dementia valued sensitive, appropriate, accurate, timely discussions, which many felt were pivotal to EoLC preferences and choices to be made and known. Reflecting on his lived experience, participant

[9] Community relationships denotes to social networks such as the church, friends, neighbours and the day centre (valued by many participants in this research)

6 emphasised the importance of honesty and openness, particularly around prognosis as this brought peace of mind to him and his family:

> 'if people talk to me about my choices and how I would like things to be done in a nice and respectful manner, that is fine with me. If the sensitive information is given to me with honesty, it's fine. It is not helpful not to know about what is going on with my health. If I will die in the next few days, isn't helpful to know that so I take time to organise myself? It brings peace of mind to me that I remember well how it brought closure to me when I was told about dementia, it was hard to take but also calming because I started to understand myself and others better'(Margaret)

5.5. **Summary of Chapter**

This chapter presented thematic findings from two focus groups with 13 older African-Caribbean PLWD. The results suggest that at the EoL black African and black Caribbean older people affected by dementia have a preference to remain at home instead of going into 24hour care home settings. Accessing 24hour care was associated with loneliness at EoL, and many participants viewed care homes as disempowering contexts where one would not die in peace. The majority of older PLWD appeared to accept their journey with dementia. Their narratives revealed that they face the EoL yearning for quality of life and hope that their relatives will make the best decisions for them. For many, the underlying belief was that God is the giver and taker of life, and preparedness for EoL and related meanings were negotiated from this position. While most participants expressed a general sense of preparedness in facing the EoL, including accepting their situation, praying to God appeared to be a solace source. In the broader sense, their religious views appeared to be a barrier to future care planning as thoughts about the future care needs was less critical to them due to the belief that when God says it is time to die, there is nothing that can be done.

A need to maintain respect, privacy, and dignity at EoL was a crucial issue associated with 'dying in peace' by many participants. Living with dementia was perceived as a journey with lots of ups and downs. All in all, this chapter's findings show that older African-Caribbean PLWD place greater responsibility on their families to provide the care and support they need and to make the right EoLC decisions.

CHAPTER 6: FINDINGS - CURRENT CAREGIVER INTERVIEWS

6.1. Introduction

This chapter details findings from interviews with seven current caregivers of community-dwelling PLWD who are from African-Caribbean ethnicity. The primary focus and aim were to contextualise experiences and perceptions – lived and experienced versus hopes and expectations of care at the EoL for PLWD drawing on current caregiver perspectives. Current caregiver interviews sought to explore: What is it like to be a black African-Caribbean caregiver to a person with dementia in the context of future EoLC?

6.1.1. Participants characteristics in current caregiver interviews

Table 7 below introduces current caregiver interview participants

Table 7:Current caregiver interview participants

Participants name	Caregiving context
Chinua	Identified himself as being Western African by birth but has lived in England since 1996; his father suffered a stroke at the age of 50 and developed dementia 2-3 years later. Chinua worked in a care home and was fully involved in the care of his father at home. He repeatedly referred to dementia as 'a curse to our community' and maintained that the Bible says children must look after their parents.
Daniel	Along with his sister and the extended family, Daniel looks after his parents. He described his father as having 'refused to go for checks' after having been the primary carer to his wife (Daniel's mother) before the

	family took over the care after noticing increasing changes at home.
Lindy	Daniel's sister looks after her mother who is living with dementia. She spoke of her Caribbean roots and experiences, including her faith in God as being her source of solace when things were difficult.
Joyce	Looks after her mother and father who she describes as the first generation, having come to England on HMS Windrush in 1948. She emphasised that her parents should remain at home as she does not want her family to be neglectful.
Sofia	She is of North African background and described herself as a trained psychiatric nurse who has worked in various care settings. At the time of the study, she had just taken early retirement to look after her mother. Her father, who she described as having worked as a bus driver all his life, has now developed mobility problems affecting his ability to provide care to his wife.
Maranda	She described herself as being Caribbean by background. She stated that she was the primary carer to her husband, who she described as 'very unwell' at the time of the interview. Her family is from a nursing background, and her understanding of dementia was detailed. During the meeting, she emphasised that her husband would end his life in a hospital rather than in a care home. She cited recent abuse of older people by carers in homes as the reason behind this.

Joseph	Looks after his parents and was firmly against the idea of placing people in care homes. He continually emphasised that 'as black people, we don't put people in homes to die there, we don't do that'.

Four core themes with associated lower-level themes emerged from data analysis. Table 10 below summarises them prior to the detailed discussion that follows.

Table 8: Summary of core and lower-level themes

CORE THEMATIC AREA	LOWER-LEVEL THEMES
MAKING SENSE OF UNFOLDING EVENTS BY FAITH TO GOD	• God as the giver of strength
LIVING IN FEAR OF MAKING WRONG EoLC DECISIONS	• Living in fear of being misunderstood and blamed • Collective decision-making
TWO SIDES OF THE COIN	• Death of care recipient as the end of suffering • Death of the care recipient as the end of one's caregiving role • Anticipatory grief

6.2. Making sense of unfolding events by faith to God

This central theme relates to current caregivers' quest to understand and make sense of the unfolding events in the context of their faith, cultural, religious beliefs and what it is like to be a black African/Caribbean person affected by dementia. This appeared to shape the perceptions lived and experienced that many carers expressed regarding the nature of care that they were providing at that time and wished for their relative in the future.

When referring to possible resuscitation or life support at the EoL, Chinua draws on knowledge as a care assistant and religion to make sense of things:

> I do not think I would be happy for my father's peace to be disturbed (...) it is against our faith to allow that to happen [resuscitation] (..) I mean a man like my father who has grown up great-grandchildren would not worry about living an extra day, you can't go against God's will (Chinua)

For Daniel, people should be allowed to 'rest'. He supports this by highlighting that he has faith in Christ:

> As believers in Christ, we let people rest with respect, it is good to end that way. My mother is tired (..) she has had a life; I think to have her fed with tubes or stopping her from leaving [dying] would be disrespectful (…) I know how he does not like things like that (…) tubes and needles stuck on his body why?... (Daniel).

Daniel, a carer to his mother with dementia; commented that he was aware his mother had 'gone into a dip' in her health. He goes on to talk about 'waiting to hear something'. His wish to provide good care to his mother seems to be through a cultural lens, suggesting caregiving is reciprocal:

> '…she has gone in a dip since going to [name of hospital] and I have been waiting to hear something (…) I am not sure it would be good news to be honest……it is now her turn to receive our love and care, you see, I will make sure she has the best care to the end, that is what most black people still value, it is our culture to respect older people (Daniel)

Concerning the future, discussing the EoL issues was not welcome for some carers as it may suggest there is no hope. Chinua talks about having such discussions as difficult, with a potential to have a different meaning from the perspective of this father:

> I don't think I would talk to my father now (..), I don't see the point...to him, in my culture, this may mean something different, you know (..) like, maybe (..) like (..) there is no hope, I think it's just difficult to do that... (Chinua)

For others, it was against their religion to discuss death and dying. Again, God 'knows everything':

> As a Christian, I do not see the reason [for discussing death/dying] (...) the Almighty is the one who knows everything… (Joyce)

Some commented that if they were to discuss anything with their relative with dementia, they would prefer to do so while their relative was 'not yet gone' although upon realising that her relative's dementia has gotten worse, it may no longer be feasible to have these discussions:

> '…the harsh reality is that life ends, whether we like it or not. Auntie [name] does not even recognise me now, or any family member, she does not recognise her home as hers all the times (…) it's awful (…) if I can take things back, I will do things differently; I would talk to her about how she would want us to do things while she is not yet gone, even though this is not our ways of doing things' (Lindy)

Joyce, unlike Lindy, has a different view when it comes to discussing future care needs when a person is 'not yet gone'. She implies that it would be unnecessary to talk about the future when the person with dementia is trying to get to terms with their situation:

> How do you even start talking about death when a person is down in the dumps from realising they have dementia especially early? I think it would distress the person who may be trying to come to terms with things (Joyce)

Joyce's view is also echoed by Chinua:

> ….as you may know, a person with this illness [dementia] may be trying to understand how they will live their lives….it would do more harm to say things like how do you want us to look after you at the end of your life...like I said earlier, this would be taken differently by my dad. (Chinua)

For others, talking about death [now] is thought to bring sadness, and could hasten their relative death:

> …. you may know this, talking about death is not a good idea; I think it would be disrespectful and insensitive to the situation, I mean the Bible says we must be careful about what we talk about (..) I think it would invite death... (Lindy)

The ‘now’ is more important than the future for Chinua and family –a time to ponder deeply on existential issues:

> We just need to take a deep look at how we can have quality time with my father. As I speak, he just came out of hospital (…) things are not looking bright for us (Chinua)

However, for Joyce, the pain of seeing her relative with dementia gradually decline her and her family look beyond the ‘now’. She does appreciate that in her culture, talking about death is not commonplace:

> Now that we her decline quicker than before, as a family, we have now started to think about what we can do now (…) I mean what we can put in place (….) but it is not easy to talk about death in my tradition….’ (Joyce)

In his story below, Joseph questions the relevance of some traditional beliefs that he feels can prevent people from providing good care for the dying:

> ...I've been a carer for years, I think people should be careful about these beliefs… I know people who believe that when you talk about something, it will happen to you [laughs]. These beliefs stop people from talking about important things… (Joseph)

Many felt that conversations about EoLC choices and preferences should take place, though the nature of conversations and the time of such discussions must be delicately approached. Sofia revealed that she had previously looked after her auntie, father and now her mother. She reflects on the importance of discussing future care needs but appreciates the sensitivity required around that kind of dialogue:

> ‘...having looked after two people with dementia in my family, I know how important it is to talk about things as a family, yes it’s difficult to do that but very important (…) As I have said this already, I think talking about death can be insensitive to the situation, well (…) in all fairness, it has always been our culture never to talk about death (Sofia)

When asked further to explain further, like Chinua, Sofia draws on her working experience and highlights a need to look at how some of the beliefs can ‘hold back’ people in relation to the EoLC:

> ...I know that the illness would get worse; I have nursed people dying from the disease (…) so, why should I allow some of the beliefs from our faith or culture to hold me back from making arrangements or discussing things with my mother? (Sofia)

Family caregiving to a relative with dementia seemed to involve constantly adapting to change, and could have long-lasting negative effects on the lives of the carers:

> You never know what would happen in a week's time, let alone the next day. I think the main thing I can think of is that when I started to take care of my auntie, I stopped everything (…) I mean all I do is look after her, nothing else…as you can see, my ankles are swollen; my health has gone down over the past few months, but God will see me through this…(Sofia).

6.2.1. God as the giver of strength

For some carers like Chinua, there was a strong belief that God was the provider of strength, without which one would not be able to continue with their caregiving role:

> I wouldn't manage this [caring], it is the strength that I get from God' (Chinua)

> When I kneel and ask God to see me through to another day, I always feel differently, I think the energy and feel determined to continue…. prayer for me is like renewing wedding vows [laughs] (…) that's my source of strength (Lindy)

For others, their faith helped them to connect emotionally with their loved one with dementia:

> When we pray, I hold his hand, I hold it tight (..), I think of how good things have always been, I feel connected to him, it is incredible (Sofia)

> ...when hope seems to be fading away and my energy levels are going down, I pray and out of nowhere, there is too much to give…we feel like a family again'(Daniel)

Throughout the interviews, many carers referred to the biblical texts when narrating their experience:

> ...the Psalms teaches us that God is our refuge and strength, that how my dad who I now look after always said' (Chinua)

> As sad as I am, the book of proverbs says when we believe in the lord, we are safe and we should not grieve but be happy, that's how I take things…it is that way for now' (Daniel)

Concerning the end of EoLC, many carers held a belief that their faith in God helped them to cope with the fear of the impending reality:

> …we cannot know what time, what day of the month or year, that part is for God, He knows when, why and the exact time (Maranda)

Similarly, Joseph's comment takes from his Christian beliefs:

> only the Lord knows when she is going to die, we can prepare for tomorrow, but God may have a different date, this illness steals people from us, we just need to value our time with our loved ones with it [dementia]...'(Joseph)

Religiosity appeared to be a key contributory factor to how the African-Caribbean caregivers negotiated their day-to-day lives. Hope emerged as an integral phenomenon that many consistently spoke about in the context of their Christian beliefs. What emerged as striking but rigidly meaningful to some participants was that prayer was often painted as a more reliable approach to managing adversity and ill-health than mainstream health care:

> If you are a believer, you know this, praying is the only way to overcome our problems, when I pray, I feel hopeful. I believe that a powerful prayer can make us stronger when we face difficult times. Dementia takes the person you know slowly away; it is an evil illness. Sometimes it is always about taking tablets; prayer can heal (Chinua)

> Part of what I do is to sit at my auntie's bedside and read the bible, then pray. I do not just give the care she needs; I make sure her prayer needs are met; after all, excellent care for a person who may soon be gone is not to forget to keep them in the hands of the Lord, which is very important (… it can be anytime from now, but that's not for me to tell, God who knows what we need as his creations, we do not need to ask…' Lindy)

The central belief was that a person's life and death are beyond an individual's control and that it was God who many saw as having higher powers:

> I have been a carer for a long time now…. but through my faith, I have overcome some of the difficult moments of caregiving. My father raised me well; I need to do the same to him. His wish is to stay close to his family and to die here [own home] (…) we will be blessed if we make sure his wish is respected…. (Joyce)

> Yes, she has been taking tablets since she had it [dementia] to slow its progress. As I have said earlier, we have been told that she is at the end of

her life. If I were able to do anything about, I would walk to the moon and back for her to get well. I guess the only thing we can do is to make sure she is well looked after until she leaves us [dies] (Lindy)

She has never distanced herself from God that is why as she is now bed-bound; reciting the Word of God brings her closer to God. As I said, God talks to us in many ways (Lindy)

6.3. Living in fear of making wrong EoLC decisions

Decision-making was perceived as rather a collective task, and many carers were concemed about making the wrong care decisions for their relative. Caregivers revealed concerns and worries regarding decision making for care. Many were worried about making the wrong choices that do not represent their relative's wish.

Cultural and religious beliefs rooted within the respect of older people as deserving to be looked after were central to decision-making as stressed by Chinua:

The Bible teaches us to take good care of older people so that our days will be multiplied (Chinua)

Many participants commented that one of the many things they feared was making wrong decisions. Getting things wrong was understood to be a disrespectful act, and something mostly frowned at by many. About decisions regarding 24-hour care placement, Maranda said:

...what if I get things wrong? What if he comes back home after taking him into a home, how will I face him, when I think about it, it keeps me awake at night... (Maranda)

Many family caregivers held a belief that placing or allowing their relative to access residential care would accelerate their deterioration and decisions associated with putting a relative in care were to be approached with great caution:

I remember how we had to take my uncle to a home due to concerns about his safety. It was not easy for us to agree to it, we did not have any solution. What really hit us hard was that in the space of three weeks, his health went down badly, I mean, it was quick, he died nine months later. Now, even when things get tougher with my auntie, I will think twice about it (Lindy)

Not only did many hold contrary views on nursing or residential care but also some had a belief that residential care was a place that people who had no family to look after them go to die. This view had some connotations of shame:

> I suppose a family who fails to look after their loved one would find it easy to decide to take their relative into a care home to live and die; I think it can be selfish to do that (…) especially if the decision is for the benefit of the family not the person with dementia. I understand if a person does not have a family, but the care homes that I know are not good places, people in there always have their heads in their hands… (Joseph)

> He is not going into a home that is a decision that I cannot change. He will die in his house. If he dies in hospital, fair enough, but not in a care home, no…' (Maranda)

Regarding the place of care throughout and at the EoL, family caregivers found the decision or similar thoughts of having their relatives in nursing or residential care as neglectful and shameful. Such a crucial decision was not to be made by one person:

> I have had many meeting with social workers and our family doctor recently (…) my health hasn't been good (..) it hasn't (…) it's a difficult job, you just can't tell what is going to happen (…) even so, I can't decide to have him in for respite because I know my family would not see things from a positive side…. it's better to have them around to make that decision' (Maranda)

For some, it was not just making decisions collectively, but making sure there was no opportunity for blame, especially when the community judges the family:

> I always feel as though I will put my family's reputation at risk if I make mistakes or rush into making decisions (Chinua)

> ...it is a bad thing; I would just avoid doing anything that would affect my family…. I don't want them to be judged (Lindy)

Deciding for a relative to go into 24hr care was approached with fear, with many suggesting a need for the 'family to come together and agree':

> I know how people talk about these things; I do not want my family to go through that kind of negativity. I am not saying it's wrong to have a person put in a care home; I suppose it's up to the family (...) I just know that it is not common for most black people to do things that way…. (Sofia)

About the type of food appeared to concern some caregivers:

> It is not a good place for black people to go in, the food is horrible in most of those places, and the places are noisy and just not homely enough for a peaceful death that we all wish (Sofia)

Many felt that they would put up with formal carers visiting at home than have their relative in institutional care at the EoL:

> I will not mind having people come to our house for his treatment and things like that. I know this from our neighbour, it worked well for them (..) it did (…) rather than have her in a home or hospital ward, I prefer home visits to care homes, she knows her place and does not like going away, whatever the case may be, now or at the end of life, putting her in a home is a decision that we can agree on, I don't see it happening, my family would not take her to any place (Joseph).

> I don't like many people coming in and out of our house, but I will rather face that to keep him at home than take him somewhere else (Maranda)

6.3.1. Living in fear of being misunderstood and blamed

Many carers were concerned about being misunderstood by their families and the care recipient. Although it was important for the family to be involved in discussions regarding their relative's care, it was often difficult to have everybody to agree on aspects of care:

> Sometimes I do not think my children get it, they do not understand some of the things that I say about their dad, and I have turned help away because I am not sure my children will know why I have accepted it (Maranda)

> Last week I had a social worker visit us at home, as soon as I mentioned it to my brother, it was like I went behind his back….no body understand you if you are caring for a person with Alzheimer's (Lindy)'

From Daniel's point of view, being misconstrued can trigger unwanted family dynamics:

> We are a huge family, we take turns in doing it [caring] but sometimes when I suggested errr, say (…) sending her for a week's extended respite care, everyone was like, what, we can't do that, are you tired, have you lost the direction, we have never done that, homes are bad, don't you see what's on the news (…) to be honest, it caused a lot of unsolicited tension in my family… (Daniel)

Joseph too fears being understood by the care recipient and thinks it would be unforgivable to do things against the person:

> I would rather die from tiredness than give up…. nobody would understand why, so (…) why would I take her away, I have done this (…) she will not forgive me for doing anything like that [taking her into care] (Joseph)

6.3.2. Collective decision-making

Collective decision-making was perceived as the norm, and when things went wrong, blame was not to be made to an individual. Others, particularly younger family carers, stated that busy lifestyles often made it difficult to 'get the family together' where a decision was to be made quicker. One carer, Sofia, reflected on a previous experience in which family members who live far were unable to 'get together' on time to discuss a need for emergency respite due to her [Sofia] being ill to provide care. While the family had phone conversations, she reveals how her family were unhappy that she took the care recipient into respite care:

> I tried to get them together though, I tried, I said 'hey we need to get together and talk, I need urgent help, I can look after mom, I need us to talk, I have had a chat with a social worker' nobody came back to me on time, it's hard, they work, they know I am with mum all the times, to get my family together isn't a quick thing' (Sofia).

In conjunction with a collective approach to making care decisions and the possible family fallout where disagreements occurred, Lindy went to say:

> …we have to agree as a family; I recall how differences among us caused a bit of tension, it happens, people fallout just like that…...family members who don't do much expect more…'(Lindy)

Such experiences appeared to influence how caregivers thought about the EoLC decisions. For instance, referring to future care at the EoL, Sofia commented that she would rather 'delay' making decisions until her family reached a consensus. However, in her explanation, Sofia acknowledges that there are situations in which decisions are time-bound, and that can affect the care:

> If it gets to a position that I am expected to make a decision (…) alone, like anything (…) alone, about my mother's care, I would rather delay that, I will

> choose to have the whole family agree first, I know that some of these things must happen quickly they [healthcare professionals] would be expecting you to say something, but if there is no rush, I will wait for everyone to agree…., it is better that way' (Sofia)

Similarly, Chinua who questions whether 'old ways' of a family approach to decision-making should be abandoned, talks about the unpredictability of dementia and reflects on his lived experience on which his family was embroiled in a disagreement. While he acknowledges the benefit of a collective approach to decision making, he feels that the relevance of the traditional approach to making decisions may be a barrier to the flow of care to the relative with dementia:

> Our communities are changing, many things are changing, never in my life did I see this coming for me, now, I am a carer, I think old ways of doing things can be challenging to fit in, a good example is my family, they all live far, they work, they have their own families, I have a job, umm it's hard to have everyone together at once, I have told them we need to change, umm we can't meet all the times. After the fallout, we had last time; we have agreed that we talk over the phone, which helps. Disagreements are not reasonable, I know from experience, it can stop other excellent services to the person with the illness [dementia], and we have agreed we cannot continue like that... (Chinua)

To Joyce, a common way of making care decisions for a relative may threaten the autonomy of the individual with dementia and their right to make decisions:

> We must think about the person. Ideally, my dad should make his own care decision (...) that is my dad's right. As a family, we often failed to bear that in mind when making decisions (Joyce)

In collective decision-making, family members may have conflicting views based on their input and understanding of the situation. Here, below, Daniel reflects on his experience but also reveals how family members who are less involved may exacerbate an already unstable environment:

> …It can be puzzling, you know, one must understand how we value making things together, it can even get worse if family members do not agree to something proposed… (Maranda)

The African-Caribbean family caregivers placed great emphasis on family ties. Although some felt that their families live far apart, having them participates in the discussions and decision-making for many emphasised their relative's care:

> Well, we do not expect younger people like me to make decisions on behalf of an older person; it can be taken as disrespectful. Until you understand how dementia affects people, then you know, it is not in my culture to just say things as if the person is a child, no, that is why it can be difficult to discuss things ahead…(Daniel)

For most caregivers, families were no longer as culturally 'intact' as previously known. One carer described the family's decision to have their loved one in a care home as worse than anything she had ever gone through:

> I still can't get over it, we don't do that, we don't take our older people in nursing care homes (…) we don't (…) nursing homes are not made for us' (Joseph)

> We must accept that we are here; we are in a westernised environment. I mean, yes, we can still cling to some of the things we know, but it takes an excellent look to understand that we are no longer at the same position culturally as when, like, my father came in this country, I think I read a lot of things, that is why I see things slightly different (Chinua)

6.4. Two sides of the coin

The theme *two sides of the coin* represent the caregivers' views of death as being 'two-sided'; firstly, many carers perceived it as relief of suffering and, secondly, as the likely end of their caregiving role. These views were expressed with a great deal of difficulty and a sense of guilt with many carers noticeably hesitant to talk about death while referring to their relative.

6.4.1. Death of the care recipient as the end of suffering

On this side of the coin, carers perceived death as being the termination of suffering. Although actively providing care, some family caregivers, like, for instance, Chinua, looked ahead time when God would 'take his [father] soul' ending all the suffering:

> **Chinua:** Sometimes, I sit down and think, well, my dad has suffered a lot with this illness [dementia]. I sit there like a lost hunter, you know, that kind

> of lost feeling and just think, think think, then, again, I also realise how difficult things have been for my family (…) I sit and think, I look ahead, and I feel hope, I hope when God takes his soul (…) that, to me, would be the end of all his suffering….'
>
> **TD**: The end of his suffering, you said?
>
> **Chinua:** As you now know, my dad is unwell right now, from my experience as a care assistant; I know where we are going from here (…) so (…), he has already suffered so much
>
> **TD:** You mentioned, you know where you are going? Can you please tell me more about that?
>
> **Chinua:** he is going down very quickly, I know, he has not got long left. I do not see why he should suffer more that he has had (…) he says it to us, he does not want us to feel burdened…. the earlier God takes him, the less this disease would torment him…'

Seeing death as the end of suffering seemed to be influenced by family caregivers' awareness of dementia. Lindy, who previously looked after her uncle who died with dementia, commented that she did not wish her auntie, who is currently looking after 'to suffer like my uncle did' She maintains that dementia has 'already taken my auntie' but quickly substantiate her wish for she auntie to 'go early and avoid suffering'. To her, it is essential to 'live with a positive picture of the person'. Here, in her story, she talks about how death can be 'blessing' and how it can 'end suffering':

> …I cared for my uncle with a similar illness, I know what I am talking about; I know what is on the way and what is essential at the end of life. The sad reality is that death will come anyway, to me, as much as we all want our loved ones never to die, I think death can be a blessing in that it can end the suffering.... we must remain with positive pictures of our loved ones…(Lindy)

While many African-Caribbean current caregivers of PLWD described quality care at the EoL as one in which a person is comfortable, has his or her dignity maintained, stays at home and has the family at bedside, one carer, Maranda, commented that many families would rather face the 'pain losing a loved one with dementia' than 'see them die slowly and painfully'. She talks about 'facing reality and accepting God created us to die'.

> As a carer, you think about things like it [death], and since this illness has no cure when it gets worse, you just wish your relative never suffered a lot… (Maranda)

Daniel sees his mother's frequent hospital admissions as tormenting her, leading to a lack of quality of life. He considers death an impending loss but also sees it as a relief from the suffering she has endured over the years:

> My mom has been in and out of the hospital, COPD, pneumonia, chest infection; it has all been like a cycle. She is tormented, she is tired, and she has no quality of life. She is just there (...), no quality of life at all, nothing (...), she cannot make her needs known, she is just there, breathing, of course, I know she doesn't want to live anymore, even though we do look after her well, she wants to go (…)I want to see her free from all the torment she has gone through… (Daniel)

6.4.2. Death of the care recipient as the end of one's caregiving journey

The other side of the represents how carers perceived the EoL of their relatives at the end of their role. Many looked ahead of their current position with mixed feelings. Not only did they see the inevitable death of their loved one as the end of the 'suffering' and 'torment' but also as the end of what they have done for many years.

> …it now almost six years, this [caregiving] has and continues to be my job when he is no longer here…. then, that would mean the end my role and all (Maranda)

> I know (..) I see it coming soon, he is not well at all (..), had to say this (…) err, maybe the suffering will go, it's too much for him…I know what he is thinking, all he wants is the torment to end (…) he wants to go…I know' (Chinua)

Other caregivers like Sofia saw it as not only the cessation of their role of caregiving but also as the end of living on the edge all the times, something that she believes would be the way God wants things to be:

> All we wish for is for him to be taken good care of to the end of life, the way he wants not what we can or cannot do. It's our duty as his family to look after him, but when it happens, I can't think of anything at the end of being on edge all the times (Sofia)

The anguish of seeing his father day in and day out with and his journey with dementia is Chinua's concern. He too sees the EoL as the culmination of all he has been doing. However, all he wants is to look back with good memories:

> I do have moments when I think about what is next, especially when things aren't good, I know that my duty will end at that moment, doing everything for him, taking good care of him, all will good memories (Chinua)

Like Chinua, Maranda talks about living in a persistent state of pressure, comparing how things used to be and how they are now but what is important to her is 'reaching the finish line':

> I am happy I have kept my husband at home; I have done my duty as a wife and will continue (…) he too would have done the same for me. What I pray for is to reach the finishing line of this demanding journey well and to move all with life... (Maranda)

6.4.3. Anticipatory grief

During the caregiving journey, family carers often begin to grieve while the person with dementia is still living. Participants' accounts of their experience revealed that family caregivers often live with grief from the point they realise the loss of the 'premorbid self' of their relative due to the progressive cognitive decline and loss of skills of daily living. Anticipating future emptiness was a core component essence during current caregiver interviews and encompassed their worries about anticipatory alterations likely to materialise in the event of a death of the care recipient. I recall vividly how emotionally charged was this part of the interview for most of the current family caregivers. Some commented that they felt they had 'lost' their relative in many ways even though they were still living; therefore, thoughts of not having them around seemed, to some, an extension of their current situation rather than a new phenomenon. Take, for instance, Chinua's response during the interview:

> **Chinua**: It is as if my dad is long gone, at the same time he is around. Some days he would say things that when I turn my back, I say, 'where is that coming from? His funny and eccentric persona comes to life, then, (…) then, we go back again to confusion, he does not know who I am, he does not recognise his home like his, and I think, I had him yesterday, where is he gone? I've seen my father change over time from a clean, funny and independent man to a person I struggle to understand at times when I look back, I miss the father I know when I look ahead, I feel empty while he is beside me, I think the emptiness of my life, and I struggle to imagine my life after he completely gone
>
> **TD**: When he is completely gone?
>
> **Chinua**: yes, well, yes, I mean it feels to me he is gone already in many ways, but then someday he is back; it is so hard to know what would happen. Over the past four years, I have learnt more about dementia, I know what is

> ahead of us, my friends have gone through similar situations, I know [tearful] (…), sorry, sorry (…) I think when my dad dies, to me, it will look like he is dying for the second time. That is how I can put it across.

Most African-Caribbean caregivers lived experience accounts revealed a rich sense of preparedness of what many understood as an inevitable phenomenon, including some anticipated changes, [as indicated by Chinua quotes above] there was a strong sense of anticipatory emptiness but also a sense of achievement:

> '…. She is not going to live long from now, I know that as sad as it makes me feel right now. The question that I am struggling to answer is what am I going to do? Whatever happens, I think my life will go down, that is what I see happening. All I've done and all I do now is taking good care of her, making sure her life ends well (…), making sure she is happy in her world, that kind of thing (..) nothing else. At the end of everything, I want to look back and say, 'I did all I could do to make her life end in a dignified manner' (Lindy)

For many carers, this lived experience of anticipatory 'empty future' without the care recipient [the person with dementia] often led to feelings that were punctuated with uncertainty and despair. Imagining the future without their relative was a distressing thought to most carers. However, Joseph commented that anticipating grief and emptiness in the future allowed him to feel emotionally prepared. Here, below, Joseph talks about 'developing shock absorbers' that he feels stems from his acceptance of the inevitable future. Joseph emphasizes that ensuring his wife stays at home whatever happens, as he does not trust any person to provide quality care:

> If you see the state, she is right now; you will see what I mean. What many people I meet struggle to get on with is understanding that whether we like it or not the situation will never remain the same, that's a painful thing to think but worth doing. Fair to say every time I think like this; it usually makes me feel equipped for whatever happens from now (Joseph)

Primarily, most of the African-Caribbean caregiver lived experience descriptions showed that they often experience feelings of loss on a daily basis. Some caregivers commented that knowing what was unfolding slowly ahead was necessary, and others said that experiencing feelings of loss, made them negotiate a sense of preparedness. As such, providing care and anticipating the loss of their relative at the EoL appeared to be an ambiguous experience, take, for instance, Maranda's account:

> ... you have to (…), umm, like, a way of accepting that the home situation will change, it won't remain the same, so, really, to me, being prepared means I can look after him with serenity and peace of mind because most things that I know should be done are in place already… (Maranda)

In conjunction with the ambiguousness of the experience, Daniel explained:

> You will never know where you stand, some days the person is lucid and his or her usual self and some days the same person is in the gloomy little bubble. I think whatever the case is, making sure my mom is happy in her space, making sure she is content and comfortable now until the end is more important for me (Daniel)

6.5. Summary of Chapter

This chapter presented thematic findings from interviews with seven current African-Caribbean caregiver interviews. The findings suggest that caregivers draw on their faith/religion and culture to make sense of the unfolding events in their caregiving journey. Concerning EoLC, the family carers often anticipate the loss of their relative with dementia but fear making the wrong EoLC decisions. As expected, collective decision making was emphasised by many caregivers and access and use of the available services for support appeared to be hindered by the caregivers' fear of being misunderstood and blamed by those around them.

Religiosity appeared to be deeply embedded in African-Caribbean caregivers' everyday lives. For example, faith in God was rather more than religious practice but an everyday way of life - a way of doing things and a basis from which they sought understanding of the now and the future. For most the caregivers, the death of the care recipient was marked the end of both their caregiving role and was the end of the care recipients' suffering.

CHAPTER 7: FINDINGS - BEREAVED CAREGIVER INTERVIEWS

7.1. Introduction

This chapter details findings from phenomenological interviews with six bereaved family caregivers[10] of people with dementia from black African-Caribbean ethnicity. Seven main themes emerged from the data analysis, and these are: living with uncertainty and continuous change, God knows what he is doing; being a caregiver an African-Caribbean family caregiver at the EoL of a person with dementia; experiencing loss before physical death; explaining the phenomenon of EoLC in dementia; experiencing inadequate support and making decisions. The primary aim was to understand the way things appear to the black African-Caribbean bereaved family caregivers of people with dementia through their lived experience.

Van Manen's (2014) five existential lifeworlds were used to illustrate and make sense of the EoL dementia caregiving. Thus, key themes are presented according to the five existential lifeworlds: relationality, spatiality, temporality, corporeality, and materiality. When making sense of caregivers' stories, during the analysis process, I aimed to develop an understanding of the phenomenon of EoLC, and as I present the essential elements of EoLC, in dementia, I continually ask myself 'what is the lived experience of bereaved African-Caribbean caregivers of people who died from or with dementia? How do these family caregivers make sense of their experience at the EoL of the person they provided care? What, if any, is the essence or nature of the care they provided?

7.1.1. Participant characteristics: Bereaved caregivers

Table 9 below presents bereaved caregiver interview participants. Pseudonyms are used throughout the thesis to protect participant confidentiality.

[10] In this thesis, I adopt Reinhard, Given, Petlick & Bemis definition of the terms *family caregiver* and *informal caregiver*: 'an unpaid family member, friend, or neighbour who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care.

Table 9:Bereaved caregiver interview participants

Participant's name	Caregiving context
Chipo	Is from a Southern African country and had looked after her father up until the end of his life. She spoke at length about how the family went up and down to the hospital for investigations on her father, up until the diagnosis was given. Dementia was a new phenomenon for her; she explained that she had never heard of it before her father had the diagnosis. At the time of the interview, Chipo had gone back to work after a long break. She spoke about difficulties coordinating the care of her father towards the end of his life and her lived experience of facing continuous change.
Martha	Looked after her husband of 56 years and described herself as being of Caribbean background. She spoke at length about her supportive family. God was the source of her daily strength during her caregiving role, and all that happened was God's will. She talked about prayer and was thankful for the support she got from her Church. Even though her family were supportive towards the end of her husband's life, they were often not around, and Martha described, 'how small the world was' for her, which was further strained when her husband started not to recognise her.
Mavis	described her family as being from the West Indies. She looked after her parents and held

	a belief that God was punishing her family through dementia. She explained how she lived in denial, even when her mother was towards the end of her life. She talked about how 'comforting' it was to her when the community palliative nursing team regularly visited her mother. She commented that most people of a black background, 'like to keep things within the family as talking to people about things such as incontinence and aggressive behaviours 'could be humiliating.'
Noah	Introduced himself as being of Caribbean background. He looked after his father, and his experience was captured by, 'all I wanted was to make sure he was comfortable. Whatever the issues, I just wanted to hold the bull by its horns. You can ask any person who has looked after somebody with dementia; they will tell you the same.'
John	Described himself as being of Caribbean background and was the primary carer to his father until the end of his life. He emphasised that it was against his culture to 'air dirty linen outside' – meaning that he hid his experiences from outsiders to avoid 'unwanted stresses'. John emphasised a belief that his dad, 'passed away at peace' having had the time to 'pray to God and reconnect with Him.'
Maria	Looked after her mother, who she said came to England at the age of 22 from the

	Caribbean peninsula. She explained how her mother was often 'not comfortable where there was nobody of her colour'. She revealed that she was 'criticised' for accepting a care package for support and feels that without the help, caregiving 'would have destroyed me.'

Five core themes with associated lower-level themes emerged from data analysis. Table 10 below summarises them prior to the detailed discussion that follows.

Table 10: Summary of core and lower-level themes

CORE THEMATIC AREA	LOWER-LEVEL THEMES
LIVING WITH UNCERTAINTY AND CONTINUOUS CHANGE	• Facing the change • Experiencing hopelessness and anger' • Living in denial: 'it wasn't sinking in'.
'GOD KNOWS WHAT HE IS DOING'	• Negotiating meanings through prayer • 'God is punishing us.' • Wearing a brave face • Circumnavigating limitless obligations • Feeling trapped
SUFFERING IN SILENCE	• 'We never air dirty linen outside' • 'It felt like I was on an island alone'

	• 'I was responsible for everything' • Fear for being perceived as a failure'
ANTICIPATORY LOSS	• Unanticipated circumstances • Maintenance of dignity and comfort
AT THE CROSSROADS	• Looking back with regret • Realising the lost opportunities for early EoL discussions

7.2. Living with uncertainty and continuous change

Living with uncertainty and continuous change illustrate the nature and unpredictability of caregiving to a person living with dementia from the point by which the person receives a diagnosis to EoL. Participants talked about how they lived lives punctuated by uncertainty and confusion as to 'what would happen next'. *Living with uncertainty and continuous change* revealed how the African/ Caribbean bereaved caregivers often had to adjust to the changing needs of the care recipient in the context of uncertainty and change:

> '…the worst of all things was to know what would happen next because nobody gave me a good answer, it became an everyday question.
>
> Meanwhile he was no longer able to eat or drink without support……nurse and doctors were visiting, and still, I didn't get to know what was next' (Martha)
>
> 'It was difficult to plan things, what can you do when you can't even figure out what is going to happen tomorrow, the question keeps coming until the end' (Chipo)

Positive experiences were described as 'being with' and 'being there until the end', uncertainty often lingered throughout the caregiving journey. Most participant accounts illuminated changing relationships as the person living with dementia deteriorated in all aspects of daily living:

> The fact that I was with my mother until she passed on brings joy to me; it will never fade away. Even though it was not easy for everyone to know when and how she was going to go, I still feel happy that I did all I could, never mind the amount of work and stress' (Maria).

Indeed, adverse experiences were described regarding stress that developed from carers' realisation of the care recipient diminishing health and skills:

> The hardest part of my experience was when my father could no longer feed himself. Even went suddenly went down from that point, that, to me, was hard to take in, I guess it's because knew the man that he was, it was no longer him' (John)

7.2.1. Facing the change

The subtheme 'facing the change' illustrates the nature by which carers navigated their lives as both living their own lives and as living lives that revolved around their role as caregivers. Most of the carers described how they faced each day with a sense of wonder as to what next was going to happen:

> I recall thinking 'is this day going to be like yesterday, what is going to happen today', after all, you are trying, by all means, to make sure things are done the right way. I had a lot to do with my health, diabetes management, doctors' appointments, you name it, but then, it got to the point that she was poorly, and whatever I wanted to do, I had to think about her first' (Maria)

Because the care needs of a person living with dementia continually change as they negotiate their journey with the condition, most of the African-Caribbean bereaved carers described some difficulties centred around changing or altering their lives to fit in with the 'constant change' such as the fluctuating needs of the care recipient. However, the anticipation of the EoL not only conjured feelings suggestive of despair and anger but also often exposed these caregivers to loneliness and social isolation due to living with denial and uncertainty:

> As I have said it earlier, the harder it was to get answers about what was going to happen, the more I became frustrated, angry and lost. …, at that time because you are frightened about something terrible happening when you are out, for shopping or to see a friend, you just stop everything.… the thought of something terrible happening keeps you as a hostage, no difference to a prisoner' (Martha)

> I had to be with her(…) I couldn't be away much, yes, nurses were regularly visiting, in and out, you know, but they wanted me to answer some questions on her behalf, so, if my family were busy, I had to be home, because she was no longer able to make her needs known anymore, that made me feel stuck' (Mavis)

In relation to *'Facing the Change,'* most the African-Caribbean bereaved family carers in this study reported that caring for a relative with dementia at the EoL was a demanding role, with little time for rest. Some explained that in the period leading up to what used to be frequent hospital admissions, their relatives frequently became more challenging to care for because of disorientation, anxiety, pain and reduced physical function:

> '…always something going on if it was not a hospital admission, I had to deal with a lot of telephone calls, I had to check we had enough pads, medication, I had to know who and when among many professionals was visiting, all this meant that there was not enough time to rest, and even worse few days before he passed on' (Chipo)

> 'She would become very snappy and short-tempered, sometimes difficult to manage, hitting out at me or any person trying to help, I would ask the nurses to check her for yet another water infection, there was always something changing…'(Maria)

7.2.2. Experiencing hopelessness and anger

Moving on from living with uncertainty and dealing with change, feelings of despair and anger were commonly expressed in many bereaved caregiver stories. The participant stories illuminated that the caregiving role was not always static; in fact, it was ever-changing. The caregivers often experienced hopelessness and anger due to the need to catch up with the increasing care needs of their relative living with dementia. Towards the EoL, family carers' stories revealed how they were hit by the reality of their relative's deteriorating health often accompanied by changes in their care needs. This demanded family caregivers to adapt along those changes to meet their relative's care needs. However, along the process, caregivers described a tension between their caregiving role and the multiple challenges of managing their own lives. This often resulted in significant strain and feelings of hopelessness and anger.

Here, in the excerpt below, John reveals how his experience of anger about his situation became part of his everyday life. He talks about how 'the whole thing' brought a sense of resentment which he had to get on with, including how the demands of caregiving made him abandon his hobbies to meet the demands of providing care to his father:

> It is awful; the anger never goes; it is something that I slept and woke up with. It started when the whole situation became a reality; you feel unfortunate to be in such a position, you ask yourself why me, why us, what have we done? In the beginning, all went well, then he came back [from hospital] worse, so we had to do most of the things for him. I had to stop being part of a rumbling group; I couldn't

> go to the city hall as I was a member of the choir, I mean, one by one, I stopped doing things I liked, that made brought a lot of frustration with it' (John)

Similarly, the experience of anger, for Martha, was never-ending and remained behind the scenes:

> I used to wear a smile when I meet people, but every time I did that, anger was at the background of the smile; it is something I had to continually try to get rid of (Martha)

For some bereaved caregivers, when their relative was approaching the end of their life, anticipation of death often incited fear, and fear gave way to deliberate avoidance, and all these experiences contributed to anger:

> I remember how thinking about what was about to happen threw me off the cliff. I was frightened all the times and had to avoid being among other people. The thought of losing my father was always in my mind and would ask myself what we did as a family do be in such a bad position, then I will get angry about things (Chipo)

These feelings increased when the person with dementia was nearing the EoL; and most African-Caribbean bereaved family caregivers referenced altering relationships, 'losing' the person the caregiver had known well, the relationship they had, loneliness and social isolation and changes that were likely to happen in the future.

While there is a sense of self-blame in Martha's quote, there is a strong sense of anger surfacing in her experience:

> We have been around the world, we did everything together, and then, everything stopped. Every good time we shared is gone, funny conversations we used to enjoy, all gone, everything…' (Martha).

At their relative's EoL, family caregivers may be exposed to making difficult decisions that might be against what they know about their relative, and this can leave them torn:

> What do you do, here you have a person dying, you know what they would have wanted, they can no longer make their needs known, and everything is dependent on you and some of your family? Would you have your mother or father, who is dying to eat and drink with tubes, have many needles pricking their poor skin? Do you take them to [St? Name of local hospice], hospital or care home? This happened to me (...) you know whatever I did, I still questioned whether I was selfish, and making one of these decisions was heart-breaking (Chipo).

Other caregivers commented on how unprepared when it came to difficult decision making about end-of-life care, such as how to respond if the person needs hospitalisation or a crisis develops. Uncertainty often led to distress:

> …it was very difficult to know what to do when she was not well… because I was worried, that she might end up dying in the hospital against her wishes' (Mavis)

Despite experiencing hopelessness and anger, the bereaved African-Caribbean caregivers' lived experience revealed that many chose to *suffer in silence*.

When Martha was informed that her husband was approaching the end of his life, she describes realising that death was imminent, and the principal objective was planning a final farewell by inviting church friends and their extended family. She also talks about how she felt angry and hopeless from realising that she was about to face life alone, and how being alone was going to be different:

> '…always thinking about ahead and how I was going to manage without him. For the last six years, all I did was look after him, umm, that is all, nothing else. Now that he was dying, what else was left for me? Nothing; and when he died, everything stopped, my life stopped at that moment, it could have been worse if I didn't have my family and church brethren to see me through' (Martha).

7.2.3. Living in denial: 'It wasn't sinking in.'

Even though most of the bereaved African-Caribbean family caregivers of people with dementia valued 'being there' and 'being with' their relative up until the EoL, most of the carers' lived experience descriptions revealed a sense of denial – a repudiation and deliberate avoidance of the reality of seeing their relative's health deteriorate:

> 'It wasn't sinking in at all (..) em (…) I tried, by all means, to avoid thinking about what was about to happen (..), I tried to keep it that way, it was comforting to avoid thinking about the bad news, even though signs were clear to me that my dad was not going to be with us in a week or so' (John)

Though there is a sense of avoidance in Mavis's account, her priority was to be there and to be with her mother:

> '...what I wanted was to be with her, to be there for her, now, there were times when I thought she was dying, but that never came across as real, if that makes

> sense, I used to tell myself 'nothing will happen she is not going to die, not now, not tomorrow' (Mavis)

Participants' avoidance of facing the unfolding reality reinforced a sense of hope because without hope, being a caregiver to a person with dementia at the EoL became like living 'in an island of my own':

> I just couldn't take it in, I mean they [nurses] explained everything to us when we were advised to be at his bedside, part of me still believed, no it won't happen, he was going to win the battle, he's survived cancer, so he was going to fight again, I didn't want to give in because if I did, that would have taken me down' (Chipo)

When Martha's husband was nearing the EoL, she describes trying to make sense of the situation as 'confusing and difficult to accept'; however, the experience made her feel alone:

> Well, as I said, many people were around, but strangely, I was alone, everything was blurry and foggy. Just then, I realised how small the world was for me' (Martha).

7.3. 'God knows what he is doing'

Faith in God came out as an essential element to the participants' meaning-making process. The theme *'God knows what He is doing'* illustrates the extent to which the bereaved African-Caribbean family carers accepted the loss of their relatives and reveals the solace the carers found through their religious beliefs. These beliefs surfaced in most of the participant's descriptions of their lived experience from the onset of being a caregiver to a relative. On the other hand, participants' frequent reference to God appeared to exemplify a journey from acceptance of the situation, recognition of the role as caregivers and acceptance of [*anything*] that befell the care recipient. *God knows what He is doing* is further illustrated in the sub-themes '*Negotiating meaning through prayer'* and *'Wearing a brave face.'*

7.3.1. Negotiating meanings through prayer

As already indicated above, during the phenomenological analysis of the experiential accounts of these African-Caribbean bereaved caregivers of people with dementia, I actively detected that not only was religion and spirituality an essential element of being an African-Caribbean family caregiver but also an everyday ingredient in the lives of these people. Faith – a belief in

God, The Almighty, was a source of strength, resilience, yet its unintentional significance at the EoL of the care recipient, it became the main tributary to of hope and strategy for coping with the everyday caregiving role.

Intimately related to the belief that *'God knew what He is doing'* is how the African-Caribbean bereaved family caregivers appeared to use prayer as a tool to fuel hope and resilience in their day-to-day caregiving role. Most of the caregivers commented on how praying and going to church was important to them even though it was at times, impossible to maintain regularly due to caregiving. Take, for example, Martha, a bereaved wife's description of how praying to God and having church friends visit frequently brought hope, purpose and meaning for her particularly when her husband was at the end of his life:

> ..I couldn't manage anything, without it [prayer] it's fair to say when we were told that he was not going to fight through, we prayed, the church was with us all the way, that's how I continued to look after him' (Martha).

Hope and a sense of purpose surfaces in Chipo's account, she talks about how she often negotiated solace through prayer:

> Well, praying brought comfort whenever my head was buzzing, looking after the person who raised you and who is now relying entirely on you…. you got to have inner power, you got to stay strong, prayer was so important to me and my family' (Chipo)

Likewise, for John, prayer a way of expressing deep feelings and perhaps a natural way of 'being strong' when suddenly providing care to his dad whose premorbid life was defined by independence and teachings of self-sufficiency:

> At the end of the day, I was his son; I knew him from day one of my life…an independent man who taught me to be the man I am today, who taught me the importance of fight through…., now I see him losing the battle. That was very hard to deal with. I had to find some strength and prayer became the only way forward (John).

When other approaches to coping methods became obsolete, Martha reveals how praying at bedside made it easier to counteract some of her hopelessness feelings. Being able to overcome hopelessness helped Martha to shift her focus to providing and coordinating the EoLC to ensure her husband had what she described as a respectful death:

> Everything seemed to be falling, everything, so, whenever I was sat there with him, he would ask for Martha, his wife, that was hard to understand, it hit me hard, but I never took my eyes on his dignity, I wanted him to be as happy as he can…. praying helped me a lot' (Martha).

Because her father was an avid churchgoer, Chipo describes that while it was imperative for her to 'stay close to God' through prayer, reciting biblical text for her dad often 'made his face beam with joy' even though 'we were waiting for God to take him':

> 'every time I read the Bible aloud, he would smile, a deep smile and his face will beam with joy, when he did that, my day was good, even though I knew his time was not long'(Chipo)

Most of the participants' accounts were described and framed from a religious standpoint, illustrating the importance of finding meaning through prayer as well as how the participants used prayer to remain connected to their relative at the EoL:

> We are Christians, praying is all I can do, through it [prayer] I can cope, it made me feel connected to mom spiritually…. (…) I mean, felt God's presence every time I prayed, and I know mom had a peaceful passing' (Mavis)

The meaning of spirituality appears to be embodied in John's lived experience description, of what he views as the quality EoLC:

> …going back to what I said earlier, yes, to me, dad had quality care throughout because I focussed on doing things he liked, such as praying, church, his grandchildren, singing…' (John)

While most of the carers talked about how they found solace through their faith, one participant –Maria; revealed how she questioned the presence of God when she was struggling to cope following her realisation that her father was approaching the EoL.

Interestingly, she quickly identifies that prayer was less critical for her than to her father. She comments on the importance of maintaining the dying person's religious beliefs by asking people from her father's religious community to visit and pray with her father on a regularly:

> Looking back now, I remember feeling very low and tired, and I even questioned whether God existed, yes, I did, but then I knew my dad's faith, he has always been a staunch believer, so I made sure that I invited people from his church to visit regularly' (Maria).

The maintenance of beliefs was highly regarded by many African-Caribbean bereaved caregivers. Mavis reflects on how her mother taught her that regularly reading Biblical texts kept the family connected to God. She further clarifies that when her mother was at the EoL, she and her family kept her mother's favourite gospel music playing at the background and asserts it brought comfort to her mother:

> Besides reciting her favourite verse, in the book of Isiah 41 verse 10, we kept it [music] going all the times, she loved it. It meant the world to her' (Mavis)

Indeed, while most of the participants talked about their ways of finding solace despite challenging times, the prevailing view was that quality EoLC must enable the maintenance of one's religious beliefs, allow the caregiver/s to remain connected with their dying relative through praying together. The importance of connecting with their dying relative based on John's lived experience as a caregiver was not to be overlooked at the EoL. John describes how it allowed him as the eldest child to have 'deepest EoL discussions' that he believes wouldn't have been possible if his father was in a care home, hospital or hospice:

> '... I couldn't call it a good death, or good care for that matter (…) no (..) if my dad's Christian faith was left out, or if I wasn't able to pray with him until the end(..) um, I think part of him as a person would have been left out. He lived his life like that, so, it was important to keep his faith going (…) and um (..) to keep ours [family] going [coughs] as a Christian I believe that prayer connects you with the person who is dying (…) um (..) that's what I used to connect with my dad' (John)

God knows what he is doing and finding meaning through prayer revealed a sense of resilience and tenacity among the bereaved carers, an essential part of what it means to be in a caregiving role at the EoL for black African /Caribbean family caregivers in dementia.

Proving EoLC at home to a person with dementia was described as a problematic and progressively complex task. Despite facing real everyday caregiving burden, maintaining a positive outlook was important. Participants accounts revealed that being a caregiver at the EoL was not limited to providing or coordinating practical care (where the other family members or formal support was in place) but that the essence of caregiving to a dying relative was a multifaceted role. This role was indebted on resilience despite the uncertainties involved; however, 'wearing a brave face' was an essential meaning for moving forward.

For example, most of the bereaved African-Caribbean caregiver described that each day came with unanticipated developments, such as emergency admission to hospital of the care recipient or a noticeable decline in health that one participant described as being a reality which 'hit hard us hard'. Also, feelings of hopelessness and significant caregiver stress seemed to punctuate the caregiving role, prompting them to seek techniques to get on with caregiving:

> I think the most difficult of all the issues I can tell you about during the last few days of her life was seeing how frail and weak she was, that reality hit us hard. Sometimes the road to the hospital came without warning; you never have to know what was in the pipeline, never (..), however, having people from church on a regular basis helped a lot, sometimes it was necessary to find a way to get on with things' (Maria)

For many, one must be resilient to be a caregiver at the EoL because fear and uncertainty will always linger around as each day passes by. Below, John and Mavis discuss resilience in the face of uncertainty, but their lived experience accounts reveal that the main hope that kept them strong was ensuring that their relative received the best possible care at home:

> '…got to a time where I needed to look at things more positively, mind you, this was right towards the end of his life. Convincing myself that everything was alright helped a lot, I started to feel in control and less uncertain about what was to happen next…'(John)

> Nothing but prayer, which is all I can say, I cannot think of anything. It [prayer] made a considerable difference; without it, I would not have managed for long. God is good…' (Mavis)

A common thread that permeated most of the participants lived experience descriptions was that providing EoLC to a relative could have been better if they knew some of the available support and services during or at the onset of their caregiving role. However, for some, 'despair and panic' made them not look beyond their role of caregiving and fears around being seen as a failure by relatives and friends made it difficult to navigate the system for support but to 'hold the bull by its horns':

> I would say things could have been much easier if I knew more about the services out there (..) that's how I see it (..) I started to know about them very late. I mean many of these services would have helped a lot (…) being aware of them right at the end of her life did not help us at all. I suppose (..) em (…) the despair and panic along my caring journey, all the stress and confusion (..) em all that, like (..) made me focus on one thing only, that is, giving her the best care at home. (Mavis)

> All I wanted was to make sure he was comfortable. Whatever the issues, I just wanted to hold the bull by its horns. You can ask any person who has looked after somebody with dementia; they will tell you the same' (Noah)

For some carers, resilience eroded hope, and their experience initiated a belief that the whole situation was either a *test from God* or *punishment from Him:*

7.3.2. 'God is punishing us.'

Many bereaved African-Caribbean caregivers stated that their relative's dementia could have been God punishing or 'testing' them through the person with dementia.

Chipo talks about her belief that what may appear as 'misfortune' for the family could be a 'rude awakening' to ensure their allegiance to the Almighty:

> Sometimes God makes things look bad or put a family into trouble, and that can be like a rude awakening of pushing them to tighten their faith to God. This might be hard for you to understand.…' (Chipo)

Adding to Chipo's viewpoint, John asserts that in providing care to his dad towards the end of his life, his priority was to ensure his father was at 'peace with God'.

When asked why ensuring his dad was at 'peace with God' was a priority for him, John explained that he believed that before a person dies; they must negotiate their relationship with God so they can 'rest in peace'. In John's view, quality EoLC should allow space for a person to connect with God, or for non-believers to reflect on their purpose such that they approach the EoL with what John describes as 'closure':

> I believe when things fall apart, and your life is about to end, it is essential to be in good terms with God. I wanted my father to make peace with God so he can rest peacefully. That is why towards the end of his life, I used to invite our church to come at our house to pray with us (...), erm, for God to have mercy on him; and for my dad to pray to God and reconnect with Him. I do not think you need to be a believer in God to be at peace, nobody wants to die with many issues in their head, and it is about clearing your soul for all the sins you have committed in your life, which helps you to find peace and closure before going [dying] (John)

John's belief embodied in the excerpt above was echoed in many of the participants' stories, particularly the idea of 'being the hands of God' when the EoL approaches:

> It is important to be in God's hands, to have a moment to ask for His forgiveness before passing on' (Martha)

Many African-Caribbean bereaved caregivers who participated in this phenomenological study described themselves as Christians, and their stories were decorated with some beliefs that are embedded within Cristian faith. One view they emphasised was that death was a consequence of sinning; and that when a person dies, it was not that they were never going to 'rise' but that death itself was a transitory phase in which the dead person needed to rest in peace until the returning of God to 'rise' them again:

> I believe that when we die without sin, we rest in peace, even when we have gone through tribulations in our lives. Alzheimer has, to me is a tribulation, it is (…), and when Christ returns, we will rise again…. this is important to understand if you are a believer… (Mavis)

However, most participants commented that good care at the EoL should meet the person's religious needs while abstaining from 'punishing' the dying person, for example, through burdensome interventions to ensure the dying person has time to reconnect and reconcile with God. Chipo's lived experience description reveals more about what she perceives as quality care at the EoL. Furthermore, because her dad was also living with cancer when his dementia worsed, Chipo questions whether there was any need for him to go for further investigations. She calls the medical investigations as 'further torments' to that he was already experiencing. To her, the discontinuation of some of her dad's medication indicated good care. However, it was also critical for her dad's religious needs to be met:

> '…I remember asking myself what is the point of my dad going through a series of investigations for his cancer if his illness [dementia] was not going to get better anyway (…) em, at that time he was weak and frail already (….) he was not going to make it through the investigations…he didn't want any further checks, he was tired (..) my family agreed with the doctors that we didn't want him to go through that…., he didn't deserve further torment (..), I think it was unnecessary (..) he was already taking a lot of tablets that weren't of any help, stopping them meant he had a quality of life without being heavily medicated (Chipo)

On a similar note, John remarks that many people from African-Caribbean background 'have no clue' of dementia. John's claim raises important questions as to how a lack of understanding of dementia relates to the quality of care at the EoL:

> Many people I know, do not know dementia is real. Some see it as a mental health difficulty; I think there are many people like that. In my experience, as a carer, there is a need to understand dementia and how the person may behave as this can reflect on the care that is given to the dying person (John)

Seeing dementia as punishment from God appeared to impact on caregiver opportunities to have discussions with the person with dementia at a suitable time [discussed further in 'Lost opportunities']. Here, Martha and John talk about what they wish to have done if their understanding of dementia was good from the beginning:

> If I knew about it [dementia], I would have capitalised on time, I would have talked to my father more about specific issues such as his wishes and needs before communication, and his capacity to make his own decisions was affected, this would have made things easy for me' (John)

> I would not hesitate to talk about things as early as possible, I realised it late though, in my experience, maybe that is the most important thing one can do…' (Martha)

7.3.3. Wearing a brave face

Wearing a brave face illustrates 'getting on' with the caregiving role. Many participants perceived their situation and that of their relative with dementia through their religious/faith lenses, and this made them wear brave faces to get through each day despite facing uncertainty and continuous change. By 'wearing a brave face', these family caregivers continued to provide the care. In the excerpts below, Mavis and Martha describe how they 'wore brave faces' to keep going. They also reveal how this could have led relatives being admitted to care homes:

> In our culture, you know you have to do it [caregiving], but to it, you have to wear a brave face to get on with your daily tasks. I think my faith to God helped a lot (..) I needed to wear that king of a face (..) umm, it was not easy though (…) because when you realise the person you love is not going to be with you for long, that's tricky to take in, even liaising with healthcare professionals couldn't have been easy without it [brave face] …he would have ended up in care home (Mavis).

> I think I needed to be brave to keep going (..) he may have ended up in care because they were going to see me as unable to get on with things' (Martha)

'Wearing a brave face' was used by Mavis to cope with bad news. Here, she talks about how she cried when the district nursing team informed her and her family to 'be ready for anything':

> I needed to remain strong to deal with the situation, mind you, this was not as easy as I am talking now (…), I tried to normalise things by keeping my face as bold as possible… (Mavis)

Providing EoLC at home to a person dying with dementia involves communicating with healthcare professionals who are involved in the care of that person. For family caregivers, this includes hands-on interventions to maintain comfort and personal hygiene, liaising with or discussing the relative's care with the visiting professionals (e.g., district nursing personnel, social workers, Admiral Nurses, doctors, OTs Physiotherapists etc.). Below, John talks about the importance of being bold amid carer stress, interestingly, he reveals that 'unmasking his brave face' encouraged him to accept the support offered by professionals:

> '…there is a lot to do, it is not just about daily tasks, and it's more than that. Think about this, a social worker, physiotherapist, diabetic nurse just to name few, used to visit regularly, erm, all these people talked to me about dad's care. It was hard work. I think a bold face can see you through many things, but there is a point, a point the boldface has to go, when I did that, I started to feel open about taking some home support that I was offered' (John)

In conjunction with *'wearing a brave face'* and as already discussed above, most of these African-Caribbean, family caregivers saw their role as an obligation - a 'must-do' role. What is protrusive in their lived experience descriptions is that seeking help or support often brought more agony and worry as opposed to relieving carer burden and associated stress. Below is what Chipo said during the interview regarding her lived experience of 'bottling up' the reality of the situation at home during needs assessments. Chipo further reveals the reasons why many people decline formal help and the importance of accessing the available support:

> **Chipo:** I do not know why I did it, but I admit did it, I regret being secretive about what was going on because it was not helpful. What I can say to you now is that bottling things up can be a disaster for those who are taking care of their relatives. To me, it denies yourself the very support you need so you can have enough time to spend quality moments with the person who may not live for long.
>
> **TD:** Can you think of any reason why you chose to be secretive about the situation at home?
>
> **Chipo:** I think I was worried about [name of husband]'s response to having people in the house. As a daughter, I had to make sure my dad was looked after well. Also, I was more concerned about what other people were going to say if they saw strangers flooding our house, in and out, in and out, you know (...), that was the case with me (..) people are quick to talk about small wrong things instead of big, good things. One thing that every carer will tell you is that you do not want to come across as a person who failed to cope, who was unable to look after her father, mother husband or wife, it can be taken as a sign of weakness.'

John describes that formal EoLC support at home allowed him to 'gain some energy' and to focus on quality time with his father. To him, wearing a brave face should be avoided as many people can appear to be in control, yet they are experiencing significant stress:

> '...having carers in made all the difference. I was able to have time with my father and the family without pressure because I was no longer doing a lot. They were doing a lot of practical stuff. I think pretending to be in control while the situation is bad should be avoided…' (John)

7.3.4. Circumnavigating limitless obligations

Circumnavigating limitless obligations exemplifies the diversity of day-to-day tasks of caregiving at the EoL. Dementia often affects people in different ways. No two people with dementia experience it the same way, and indeed, at the EoL, people have different wishes and approach death in many ways. Some approach death with significant anxiety, while others approach the EoL with a sense of accomplishment and closure. Thus, those who are providing care often face limitless obligations while delivering the EoLC. For many of the bereaved caregivers who participated in this research, giving care to their relative was a multi-faceted task that required resilience, acceptance and was filled with uncertainty:

> I knew that the next day was going to be hard when I had a bad night sleep, sometimes I spent the who night asking myself question after question and trying to make sense of our situation. Her last week was bad, she was anxious, shouting and calling for me almost all the times, I will spend the whole night awake, and the next day everything was just not easy to get on with (Noah)

While some initially perceived their relative's journey with dementia as a form of mental illness as already discussed, others believed witchcraft was to blame, towards the EoL, most family carers revealed that their knowledge of dementia as a condition had rather improved considerably, a radical shift from the previously held views. Moving from previously, held perceptions to understanding and providing EoLC often exposed the family caregivers to a new reality that many did not anticipate:

> '…moving away from my initial understanding of my husband's situation was a journey that I never thought about. As you may have heard from others, I honestly never thought I would be a carer to [name of husband], never. The good thing is that all my beliefs about it changed, and at the end of his life, I had sound knowledge to understand him, to get on with some of his behaviours and most of all, to give him the right care (Martha)

However, *circumnavigating limitless obligations* epitomises the often-taken-for-granted everyday experience of supporting the person with dementia. Examples include assisting the person with all their care needs. Some participants felt that due to the diverse nature of caregiving at the EoL, describing the nature of the care interventions was not enough to illuminate the everyday involvedness of being a caregiver at the EoL. John describes that when he talks about helping his dad with his medications; he feels that the statement lacks clarity as it does not adequately capture the real-world hassles of managing and administering multiple medications at various times of the day:

> 'Umm…all I can say is that telling them that dad needed assistance with dressing does not cover that he was often hitting out and aggressive, you know what I mean? Again, saying I was managing my dad's medication does not cover going to the chemist, giving him his insulin, giving medication at different times, at night, for example. These are tasks that you must face, and you must do, and to continue doing, exactly (...), yeah, from my experience, some hidden tasks that can be overlooked by professionals (John)

Circumnavigating limitless obligations also represents the essence of making decisions on behalf of the person with dementia at the EoL. Participants talked about decision making as the most difficult of all aspects of being a caregiver to a person with dementia at the EoL. For some bereaved family caregivers, deciding on behalf of an adult person brought mixed feelings as to whether the decision would have been correct if the older person was still able to make decisions. Martha describes this as a stressful task:

> The doctors and the nurses expected me as my husband's carer to answer questions, and whenever I did, I used to be stressed, questioning the very decision that I have made. After all, he was an old man; a mature man, not a child, deciding on his behalf was more stressful than the caregiving part of it' (Martha)

At the EoL, people with dementia may experience other health problems other than dementia and hospitalisation may become unpredictable. Family caregivers often make decisions, but then question whether the decision they have made reflects the person's wishes:

> '…to me, knowing whether or not to have her taken to the hospital was hard because I didn't want her to die there. At the same time, stopping that from happening brought stress because I felt as though I was preventing her from getting the treatment she needed, this part, to me, was distressing and perhaps the toughest of being a carer, it almost killed me (Maria)

Family caregivers often make decisions based on their knowledge of the care recipient's wishes, or at least what they feel could be what the person would have chosen should they had the decisional capacity at that time. However, some African-Caribbean bereaved caregivers felt that due to communication problems at the severe stage of dementia, it was hard to know whether the person with dementia's preferences and wishes remained the same:

> It was ok to give him the care, to try everything possible, but because verbal communication was no longer possible, of course touching and holding hands is another way of communicating, it was depressing to just do things without asking him. I guess the question is how I get to know whether the decision that I have made represent his wishes or mine (Chipo)

7.3.5. Feeling trapped

Circumnavigating limitless obligations [discussed above] revealed the 'limitlessness' of family caregiving tasks, *feeling trapped* illustrates the extent to which the family caregivers can be immersed in the caregiving role, so much so that pursuing personal activities becomes difficult. A careful hermeneutic analysis of participant's experiential accounts revealed that feelings linked to being 'trapped' were an essential aspect of the caregiving journey. However, due to the increasing care needs at the EoL of their relative, caregivers felt more trapped because they had to adjust to the situation. Because caregiving was perceived as 'an obligation' rather than as a role that one can do or not do, most of the bereaved caregivers, Maria, for instance, felt trapped in her position:

> 'yeah, erm, I suppose, it is not that I didn't want to do other things at that time, I remember that at some point, I wanted to go on holiday, I wanted to do this and that, go out with friends (..), but because she needed help all the times, I couldn't go away. That made me feel stuck…' (Maria)

Perhaps juxtaposed with *circumnavigating limitless obligations,* some carers revealed that due to perceived negativity from their wider community, *feeling trapped* compelled them to continue with their caregiving role, though at times some felt unprepared to adapt to the dying individual' s increasing care needs, let alone continue with their role in the following day:

> I was not sure how people would react to me. As a Christian, I wanted to do the right thing, but sometimes I felt that I was unprepared to change. Thinking about tomorrow was equally depressing because it was always hard to guess what will happen' (Noah)

For John, facing limitless obligations with insufficient support from other family members 'trapped' him and affected his health. He talks about postponing some of his doctor's appointment due to fears of leaving his dad alone, but ponders that accepting formal support was difficult, despite a clear need:

> To be honest, here, I think some of my family were not as helpful as I expected, that left me with more to do. As a result, I remember postponing my appointments many times because I did not want to be away from my father. I was also worried that they might take me in for a long-awaited operation on my knee. I was still uncertain whether to ask for help, and I think I did a lot of harm to myself by doing that (John)

The issue of overlooking their health as caregivers is further revealed by Martha. She describes how focusing on her role as a caregiver made her 'feel like a caged animal', and she annotates that the genesis of her current health problems was from being 'stuck' on her role and the reality of circumnavigating many obligations:

> Giving my husband the possible care at home is my greatest achievements even though I used to feel like a caged animal. I think my current health problems started at that time; I looked over my own needs, which is true. I forgot that I had a life to live after everything (Martha)

Juxtaposing *circumnavigating limitless obligations* is the fact that most caregivers knew they needed some support to look after their relative at home but chose to face the unlimited everyday tasks of providing care alone or within their family. Some African-Caribbean bereaved family caregivers commented that fear of 'what people would say' and a reluctance of allowing professionals to visit made them reject some support offered to them:

> Yes, I was aware that I needed just a little support to cope with things. I think what makes seeking help difficult is that some days can be easy, smooth, and some can be bad. Therefore, I chose to continue like that hoping the situation would be ok (Noah)

> I have said this before; I was worried about other people's comments once they realise different people flocking in and out, there is more to be a caregiver than you, and I know (Chipo).

7.4. Suffering in silence

Despite the uncertainty of caregiving and the challenges associated with providing EoLC to a relative with dementia, most African/Caribbean family caregivers spoke about how they faced various difficulties in silence due to the view 'we never air dirty linen outside' This theme *'suffering in silence'* describes the extent to which most bereaved caregivers shouldered the burden of caregiving whilst being unable to talk freely about their everyday challenges due to fears that doing so would expose the family's situation to the outside world. For example, Martha gave up her work early to be a full-time caregiver for her husband, who suffered a stroke a day before his 50th birthday. Her husband was then diagnosed with dementia at 53 years of age and, in her lived experience description, Martha talks about how she spent 12 years providing care to her husband without any other support other than little breaks that her daughter and son, who all live far, would occasionally offer. In relation to the theme *'suffering in silence*', Martha comments on being offered formal support, however, on many occasions, she declined the offer as she felt it was not 'going to look good' to others that 'we have lots of people coming in and out of our house':

> What I can I say is that I was not going to take it [help] because I wanted to do things the way he would feel the warmth. Of course, nurses visited us and offered support and advice. People from [hospice name] came to talk to me and brought some papers for me to read, that was great. The problem is that allowing that to happen was going to look good. To avoid any issues, I kept quiet and continued. I regret that it, I now know it was not a good idea (Martha)

Martha's experience described above is further echoed by Noah who reveals that he shouldered the caregiving role behind the closed doors:

> It was not bad when she was going to [name of day centre] two times a week. However, when her condition deteriorated, she was no longer able to walk. Things changed; I mean (...) was the only person who was doing everything behind the doors. It is my culture to do that, I cannot change it, I am African, and that is what we do, it was necessary to look after my parents, not by choice but by right of virtue. Here is the point I want to make, to get through this, there is a lot of suffering behind the doors (Noah)

Martha and Noah's experience is further echoed in Maria's quote below, which reveals the essence of *suffering in silence* despite the increasing care needs of a relative at the EoL:

> Towards her death, people were tired of helping. I think people and relatives assume that there is less to do because the person may be bed bound, and some people may talk to you as though having carers to help is a disrespectful thing to do. With that in mind, the better choice is to close your mouth and continue.

> Looking after older people is something, we must all do without hesitation… (Maria)

Not only is the issue of trust at the centre of declining care, suffering in silence further revealed fear of the stigma that many caregivers experience. The stigmatisation of dementia was mainly through uninformed perceptions of illness as many believed that the condition brought shame to their family with some relating it to as being a punishment of their early life wrong doings that may have angered their God. This stigmatisation of the illness was also described in conjunction with a sense of fear of being perceived as a failure within their immediate social networks:

> The disease [dementia] is not something you want people to know (..) I think people still see it as a shameful illness to have (..) i think it changed people's perceptions about our family…. I recall worrying that my family was going to be isolated by people in our community…. (…) believe me (..) as we talk now, many people I know do still think that you can get it [dementia] if you did something which angered God in your early life (Maria)

> You must understand that failure to take good care of your parents is highly frowned at by most black people (..) it is disrespectful and shameful, but the illness we are talking about here is still perceived as a curse to the family and punishment from God. The Bible teaches us to look after our parents so our days can be increased, that's why I felt uneasy to talk about the difficulties I was facing to make sure my father remained at home (John)

Other bereaved carers talked about their reservations in taking up formal support in fear of backlash by the care recipient, including concerns regarding the dignity of the relative:

> There was a point where I was tired, but before agreeing to a package of care, thoughts about how my father was going to take it stopped me (Chipo)

7.4.1. 'We never air dirty linen outside.'

'We never air dirty linen outside' represents African-Caribbean carers' tendency of prioritising privacy and cover-up of things and explains the 'suffering in silence' further. There was a natural feel that participants had reservations about openly discussing death and caregiving. Some participants believed that having open discussions about dementia and related care at the EoL was a disrespectful act that could have provoked unnecessary anxiety to the relative with dementia:

> I avoided talking about dementia and things like that because I believe my father would have thought I was giving up, or disrespectful. I remember how talking about the end of life and death can bring anxiety before things even get worse, after all, it is against my culture to air dirty linen outside' (Noah)

However, others believed that talking about death, invited it within the family:

> The bible teaches us to be careful what we say with our tongue, whatever you say, comes to pass, to me, it is unwise to go about talking about your personal life issues' (Chipo)

While communication with the relative with dementia, healthcare professionals and other family members were valued by many participants, giving some details such as carer stress or expression of unmet needs to the 'outsiders' was prohibited. In her comment below, Martha describes that she was always 'on edge' when healthcare staff spoke loudly about dementia and care progress during their visits at home, even though some of the things were expressed hypothetically, she reveals her belief about the power of the spoken word:

> When they [community palliative care nurse) came in to look at his medication, sometimes they would say this and that and would whisper, 'please don't say that, please avoid that, it will happen as you are saying it' that's my belief, every person's word is powerful' (Martha)

Mavis explains that from an African perspective, it is vital to 'keep things within the family and to deal with whatever problem as a family'. She further talks about the shame that is talking about family problems such as how the person with dementia is behaving can bring humiliation instead of sympathy:

> It is not surprising that most black people like to keep it [caregiving] within the family; it is how we have always been (…) we keep things away from the public (..) that is what family is all about (Mavis).

> I don't think disclosing to people that your relative is dying with dementia would be helpful in any way (..) umm, because you now have to talk about their [relative with dementia] behaviours like (…) things like aggressive outbursts, soiling themselves (…), I mean that can be humiliating (Noah).

Similarly, John emphasises that it is against his culture to 'air the dirty linen outside'. His view is supported by the belief that talking about difficult personal experiences can unintentionally bring self-inflicted shame:

> That is a big no; you must protect the dignity of the family. Even when my dad's care was demanding 24/7, I tried to avoid saying this and that to people, because after the passing of my father, people would have started to see the bad picture I painted about things, which can cause unwanted stress' (John)

Despite issues revealed by the theme *'Against own culture to 'air dirty linen outside'* other participants commented that encouraging their relatives to attend a day centre often made them feel as if they had let their relative down, the benefit of having time to do other things was helpful. Navigating the locality of services that cater to African-Caribbean people with dementia was not easy for Chipo:

> We tried to find him the right place because we had no choice. I was so tired; I needed a break, just a few hours, nothing more. My brother lives in London, and my mum has her health issues, all the care was on me, not for one person but two. After looking around, I found [name of day centre], and we tried him there, as it was a place, we thought he would quickly settle, and thank God, he did. There is a lot of stigmas attached to taking your relative to a home, it tears you apart, but sometimes you have no choice…' (Chipo).

Against own culture to air dirty linen outside acted as a barrier to African-Caribbean family caregivers accessing services:

> 'Our people need to move away from feeling bad when they take a relative to a day centre. We need more transparency about things because, as a carer (..) ermm, I know, I've witnessed how beneficial it can be for the person you look after to go to a day centre or respite can be, especially when you at your wits end'(John)

While keeping things within the family was an essential thing to do to some participants, caring for the person at home fell within the theme *'against own culture to air dirty linen outside'* and influenced negativity towards the institutionally based EoLC:

> For me, taking my dad to a [name of day centre] helped him a lot, but it was the most difficult decision I made, at the end of his life, I wanted him to be at home. Dying somewhere else may have made him die with no peace of mind' (Chipo).

7.4.2. 'It felt like I was on an island alone.'

In relation to the subtheme *'we never air dirty linen outside'* illustrated above, being an African-Caribbean caregiver to a person with dementia at the EoL was a family based and lonely yet challenging role for many bereaved carers. *It felt like I was on an island alone*

embodies a myriad of real and vicarious challenges that being a caregiver to a person dying from dementia was like from the perspectives of the bereaved caregivers. As discussed, the subtheme reveals the experience of social isolation and loneliness and the impact this had on caregivers who described how they often singlehandedly shouldered the burden of caregiving without reliable support. Furthermore, *'It felt like I was on an island alone',* exemplifies the essence of the family caregiving role in dementia EoLC. Most of the African-Caribbean bereaved family caregivers valued being with, and being there for their relatives up until the EoL, however, their everyday caregiving role made them to feel lonely:

> ***Martha:*** 'as much as I tried to look after him well, to the best of my ability, sometimes the whole situation made me feel as if I was in an island alone (..) it really did. Some days were ok, but mostly I felt lonely, tired and angry and hopeless and then the question, 'how long can you do this' kept flashing.'
>
> ***TD:*** You mentioned that sometimes you felt as if you were on an island alone, can you tell me more about that?
>
> ***Martha:*** 'well, a lot of things joined together really, first, each day used to be different in many ways, but it was not always easy to tell how the next day would look like.'
>
> ***TD:*** umm'uh
>
> **Martha:** 'sometimes I felt angry that I wasn't living the life I wanted to, I blamed myself, I cried (…) I can safely say some days were just right. I would feel hopeful (..) positive umm (…) and happy about the way I was looking after [name of husband], I mean it's like you take each day, I would prepare for anything, it was hard to tell things'
>
> ***TD:*** Sometimes, you felt hopeful?
>
> ***Martha:*** yes, hopeful, occasionally (...) because he was ok, but deep down, the anger never left, to be honest. Before you ask me, what made me angry, let me say this; (..) umm, I think when you look up to God and wonder why HE is punishing you so severely, anger becomes part of your life, you ask, 'why me, why us, very hard to understand why.'

While there was a general acknowledgement of the importance of support to have brief periods away from the responsibilities of providing care, some carers described 'feeling trapped' in their role:

> I suppose the fear of something terrible happening made me avoid leaving him; I think that was the main reason why I felt as though I was trapped at home. There was nothing else to think about excerpt taking good care of him'(Chipo)

However, other bereaved caregivers revealed that accepting formal support made them feel they have let their relative down:

> Of course, it was good to take time away from everything…. Her social worker organised people to look after her so I can take breaks every Tuesdays, I still couldn't use the three hours, I didn't want my mother to think I was letting her down that way'(Maria).

Other family carers talked about the importance of compassionate staff – being 'in good hands'; however, this did not overshadow the guilty feelings:

> '...knowing he was with warm-hearted people was settling whenever I let him with the carers, even though I knew them, I was sure he was in good hands, it was still hard to avoid the bad feeling, really difficult'(Chipo).

Other carers spoke favourably about the importance of support at home:

> 'I think towards the last week, or so, the community nurse visited twice, morning and teatime, their visits were comforting (…), I suppose, talking to me about my feelings helped a lot' (Mavis).

Accepting 'help' was not an easy decision because most of the African-Caribbean family caregivers saw their role as an obligation to be fulfilled. Having professional caregivers in at home to provide care appeared to be a difficult decision. One participant described her uneasiness in accepting formal care support towards the EoL due to fears that taking time away would result in 'missing the moment'- the 'moment' being the passing on of her husband which she described a moment she could not afford to miss:

> Because to me, looking after him was my duty, you know, yes, I was sometimes at the end of my tethers but still, having people take over the care was not easy. That's why I was initially unsure whether to take the help or not because what if I go away and miss the moment, to avoid all this, I chose to stay at home as possible as I can, it would have killed me to miss the moment, not to say goodbye to him, I couldn't afford that'(Martha)

A combination of various factors, including but not limited to doubt, mistrust of formal carers by the family caregivers and the subsequent experiences of carer stress and guilty was mostly

apparent in most the African-Caribbean caregivers lived experience descriptions. Together with the caregivers' reluctance to take some time away brought by mistrust of the care that formal caregivers[11] provided. These factors were a barrier to accepting much-needed support at the EoL. Fears about the care recipient's response to 'strangers' and the perceived impact on the dying person's EoL experience also contributed to *It felt like I was on an island alone*:

> You never know how the person takes it, I knew my father very well, he was a private person, so, I, (..), I was not in a position to distress him further, he needed peace of mind, not to hear new voices around him, even worse when I was not sure about the people, it was more unsettling to me than to him. So, we made it a family role to be with him' (Noah)

While *'it felt like I was in an island alone'* revealed loneliness and social isolation as the essence of being an African-Caribbean caregiver to a relative with dementia at the EoL, there was a strong sense of fear of being a failure by the community. This fear permeated many of the participants lived experiences, and a hermeneutic circle on caregivers' experiential material illuminated it as not only an overarching issue but also, a factor that influenced how the African-Caribbean bereaved caregivers negotiated their role on a day-by-day basis.

7.4.3. 'I was responsible for everything.'

In relation to *'it felt I was on an island alone'* is the sub-theme *'I was responsible for everything* which explains the magnitude of the care tasks that the caregivers were responsible for, and how this often led to 'suffering in silence'. Being a caregiver at the EoL was described as a role with limitless tasks beginning with providing and coordinating round the clock care, whilst also managing their own lives:

> While I never lost sight of giving her the best care, the amount of work often increased without any notice, so, I had to adjust to that, as challenging as it was' (Martha).

In conjunction with experiences of being responsible for everything, John describes that he had to single-handedly juggle tasks as most of his family intentionally avoided seeing him [John's dad] in his frailer condition because it was distressing to them:

[11] In this thesis, the term formal caregivers refer to paid healthcare staff, whose delivery of service is for remuneration purposes.

> Some of my family could not cope with seeing dad the way he was, so they avoided helping. During his last week, there was a lot to do, and nobody was around to help me (John).

Maria also commented that because her mother was not able to communicate verbally with her and others, including healthcare professionals, some of her family avoided giving practical support and some even told her that they feared seeing her [care recipient] towards the EoL could blur or distort the picture they had forever. To preserve it, some family members withdrew from giving Maria support to deliver the care:

> It is not something you would want to do again, caring for a person you have known for years and seeing them unwell deletes the picture that you may have had for years about them; sad isn't it; but that's dementia, evil; evil(...) so evil (Maria).

Some caregivers talked about the positive experience of being at the bedside of their relative with dementia, as the person approached the EoL, caregiving became a harder as the person would appear to be dying though would 'pick up' again. Due to the anticipation of the 'bad news' and the real underlying feelings of hopelessness and anger often led to further stress:

> 'I carried everything on my shoulder; the question was for how long' (Martha)

However, despite being responsible for the bulk of the care – 'carrying everything' on her shoulders, Martha reveals that the emotional support she received from the regular home visit by community nursing staff helped her to cope and to 'feel supported' thus allowing her to manage some of her husband's challenging behaviours:

> '...their [community palliative care nurses] visits were so helpful in many ways. Sometimes talking to someone made a huge difference, I mean it. My children lived far, and I have to say at times they didn't have an idea what I was going through, everything was facing me' (Martha).

For Chipo, the theme *'I was responsible for everything'* not only illustrates the nature of caregiving and workload, but also includes making decisions on his father's behalf, and on many occasions, family dynamics often crept in, altering relationships much so to the agony of every family member:

> I think the family can also be a problem because they can expect more while doing less. I remember how it caused arguments between my siblings and me. It was not a nice thing, especially when I was always stressed about the situation. When

> something like that happened, it used to take my concentration away. I think it also affected the care because I used to feel disturbed' (Chipo).

Some caregivers talked positively about their role and achievements, at the EoL of the care recipient, *being responsible for everything* weighed heavily on them:

> It was satisfying to do everything possible for him to stay at home and for his end of life to be as good as possible; doing all the tasks with little help, and sometimes nothing at all was easy. Looking back now, I still feel proud I went through that without giving up (John).

For some bereaved caregivers who had young families, mitigating the burden of providing care to a relative at the EoL and associated responsibilities often impacted on their parenting role negatively. Mavis describes how *being responsible for everything* made it difficult for her to manage her time between her two positions. She became tearful when describing how she felt she had neglected the needs of her young family:

> I had no time with my children [tearful]. I wanted to see my mother through. Sadly, I wasn't able to manage both' (Mavis).

John's story further illuminates the emotional burden he and his family experienced:

> Every time I realised how frail he was becoming; I would sob repeatedly. I remember being referred to a psychologist for help, but that was another time wasted. The funny thing is that when I cried, I usually felt better for a while before doing it again, I think it is hard to give care to a person you love towards the end of their life, it is emotionally draining. (John)

7.4.4. Fear for being perceived as a failure

Fear of being a failure exemplifies participants concerns of being perceived as 'failing' in their role of providing care to their relative at EoL and is one of the reasons for 'suffering in silence'. For example, Chipo strongly emphasises her fear:

> 'What would other people think of me if I put dad in a home to die, as an African, that's is something I didn't want to go through' (Chipo)

The fear of being perceived as a failure is emphasised in Mavis' tone in the excerpt below. It clearly illustrates her concerns about how people in her community were going to say if she failed to meet the demands of caregiving:

> 'Even when things were hard at home, demanding, confusing, sometimes up in the air (…), umm, (...) I chose to continue, to try my best because I was always worried about what other people were going to say about me' (Mavis)

To Maria, the thought of being criticised for accepting help at home would have 'destroyed' her:

> 'People sometimes do not get to know much about what is going on at home, they are quick to label you as a witch, as evil, and uncaring if they see you going out when carers are with your loved one, that is something I could not cope with, it would have destroyed me'(Maria)

The fear of criticism by other people[12], was a barrier to accessing support and services; and perhaps highlights a sense of obligation to the caregiving role that many felt affected their wellbeing:

> I think worrying about it [criticism] made me think twice about whether to take the help or for us to do everything, as the oldest son, giving up would have made me look weak. As I have told you, seven months later, my health has gone down….' (John)

It was apparent from the participants lived experience that this was of significance to being an African-Caribbean caregiver and perhaps a viewpoint that allowed many carers to soldier on in their role despite experiencing multi-faceted challenges. Mavis, who also looked after her father with dementia and then her mother within a short period, reveals how he decided to look after them at home to avoid being framed as evil by his extended family and church friends:

> I have to admit; I had to close my eyes and ears to take some help at home. It was hard, it killed me, I still feel guilty about it, but I could not have managed my dad's care as well as my mom's, there was no way, I would be a dead person by now, it was too much. Nobody helped me, they [family] all leave far, I mean, without taking some help, I would not have managed to look after my mom because she too wanted to stay at home like dad and going somewhere to die was not an option' (Mavis).

For some, the '*fear of being perceived as a failure'* was further compounded by the fear that their relative would experience terrible and painful death in a care facility. Noah reflects on his thoughts before the passing of his mother. His lived experience illuminates fear of a

[12] 'Other people' hereto denotes to people known to the caregiver, which includes distant relatives, neighbours, church friends and so forth.

backlash from the community and concern of the care recipient's response to being moved from their home at the EoL:

> '…the question that haunted me when my mother was referred and accepted at [name of hospice] was what if she dies badly in a place, she was not familiar with? Again (..) you know (…) eh (..) most Jamaican people would agree with me (…) failure to take good care of your parents could make other people look down at you and you do not want your parent to die unhappy about you taking him or her to a home to die…' (Noah)

However, most of the bereaved African-Caribbean family caregivers revealed a sense of acknowledgement that they would have done things differently if they had the knowledge they acquired after the death of the care recipient. Some felt that being a caregiver gave them little chance of exploring alternatives, as their focus was to provide care to their relatives and to avoid being a failure by others:

> If I can do it again, I would not think about what other people would say, at the end of the day, people talk, they say good and bad things whether you like it or not, that is human nature. I guess when your mind is stuck on making sure your mum, dad, wife, husband, or whoever you are looking after get the right care, your mind is stuck on that, nothing else' (Chipo)

7.5. Anticipatory loss

This theme describes how the family caregivers experienced loss before their relative died. In most cases, the anticipation of loss started when the caregivers noticed their relative's mental and physical health decline overtime. The subtheme 'unanticipated circumstances' explains some unexpected events towards EoL and 'maintenance of dignity and comfort' describes the caregivers' efforts in maintaining their relative's comfort and dignity. The gradual decline overtime triggered a sense of loss whilst their relative was still alive and when they finally died, most carers felt as if it was their relative's second death:

> 'Here is the thing, I was with my dad all the times, and I could see the changes, well, he no longer wanted to get out bed, he was weak and didn't eat or drink, here was just there, breathing of course…. but the feeling started a long before his death when he died, to me, it was like a second death.…' (John)

For other carers like Mary who had seen her mother's health decline, the experience of grief associated with anticipatory loss made her to expect the worse. She talks about 'real death' as if her mother had died another type of death already:

> I recall being told that as a family we needed to be close to my mother as things were not looking good, I saw her go down, and I knew something was coming and when once it was apparent to us that her real death was on the horizon, we all started to feel the grief…. I say her real death because, from day one, dementia changed everything; we lost her along the way (Mary)

7.5.1. Unanticipated circumstances

For many caregivers, the experience of anticipatory loss was often accompanied by unanticipated circumstances especially towards the end of their relative's life. For instance, some ended up dying away from their homes following unexpected hospital admissions. In most cases, the caregivers would have not anticipated things to unfold this way. As such, related to the theme 'anticipatory loss' is the sub-theme 'unanticipated circumstances' which describes how most caregivers' wish for their relatives to die at home was unexpectedly changed by some events that unfolded at the EoL. For many, dying in the hospital was not what they would have wanted, and when this happened, albeit unanticipated, the caregivers were left with a guilty feeling knowing that their relative's EoL wish was not respected.

In the excerpts below, Martha and Mavis describe how circumstances unexpectedly changed towards their care recipient's EoL leading to death in a hospital setting rather than at home as they wished. Martha still feels guilty about how the circumstances unfolded, while Mavis still feels that she let her mother down by not meeting her wish:

> 'All I wanted was for him was to die in his home (...) because I know that is what he's always wanted; I knew that very well. Sadly, few days before his death, he went in [hospital] with a terrible chest infection, and everything happened so quick there (…), so quick, he died before returning home' (Martha).

> '...As hard, to think about as it is right now, she ended her life at [name of hospital], that's not what she wanted. I still feel guilty about it, you know (..), I let her down that way, maybe I should have requested to treat her at home or something like that' (Mavis)

When Maria's mother was approaching the end of her life at home, where she had always wished to end her life, she developed pneumonia and was taken to hospital for treatment and

ended up dying in hospital. Although Maria acknowledges that she had no control of the situation, the unanticipated circumstances that unfolded resulting in her mother dying in the hospital has not faded away from her thoughts:

> 'my heart is still bleeding, even though I had no control of the situation, I guess I still feel this way because of what I know mom wanted, I can't fault the care she received though, it was good' (Maria)

She further highlights her views regarding the insertion of a urinary catheter and describes how she found her mother 'at the edge of the bed with cracked lips and dry skin despite asking staff to apply a special lotion that she gave them. For Mavis, her mother's situation demonstrates experiences of inadequate EoLC:

> 'Towards her last few weeks, mum needed a catheter (….) I think it helped us a lot because her mobility was very poor. The problems were that she was pulling it off and her bed would get soaked in urine and found her all wet and soaked in her urine, sometimes her lips and skin was so dry although I always made sure I gave staff some lotion for her skin. I still use this as an example of poor care in our hospitals' (Mavis).

Sometimes the circumstances were favourable and anticipated. John's father died at home. John explains that his father had a 'comfortable passing' as he had pain relief regularly. In addition to this, John acknowledges effective communication maintained by homecare nurses:

> 'once he had it [syringe driver] on, he calmed down, I mean that to me (…) was clear evidence that he was not in pain at all, and in all fairness, the nurses made sure my dad was comfortable. They spoke to him, explained everything and discussed dad's situation with me, sometimes they telephoned me for an update. They were excellent, far better than hospital nurses were' (John)

However, some bereaved caregivers had different experiences. For example, Chipo's dad reverted to his Shona language and communication with professionals was affected. Although Chipo and her family were involved in the care of her father, she talks about unmet care needs and feels that the care that her dad received at the EoL did not meet the expectations. While her dad had 'few visits' from district nurses, Chipo feels that her dad's dignity was not maintained:

> 'I understand, it may have been hard for them to know what to do because dad went back to using Shona after years of communicating in English, I don't understand why, but that shouldn't be an issue to qualified individuals, so we [family] had to

> get on with things because they said he was aggressive and verbally abusive. The few visits he had was to treat him for pain and aggression, but then his last week was the worst because they came in and out without really doing much'(Chipo)

She further comments that her dad's physical comfort, privacy and cultural identity were not respected at the end of his life:

> 'I think they didn't respect my father for many reasons, I do. Sometimes young girls came to see to my dad even though I had told them that he didn't like to be helped to change and dress by younger female staff, that's why my dad's cultural identity as an African man was not respected enough, I mean his comfort wasn't a priority to them, but some were understanding and caring'(Chipo)

7.5.2. Maintenance of dignity and comfort

Despite the experience of anticipatory loss and unexpected occurrences described by the majority of bereaved African-Caribbean caregivers in the theme 'anticipatory loss' and subtheme 'unanticipated circumstances', most of them held strong views about the salience of maintaining their relatives' dignity and comfort throughout their journey with dementia even when unanticipated events unfolded at the EoL. The subtheme 'maintenance of dignity and comfort' describes the importance of dignity, respect and comfort at EoL. For example, in addition to her experience of anticipatory loss, when elucidating the essential meanings of EoLC in relation to dementia, Martha, not only describes how she focussed on maintaining the dignity of her husband as an integral feature of EoLC, but she also reveals her concerns about suboptimal EoLC in hospital settings based on her previous experiences:

> It is not me; we all know it is important to do everything possible to respect people when they are dying, that is what I wanted for him, and I know that is what he wanted. I made sure he was clean, had clean clothes all the times, nourished, changed and comfortable. Go and see what is happening in the hospital wards, it is noisy, sometimes more chaotic, people often die laid on their mess, dirty, with no peace at heart, that's disrespecting the person' (Martha)

For some caregivers, maintaining the person's dignity was described in terms of privacy and respect. There was a general agreement among participants that their relatives' privacy and respect was better achieved at home as opposed to a care home/hospital setting. Other bereaved caregivers such as Noah felt they respected their relative's wish because there were no unanticipated events:

> '…looking back…. I think allowing the person to die in privacy is as good as respecting him or her. That is why I am so glad that I met my mother's wish of dying at home. I don't think there is any privacy or respect in dying in an open ward…' (Noah)

In conjunction with maintaining dignity and respect of the dying person with dementia, almost all the bereaved carers commented that home was the place they wished their relative ended their lives, although, for some, this changed towards the EoL. When asked about why she felt their home was the 'suitable place' of delivering the EoLC, here is what Maria said:

> I think I said this earlier, my mother always said, 'Maria, don't take me to a care home. I want to be at my house when the time comes'. I think going against her wishes would have been a disrespectful thing to do (...) thank God all went well (Maria)

John raised a similar but slightly different viewpoint on the idea of dying at home:

> Waking up in the middle of the night and seeing my dad laid comfortable on his bed was the most comforting thing, I think staying at home made a huge difference in his EoL experience, taking my dad to another place to die would have made him curse me in his heart' (John)

When unexpected events resulted in an individual's wish to end their life at home being destabilisedit impacted on the caregiver-care recipient relationship. Mavis' example of a marathon runner who trips just before the finishing line captures how EoLC wishes were often changed unexpectedly just before the person's death:

> I still feel bad about it; her admission to the hospital a week before her death to me was unexpected. Dying in the hospital ward was against her wish (…) em (…) it was like a runner tripping before the finish line, but at the same time, it was unavoidable [tearful] (…) I think it affected the close relationship I had with my mom [tearful] (…) umm, it was a good but sad ending' (Mavis)

There were many examples of how the care recipients had been treated with respect and dignity by the caregivers. For John, whose father was admitted to a care home for respite but retumed home towards the end of his life, keeping him as clean as possible despite incontinence problems meant that he had a dignified death:

> That made the difference, I think. I made sure my dad was always clean, changed and I made sure that his skin was kept soft with lotion, something that I struggled

> to have it done when he was at the respite centre for two weeks. To me, he had a dignified ending' (John)

7.6. At the crossroads

This theme captures participants experience around making choices on behalf of their relatives. Some of the issues relating to EoLC decision making have already been highlighted in other themes. Many participants talked about being exposed to making difficult care decisions on behalf of their relatives. Because most African-Caribbean bereaved caregivers' understanding of dementia and its progression appeared limited, for example, seeing it as a normal ageing process rather than an illness, some participants commented that being asked by healthcare professionals to make or participate at the EoLC decisions making for their relative was a challenge:

> Very difficult, as his son, I saw it as my duty, but I didn't know whether to agree or disagree, how was able to know whether my father was happy to be resuscitated or not, so, I agreed, at the same time I didn't want him to be troubled any further' (John)

> Like I have said earlier, I regret not talking to my mother at the earliest convenience (..) I never thought it will get to a point where doctors will need to ask me all the questions about her treatments and wishes. It was challenging to say whether or not she needed to be fed through tubes (Maria)

Participants reported that once they came to terms with 'feeling trapped' they were able to reflect on what they knew could have been chosen by the person nearing the EoL. For example, Martha describes how she found it much easier to agree with the doctor's suggestion of discontinuing some her husband's medication because she was aware that throughout his life, he was always reluctant to take tablets and had pointed out that he would not like his life to be 'extended' if he was approaching the end of his life:

> Making the decision for some of his medication to be stopped was much easier. I knew he would have said 'No' to that, he was a man who believed that when it is time to go, there is nothing else that can be done. He was against extending life by any means; he did not like that sort of things. I agreed with the doctors because I knew that it was also his interests (Martha)

Disagreements between families can further exacerbate problems in the decision-making process:

> My family wanted everything to be done, the doctors and nurses to do all they can do. I was against that (…) her skin was severely bruised by the needles...em (..) she was very unwell (…) I think comfort care was the way forward for her (Mavis)

> Sad times when family disagree, I cannot think of anything that caused stress to me besides my brothers and me disagreeing. They wanted her to go to a place that side of the city [hospice] to be looked after and to die there, I disagreed. Thank God, the nurses came home to look after her instead of her going away; I cannot thank them enough for that (Maria)

John reveals feeling 'trapped' but also 'powerless' after letting the ambulance staff know that his dad's wish was to be cared for and to end his life at home. Because the ambulance staff suspected that John's father could have had a chest infection, admission to the hospital was completed to address that, while this was to treat his father, John comments that he could have died in the hospital against his wish:

> The doctors and nurses' decision were always first. Few days after I was informed that my father was nearing the end of his life, he was taken to the hospital for a chest infection. I was against him going away because I was petrified that he would die there, the problems were that they [nurse] said they wouldn't leave him at home like that, I asked them to treat him at home, but they said he needed admitting to the hospital, can you see how difficult things can become, on that day I felt powerless, it stressed me out (John)

7.6.1. Looking back with regret

Looking back with regret encompasses the pre-caregiving and post-caregiving experiences of the African-Caribbean bereaved family caregivers. The significance of this theme is around 'learning on the job' and how the caregiving role catalysed a change of previously held perceptions, for example, understanding dementia as an illness rather than a natural way associated with being old:

> Five years of caring for my father taught me a lot. I know more about dementia now than before. I think taking him to many of his appointments at the memory clinic and talking to the nurses and some of the information that they used to give us also helped…' (Chipo)

Other bereaved caregivers emphasised on the importance of early discussions about future care:

> …having the conversations early is essential, maybe the most crucial thing in my opinion (...) because, the person may not be able to communicate verbally, necessary to ask them about their future care choices (Martha)

Participants made it clear that such discussions were fundamental to EoL decision making with some participants like Mary and Mavis calling for adequate information about the progression of dementia and potential loss of decisional capacity at the earliest such that caregivers capitalise on the moment:

> It would have helped to know how dementia affects the person when she was given the diagnosis. I am not saying that we were not provided or informed anything, I think when my mother was told about it, our mind was already full of worries, talking to us when things were falling apart did not help, I feel more should be done to help people understand this illness. When the person gets to the end of their life, the missed opportunities haunt the caregiver, which is my biggest regret' (Mary)

> If I knew that it was going to be hard or impossible for her to make her own decision, I would have used the time to discuss everything, unfortunately just a year down the road, her condition went downhill faster…' (Mavis)

Being a caregiver often involved uncertainty, anxiety, and significant carer stress. Many participants talked about the importance of avoiding 'suffering in silence' by being open to support needs and to allow the palliative nurses' space to alleviate some of the caregiving duties. Though some participants felt that the caregiving role itself makes a person be 'blinkered' towards providing care, it is vital to look after one's health needs rather than 'self-neglect' as the effects can be long-lasting:

> You forget about the outside world; you forget about your health and all you are focussed on, your eyes are stuck on giving the person the best care, I did that (..), I did everything, I refused some help until I couldn't manage any more, big mistake that. It is something which you do not realise you are doing. It happens (..) I think it is a form of self-neglect… I have not been in good health since then (John)

Martha's comments below make valuable suggestions about what she feels can help black communities:

> Encouraging people to access, the services should be the focus; getting those services in and being open to what is going on at home can help, that is my experience, black communities must be helped to understand this illness' (Martha)

Participants expressed concerns that dementia remains a stigmatised condition among African-Caribbean communities and people often choose to avoid accepting the reality of it – not because they do not realise its dementia, but because accepting the situation was hard:

> I think many people like me chose to avoid things even when it is clear there are more problems to come. I remember thinking, what is going on here, why is our life like this, then I t thought, is he going mental, have we been cursed, is God punishing us for something my family did? The way forward then is to act as if nothing is happening (Chipo)

While John's understanding of dementia has changed since being a caregiver, he reveals that many people still do not understand dementia, and this has implications on the EoLC:

> Many people I see and talk to still see dementia as nothing but a natural way of getting old. This kind of thinking does not help when it comes to caregiving at the EoL because if I did not know about my father's behaviours that were out of his character, I would not have managed his care. I suppose he would have ended up dying in hospital (John)

From Martha's lived experience, meeting people's religious needs must never be overlooked at the EoL:

> In my experience, helping the person to have inner peace when they are dying should not be ignored. My husband grew up as a Catholic, having our church friends around made him happy, and I know it brought inner peace for him (Martha)

7.6.2. Realising lost opportunities for early EoL discussions

There was a sense of realisation of lost opportunities of discussing future care with their relatives in most caregiver stories. This was mainly commented on in relation to what most carers felt they would have done early in their role if they were aware of what was likely to unfold. For Noah, it was until his father's verbal communication became poor:

> It is a sad thing to think about. It is something that I live to regret. If we knew what was going to happen, we would have sat down with my father and encouraged him to tell us how wanted things to be done. At that time, I suppose it was out of my mind that one day he was not going to be able to make his needs known verbally' (Noah)

Martha's story covers what Noah says above, but she is quick to relate her realisation of lost opportunities to lack of understanding of dementia and its progression:

> I do not doubt that if I knew what I have learnt about dementia and how people go through it; I would have started to talk to my husband when things were still ok. I feel sad that I had to think about what he would have wanted about his care while he was with me (Martha)

The lived experience of realising lost opportunities is still vivid for John. He reveals that as it was the first time, he had encountered a family member with dementia, he had no understanding of it before this and feels that he should have done things differently:

> It almost a year since my dad passed on, but I still look back and think I let time pass by without taking advantage of it. I think (...), I think, because my dad is the first person, I know in my family to have dementia, we all learnt a lot from him. I suppose I could have been more knowledgeable if this was not the case, and I am sure I wouldn't have allowed things to get to a point where he was unable to say something to us (John)

John further describes how useful the 'little' information he had from talking to his father helped in the decision-making at the end of his life. However, John feels that he would have discussed his dad's preferences of care in a more in-depth way if he were aware things would change:

> The little information I had from talking to my dad was essential for making decisions about his care. I was well aware that he always wanted to die at home. He said his wishes many times. When it came to deciding whether he needed to go into care, I remembered his words and made sure he remained home' (John)

There was a feeling that should the family carers had a better understanding of dementia, and how it progresses, opportunities to discuss future care needs would have been prioritised. Others realised that they overlooked the 'signs' and when they sought help, it was late:

> To honest, when I took him to the doctor, it was over two years since I had noted some signs that I now understand were showing he had dementia. I think I lost some time in that way and realised late when the situation had gotten worse' (Martha)

7.7. Summary of Chapter

In this chapter, I presented thematic findings from phenomenological interviews with six bereaved family caregivers of African-Caribbean background. The goal of this study was to understand the lived experiences of bereaved African-Caribbean family caregiver who provided EoLC to a relative with dementia in the community. Caregiving at the EoL is associated with carers living with the uncertainty of continuous change. When faced with uncertainty, family, the carers use prayer to negotiate meanings as 'God knows' the way. Because of secrecy ['never air your dirty linen outside], African-Caribbean carers appear to experience burden 'in silence' yet they see themselves as 'responsible for everything'. The thematic further illuminates that while most carers of a person with dementia prioritise the dignity and comfort of the dying relative, they often experience inadequate support and may find it challenging to explore the labyrinth of the health care system. The theme 'at the crossroad' depicts the difficulties associated with decision making by family carers at the EoL, and when many looks back to their caring journey, they do so with regret, wishing they could have done things differently.

CHAPTER 8: DISCUSSION

8.1. Introduction

In this chapter, I aim to discuss the findings in relation to previous literature in order to contextualise them within the existing body of evidence related to EoLC for minority ethnic PLWD in the UK. During the last three chapters (5,6 &7), I focused on presenting findings devoid of any theoretical explanations, which is in keeping with van Manen's phenomenological research approach. The main aim of the overall study was to explore the lived experiences of dementia care and perceptions of related EoLC among older African-Caribbean PLWD and family caregivers. In Chapter 2 of this dissertation, I provided an overview of research evidence on EoLC for minority ethnic PLWD in the UK. Based on the review of the literature, I made an explicit argument to discuss how faith beliefs and cultural influences appear to contribute to African-Caribbean people's experiences of dementia and related EoLC. The cause and effect of late dementia diagnosis and the stigma attached to access and use of services are discussed. The review of literature (Chapter 2) showed that there is very limited research evidence on EoLC for minority ethnic people with dementia in the UK (Connolly et al, 2012). There was even very limited experiential-based evidence on EoLC in the context of dementia. This study explored the lived experiences versus hopes, perceptions and wishes in relation to the EoLC for PLWD who are of black African-Caribbean background. In the next sections, I discuss the contribution that this research project makes within the growing field of palliative and EoLC for minority ethnic PLWD.

8.2. How faith, beliefs & culture influence/contribute to inadequate experiences of EoLC

The primary aim of this research was to explore EoLC among community dwelling PLWD who are from black African and black Caribbean ethnicity and their family caregivers. Studies on minority ethnic groups show low use of palliative care services (Koffman et al., 2007). One possible explanation for this based on this research is that carers from minority groups feel obliged to provide care to their relative with dementia at the EoL and this is influenced by a sense of duty based on their religious beliefs. For example, both PLWD and carers belied that God knows what He is doing regarding their situations. As reported in Parveen and Oyebode (2018), the participants' faith in God and their cultural beliefs appeared to have an influence

how older African Caribbean perceive quality EoLC. It was also the lens by which the caregivers made sense of the unfolding events. Some carers were fearful of making the wrong EoLC decisions for their relatives. Among BAME communities, dementia remains a highly stigmatised condition, and knowledge regarding its progression remains comparatively lower among minority ethnic groups in the UK. Overall, in this study, I found that poor awareness of dementia often impinges on timely diagnosis and African-Caribbean people's attitudes towards formal dementia care service, including uptake of EoLC as in fig1 below. It was clear that problems with the first stages of the Dementia Care Pathway (Awareness and Identification) (Ahmed et al., 2016), appeared to have a knock-on effect on later stages, including the EoLC. For instance, the lack of dementia awareness in this study means people receive their diagnosis at an advanced stage of the condition which then impacts on discussions about wishes and preferences as communication would have been affected by advanced dementia. Thus, this can ultimately lead to poorer EoLC outcomes that do not incorporate the desires of individuals with dementia. These issues have been highlighted in many studies, though not in the context of EoLC. For example, Mukadam et al. drew us to the conclusion that BAME people's cultural position and religiosity influenced dementia awareness.

Similarly, Nyatanga (2001) has argued that one fundamental characteristic of quality EoLC is its responsiveness to people's cultural needs, an issue often overlooked. This is important, considering that in this study, the meanings and perceptions that were primarily influenced by PLWD, and caregiver ethnicity shaped their understanding of EoLC. Some older black African-Caribbean PLWD and family caregivers accepted dementia as an illness while others thought it was a punishment from God. What I also found in this study is the fear of being a failure by the community, and the negativity attached to the perceived response to accepting formal help. This has not previously been reported in relation to dementia EoLC. These issues are complex and often embedded in a traditional and cultural understanding of caregiving as being a responsibility of the family (Kenning et al., 2017; Parveen et al., 2016). Kenning et al. (2017) reported that many carers were concerned about people they do not know visiting them regularly. This is a barrier to care for a person nearing the EoL.

The lived experience and meanings attached to being an African-Caribbean person living with dementia were captured in focus group discussions (FGD) in study 1. They stated that they did not wish to end their lives 'in old people's homes'. This wish was stressed by the majority of the older people during the FGD and appeared to be underscored by negative views attached to institutional-based care. When all the above arguments are brought together, there appeared

to be a strong link between the older people's negative perceptions of institutional based care and their expectations of family-based care.

8.2.1. Expectations of care and family values

In this research and previous literature, people from minority ethnic communities perceive caregiving as a family task (e.g., Johl et al., 2016). PLWD expected care from their family in return to early life input into the family. On the one hand family caregivers felt obliged to provide care, despite facing uncertainty and continuous change. For example, admission into a care setting at the EoL was frowned at and considered to be against their African-Caribbean values by PLWD and their caregivers. Previous evidence (e.g., the VOICES survey, ONS, 2013) consistently shows that many people prefer to die at home, therefore, the findings of this research are consistent previous evidence but illuminate the basis of stigma attached to the use formal dementia and EoLC services. It also highlights the complex nature of barriers to care for these cultural groups, especially the role of the family in caregiving. Unlike in Mohammed (2017) in which the confusion was around who among the visiting professionals was responsible for certain aspects of the care, the carers in this study were more concerned about people's comments when carers visit. One carer revealed that she had to stop the care package for this reason. This finding could partly answer why service usage among BAME groups continues to be consistently lower (Mukadam et al. 2015; Johl et al., 2014; Calanzani et al., 2013).

African-Caribbean people remain faithful to the notion of family. Findings in this research stresses the importance of family as an essential source of support and care. There was a sense shame to the family when the family members fail to provide care to their relative with dementia. Filial responsibility appeared to be underscored by a sense of pride and honour, which was mainly expressed in terms of how the family was perceived within the community. Although findings about the importance of family is in relation to EoLC, there are some overlap with those reported in Lawrence et al. (2008), who found the delivery of care to a relative with dementia was mainly within the family. Accessing outside support other than that provided by the family was rarely considered easily, however, the position that the family hold may be altering as family structures are changing (Bhattacharyya & Benbow 2013).

In most minority ethnic groups, decisions about health care are sometimes collectively made, an approach that is not incompatible and at loggerheads with the Western culture which

embraces self-determinism in healthcare decision-making (Yeo & Thompson 2014). However, there was a difference between older people's expectations of care and the caregivers' role. Family caregivers felt obligated to provide care; however, some were not sure whether the role of the family would remain the same in the future. This suggests that these family values may no longer be applicable overtime, which contrasts with some assumptions in the literature that 'they look after their own' (Cheston et al., 2017). Nevertheless, the family remains essential, and services designed to meet the EoLC needs of PLWD from BAME communities need to accommodate the role played by the family.

I found that African-Caribbean older people with dementia hold a fervent hope and expectation that their family will go an extra mile to provide care throughout their journey with dementia to EoL. However, on the carers' lifeworld, there was a sense that looking after one's relatives encourages God to prolong one's days of life. The same belief supported caregivers' reluctance, particularly younger carers, to place their relative with dementia into care, even when they were experiencing significant carer stress. Grande et al. (2009) explain that informal carers are fundamental to the delivery of EoLC and the majority of people's wish to die at home and are crucial to ensuring that the current policy of supporting people to exercise choice at the EoL is achievable. As discussed, black minority ethnic carers experience ambiguous loss as they journey through caregiving to EoL, however, face various challenges including ambiguous loss and barriers to accessing support; and are therefore positioned to experience health problems (Chan et al., 2013). These findings build on Seabrooke and Milne (2004) who found that despite the carers' experience of significant stress levels, they refrained from considering relinquish their role. Not all carers rejected the support offered to them, and some regretted soldiering on (in fear of their community) up until their health crumbled. Despite this, both PLWD and carers shared the view that 'we don't take people into care homes to die'. This shows some culturally rooted challenges across all the stages of the dementia pathway, from preventative measures, diagnostic work, up to EoLC.

8.2.2. Working around faith barriers to facilitate effective EoLC planning

Religious beliefs were strongly expressed by many PLWD and family carers in this research. Again, when it comes to future care planning, many carers held a view that it was God who can give and takes life. Such beliefs can act as a barrier to ACP. For many of the participants in this research, it is God who knows when and how the person would die. Therefore, planning was not emphasised, yet for EoLC to be improved, the DoH (2009) recommends that 'people

with dementia and their carers to be involved in planning end of life care' (p.88). Based on the findings reported in the previous three chapters, a more useful approach may be a focus on improving minority ethnic communities' awareness of dementia, access to services and more natural navigation within the healthcare system. In broader view, considering how issues of faith were emphasised by participants in the research, the findings demonstrate how important it is for healthcare providers to develop an understanding of cultural and religious beliefs that appear to be the basis by which minority ethnic communities perceive their care (Turner et al. 2005). As EoLC was perceived as good if it considered the faith needs of the person with dementia and his/her family, Regan (2014) has suggested that it could be useful for care providers to promote service uptake by looking at ways of attending to faith issues as many minority ethnic groups often show concerns about their needs.

8.3. Cause and effect of late diagnosis

As demonstrated in this study, understanding of dementia as a progressive and incurable condition remains poor across minority ethnic communities in the UK, despite the increasing prevalence of dementia (Berwald et al., 2016). People from these groups present late to dementia services (Mukadam et al., 2013), which leads to late diagnosis of dementia when the illness has become severe enough to impact on the implementation of ACP. Because most minority groups get diagnosed late compared to their White British counterparts, opportunities for early discussions regarding future care wishes are lost. The absence of the voice of the person dying with dementia, which could have been documented in the ACP has real implications on the quality of EoLC. Therefore, there appears to be a cause and effect between late diagnosis and quality of EoLC. Although poor understanding of dementia by UK minority ethnic groups have previously been highlighted in other studies, for example, Berwald et al. (2016), who found that participants from African-Caribbean ethnicity believed it was unnecessary to take their relative to a doctor even when they exhibited signs related to dementia, there has been less emphasis on the cause and effect between poor dementia awareness and EoLC as demonstrated by this research.

In addition to the literature on dementia among minority ethnic groups and late help seeking (e.g., Mukadam et al., 2013; Kenning et al., 2017), findings in this research suggest that late help-seeking impacts on future or ACP. Lack of advance care plans have been associated with difficult EoLC decision-making by family members who may take the position of proxy

decision maker, yet they may not be fully aware of their relative's EoL wishes. For example, a recent systematic review of reviews exploring the perspectives of patients and informal caregivers regarding the implementation of ACP discussions across different illnesses (Hall, Rowland & Grande, 2019) reported that family caregivers of people with dementia 'face uncertainty around legalities and patient wishes and are often unprepared for involvement in ACP' (p.327). As a result, people dying with dementia are exposed to poorer EoLC experiences, and when the care is delivered, the EoLC lacks the voice of the dying person, and often does not represent their EoL wishes (Denning et al., 2011).

Furthermore, inadequate knowledge of dementia and the tendency to live in denial revealed in family caregiver interviews is evidence that family caregivers may not be aware of the progressive nature of dementia, which then affects the 'timing' required to implement ACP (which essentially requires those around the person with dementia to anticipate the loss of decisional capacity). Family carers in this study reflected on 'missed opportunities' of carrying out some discussions about future care with their relatives while decisional ability was still intact.

8.3.1. Late help-seeking as a barrier to person-centred EoLC

The late help-seeking reported by previous studies has mainly been from studies mostly exploring perceptions of dementia, barriers to service use, timely diagnosis, and effectiveness of dementia treatment options (Mukadam et al., 2011). The available literature has not highlighted the link between delayed help-seeking and EoLC. While USA based studies have highlighted the existence of disparities in ACP between African Americans and Caucasians, there is minimal UK evidence of the use of ACPs in the context of dementia among BAME groups. Braun, Beyth, Ford & McCullough (2008) maintains that EoL treatment choices is hugely affected by an individual's race and ethnicity. For example, previous studies have consistently reported that compared to their Caucasian counterparts, African American patients favour more aggressive. Braun et al. (2009) cite lower use DNR orders while most are highly inclined to use cardiopulmonary resuscitation (CPR), feeding tubes while there is a reluctance in withdrawing life-sustaining therapies even against health care professionals (Braun, Beyth, Ford & McCullough 2008).

In dementia care, ACP involves a process by which individuals discuss and record their future EoL wishes, preferences or choices before their decisional capacity is lost (Robinson et al.,

2011), thus promoting self-determination having some control in how one prefers to be cared for at the EoL. While previous evidence suggests there is value in implementing ACP, such as ensuring personalised care at the EoL, there is limited evidence available about how ACP is being used by UK ethnic minorities principally in the context of dementia.

Based on the Mukadam et al. (2011) findings that BAME people present late to dementia services, and conclusions in this study, it is likely that as awareness of dementia improves, minority ethnic groups are expected to access dementia care services, as well having dementia diagnosed timely. This would potentially lead to the use of future care planning through religious beliefs that 'God knows' one's future can be a barrier to (participants in this study maintained a strong a view that it is God who plans the future). Furthermore, for ACP to be useful in the context of BAME dementia EoLC, there is a need to understand the religious views that are inconsistent with planning. As a process, ACP involves an individual who, upon anticipating the loss of decisional capacity in the future, initiates early discussions about his or her future care preferences or choices including the EoL wishes, that is, how the individual wants to be cared for in the future and having their wishes documented.

In dementia, it is critical to note the significance of timing in implementing the discussions as failure to do so may mean a person, whose dementia may have moved to an advanced stage, is no longer able to discuss their needs due to the decline in their cognitive abilities and communication. Previous research has shown that BAME people often present late for services, usually when their dementia has advanced; therefore, the implementation of ACP may be difficult as a result. There is insufficient evidence on the effectiveness of ACP for BAME people, although indications from the USA suggest minority groups often to do not have ACP in place compared to their white counterparts.

The conflicts between palliative care philosophy and religious underpinned values have been highlighted in previous literature (Koffman et al., 2008; Ahmed et al., 2004). This could be the answer to low service use by BAME groups. The challenge is that dementia itself is not straightforwardly easy to diagnose and when coupled with the tendency of normalising early signs of dementia as a part of a natural way of ageing typical among BAME communities, the feasibility of implementing ACP on time can further be a challenge as timing is critical (van Der Steen et al., 2014). van der Steen, Heymans, Steyerberg, Kruse & Mehr (2011) suggest that the justification of early future care planning is tied to problems associated with predicting

prognosis in dementia. Without ACP in place, the family and professionals would base the person-centeredness of EoLC on best interest decisions, which may not reflect an individual's preferences.

While future care planning can allow the voice of the person to be heard and can also help families and professionals in the decision-making process which can improve the person-centeredness of EoLC and quality of life. However, many participants expressed concerns that do so early suggested there was no hope. Similar findings were stressed by many participants in Caralis et al. (1993). For care to be 'person-centred', the person who is receiving the care should have a say in the formulation of that care (Brooker & Whooley, 2007). Late diagnosis and uneasy association with services by BAME groups may lead to lost opportunities for discussions about future care. An implication of this is that family members may make decisions based on what they know rather than what the person with dementia would have wanted.

8.3.2. Late Diagnosis/Decision/Discussion Mutes the voice of PLWD

The normalisation of early signs of dementia common among ethnic minority groups (Seabrooke Milne, 2004) (Berwarld et al. 2016) means that the majority presents late to dementia care services (Mukadam et al., 2011). By this point, decisional capacity has deteriorated, meaning opportunities for discussing EoLC between the family and the person with dementia are reduced. In the context of EoLC for PLWD, timing is crucial, although this would appear to be further hindered by some religious beliefs such perceiving God as the knower of the future and the 'giver and taker of life'. In the context of EoLC, family caregivers or those close to the person with dementia, often have some idea or understanding of the individual's care preferences (Davies et al., 2014). Despite this, the problem to note is that so often, family carers have different views to that of the person with dementia (Bamford & Bruce, 2002), and therefore, without capturing the voice of the dying person at the earliest part of their journey with dementia, the EoLC may lack its person-centeredness. In this sense, it can be argued that receiving a late diagnosis mutes the voice of many minority ethnic groups and affects the quality of care at the EoL.

8.4. Stigma as a barrier to access & use of available EoLC services

Dementia remains highly stigmatised among African-Caribbean PLWD and an illness which is not well understood (Berwald et al.,2016). Despite this, family caregivers are often expected to make complex EoLC and treatment choices on behalf of their relative with advanced-stage dementia (Caron, Griffith & Arcand, 2005). Concerning decision making, Yeo and Thompson (2014) have pointed out that Westernised models of care that emphasises autonomy, self-determination, caregiver education and caregiver support may not be applicable in cultural traditions in which the family position and responsibility in providing care to the elders or filial piety remains embedded in everyday life. ACP are useful in assisting families and healthcare professionals to make EoLC decisions, however, for many BAME people, implementing ACP is often hindered by late diagnosis and delayed help seeking (Mukadam et al, 2013). Placing a relative with dementia in 24hour nursing or residential care home environment can be taken as an abandonment of the older person and often unthinkable among some cultural groups, even when there is a clear need for support (Yeo & Thompson, 2014).

8.4.1. Uneasy relationship with support services

People from ethnic minory groups with dementia and their families, including those from African- Caribbean communities still have an uneasy relationship with care services despite an increasing need for support. A review of literature by Mukadam et al (2013) reported that lack of help-seeking by dementia patients impacted on early intervention and commencement of treatment. Early helpseeking is imperative to decrease the burden that can be caused by dementia and is crucial for early discussions about EoLC preferences, especially for minority ethnic groups (Bullock, 2011). Some PLWD voiced that they would rather be dead than be placed in a care setting. However, many trusted their families on making what they considered to be the 'right decisions' at the end of their lives. This expectation did not match with the caregivers' experiences who expressed a great deal of worry whether they will make good decisions at the time their relative approach the EoL. Family carers face challenges when it comes to making EoLC decisions (Johl et al., 2016). Both bereaved and current carers were not confident their decisions reflected the wishes of their relative. This means that decision-making was approached hesitantly, with some carers stating that they would agree with whatever the health professionals suggest at the same time expressing their worries around care home or hospital-based care as reported in a review of literature exploring barriers to access and use of dementia services by ethnic minority groups (Kenning et al., 2017).

This finding is consistent with CQC's (2016) report '*a different ending, addressing inequalities in EoL care* in which previous carers stated that before their relative's receipt of EoLC, they did not know about the care or how to navigate the system to seek it. While many previous studies have reported lack of service awareness as being a historical barrier to care for BAME communities, findings in this study add further insights into the complex nature that fear of community stigma has when added onto the current lack of awareness of services about EoLC. Throughout this research project, I found that participants' emphasis on filial piety influenced their experiences of care, but the stigma itself was about avoiding experiences of shame to the family in the eyes of the community. This finding highlights the importance of understanding people's culture when providing dementia care and related EoLC.

8.4.2. Expectations related to care

All the participants described themselves as Christians. They drew their meaning about living with dementia and providing care from their faith in God. Many older PLWD expected care from their family as a reciprocal gesture for the input they had contributed to their family. Likewise, carers felt obliged to provide care with many reciting Bible verses to substantiate their position as carers. Although issues relating to filial piety has been highlighted in previous studies (e.g., Kenning et al., 2017), expectation of care has not been fully discussed in relation to EoLC. Lawrence et al. (2008) found that family caregivers of PLWD from Black Caribbean and South Asian communities maintained a traditional caregiver ideology compared to White British caregivers, with the majority perceiving providing care as a natural, honourable, and expected task. Although this is also acknowledged by Parveen and Oyebode (2018), they argue that there is very limited evidence that this is a shared view across all UK minority ethnic communities.

The issues of care giving as being an obligation has been reported in previous research (Kenning et al, 2017, Parveen & Oyebode, 2018; Johl et al, 2016). Most participants in this research perceived providing care to their older family member as an obligatory gesture - a reciprocation for the input that the person had done to the family. For many, this was a respectful thing to do as enshrined in the Holy Bible. It should also be noted that most participants identified themselves as being Christians. The approach to caregiving by minority ethnic groups is comparably different to White British. For example, Parveen and Oyebode (2018, p.1) states "care is more often shared between several of adult-children, and therefore

dementia has a more widespread impact on the family beyond the main carer". Regarding EoLC, discussions about death and dying were viewed as unnecessary as the older person may consider that as loss of hope. In this study, this came across when I asked bereaved caregivers about ACP. Bereaved carer interviews also highlighted that carers lived a life convoluted with the worry of what was going to happen next. Towards the EoL, carers chose to stay with their relative all the times, which often led to social isolation and reduced personal health, including the abandonment of personal career aspirations by younger ones.

8.4.3. Religiosity & Beliefs (cultural) as essential elements of EoLC

Participants' stories showed that their religious principles were at the core of their lives. Similar to Koffman et al. (2008) study exploring perceptions and meanings ascribed to religion and spirituality in which Black Caribbean people with cancer held a belief that God helped them understand their illness, participants in this research also drew extensively on their Christian faith, Christianity was the only religion that the participants mentioned. Experiences expressed by the participants support Brown's (2014) conclusion that 'beliefs and attitudes towards EoLC depend on religion as well as the culture of an ethnic community' (p.3).

Similar findings have been reported in many previous studies (e.g., Parveen et al., 2017), although this study explored perceptions of dementia, not EoLC as in this study. These religious beliefs are distinct and strongly expressed, and as I have stated, they seem to be more than faith in God but a way of life by which everyday experiences are sieved through.

This suggest that when considering the EoLC experiences of minority ethnic groups with dementia, issues relating to their faith or religion should not be overlooked. For the family carers who participated in this research, religious practices such as praying played a significant role as a source of resilience, and reflect issues reported by Levkoff et al. (1999) whose study participants reported using prayer to cope with the everyday demands of caregiving.

For older PLWD in this study, God was perceived by many as 'the giver and taker', all that happens in life sits within the prism of one's destiny, and it is God alone who has the power to determine things. This belief was mainly referred to in relation to a sense of preparedness and fearlessness that older PLWD appeared to have developed along their journey of living with dementia. Katsuno (2003) found that people with early-stage dementia held strong beliefs that prayer enhanced their coping abilities and QoL. Service providers' ability to provide relevant services that are responsive to the diverse needs of caregivers necessitate an understanding of these religious and cultural contexts (Giunta et al. 2004). In the USA, culturally sensitive end-

of-life (EOL) care has been made a national priority (Smith et al., 2008), the UK appears to be trailing behind, with evidencing consistently highlighting unmet needs for BAME groups (APPG, 2013; Ahmed et al., 2017).

While Mukadam et al. (2010) reported similar conclusions regarding the use of religion in the context of dementia care related experience, this finding not only confirms that there is a strong relationship between individuals' religious and cultural beliefs and how they perceive illness and disease, including the meanings they negotiate in their everyday living with a terminal condition but brings new insights in that the participants believed it was God who has the power to give and take one's life, an issue highlighted by Levkof et al. (1999) as being a substantial barrier to help-seeking among religious BAME communities.

Religious beliefs appeared to have a strong influence on how PLWD made sense of their situation. While this is consistent with some studies found similar, questions are often raised in conjunction with differences within the wider UK BAME community making it difficult to pin down the religious and cultural beliefs relevant to a given group (Bhopal, 2004; Uppal & Bonas, 2014; Regan et al., 2013). As such, inferences made on such findings should be handled with sensitivity and care (LaFontaine et al., 2007).

The church community was a vital source of support for both older African-Caribbean PLWD and family caregivers. This could answer why many PLWD and caregivers' saw their everyday life experiences through the lens of religion. Also, while the participants' faith and related beliefs were meaningful to them, some participants perceived quality EoL as the care that promotes a person' religious/spiritual needs. Thus, acceptance of one situation was expressed by many participants in relation to everything being God's will. This may suggest that religion can be a barrier to care as reported by many previous studies (Regan et al., 2013; Regan, 2014; LaFontein et al., 2007) and is in keeping with Mukadam et al. (2011) and Regan et al.'s (2013) suggestions that it is imperative to understand BAME communities' beliefs and practices if barriers to dementia-related care are to be removed. Religion facilitated participants in the quest for meaning in the face of dementia in Stuckey and Gwyer (2003) study. This research has shown that the period towards the EoL is a challenging time for African-Caribbean family caregivers. This was further compounded by the fear of being judged by the outside world. In part, these findings are in keeping with issues highlighted in Regan et al. (2013) review which found that people turn to their religion to cope, however, this can also inhibit access to care for certain minority groups.

8.4.3.1. The culturally driven expectation of care can influence help-seeking

The most compelling findings of this research concern to the role that cultural beliefs play in understanding dementia and related EoLC. Culture is deeply immersed in how people find and use healthcare services as it informs how individuals identify themselves and their healthcare needs (Botsford & Harrison-Denning, 2015). Concerning culture, Bhattacharyya, Benbow, & Kar, (2012) suggests understandings of how dementia is conceptualised among BAME groups can ensure services, including EoLC, are culturally sensitive. The expectation of care from the family by Older African-Caribbean PLWD was expressed from a reciprocal position, with many commenting that it was time to receive support from one's family, having provided for them in the past. The reciprocal expectation of care was explained through biblical excerpts mostly by those who were caregivers to their parents. For instance, biblical texts that suggest children should take care of their parents, so their days of life are multiplied were recited as evidence supporting the older people's expectations of care. What was fitting with older people's hope was that the caregivers (mostly younger ones) had similar views based on their Christian faith. Another critical related issue aligned to expectations of care was caregivers' concerns about large numbers of healthcare staff visiting leading to regrets for accepting formal care support. One reason commented by many carers was a need to protect their relative's dignity as in Kenning et al. (2017) study. With reference to dementia, Janevic and Connell (2001) found that the cultural norms that a group holds, including stigma and meanings they attach to their condition, influenced how they interacted with the healthcare systems.

8.4.3.2. Acceptance of destiny

Phenomenological caregiver interviews allowed the voice of African-Caribbean family caregivers of people with dementia to be heard and their stories provide insights into the caregiving experiences of African-Caribbean family caregivers. PLWD and their family caregivers appear to move from asking for answers to the acceptance of their situation. Recognition of one's destiny - a theme identified in current caregiver interviews exemplifies a sense of hopelessness and loss of control of the situation that the majority of the carers experienced. These findings support an interpretive phenomenological analysis of a sample of Asian caregivers (n=6) by Tuomola, Soon, Fisher and Yap (2009) who concluded that due to the obligatory perception bestowed onto the caregiving role, this 'acceptance of destiny' was brought by an assumption that caregiving was part of the caregivers' lives. While this suggests the meaning and primacy by which many participants made sense of their situation, it also

implies that there is nothing that can be done, as many in this study took to a view that God is the giver and taker of life Jolly et al. (2009) explains that the existence of fear, shame and stigma among cultural groups often leads to issues being hidden.

8.4.4. Perceptions of quality care at the EoL

Quality person-centred EoLC has been described in terms of responsiveness and attention to the needs of a person who is dying, which extends to the provision of support to those close to him/her. As in Johnson et al. (2013), participants in this research talked about a need for symptom management- being 'at peace' towards the last phase of life to enable comfort at the EoL. Participants in this study saw death as an occasion that requires family members to be present, which many perceived a component of excellent care at the EoL and respect of the dying person. These findings support Graham et al. (2013) who explored traditional healers' views of what constituted 'good death' in the context of mental health and found that being with the dying person was crucial in maintaining comfort, restoring relationships and gain a verbal will from the dying person.

Older African-Caribbean PLWD and family caregivers' value their faith in God, and their perception of care was described in conjunction with their religious beliefs. Many studies have highlighted the importance of culture and religion among minority ethnic groups (e.g., Regan, 2014; Regan et al., 2013). A need to consider the salience of religion and culture in EoLC was expressed by many participants in this research, therefore, there is a need to incorporate and embed this when providing healthcare services to people from ethnic minority backgrounds. A report commissioned by Marie Curie (Calanzani, Koffman and Higginson, 2013) found that unmet needs and disparities in palliative care still exist among people from BAME backgrounds. Among other explanatory factors, the report highlighted that lack of sensitivity around cultural and religious issues often led to mistrust and low service uptake (Calanzani et al, 2013).

Similarly, a recent report by CQC (2016) found that people from minority ethnic groups face an array of barriers to quality EoLC, such as uneasy relationships with services and a lack of culturally sensitive services. An area for consideration revealed by this study is that despite strongly expressed reservations about receiving care, the older African-Caribbean PLWD who participated in this study were all service users of a charitable resource centre explicitly catering for African-Caribbean communities. For caregivers, the resource centre provided their

relatives with an atmosphere in which they can relate to others and for social stimulation. For older African-Caribbean PLWD, the resource centre was a useful care setting as it offered opportunities to meet up, play card games and eat traditional food dishes, one of the meals being slow-cooked oxtail stew and rice that I ate during one of the interview sessions held at the centre. The critical but notable question associated with this is, why did they not have negative views of this resource centre? Was it not a care setting? A possible explanation could be that this group of people associated the environment as like their homes based on the type of food, ambience, and shared belief systems. Possibly, participants related to one another based on their ethnicity or culture as the resource centre provides for the African-Caribbean community, thus supporting a central theme in Leininger's (2002) culture care theory.

8.4.5. The importance of family and community connections

When analysing the data from the three sets of participants (PLWD, current and bereaved caregivers), it was apparent that family and community connections remain one of the crucial issues for some BAME groups. For instance, older PLWD held strong expectations of receiving care and support from their family caregivers who felt burdened in their role. In contrast to these deeply held expectations, most caregivers reported feeling obligated to provide care as reported in Mukadam et al. (2013). However, in this research, there was a strong emphasis on caregivers' fears of being perceived as a failure to look after a relative at the EoL by their community network, resulting in most family caregivers having to shoulder caregiving burden. This was not because the family caregivers lacked knowledge about the available services for support as reported by Mukadam et al. (2013), also highlighted in Bewarld et al. (2016), but because the fear of being perceived as failing their relative with dementia by asking for formal support appeared to outweigh the need for help or support. Even when access to 24hour care was necessary to meet their needs, older BAME PLWD who participated in this research expressed a strong desire to remain in their own homes and expected their care and support needs to be met by their family members thus overlooking the associated burden of caregiving. Previous studies (e.g., Kenning et al.,2017), have further highlighted how BAME family caregivers' often feel obligated to provide care to their relatives mainly due to a need to maintain the family's status within their community and due to the stigmatisation of help-seeking as failure to provide family-based care (Johl et al., 2016) Although these tensions have been noted in previous literature, the extent to which they reinforce the widely known

reluctance to ask for help, including EoLC has not been emphasised as reported by the participants in this research.

Therefore, the existence of the uneasy relationship between expectations of care, the importance of family/community connections, family-based care and shared decision-making in EoLC as noted in the three sets of participants in this research echoes Calanzani et al.'s (2013) call for an urgent need to enhance cultural competency among care providers to improve the EoLC experiences for BAME groups

8.5. Contribution made by this research

The contribution to knowledge that this research makes is from a methodological position and theoretical perspective. From a methodological viewpoint, the study applied a phenomenological methodological design to create multi-perspective understandings of EoLC from the experiences of older African-Caribbean PLWD, current family caregivers and bereaved family carers. Thus, the three studies that make up this thesis (Focus group study with PLWD [Chapter 5]; Current caregiver interview study [Chapter 6] & bereaved caregiver interviews study [Chapter7]) together make a unique contribution from a methodological perspective. This thesis is a product of an in-depth empirical work exploring the EoL for a group of minority ethnic PLWD and their family caregivers which is in line with essential research priorities emphasised by NHS England (2016), Department of Health (2009), Care Quality Commission (2016), European Association of Palliative Care expert consensus on optimal EOLC in dementia (van der Steen et al., 2014). This research has also answered a more recent call for urgent UK based research on minority groups with dementia by Koffman (2018). It has shown how understanding the influence of people's culture and faith beliefs influence their EoLC experiences. Culturally underpinned perceptions of dementia as a normal ageing process have an impact on minority ethnic groups engage with ACP. Based on this study's findings, there is a need for targeted campaigns to challenge the stigma attached to dementia to encourage early help-seeking, early discussions about future care and access to dementia EoLC services. This is important as dementia prevalence is thought to be higher in UK minority groups due to the existence of dementia risk factors such as hypertension, obesity, and diabetes (Moriarty et al., 2011). Chapter 3 identified that there is limited evidence exploring the experience of minority ethnic PLWD in the UK. This study provides new insight into the experiences of African-Caribbean PLWD and their family carers. The research specifically focused on community-dwelling individuals, as there appear to be more studies on PLWD who are in care homes, although these are not minority groups.

One perspective that this research brings to the fore as previously reported by Moriarty et al., (2011) is that minority ethnic groups prefer to end their lives in the homes for many reasons which have not been reported in more detail in previous studies. For example, older African-Caribbean PLWD associated their own home with a peaceful death. However, despite this many of these people die in care homes and hospital wards (Sampson et al., 2010), because they typically seek help at the point of crisis. Without an understanding of people who are

living in the community, EoLC for those nearing the end of their lives may reflect the views given by people who are permanently placed in care homes, which may affect its person-centeredness. Thus, having the voice of PLWD about their needs as autonomous individuals' means the care can be tailored to their needs.

8.5.1. Challenging the misconceptions

The findings show how African-Caribbean PLWD and current and bereaved caregivers negotiate meanings from their experiences of living with dementia and family caregiving. It has often been thought people from BAME communities 'look after their own' (Department of Health, 2001). While true to an extent, but also inadvertently a barrier to reaching out (Cheston et al., 2017), participants in this study revealed the contrary. Some carers (both bereaved and current) - especially the younger ones who have acculturated to the Western ways of life stated that taking their relatives to daycare helped them to cope. This highlights the shifting perspectives between the older generation and the younger ones - a call for service providers to be prepared in the future as more BAME people may seek and use formal services than previously known.

Dementia prevalence is increasing globally, and there is no current cure for it. This means that many people will continue to die from the condition (WHO, 2017), and in the UK, death by dementia has leapt to the lead, surpassing other terminal conditions (Office of National Statistics, 2016). Despite an estimated 850 000 PLWD in the UK, of which 25 000 are thought to be from BAME groups (Moriarty et al., 2011, APPG, 2013), previous work has found that people dying from dementia continue to receive inadequate care at the end of their lives. In its entirety, dementia takes no ethnic or cultural barriers. Thus, it affects people from various backgrounds and does not discriminate (APPG, 2013). Given the projected increase of dementia in the coming years EoLC should not only meet the needs of individuals with dementia but should also ensure family caregivers needs, and experiences are not overlooked (APPG, 2013).

Chapter 2 (literature review) showed that in the UK, there minimal research that has explored the EoLC experiences of minority ethnic groups in the context of dementia (Connolly et al., 2012; Koffman, 2018). Globally, the poor care for PLWD at the end of their lives has generated a burgeoning literature base, including a White Paper on optimal palliative care for this patient group (van Der Steen, 2014). The projected increase in dementia prevalence in UK black ethnic

groups (Pham et al., 2018; Adelman et al., 2011) means many people will die from this life-limiting condition as such, an understanding of the EoLC needs of an ageing and culturally diverse population can be of help at this time.

Given the lack of understanding of how best to provide care to minority ethnic groups dying with or from dementia (Connolly et al., 2012), this study provides new insights regarding EoLC from the perspectives of black African and black Caribbean PLWD and family caregivers.
This study has enabled a unique exploration of EoLC among African-Caribbean PLWD and family caregivers within the UK context. Previous studies have highlighted that PLWD continues to die badly globally (van der Steen et al., 2014], with EoLC mostly suboptimal and disjointed (Sampson, 2010). Various barriers to EoLC for PLWD have been identified and include a historical tendency, not to classify dementia as a terminal condition (Lillyman & Bruce, 2016; Thomas, 2010). For instance, Sachs, Shega and Cox-Haley (2004) point out that a significant obstacle for palliative and EoLC for PLWD is around the identification of the person as dying. Findings of this study support Sachs et al.'s (2004) claim that families often live in denial and do not view dementia as a condition, which will lead to death. Caregiver interviews in this study showed that living in denial acts as a barrier to early discussions about future care. This finding is in keeping with previous studies that explored barrier to ACP in dementia (e.g., Baker et al., 2017; Poppe et al., 2013). This research has allowed the voice of an under-researched group of older black African-Caribbean PLWD and family caregivers to be heard in EoLC research, illuminating a critical area within the dementia care pathway (Moriarty et al., 2012; Calanzani et al., 2013, Connolly et al., 2012).

In the context of dementia, the study has highlighted how African-Caribbean PLWD and their families use religion and culture as core meaning-making elements and highlighted how an interplay between the two underscores the paths taken by this group of people towards the EoL. The influence of religion on how illness is perceived has been reported in studies exploring cancer among the African Caribbean (e.g., Koffman et al., 2008). Similarly, participants' stories in this study showed how they draw their meanings of living with dementia and providing care from their faith in God. Martha, a bereaved caregiver in this research, offers an excellent example of how religion was not just a set of beliefs, but also a way of life. She revealed that she would not have managed to do anything without prayer in her caregiving role and when facing uncertainty about her husband. As in Regan (2014), PLWD and family carers

expressed similar views regarding prayer, perhaps an indication of the role that religiosity plays in meaning-making among this group.

8.5.2. Responding to calls for EoLC research for minority ethnic PLWD

In a recent editorial piece on current issues in palliative and EoLC for PLWD, Hughes, Volicer and van der Steen (2018) on appreciating the lack of research in this area refer to Murphy et al., (2016) review in which only three studies met the inclusion criteria. While there is, overall, a surge in research looking at palliative and EoLC in dementia, Hughes et al. (2018, p.591) stress that there 'is a need for more work in the area of dementia and palliative care'. A careful exploration of the literature identifies that generally, within the UK EoLC for PLWD from BAME communities are under-researched, despite previous studies suggesting that dementia prevalence is higher in these groups compared to the white UK majority. The United Kingdom is one of the culturally and ethnically diverse countries in Western Europe. Given a current emphasis on the person-centeredness and culturally responsiveness of care, it is crucial to deepening understandings of ethnic minority groups across communities if palliative and EoLC for the dying is to be regarded as person-centred and culturally responsive. While a need for the recognition of diversity within individual groups and between and across BAME groups in the UK have been emphasised in literature (CQC, 2016, Botsford et al.,2015, La Fontaine et al., 2007; Nyatanga, 2001), studies continue to apply the acronym BAME as a standard reference to distinct groups within minority ethnic UK groups. It is an issue that this study has emphasised and some scholars (e.g., Vickers et al., 2012) argue that failure to delineate between groups assumes similarity in experiences, views and beliefs and masks specific care needs relevant to a particular group that may benefit from targeted campaigns aimed at improving services.

Hughes et al. (2018) highlight misconceptions of dementia in BAME groups that affect EoLC; firstly, lack of consensus on the recognition of dementia as a terminal condition (Hughes et al., 2018; Chen et al., 2018). Secondly, the lack of attention of how dementia differs from illness trajectory that overshadows the specific needs of PLWD and their carers. Thirdly, regarding dementia, Hughes et al. argue 'there is a problem of fit' within a palliative care approach, which calls for dementia focused palliative care. These problems have been explored in a UK government White Paper on palliative care (van der Steen et al., 2014).

Another misconception noted by Hughes et al. (2018) is that there is no difference between palliative and EoLC and regular dementia care. This overlooks the complex symptom burden specific to dementia such as its impact on communication, making it difficult for PLWD to make their EoLC needs to be known, and its unpredictable illness trajectory (Sampson et al., 2018). The misconceptions raised by Hughes et al. (2018) have been identified in Chapter 3 (review of literature) without the voice of minority ethnic PLWD and their families, the person-centeredness and culturally responsiveness of EoLC care may not be achievable. This thesis has addressed this by capturing the voice of a less heard group of PLWD, including that of current and bereaved family carers, resulting in a deepened multi-perspective understanding of EoLC. The underlying cultural and religious beliefs of the participants associated with EoLC is illuminated, highlighting a need for embedding cultural competence in practice with BAME groups in the wake of increasing dementia and cultural diversity in the UK. Cultural and religious beliefs are the lens by which care at the EoL is viewed by older African-Caribbean PLWD and their family caregivers.

8.5.2.1. Initiating a need to look at the EoLC needs of UK minority groups

There is an urgent need to narrow the current disparities in healthcare and thus facilitate trust and better care outcomes for all. With reference to the EoLC, 'such disparity of access for all individuals requiring such care ignores a basic human right to live and die in comfort' (Clarke & Phillips, 2010, p.210). To reduce these disparities, Cooper, Hill and Powe (2002) point out that enhancing cultural competence can be the basis for reducing inequalities in healthcare. To me, this is an idea whose time has come, given the increasing cultural diversity across the UK and the projected prevalence of dementia. In making few practical insinuations emanating from this exploration, I consider that research of this nature that takes from a subjective ontology means the 'reality' shaping the picture of the phenomenon under investigation is constructed and relevant to those who participated in the research. Based on the findings of this study, EoLC for African-Caribbean people with dementia needs to accentuate on taking account of cultural and religious needs as expressed by participants in this research project. Butler et al. (2016) accentuate that incorporating cultural competence as a model of care embedded within policy practised by the provider of service reduces stereotyping and stigmatisation as well as helping to establish trust and access to services.

For this reason, Butler et al. recognise provider training as the most common type of intervention for cultural competence. This is of importance, considering that findings in this

study suggest that caregiver fear of stigma and concerns around both cultural and religious responsiveness of dementia care services act as a barrier to service use. Targeting providers of services to enhance their cultural competence is likely to narrow the current disparity in access and use of services, including palliative and EoLC services by minority ethnic UK groups. As caregiving was somewhat perceived as an obligation for many - a duty that one must fulfil, being an African-Caribbean family caregiver to a person with dementia appeared to be characterised by penetrating emotional consequences. For example, others reported experiences of loneliness, social isolation and poor physical health but seeking help was instead not an option due to fear of community stigma.

An example of a cultural issue illuminated in this study is that Older African-Caribbean PWLD expects care to be provided by their families while the family carers from whom care is expected often felt 'obliged' to do so. Although Kenning et al. (2017) reported that minority caregivers took their role as an obligation mainly due to trust issues about 'outside' support and whether such support was culturally appropriate, their findings were based on barriers to accessing dementia care services by ethnic minority groups in general with very limited focus on EoLC. Similarly, these issues were raised in relation to EoLC by many participants in this study, with many expressing their worries around the quality of care in nursing home and hospitals. In addition to this, for many, acceptance of formal support would incite negative response by people closer to the family which led to family carers feeling trapped and oblidged to take care of their relative person with dementia. Addressing these concerns requires a deepened understanding of the underpinning beliefs and, without such knowledge interventions designed to reduce inequalities in health and care are likely to be less effective. These feelings were underlined by religious beliefs with many of the caregivers reciting biblical text whose central message is that taking care of your parents multiply your days of life. It is unclear how perceptions that take from culture and religion can be delineated. Therefore, for quality person-centred EoLC, people's culture and religion should not be overlooked. Community stigma – the fear of being perceived as a failure by others and the inherent respect for older people by this group, and to an extent being perceived as 'evil', exemplifies some deep routed cultural connotations that shape the meanings family carers ascribe to their experiences.

Many caregivers expressed feelings of guilt, anger, and despair, however, what was apparent from their stories was that most of them live in denial about dementia and its progression, which leads to ambiguous loss – missing their loved one despite their physical presence. As

expected, dying at home was preferred by many, while dying in 'old people's home' was highly frowned at by the older PLWD. The main aim of this study was to uncover and explore experiences of dementia and related EoLC for community-dwelling older African-Caribbean PLWD and their family carers (Dlamini, 2015). The study's main aim was accomplished by illuminating essential themes from the lived experience descriptions of older African-Caribbean PLWD and the current and bereaved caregivers' stories. I have made the suggestions above based on the thematic findings (Chapter 5, 6 &7) of this research, and practical implications can be gleaned into the understanding of quality, culturally responsive EoLC that meets the unique needs of this group. Therefore, it would appear inattentive and negligent to disregard how we might use findings from this research to inform dementia and EoLC practice and policy.

8.5.3. Involving PLWD in research and challenging the 'hard to reach' narrative

This study involved PLWD as participants. A key achievement of the study is that the participants were from a seldom-heard group in research. Therefore, it should be noted that it is not only PLWD who contributed to this research but a group of older people from a minority ethnic group. Involving PLWD in research is subject to an array of ethical and practical issues but is achievable (Gove et al., 2018). When this is added to ethnicity, the challenge is not only ethically involving PLWD but also reaching out to a group of people who may feel vulnerable from their minority ethnic status and threats to their autonomy caused by dementia. Despite the ethical issues such as gaining informed consent, the active participation and involvement of PLWD are imperative to improve understanding of the lived experience of dementia. As was my experience in this study, families and professionals alike often take a 'gatekeeping' role to protect the person with dementia. In so doing, they often overlook the autonomy and self-deterministic right that of the person and may discourage participation (Gove et al., 2018), thus ignoring their capacity to meaningfully contribute to research as noted in this study (Alzheimer's Europe, 2011).

This research has shown a need to avoid overlooking the abilities of PLWD in research. In part, as noted by Gove et al (2017), researchers often concentrate more on the need to protect PLWD in research as a vulnerable group and consequently avoid involving PLWD in research. However, this emphasis can deter researchers from navigating meaningful ways of involving PLWD in research. For minority groups, this can further extend the currently acknowledged underrepresentation in research and healthcare. In light of increasing dementia prevalence, failure to involve PLWD can maintain the stigmatization of the condition and can perpetuate a view that PLWD are unable to contribute to society. The focus should not be placed on deficits but rather on finding frameworks to assist PLWD to actively participate in research (McKeown et al., 2010). Based on experiences in this research, discouraging a person with dementia because of deficits skills of daily living can prevent PLWD from having their voice heard. Equally, it is crucial to listen to the 'gatekeepers' concerns as they may have some concerns that the researcher can clarify. Gove et al. (2018) make a firm emphasis that the wishes of PLWD should be prioritised over that of families. While the two families who did not want their relative to participate in this research were acting in the best interest of their relative, it was essential to ensure they were aware that their relative wished to participate in research (Dewing, 2007). If consent was obtained at the point the relatives discouraged their relative

from participating, there was a need to prioritise the rights of a person with dementia and to support them to participate in research and have their voice heard (Gove et al., 2018).

Alzheimer's Europe's position is that PLWD, at all stages of the illness, should not be excluded from research (Gove et al. 2017). Researchers should consider all possible measures to involve. Informed consent and protecting confidentiality are critical ethical issues in research and challenges for research in which PLWD are active participants. I feel that the methodological choices I made have led to findings that shed new light on EoLC for people with dementia and offer opportunities for a deepened understanding of what it means to be a black African-Caribbean person with dementia. Focus groups stimulated a discussion and allowed the generation of experiential data on a potentially emotionally charged topic area of the EoLC and the experience of living with dementia. Although two participants kept leaving the group and returning, the nature of interaction among PLWD during the interview was a highlight. Focus group may have appeared to be less formal for older PLWD in this study compared to individual interviews as also noted by Bamford & Bruce (2002).

8.5.4. Altruism

Altruism tends to be a key factor in encouraging participation in research (Gysels, Shipman & Higginson, 2008), and has been defined as 'intentional, voluntary behaviour that is meant to improve another's but not one's own condition' (Carrera et al., 2018, p.3). During the process of recruiting participants, several potential participants and their families needed to know how their participation would benefit them. When I explained that there was no direct benefit, but that the findings of the research could contribute towards how EoLC is delivered. Some family members who acted as 'gatekeepers' demanded explicit details about the research, including an explanation about what was expected of their relative. Despite PLWD providing their consent to participate, towards the date for focus groups, two family members stopped their relative from participating in the research. As in Gysels et al. (2008), their decision was tied around the question about the benefits of participating in the study. Some voiced concerns that their relative's contribution could affect the care and support they were receiving at the day centre. Addressing these concerns helped other family members. This made the recruitment process challenging, requiring an additional time to discuss the research programme in more detail (Carrera et al., 2018). Challenges of recruiting PLWD included having to gain the person with dementia's consent and ensure accent was also gained from the family members. For others, participation was about being part of others and using the opportunity to express their

views without questioning the benefit of participating. As noted by Gysels et al (2008, p. 348) 'judgments are often based on a priori assumptions of vulnerability rather than on evidence of what is actually harmful'. In the context of dementia research, it is crucial to acknowledge that family members' concerns may be genuine as they may have witnessed a decline in their relative's wellbeing, but as Gove et al (2017) argue, the right of a person with dementia to participate in research should be considered if they have provided informed consent. As in this study, and other EoLC/palliative care research (e.g., Henderson, Addington-Hall, & Hotopf, 2005) many participants who participated in the research commented that they enjoyed participating and making their voice heard.

8.5.5. Contributions to methodology

This research project used a unique design informed by van Manen's phenomenological analysis to enable multi-perspectives about EoLC for a seldom heard group in research to be obtained. Although there is limited evidence regarding the suitability of focus groups in research involving minority ethnic PLWD, supplementing them with carer interviews enabled an in-depth exploration of the subject matter, and thus this research introduces a distinctive research design. In addition to allowing a deepened exploration from the lifeworlds of participants, focus groups enabled PLWD to share their lived experiences. This was crucial in allowing their voice to be heard, which was one of the overarching objectives of the research project. Although there were challenges during the recruitment process, the methods employed in this research has been successful in obtaining the insights of older African-Caribbean PLWD in relation to EoLC. As there is currently minimal qualitative research evidence, this study, therefore, offers new perspectives that can used as the basis for further investigations.

CHAPTER 9: REFLECTING ON THE OVERALL RESEARCH PROCESS

9.1. Introduction

The principal objective was to allow the less heard voice of this potentially marginalised or seldom heard group of PLWD and their family carers to be heard in research. As an approach to researching lived experience, hermeneutic phenomenology provides a basis for the development of human knowledge and understanding. The approach's underlying ontology places a greater emphasis on the significance and the meanings human beings ascribe to their everyday experience. The underlying ontology is in keeping with the ideals of the interrelatedness of African-Caribbean perceptions on dementia, the ascription of cultural and religious meanings to the lived experience of living with dementia and understandings of the EoLC. According to Gadamer whose philosophy van Manen utilised in developing a human science approach that informs this work, we reach new understandings when our current knowledge is exposed to another horizon through encounter (Gadamer, 2004).

The WHO (2014, p.5) defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual'. While dementia is also a life-limiting condition, palliative care has mainly focused on patients with advanced-stage cancer, with little attention being done to patients dying with or from dementia (van der Steen, 2010). As part of palliative care, EoLC focuses on supporting patients (usually with a prognosis of 6-12months) with a life-limiting illness to be comfortable and t helps families during this time and throughout the bereavement period (Alzheimer Society, 2017), despite the benefits of quality care at the EoL, dementia poses several challenges such as its long and unpredictable disease trajectory which impacts on the impeccable assessment of the EoLC needs.

One core aspect of interpretive hermeneutic methodological approach is its focus on developing a deepened understanding of a phenomenon. This relates to the perceptions between the researcher and the co-researchers (participants) in relation to the phenomenon of interest. It is 'fusion' because to reach a deepened understanding of the phenomenon, a synthesis of what is known about the phenomenon (pre-understanding from literature) and what has been

told by those who have reflected on the phenomenon. The 'horizon' in this context, does not necessarily exemplify the 'real' horizon – the gap between the sky and earth in which one can stretch his look as far possible as he can see, but in this context, the term 'horizon' relates to black older PLWD and their family caregivers' unique views – their perceptions of being-in-the-world, and reality from their lifeworlds including what that means to them. In conjunction with this thesis, PLWD and family caregivers' horizon or worldview of their experience of dementia in the context of EoLC was the phenomenon under investigation, whereas the 'horizon' or participants' viewpoint is what I seek to understand. As a researcher, my 'horizon' represents my understanding of dementia and related care and my experience related to the phenomenon under consideration.

The new understandings reached through the 'fusing of horizons' in this study is that culture and religion influence people's perception of dementia and EoLC including caregiver's decision-making that takes place throughout their caregiving role and at the EoL. Culture and religion appeared to be a barrier to help-seeking, an essential aspect that, if missed, has significant implications on the person-centeredness of EoLC. On the other hand, participants' religiosity also played a vital role as a resilience-negotiating entity. Thus, culture-specific familiarity is a basis for the commencement of the exploration of individual or family beliefs, if EoLC is to be responsive to people's unique needs. Most PLWD and the family caregivers revealed that they used prayer to make sense of their situations, and this appeared to be a way of life as opposed to being a mere practice.

Findings in this thesis show interplay between culture, religion, ethnic minority status, and how these have can influence on how older African-Caribbean PLWD their family caregivers negotiate meanings in their everyday lives. The community plays a vital role in how this group of people relate to the healthcare system. Therefore, to provide the best possible care to older African-Caribbean with dementia and their families at the EoL, it is vital to recognise not only their religious and cultural beliefs but also how these are instead a system at play.

Because of the limitation that each person who participated in the study contributed their subjective viewpoints that reflected their personal history, culture and religious beliefs, the relevance of the findings of this study is limited to context and to the people who shared their stories. Therefore, basing this claim on the results of this study, in all cases and all issues, the principal starting point in providing EoLC for minority people would appear to be tied to the question: what are the beliefs of the individual and their family?

I chose hermeneutic phenomenology informed by the work of van Manen (1990, 1997, and 2014) as a suitable research approach. When selecting this methodology, it was essential to ensure the choice depended on the research questions and the philosophical assumptions I held about what constitutes reality and knowledge. This relates the ontological and epistemological assumptions underpinning this study discussed in Chapter 3. My view is that people's experiences are different, and the meanings they ascribe to those experiences are context and culture related. Therefore, I believe there are multiple realities rather than one objective truth. For example, the stories told by each person with dementia and each caregiver represent their reality and understandings of the phenomenon under the investigation should be made from their perspectives. By 'bringing' together with the participants' 'realities' my view was that I would be able to garner a deepened understanding of EoLC from the perspectives of the older African-Caribbean PLWD and their families.

The purpose of this hermeneutic phenomenological study was to develop a detailed description of EoLC from the perspectives of a group of older African-Caribbean PLWD and family caregivers in their context (van Manen, 1997). As this approach derives from phenomenology and hermeneutics, hermeneutics was essential in achieving the interpretive component necessary for the explication of meanings embedded in the text-turned stories [transcripts] that would have been articulated in a fragmented manner (Crotty, 1998). For this reason, the research is situated within and framed around a contextualist ontological position, thus taking subjectivity as its underlying epistemological assumption.

My choice and use of hermeneutic phenomenology as opposed to descriptive phenomenology enabled the exploration of participants' experiences which allowed me to further use my prior understandings in the interpretation of participants experiences based on my theoretical and personal knowledge as highlighted in Chapter 1 where I reflected on 'my interest to the phenomenon'. The rationale behind my choice and use of a purposive participant selection approach as opposed to a random section was to reach out to information-rich participants (Patton 2002). The belief was that information shared by older African-Caribbean PLWD, current and bereaved family caregivers of this group was suitable to illuminate meaning structures of EoLC for community-dwelling African-Caribbean PLWD and their families.

9.2. Being an insider and outsider

As a researcher, I saw myself as an outsider, however, at the same time, being a black man undertaking a study in which older black people with dementia and their family caregivers were participants made me an insider. Griffith (1998) defined an insider as "someone whose biography (gender, race, class, sexual orientation and so on) gives him/her a lived familiarity with the group being researched" (p. 362). However, Kanuha (2000) explains that insider researchers often struggle to distinguish their own experiences from participants' during the research process, which can negatively affect the richness of the collected data. As an outsider in this research, the overarching objective was to conduct the research to gain an understanding of the participants' experiences. Being an outsider enabled me to take an objective stance during the research (Chawla-Duggan, 2007) while benefiting from advantages of associated with being an insider such as gaining the participants' trust more efficiently for the collection of rich data (Dwyer & Buckle 2009).

The dichotomy between the insider and outsider perspective has long been debated in qualitative research and has also been referred to as the emic (insider) and etic (outsider) perspectives (Morris, Leung, Ames & Lickel, 1999). In this research project, adopting an 'emic' view of the participants' experiences permitted an in-depth understanding of their culturally and religiously negotiated meanings relating to EoLC. Fundamental to understanding the participants' narratives was by developing trust with the participants in addition to the identity I shared them (being a black man). However, as PLWD and the family carers were older than me and thus readily taking a position as my peers in my Zulu culture, it was crucial to be mindful of the possibility of my insider position becoming a barrier to exploring some aspects of participants experiences that I related to as 'normal' (Platt,1981). When moderating the focus group and interviewing the carers I too, like Patt's (1981) experiences during the interviewing his peers, began with prolonged introductions and apologetic justifications aimed at mitigating the possible imbalance of power between myself as a researcher and the researched.

While my position as both an insider and outsider could have facilitated the recruitment process of this seldom heard and so called 'hard to reach' group of people in research (Kerstetter, 2012), there was a need to ensure the participants' issues relating to their confidentiality was addressed as part of the process consent framework. This was crucial to avoid my insider status, including being seen as a threat to the participants' confidentiality, especially when the sensitive nature of the subject being explored is considered (Serrant-Green (2002).

However, the nature of insider epistemology has attracted considerable debates in qualitative researcher (Dwyer & Buckle, 2009; Hayfield & Huxley, 2014). Despite the contradicting views about the insider/outsider researcher position in literature, in this research, my insider identity facilitated the recruitment of participants who are depicted as 'hard to reach'. However, there is a need to ensure that whatever position the researcher has (insider, outsider, or both) does not lose sight of the aim and objectives of the study, including making assumptions about the participants' experiences where the researcher has shared experiences with the researched (Kanuha, 2000). In this research, while my insider status (being a black man), as I see it, helped to accelerate the establishment of a rapport and trust by the participants, it was essential to use the position to dig deeper into the participants' experiences. Based on the depth of data collected in this research project, I concur with Dwyer and Buckle (2009) that an insider position can be used to encourage participants to open up about their experience that could have been difficult to tap into by an outsider researcher.

In this research project, Older African-Caribbean PLWD and their family caregivers shared their lived experience living with dementia, EoLC hopes and wishes and stated that they have previously not divulged their experiences to anyone in the manner they did. Family caregivers also shared their experiences of caregiving to a relative with dementia in the context of EoLC. Not only did their collective perspective make this research project unique, but that it added greater depth to the data gathered. At the end of interviews, several participants said they would have found it challenging to share certain aspects of their experience if I had not been a black man who understands them – this to me demonstrates the advantages associated with being an insider. Dwyer & Buckle (2009) concluded that participants in their study had assumptions based on distinctiveness and it felt like there was an atmosphere of "you are one of us, and it is us versus them" a view which I can relate with in this research project.

Conversely, Mercer (2007) found that being an insider can also negatively affect the research if participants assume that the researcher understands their experiences (as being 'one of the'). Such an assumption could have made the participants omit to talk about some essential aspects of their experiences that this research projected could have captured. This can prevent new knowledge to be generated. When conducting this research project, I thoroughly considered Dwyer and Buckle's (2009) suggestion that as an insider researcher, I must avoid making assumptions about participants experiences based on personal experiences but must maintain a

level of self-awareness to capitalise on probing for depth and detail during the interview process to deepen and enrich the data.

It was also essential to reflect on my feelings immediately after the interviews, as shown in the diary in Appendix Ten. The diary reflections reoriented me to the events during fieldwork, which helped to make sense of participants' stories. Over-familiarity with the research site and prospective participants has been found to lead to the development of among insider researchers (Brekhus, 1998) with the 'obvious' question often being omitted (Hockey, 1993, p. 206). Some researchers (e.g., Kanuha, 2000; Hockey, 1993) found that the insider researcher may also feel less confident to delve into sensitive questions as shared aspects of the experience under investigation might hinder the interview process and data generations. It was essential to maintain a reflective approach to avoid losing sight of the research aims.

Minichiello and Kottler (2010, p. 11) note that researchers in qualitative research often encounter "surprises, twists and turns on the road and unforeseen obstacles" that require some attention during the research process. Indeed, in this 'Journey', I experienced some unanticipated obstacles such as having to invest a substantial amount of time to build trust and establish confidence and a rapport with the day centre manager and the potential participants. Regarding 'surprises and twists and turns' - on many occasions, focus group interviews had to be re-scheduled as few participants turned up. I had to adapt to the context by being flexible in rearranging the interview times to fit with the participants' needs while being mindful not disrupt the day centre's routine.

9.3. Credibility

Credibility in qualitative research is about confidence placed on the research findings and whether they denote believable information gleaned from the participants' stories/views (Patton, 1999). This phenomenological research has managed to bring to the fore the experiences and perceptions of older African-Caribbean PLWD and their carers from their perspectives. When reporting the findings, I remained faithful to the participants' narratives and used extensive excerpts to support the themes. In addition to this, before embarking on this research, I worked in dementia care for over 10years. My experience of working with PLWD and their families can be regarded as contributing to the credibility of the research as it was crucial to use my work experience to develop a relationship with PLWD and their families, including communicating with them. I also invested sufficient time to build familiarity with

the day centre setting, which was crucial for building trust and for the collection of rich data. For example, the literature on phenomenological analysis suggests that to establish the credibility of the research project; there is a need for the researcher to understand their area of study (Roberts and Taylor, 1998).

Another critical strategy employed in this research for credibility was how I had a prolonged engagement with PLWD and their family carers. From a methodological point of view, a collection of data profoundly relied on the participants' capability to describe their experiences. In my role as a community dementia worker within a specialist NHS crisis and home treatment team, I was often intrigued by the refusal of care and support by BAME caregivers, even when there was a clear need. While expected, the above findings are in keeping with Heidegger's phenomenological philosophy that new understandings can be developed from previously taken-for-granted everyday experiences.

The results also reinforce the fundamental interpretive phenomenological methodological argument that it is practically difficult to detach oneself or 'suppress' preconceived understandings of the phenomenon of interest but that what is essential is to use such understandings as a starting point from which a deepened understanding of the meaning structures of a phenomenon under investigation can be reached. In this study, I did not attempt to detach myself from my pre-understandings of dementia and related care but used it as an essential tool of identifying the nature of 'things in their appearing' (Langdridge, 2007).

9.4. Representation/Patient and public involvement

Currently, locally, and internationally, there is an emphasis on the need to involve patients and the public in health research due to recognition that patient and public involvement (PPI) may enhance the utility and impact of healthcare research outputs (Miah et al., 2019). Given that that minority PLWD and their carers are rarely involved in research (Moriarty et al., 2012), PPI encompasses representation of patients and the public's perspectives and enabling their voice to be heard. In research, PPI is crucial as it considers that the viewpoint held by the patients and the public could be different from the researcher's (Beresford, 2013).

The current underrepresentation of people from UK ethnic minority groups in dementia care research and related EoLC requires improvement. However, this calls for researchers to develop useful practices to limit the current barriers in recruiting and involving people from

minority groups in dementia and EoLC research. Miah et al. (2019) suggest PPI and representation in research that directly influences policy and care is ethically appropriate. Alzheimer Europe (2011) has also commended involving PLWD and carers in research, which this study considered.

9.4.1. Homogeneity of sample

This study explored the experience of a small sample of people of black African and African-Caribbean by background, in a given context and time, thus limiting the transferability of findings. However, the involvement of people of black African and African Caribbean ethnic background as one group was pragmatic and serendipitous. It should be noted that the interest of this research was not to explore differences and similarities between the two groups but to explore their perceptions of EoLC phenomenologically.

Despite their different country of origin, time of immigration to the UK, previous literature does suggest that there are some shared experiences between UK black African and black African Caribbean. This shared experience includes marginalisation, racism, stereotyping and prejudice (Owen, 2013; Ford, 2008). Black Africans and African-Caribbean who participated in this research expressed similar experiences of living with dementia, perceptions of EoLC and care giving – a confirmation of shared experiences between the two groups who were serendipitously recruited for the study.

Interestingly, despite the difference in migration experiences, all participants in this study self-identified as Christians and separating them in terms of ethnic background was considered unnecessary. Therefore, this group shared some aspects of their identities such as being from ethnic minority group, being from a seldom heard group in research and experience of dementia, it could have been useful to distinguish them by background. I considered Ahmad (1996, 2002), who has argued that research tends to focus on emphasising differences rather than similarities between cultural groups.

9.4.2. Strategies for engaging with the so-called 'hard to reach' groups

Conducting EoLC research with PLWD and family caregivers of PLWD is highly sensitive. This is because discussion about EoLC issues can evoke emotions when PLWD and their families are already vulnerable because of the impact that dementia may already be causing on their everyday life. As demonstrated in this research, despite sensitivity inherent in EoLC

research, building trusting relationships with the participants can be a crucial step for researching a sensitive topic. Establishing trusting relationships requires adequate time and flexibility in scheduling and rescheduling appointments to avoid disturbing the participating organisation's routine. This was a crucial step in this research project. For example, one focus group was carried out soon after lunch to fit in with the usual activities of the centre.

Another vital strategy for establishing trust, as already indicated above, involved visiting the day centre before the interviews to encourage prospective participants to ask questions they had regarding the research. Doing so worked as the basis by which participants and I negotiated a rapport, which encouraged participation in the research. When researching minority ethnic groups, dealing with suspicion can be challenging. For example, answering and reassuring participants when questions such as, 'have someone sent you to us' was crucial. Such lack of trust demanded transparency about the research process and aims of the project. However, dealing with repetitive questions (common in dementia) was difficult.

Furthermore, the time invested towards building rapport and trust with older African-Caribbean PLWD, the management at the day centre and family carers was critical in dealing with questions regarding the use of the research findings. This is not uncommon in research; for instance, the term 'therapeutic misconception' (Appelbaum, Roth& Lidz 1982), is when participants assume, they will directly benefit from the research findings. Such expectations must involve honest discussions. Furthermore, allowing adequate time for questions, responding sensitively, and frequent contact with potential participants and the day centre staff were all essential strategies employed for voluntary participation based on an understanding of the research project.

Given an extensive evidence base of the depiction of people from BAME communities as 'hard to reach,' a variety of recruitment methods were considered to reach out. My journey through the recruitment strategy employed in this PhD, therefore, suggests that to increase participation in research, negotiating trust and with both gatekeepers and PLWD and their families was vital for the involvement in this research. Another aspect of this research worth considering relates to my position as both an insider and outsider (discussed in detail in section 9.1).

My experience in this research challenges the general presumption in the literature that the position of the insider researcher enables access to participants more easily (Kanuha, 2000). My fieldwork experience involved extensive work in establishing trust and rapport. Therefore,

access to participants was not a swift activity. The challenge I faced was to explain the research repeatedly to the gatekeepers (Day Centre management and family members) and managing their concerns about the possibility of disruptions that the research activities were likely to do at the day centre. There was a need to reschedule the focus group interviews on two occasions, which required a level of flexibility and a need to maintain contact with the gatekeepers and participants at the day centre. Also, it was imperative to strike a balance between establishing a rapport with the participants and explaining more about the research as the advantage here in that it stimulates a higher level of openness, according to Silverman (2000, p.200) can 'contaminate' the study particularly when participants are informed accurate information about the research.

9.5. Summary relating to the design & methodology employed in this research.

The strength of the study is its unique design, which includes focus groups with PLWD, in-depth interviews with current and bereaved caregivers. This allowed a multi-perspective understanding of dementia and EoLC and be an achievement of rigour. Minority ethnic groups are under-researched, and their voice is seldom heard in dementia and EoLC research, as such allowing the voice of PLWD who are from a minority ethnic group is one achievement worth mentioning. Drawing on my work experience and contact with both PLWD and their carers was useful during the interview process as well as in revealing a deepened understanding throughout the data analysis process. However, at times my experiences, beliefs and views appeared to impinge on sections of the research process.

The hermeneutic phenomenological methodological framework, which underpins the conduct of the study and analysis acknowledges the researcher has pre-conceived understandings and as opposed to attempting to bracket it. I needed to remain aware that my beliefs did not dominate the interview process or dictate the analysis of data. One can claim the research exhibit both breadth and depth as verified by its design. The above-highlighted limitations have not weakened the quality of this exploration but could work as a basis from which future studies in this area can glean ideas to strengthen their conduct. Having applied a hermeneutic phenomenological approach as a 'guide' throughout the study and made use of the hermeneutic cycle to reach to the essential themes, it is now up to the reader of this work to make his or her judgement regarding the work.

9.6. Suggestions based on the findings of this research

While research of this nature does not yield generalisable findings, in this study, the application of a hermeneutic circle in all the participants' stories across the research has facilitated a contextualised understanding of experiences of dementia care and related EoLC for a small group of older African-Caribbean PLWD and group of family caregivers of the same ethnicity. Policy formulators and service providers should have a deepened understanding of the influence that culture and religion have on people's perceptions of dementia and EoLC. To improve EoLC for African-Caribbean PLWD and their families' attempts should be made to tackle late help-seeking behaviour (seeking help at crisis point & when the condition has advanced.

The importance of timely diagnoses and knowledge of the disease and understandings of how the disease progresses could be emphasised with families. Families and their relative with dementia can be encouraged to initiate an early discussion about the future and thus develop realistic planning for the future (Brown, 2014), although it is clear from the findings of this study that such conversations are not natural for carers to initiate (Barclay & Maher, 2010). Current strategies aimed at combating the stigma of dementia and formal care and support use could encourage early help-seeking. In research, the participants represent a seldom-heard group, and in practice, the group typifies a sidelined group who have been found to experience significant healthcare-related inequalities. This research has highlighted the meanings attached by this group to living with dementia and providing care to a relative with dementia in relation to EoLC. Understandings made from their stories could be transferable to similar contexts with other marginalised groups.

9.6.1. Implications for Policy and practice

This research project has demonstrated that cultural and religious factors strongly bear a significant influence on how African-Caribbean PLWD and their family caregivers' experience living with dementia and providing care, including their understanding of EoLC. For PLWD, the impact that culture and faith extend to how they negotiate meanings throughout their journey with dementia and during the times when they face the EoL, and for current and bereaved family carers, their cultural beliefs, and faith-related views of what is expected of

them has a significant influence on how they live with uncertainty and come to terms with grief.

Therefore, practitioners who provide dementia-related care to African-Caribbean communities should ensure that they address cultural and religious needs. It is also crucial that practitioners working with African-Caribbean communities ensure they understand the complexities associated with the position held by family members and the expectations of care by those at the receiving end. This requires a suitable level of cultural competence in practice, particularly when a need to enhance knowledge surrounding the prognosis of dementia and EoLC is the overarching goal for practitioners. This is not to overlook the inherent difficulties associated with unpredictable illness trajectory of prognosticating advanced dementia. Nonetheless, there are implications on the quality of life of PLWD associated with the failure in delineating between advance dementia and whether the person is at the end of their life.

Older African-Caribbean PLWD and their families should have the opportunity to initiate early discussions about the future. However, this can be achieved when people from these groups are diagnosed at the earliest stages of dementia. Given that most minority groups present late in dementia services, there is a need for a targeted campaign in which information about dementia is sensitively communicated. Foremost in improving the EoLC experiences for minority ethnic PLWD and their families is a need to reach out to minority ethnic groups. This can be achieved when practitioners shift their perceptions towards avoiding the current dominant narrative that categorises minority groups as 'hard to reach'. The danger here is that such terms can become a barrier to exploring meaningful ways of working with people from minority ethnic communities further perpetuating the uneasy relationship with mainstream services that these groups currently have.

Therefore, policy in dementia and EoLC should make an emphasis on culture and religion as critical factors in person-centred quality EoLC for African-Caribbean PLWD as these factors have a significant influence on how they wish to be cared for at the EoL.

9.6.2. Inclusion

There is a need for great care when using terms such as 'hard to reach' can become a barrier to reaching out to people from minority groups in research and practice. Inclusion of these groups is vital as dementia is on the increase (Adelman et al., 2011). Issues about culture and faith (as

shown in this research) will continue to exist, calling for practical understanding of how these influences the uptake of services among UK minority groups. For instance, if African-Caribbean people value/prefer providing care to their relative with dementia, instead of stereotyping them as 'the look after their own' care services must be adjusted to encompass their needs. Nonetheless, the use of focus groups encouraged a discussion on EoLC, which is an emotionally charged topic area.

Furthermore, the recruitment of participants was based on their understanding of their condition and their wish to participate on that basis. Therefore, it is possible that many PLWD who were not aware of their diagnosis of dementia were excluded from participating, thus limiting the scope of data. There is a need for a framework that encourages PLWD to make their own choices in respect of self-determination. For example, their family members under an assumption that they were likely to find it difficult to express their views discouraged two prospective participants who initially showed an interest in participating in the study. While understandable, this can deny PLWD their right to engage in research. Alzheimer's Europe (2017) advises that 'researchers should ensure that they listen to the voice of the person with dementia and not to that of the carer' (p. 3).

9.6.3. Directions for future research

The literature about BAME family caregivers' experience of dementia in relation to EoLC remains strikingly scant. This is a cause for concern as the UK minority ethnic population is ageing, meaning many will develop and die with/from dementia. The use of USA based literature in this research, in which the experiences of minority ethnic groups is different from the UK evidences a need for further investigation. Further research on EoLC for people with dementia from minority ethnic groups is required to keep abreast with the current tide on which quality care that is responsive to individuals' needs lies at the core of the definition of quality care.

One finding of this study that warrants further investigation is around the cultural meanings that appear to underscore caregiving and conceptualisation of EoLC. Results from this research have indicated the interplay between participants' limited understandings of dementia, late presentation to services, delayed diagnosis, future care planning and the person-centeredness of EoLC. Access to and researching this group of people requires researchers to invest in building trust using engaging prospective participants in the discussion about the research

process. While being an 'insider' in this research could be construed as a strength, further research could benefit from researchers who identify themselves as 'outsiders' as they can be able sufficiently to detach themselves from the participants' experience to obtain a more 'objective' understanding of dementia and associated EoLC.

Future researchers may wish to consider using focus groups with people with dementia, given the success of this method in this research. Researchers who want to conduct primary research on minority ethnic groups may wish to build trust as the basis for successfully recruiting participants. This trust requires sensitivity to ethnic minority groups; a good example is how older Caribbean people in this study preferred to be called Mr. and Mrs., rather than their first names. While this may be taken for a valueless claim, it meant respect in the eyes of the older people and was the bridge to establishing a trust for participation in this research. I based on my lived research experience of conducting this research recommend that researchers who wish to engage in research with African-Caribbean successfully should ensure they offer an opportunity for prospective participants to express their concerns. This may mean supplementing information sheets with talks (though this should not affect the research itself). This extends to ensuring that the gatekeepers (relatives of PLWD, care home managers and others who are in a safeguarding position) are well versed about the study, as, without their permission, the recruitment process may not be entirely successful. Future research may broaden this work by recruiting participants from various locations given the variations in ways of living and the influence that may have.

9.6.4. Strengths and Limitations of the research

Participants in this research were from black African and African-Caribbean by background. Despite sharing similarities as being of minority ethnic group background, their experiences are different based on migration reasons and historical events. Although exploring these differences was not the focus of the research, their perceptions of EoLC and understanding of health-related issues is informed by these background experiences. Of interest in this research was to understand the lived dementia experiences and perceptions of EoLC from convenient group of older who self-identified as being African/Caribbean. Although researching people who are from black African and black Caribbean as one group raises questions around shared experiences, this research was interested in the meaning structures of subjective experiences.

Another limitation to note was that during focus groups, there was a tendency by the participants to speak over each other. Despite this, participants communicated their lived dementia care experiences and their wishes, needs, and hopes for EoLC. Given that this group of people have been categorized as being 'hard to reach' this research allowed their voice about an issue which concerns them to be heard. There were also times that two participants stood up and walked around and back during the focus group. These issues were expected, what was important was to assist PLWD to have their views heard. Overall, while focus groups yielded a rich data set in this study, I suggest that more than one researcher should attend when using focus groups for data collection with PLWD. Having more than one person offers an opportunity to support participants with dementia to participate in research who may become disorientated to time and place to be provided with reassurance while continuing with the interview. Based on my experience in this study, this is integral in conducting focus groups successfully with PLWD.

9.7. Concluding comments

Before this research project, EoLC for minority ethnic groups has not been explored exhaustively from their perspectives. This research investigated the lived experiences of dementia care and perceptions of related EoLC among a group of older African-Caribbean PLWD, current and bereaved caregivers within the UK. Although it is not the aim of phenomenological research to generalise findings, this research has contextualised experiences and perceptions – lived and experienced versus hopes and expectations of care at the EoL for community-dwelling African-Caribbean PLWD. The thesis presented new insights into how older African-Caribbean PLWD and their family caregivers negotiate their meanings associated with dementia and their perceptions of quality culturally sensitive EoLC through the lens of their faith and culture as reported in the review of the literature (Bolt et al., 2019).

EoLC for PLWD is a complex phenomenon drawing on how people understand dementia as a progressive condition. When faith and culture are brought into the equation, as demonstrated in this research project, the provision of EoLC calls for more emphasis on cultural competence among healthcare professionals, especially considering the increasing cultural diversity within the UK and the near future increase of dementia prevalence among minority ethnic groups, including African-Caribbean communities (Regan, 2014). Faith, particularly Christianity, is at the core of everyday lives of most African-Caribbean communities. Religion and culture are used as the lens by which these groups view their selves in the healthcare arena, and it is from

it that they relate to services. For older African-Caribbean PLWD, care should be provided by the family, and for many, their wish is to die in their own home as it is a place synonymous with peace at the EoL.

For the bereaved African-Caribbean family caregivers, who provided care to a relative with dementia towards the EoL, their lived experience was described in terms of living with uncertainty and continuous change when in the position of caregiving, but that 'God knows what He is doing' whenever such existential challenges present themselves. Bereaved family caregivers' narratives showed how they face bereavement with regret of knowing they should have done things differently if they had a good understanding of dementia at the onset of their caregiving journey. Perhaps a critical need to be considered is to ensure post-diagnosis support to patients should also consider enhancing the family caregivers' understanding of dementia and expectations. This is likely to enable difficult discussions and ACP to be initiated early, thus helping both the person with dementia and their families to develop a sense of preparedness, including the promotion of their autonomy, quality of life and control over the care they receive at the EoL.

For some current African-Caribbean family caregivers, God 'is the giver of strength' and the EoL of the relative with dementia is perceived as the end of suffering and caregiving. Fear of being misunderstood by others acts as a barrier to accessing support services caregiving is regarded as an obligation. In all the three studies, I found that experience was seen through the lens of religion and culture. This research suggests that carers experience significant levels of stress, partly due to worries of making wrong care decisions. This is commonly experienced by family carers, as pointed out by Payne and Grande (2013) in Chapter 2 who suggests that carers face various difficulties not only from burdens of caregiving but from the emotional aspect of dealing with things in the face of the impending EoL for their relative.

In the context of EoLC for BAME people with dementia within the UK, as far as the review of literature highlighted in Chapter 2, and as recently signposted by Koffman (2018); this piece of research responds to calls for inquiry in this area. The study has captured the lived experience of older African-Caribbean people with dementia and current and bereaved family carers in relation to dementia care and related EoLC. Their stories offer a fresh and in-depth look into meanings these groups attach to perceptions of dementia, dementia care and EoLC. The study encouraged the voice of older African-Caribbean to be heard in research. The application of 'hermeneutic circle' (Fig 1) allowed me to interpret the meanings embedded within PLWD and

family caregivers' accounts to illuminate the essence of what it means to be an African-Caribbean living with dementia and what it is like to be an African-Caribbean family caregiver to a relative with dementia at the EoL.

The research has affirmed the application and value of the hermeneutic phenomenological approach in exploring the often taken for granted aspects of people in health and social care. The three studies that make up this thesis all illuminates the influence that culture, ethnicity, and religiosity shape people's perceptions of living with a life-limiting condition while also highlighting a need to understand the diversity within the UK's minority ethnic group. Some of the common findings previously reported in other studies leading to different understandings have, in this thesis, been interpreted as grounded in the participants own narratives about EoLC – which, itself, is an angle by which this thesis contributes. For example, people from BAME groups often present late to services. Interpretation of how these can impact on the person-centeredness of EoLC has been made.

Another strength and perhaps a unique contribution that this study make is allowing the less heard or 'hidden' voice of older African-Caribbean PLWD as well as their family carers' to be heard in an issue which concerns them. The importance of understanding people's religious and cultural explanatory pathways of their health and illness, including use of available services is stressed by NICE (2018) who suggest a need for health and social care providers to understand how to work efficiently with 'cultural, ethnic, religious or other diverse backgrounds (p.6).

However, without raising awareness of dementia and reaching the 'hard to reach' to signpost BAME PLWD and their families to relevant services, cultural competence in practice are likely not to be any use. Therefore, based on findings in this study, an overarching approach to the improvement of the experience of BAME communities and the uptake of palliative and EoLC services is to target the assessment and diagnosis phase within the dementia care pathway, as it is this point that the person-centeredness of EoLC is dependent upon and should be. Person-centered in that future care discussion can be initiated timely after diagnosis allowing the voice of the person with dementia heard in ACP. As a result, having their wishes rather than their families' or professional is incorporated into the care they receive at the end of their life.

Overall, insights from this phenomenological study highlight how cultural, religious, and spiritual dimensions of dementia interconnects in the understanding of quality, culturally

responsive and personified EoLC. Indeed, as Clarke and Phillips (2010) notes, delivering appropriate EoLC for people from various backgrounds necessitates those who provide the care to be culturally informed – to the least, and to prioritise cultural sensitivity via cultural competence. To be fully recognised in the UK, in Canada, the Canadian Institute of Health Research (2007) acknowledges that the practices and values held by a health professional who delivers EoLC is key to encouraging the creation of trust in and use of services by people from minority groups who currently do not fully utilise them. This requires the health care system to appreciate the intimacy between culture, ethnicity and use of EoLC services within the population it serves and ensures its service delivery of quality care.

The findings in this study suggest that older African-Caribbean PLWD expect care from their family and prefer to remain in their own homes until they die. Family caregivers habitually perceive their caring role as an obligation and often do so in adherence to their cultural and religious belief system, even when under immense strain. Accessing formal care support is highly stigmatised, and accepting such services is highly stigmatised, as shown by the caregivers' concern of being a failure in providing care to a family member. Fear of being 'evil' and the possibility of the family's 'image' being tarnished by accessing formal care play as a barrier and represent a complex belief system which is interwoven into culture and religion. When all the above beliefs are added onto the fear of blame that most participants expressed in this study, coupled with the stigma attached to dementia by the broader community, accessing EoLC care services could remain an issue for BAME groups, enhancing cultural competency may acknowledge that such beliefs and can be a way engaging well with BAME groups, which then may facilitate the delivery of person-centred EoLC which validates respect for this group's healthcare beliefs.

To conclude, having heard the voice of older African-Caribbean PLWD and family caregivers about a phenomenon that directly affects them; I move on from here with a different understanding of the research process. I also hope the reader of this work would have a feel of what it means to be an older black African-Caribbean person living with dementia and what it means to be a black African-Caribbean family caregiver to a relative with dementia in the context of EoLC.

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APPENDICES

APPENDIX 1: Letter for support from the day centre

SADACCA Limited
(Sheffield & District Afro-Caribbean Community Association Ltd)

48 Wicker,
Sheffield,
S3 8JB

Telephone: (0114) 2753479
E-Mail Address: admin@Sadacca.org
Charity No 702393

Date: 9th March 2016

Dear Tim,

Thank you for visiting us here at Sadacca and making enquiries about the research work you would like to do within our organisation. We also thank you for informing us about your End of Life Care in Dementia research studies.

SADACCA is a community organisation aimed at helping and supporting all African Caribbean people living in and around Sheffield as part of a wider community.

We are willing to support you in the identification of potential participants who would be interested in your research.

SADACCA is also interested in the research you are undertaking on the whole and would like to stay informed about your progress, findings and results.

We would like you to come and have a discussion with some of the ladies and gentlemen who visit this establishment. We are sure they will find it very valuable and informative.

If you have any further questions, queries or support needs, please do not hesitate to contact me on the number above.

We look forward to hearing from you in the near future.

Yours Faithfully

Theresa Smith B. Ed. NLP Dip.
Voluntary Overall Co-ordinator.

APPENDIX 2: Study 1 leaflet (Focus groups)

End of Life Care in Dementia: An exploration of the views of community-dwelling Black, African-Caribbean older people with dementia and their family carers in the north of England.

WHY THIS STUDY IS IMPORTANT:

The purpose of this study is to find out more about what people experiencing some memory problems think is important at the EoL. The main purpose of the study is to gain an understanding of how people with memory problems would like to be looked after at the EoL. If you have memory problems, your views will help us understand more about future choices, preferences and wishes including an understanding of how and when to have discussions about future care and where most people choose to be looked after at the EoL.

This is an important part of care for those nearing their EoL as it ensures maintenance of comfort and dignity up until the end.

WHAT ARE THE BENEFITS OF TAKING PART?

We do not know enough about how to support people with memory problems who are nearing the end of their lives. People who are experiencing memory problems have been left out in many previous research studies. This may mean that what we know as important about the care at the EoL may not be the case.

Your contribution in this study is important as it will help expand our understanding of this important type of care.

I strongly believe that your views will be valuable. The ideas you share may be useful to EoL care service providers in our community and may be helpful towards improving the service they deliver; **however, you will remain anonymous in all publications unless otherwise, you choose not to.**

I would like to talk to older people who are:

-Of African-Caribbean background

-Experiencing some memory problems.

-Able to understand the aims and objectives to give informed consent.

-Live independently in the community and happy to have a discussion as a group.

APPENDIX 3: Study 2 Leaflet (family carers)

I would really appreciate your participation in this research as your involvement is very important. If you would like to have a chat about participating in this study or have any questions or concerns, please do not hesitate to contact me directly:

Tim Dlamini. Mobile: xxx Office: xxx

Email: themba.dlamini@hud.ac.uk

End of Life Care in Dementia: An exploration of the views of community-dwelling Black, African-Caribbean older people with dementia and their family carers in the north of England.

Who is eligible to take part?

I am also interested in talking to people who:

- Are family carers (family member or relative) who are or has previously cared for a person with dementia from African-Caribbean background.
- Over 18
- Can communicate in English
- Willing to share their experiences

WHY THIS STUDY IS IMPORTANT

The purpose of this part of a larger study is to talk to family carers about their own experiences of giving care to a person with dementia and to discuss further their views and perceptions about what is important at the end-of-life care. Together with information obtained from people who have memory problems in the first part of the study, your views/ perceptions and experiences as a current carer or a previous carer will provide some important insights about dementia and end of life care.

Going a step further to talk to family carers will offer another perspective about experiences and future choices, preferences and ideas of the end-of-life care of people with dementia from carers' point of view. If you are a current carer or if you have been a carer before, your' insights on this key issue are very important as it allows you to talk about your own views and perceptions, hopes and wishes and your lived experiences. Your contribution is very important and valuable in this key area in order to help understand the experience of family carers.

WHAT ARE THE BENEFITS OF TAKING PART?

We do not know enough about how people with dementia from African-Caribbean communities would like to be supported at the EoL. We also do not know what family carers see as important in their role and what quality care at the EoL for people with dementia should look like. I strongly believe that your views as carers are very important in furthering our understandings of this area. The information gained may be passed on to end of life care service providers in our community and may help improve this important type of care however you

will remain anonymous in all the reports. At the end of the research, you will be offered a summary of findings through this will entirely be your choice.

APPENDIX 4: Participant Information Sheet -focus groups

I would really appreciate your participation in this research as your involvement is very important. If you would like to have a chat about participating in this study or have any questions or concerns, please do not hesitate to contact me directly:

Tim Dlamini. Mobile: xxx Office: xxx

Email: themba.dlamini@hud.ac.uk

University of HUDDERSFIELD
Inspiring tomorrow's professionals

Title of Project: **End of Life Care in Dementia: An exploration of the views of community-dwelling Black African-Caribbean older people with dementia and their family carers**

You are being invited to take part in this study which aims to find out more about how the end-of-life care for people with memory problems can be better understood and improved. Before you decide to take part, it is important that you understand why the research is being carried out and what it will involve. **Please take time to read the following information carefully and talk to me about it if you wish**. Please do not hesitate to ask if there is anything that is not clear or if you would like more information to help you understand more about this research.

What is the study about? We know less about how people with memory problems from minority ethnic backgrounds in our communities approach the EoL, and what makes quality care at the end the end. To expand knowledge in this important area, it is important to consider people's views and experiences including your own, as you are from African-Caribbean background from whom this study aims to focus. We will talk to you about what you think is important to you and what you feel can be done to improve care at the EoL for those with memory problems.

Why have I been approached? You have been approached to join and share your views because you are from the relevant group of people from whom the study seeks to obtain information about memory problems and end of life care. **There is no obligation to participate; it is your choice to be involved**.

Do I have to take part? It is your decision whether you take part. If you decide to take part, you will be asked to sign a form to as part of your agreement to share your views, and you will be free to withdraw at any time without giving a reason. **A decision to withdraw at any time, or a decision not to take part, will not affect you at all**.

What will I need to do? If you agree to take part in the research, you will be invited to a discussion where you and others who have expressed an interest to contribute will talk and share views about your current care and talk about what you think is more important for people nearing the EoL. We will also talk about some related area around how you are managing with memory problems.

This would last approximately 1 hour – 2 hours and you will be asked for your agreement for the discussion to be audio-recorded for the study.

Will my identity be disclosed? Others will not know all information disclosed within the interview except you and others in the group, and whatever your own words will not be identifiable as yours and you will remain anonymous except where legal obligations would necessitate disclosure by the researcher to appropriate personnel to prevent and protecting you from harm. While the researcher will ensure that confidentiality is maintained, we cannot promise this on behalf of other participants, although it will be requested before and after the discussion.

What will happen to the information? All information collected from you during this research will be kept secure in a locked cabinet at the university and will be used for the research purpose. Anything which can allow you to be identified, such as your name, will be removed in order to ensure you remain anonymous. It is anticipated that the research may, at some point, be published as a report, should this happen, you will remain anonymous. The information you will have provided will not be identifiable as yours although it may be necessary to use your direct words in the presentation of the findings and your permission for this is requested in the consent form that you will be asked to sign before participating in this discussion.

Who can I contact for further information?

If you require any further information about the research, please contact me:

Tim Dlamini; PhD student: End of Life Care and Dementia.
Centre for Applied Psychological Health Research
School of Human & Health Sciences
University of Huddersfield
HD1 3DH
Email: u1163916@hud.ac.uk. Telephone: 01484472526

In case you have any concerns regarding the study, please do not hesitate to contact my supervisors:

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APPENDIX 5: Participant Information Sheet (Current family carers).

Title of Project: **End of Life Care in Dementia: An exploration of the views of community-dwelling Black, African-Caribbean older people with dementia and their family carers**

You are being invited to take part in this study which aims to gain an understanding of the end-of-life care for people with dementia from your views as a current or previous caregiver. Before you decide to take part, it is important that you understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information about the study.

What is the study about? The primary goal of this study is to explore the end-of-life care for people with dementia. Less is known about how people with dementia from different backgrounds in our communities' approach end of life, and what constitutes the good quality end of life care. This study aims to expand current understandings of the end-of-life care and may be useful to service providers to deliver quality care for those approaching the end of their lives. To do so, it is important to obtain your views and perceptions regarding the end-of-life care based on your 'lived experience' as a current or bereaved carer for a person with dementia from African-Caribbean background.

Why have I been approached? You have been approached because you have been identified to be either actively giving care or as having previously cared for a person with dementia from the group of people from whom this study seeks to explore views and perceptions for expanding our current understandings of dementia and related end of life care among African-Caribbean people.

Do I have to take part? It is your decision whether you take part. If you decide to take part, you will be asked to sign a consent form. However, you will be free to withdraw from participating at any time without giving a reason. You will also be able to request information

collected from you to be destroyed before the process of analysis and writing up of the report. Your decision whether to withdraw or not to take part will not affect you at all.

What will I need to do? If you agree to take part in this research, you will be invited to a face-to-face interview in a secure confidential office where you will be asked about your views, experiences, and ideas regarding the end-of-life care drawing from your caring experiences. This would last approximately 45 minutes -1hours and you will be asked for your permission for the interview to be audio-recorded for the purpose of writing a report. Should you indicate a wish to receive a final report of the study, a copy of summary of key findings will be sent to you at the end of the study.

Will my identity be disclosed? All information disclosed during the interview will be kept confidential, and you will remain anonymous except where legal obligations would necessitate disclosure by the researcher to appropriate personnel for the purpose of preventing harm, although this is unanticipated.

What will happen to the information? All information collected from you during this research will be kept secure in locked drawers in a locked office at the University of Huddersfield for 5 years and will be used for research purposes. The researcher and supervisors will be the only people who have access to the information. Any identifying material, such as your real name and place of interview will be anonymised using a unique number or a fictitious name which you will be asked to choose during the interview.

It is anticipated that the research will, at some point, be published in a journal or report, should this happen, your anonymity will be maintained, although it may be necessary to use your own words in the presentation of the findings.
Your permission for this is included in the consent form that you will be asked to sign before participating in the interview.

Who can I contact for further information? If you require any further information about the research, please feel free to contact me on:

Tim Dlamini; PhD student: End of Life Care and Dementia.
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In case you have any concerns regarding the study, please do not hesitate to contact my supervisor:
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Room
Harold Wilson Building
HD1 3DH
Email: s.kendal@hud.ac.uk Telephone:
01481473369.Professor Nigel King
University of Huddersfield
Room HHR 202
Email: n.king@hud.ac.uk Telephone 01484472812

APPENDIX 6: Consent form

Title of Research Project**: End of Life Care in Dementia: An exploration of the views of community-dwelling Black, African-Caribbean older people with dementia and their family carers.**

It is important that you read, understand and sign the consent form. Your contribution to this research is entirely voluntary, and you are not obliged in any way to participate, if you require any further details, please do not hesitate to contact me on the details below.

I have been fully informed of the nature and aims of this research □

I consent to take part in it □

I understand that I have the right to withdraw from the research at any time without giving any reason and that I can request information already collected from me to be destroyed only up until the point of analysis □

I give permission for my words to be quoted (by use of a pseudonym) □

I understand that the information collected will be kept in secure conditions for a period of five years at the University of Huddersfield □

I understand that no person other than the researcher/s and facilitator/s will have access to the information provided□.

I understand that my identity will be protected using a pseudonym in the report and that no written information that could lead to my being identified will be included in any report □

I understand that my family caregiver may also be requested to participate in this research□

If you are satisfied that you understand the information and are happy to take part in this project, please put a tick in the box aligned to each sentence and print and sign below.

Signature of Participant: Print: Date:	Signature of Researcher: Print: Date:

APPENDIX 7: Participant invitation Letter for focus group study: PLWD

Dear Sir/Madam

I am a PhD research student under the supervision of Dr Alex Bridger, Dr Sarah Kendal and Professor Nigel King based at the University of Huddersfield and would like to invite you to look at the information sheet enclosed regarding a research study that I am undertaking. The research aims to learn more about how care at the EoL for people with memory problems from African-Caribbean backgrounds can be better understood and improved. To do this, I would like to talk to you about what you think is important at the EoL based on your experiences with memory problems.

Your contribution to this project would be invaluable.

I know from my experience as a community crisis care worker that there are some areas of improvements to be made such that those who provide care to people nearing the EoL can give care that suits people's individual needs and preferences.
For these improvements regarding care end of life, your contribution and insights on this topic will be very useful in this study.

In the previous research studies, people with memory problems have not been fully involved in projects that may have had some influence on the care they receive. Given this oversight, this study aims to hear your voice as we believe you say is equally important in this matter.

This is an opportunity to share your views about what you think is important to you.

I will be interested in your opinions and views but recognise this might be a sensitive area. Therefore, during the discussion that you and others who will express their interest will take part, I will be aware of this, and I will be receptive and alert to how you feel and how much information you wish to share. It is hoped that the project, which has been approved by University of Huddersfield Research Ethics Committee could be useful to providers of end-of-life care towards an understanding your needs and to make future improvements in providing quality care for those nearing EoL.

The information sheet that I have attached gives you further information about what the research study is about and why it is important to look at this in our communities. It also gives further information about what the research hopes to achieve and what will happen if you choose to be involved.

There is no obligation to participate in this study; however, your contribution would be very important should you decide to participate.

Please, could you sign and send me back the reply slip overleaf to indicate your interests to participate or if you wish to talk to me further about this study. A prepaid envelope has been enclosed for you to send the slip back.

Sending this back does not commit you to take part at all. You can still change your mind even after expressing your interests to participate in the study.

Please feel free do to contact me if you have any questions about this research.

Tim Dlamini; PhD Candidate: End of Life Care and Dementia.
Centre for Applied Psychological Health Research
School of Human & Health Sciences
University of Huddersfield
HD1 3DH
Email: u1163916@hud.ac.uk. Telephone: 01484472526.

Dr Alexander Bridger
University of Huddersfield
Ramsden Building

HD1 3DH
Email: a.j.bridger@hud.ac.uk.Telephone: 01484472572

Dr Sarah Kendal
University of Huddersfield
Harold Wilson Building
HD1 3DH
Email: s.kendal@hud.ac.uk.Telephone: 01481473369.

Professor Nigel King
University of Huddersfield
Room HHR 202
Email: n.king@hud.ac.uk Telephone 01484472812

Please tear off the slip below and send it back using the envelope provided by (date).

……
……

I am happy to be contacted to discuss more the study **yes/no**.

If yes, please indicate your preferred method of contact by ticking in the box across in the following few sentences

I am happy to be contacted at home by the researcher to discuss this further ☐

I would like the researcher to pay me a visit at home or at the day centre to discuss further ☐

Once I get time, I will contact the researcher ☐

Name…

Signature…

Thank you for your time

APPENDIX 8: Participant invitation Letter (Family carers)

Dear Sir/Madam

I am a research student being supervised by Dr Alex Bridger, Dr Sarah Kendal and Professor Nigel King based at the University of Huddersfield. I would like to invite you to look at the information sheet enclosed regarding a research study that I am undertaking.

The project aims to learn more about care at the end of life for people with memory problems from African-Caribbean communities. To do this, I would like to talk to you about what you think is important based on your experience of caregiving to a person who has memory problems. Your contribution to this project would be invaluable.

I know from my experience as a community health worker that there is a need to increase our understanding of people's preferences and choices towards the EoL so that they can receive the care and support

In previous research studies, family carers for people with dementia have not been fully involved in projects that could have helped to improve the care that their relatives receive. Therefore, this study aims to include your voice. As you have cared or are currently caring for someone with dementia, your insights on this topic are very important. Although I am very interested in your opinions and views but recognise this might be a sensitive issue.

Hence, when conducting the interviews, I will be sensitive and alert to how you feel and how much information you wish to share.

It is hoped that the project will improve our knowledge about dementia and related end of life care and may be useful to service providers and policymakers.

The enclosed information sheet gives further information about what this research study is about and why it is important to look at these issues in our communities. It also gives further information about the aims of the study and what will happen if you decide to participate. There is no obligation to participate in this study. However, your contribution would be very important should you decide to participate.

The project has been approved by the University of Huddersfield School Research Ethics Committee

Please, could you sign and send me back the reply slip overleaf and send it back in a pre-paid envelope provided to indicate your interests to participate or if you wish to talk to me further about this study.

Sending this back does not commit you to taking part at all. You can still change your mind even after expressing your interest in participating in the study.

Please feel free to contact me if you have any questions about this research.

Tim Dlamini; PhD Researcher: End of Life Care and Dementia.
Centre for Applied Psychological Health Research
School of Human & Health Sciences
University of Huddersfield
HD1 3DH
Email: u1163916@hud.ac.uk
Telephone: 01484472526

In case you have any concerns regarding the study, please do not hesitate to contact my supervisor:

Dr Alexander Bridger
University of Huddersfield
Ramsden Building
HD1 3DH
Email: a.j.bridger@hud.ac.uk.Telephone: 01484472572

Dr Sarah Kendal
University of Huddersfield
Room
Harold Wilson Building
HD1 3DH
Email: s.kendal@hud.ac.uk.Telephone: 01481473369.

Professor Nigel King
University of Huddersfield
Room HHR 202
Email: n.king@hud.ac.uk Telephone 01484472812

Please tear off the slip below and send it back using the envelope provided by (date).

……..

I am happy to be contacted to discuss more about the study **yes/no.**

If yes, please indicate your preferred method of contact by ticking in the box across in the following few sentences.

I am happy to be contacted at home by the researcher to discuss this f…ther ☐

I would like the researcher to pay me a visit at home or at the day centre to discuss …ther ☐

Once I get time, I will contact the researcher

Name…
Signature…

Thank you for your time

APPENDIX 9: Distress protocol & Useful Helpline Numbers

If participants show any signs suggestive of distress, before, during and after the interviews, I will take the following actions:

Before the Interview: There would enough time allocated to ensure participants are relaxed before the interview begins. I will consider delaying the interview to ensure all participants are ready to participate. Should there be indications of distress behaviour, I will talk to the participants and see if I can help. Alternatively, I will request support from the staff within the day centre. If it is at the participant's own home (carer interviews), based on the level of distress, I will ensure I discuss with the participant and agree whether to continue with the interview process or plan to have the interview completed on another suitable day and time. I will also ascertain whether participants wish to continue with their initial interest to participate.

During the Interview Process: Should any participant show signs that suggest some form of distress along the course of the interview, I will discuss with the participant and consider to briefly stop the interview, allowing him/her time to calm down, or if the levels of distress are high, I will discuss with the participant and stop the interview. I will switch the Dictaphone off. I will ensure I signpost the participants to the right source for psychological help (useful local numbers would be provided). It would be important that the distressed participant is given space to express their feelings. Reassurance would be provided. It would still be important that the participant is given an opportunity to participate. Therefore, a joint decision (the participant/s and I) will discuss and decide whether it would be appropriate to continue with their participation. Options to reschedule the interview would be provided to the participant/s.

Should the agreed plan be to re-schedule the interview, the trigger issues identified during the initial interview would be handled with sensitivity to ensure the participants' will to be involved and to get their voice heard is not unnecessarily stopped.

After the Interview: After the interviews, I will not leave immediately. I will spend time with the participant/s (should it be appropriate) to identify any signs that may suggest psychological harm/distress. I will encourage participants to reflect on the interview process if they wish so that I can identify their response to their participation. Should there be elements of distress, I will find ways to discuss sensitively with the participant with the aim of establishing if there is

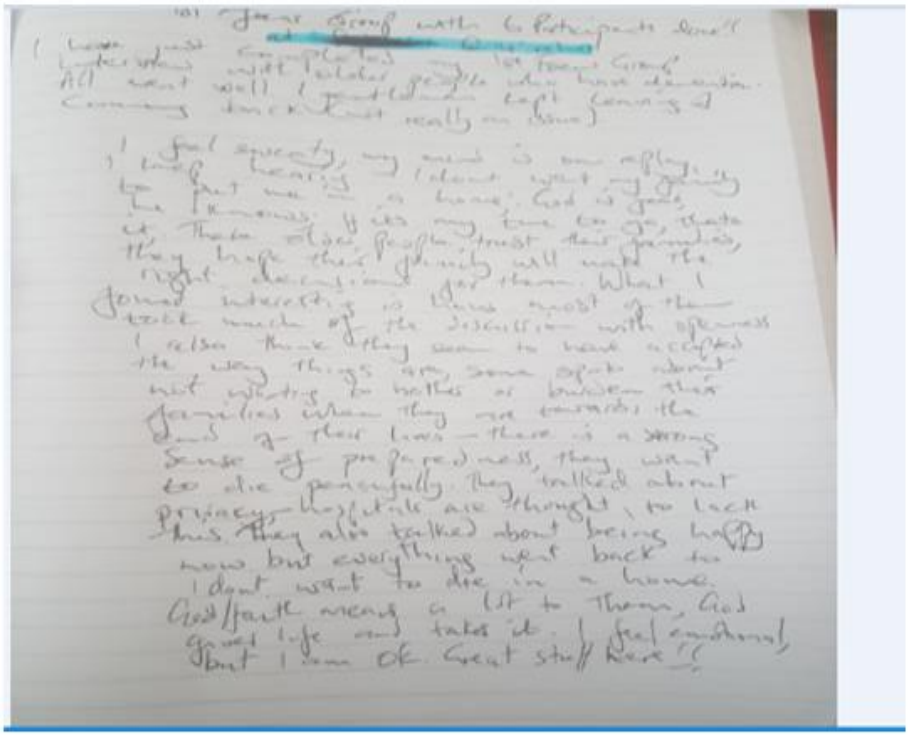
a need to seek professional help such as counselling services or self-help 24hour helpline (contact details as attached in this document). I will also ensure participants are aware that they can contact me within a reasonable time frame following the interviews, should they need to discuss their participation.

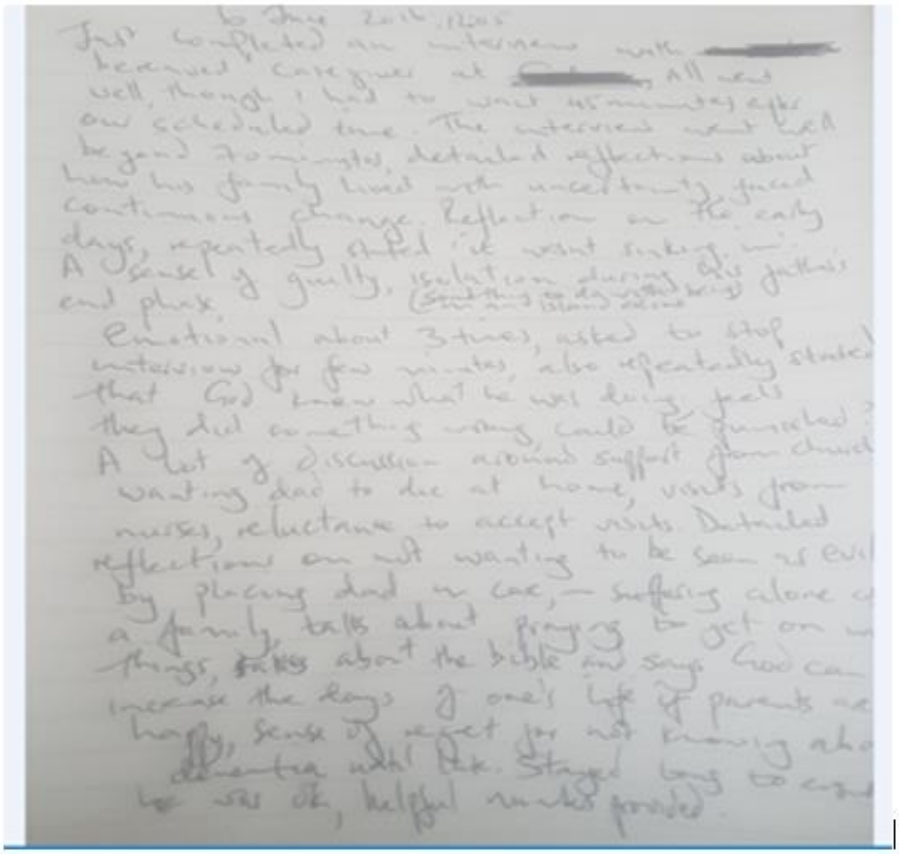
Above all, it is my primary responsibility as a researcher to protect all participants from physical and mental harm duringg the research process. The British Psychological Society (2018) ethics guidelines and values that includes upholding the privacy and confidentiality, respect for participants; shared values within communities; considerations of the broader impact of the research into the environment, issues of power; consent and self-determination guide my conduct and approach in this research.

Please note that this is not an exhaustive list but some useful contacts you may need.

1. The Samaritans: 24hour helpline, 7days a week (crisis and distress):
National: 08457909090
Sheffield Branch: 01142767277
2. Alzheimer's Society Dementia Helpline (provide information, support, guidance and signposting to other appropriate organisations):
National helpline: 03002221122
Sheffield Branch: 01142768414
3. Age UK Sheffield (general information): 01142502850.
4. Sheffield Carers Centre (support & Information): 01142788942.
5. Sheffield Afro-Caribbean Mental Health Association (Information and support): 01142726393.
6. IAPT Sheffield (Psychological help and therapies): 01142264380

APPENDIX 10: Extracts of my research diary reflections





APPENDIX 11: School Research Ethics Committee (SREC) favourable opinion notification & request for amendments

Hi Tim,

Thanks for sending through your amendments. There are one or two issues we would still like you to think about a little further, but we are happy to leave consideration of these issues to you and your supervisors, and we, therefore, **approve your project** on the understanding that you will do so.

- Your revised information sheet and participant consent form were not included with the amendments, though you described the changes very fully. We are approving your project on the understanding that the revised documents are scrutinised and approved by supervisors
- There are some remaining issues around consent which we would like you to discuss with your supervisors (no need to get back to SREP on these):
    - We agree with prioritising the wishes of the PWD if there is a disagreement with a carer as to whether the PWD should take part. Your idea of an opt-out slip for phase 1 sent home to carers also sounds acceptable, but you will need to discuss with your supervisors how you will ensure that carers have received this & you will need to phrase it carefully if there is a possibility the carer's wish for the PWD to opt out could be over-ridden by the wishes of the PWD to take part.
    - From your original application, it sounded as if 'gatekeepers' (i.e., staff at the organisation) were also being asked for their consent/approval for individual PWD to take part in your research. However, the consent form you have provided for gatekeepers refers to their consent for you to recruit generally, rather than their consent for a person to take part in your research. Therefore, it sounds as if you do not require gatekeepers to give you the OK to approach participants & I'm not sure you need the gatekeeper form you have provided.
    - Please, can you clarify with your supervisors & with [redacted] whose consent is needed for a PWD to participate & the role that gatekeepers will play? It sounds as if most of the PWD will be able to provide their own consent & we can see you have thought very carefully about consent in your original application & discussed with [redacted] so we are happy to leave this to you/supervisors / [redacted].
- We would advise you to think carefully about the format of any findings that you are going to provide to [redacted]. They seem very interested in your research, but it could be problematic to allow access to your thesis if they could guess the identities of service users from the quotes and info provided, especially if participants say anything about EoL care received from [redacted]. Perhaps you could write a summary report? If quotations from service user participants are going to be seen by others in

the service, then participants should be made aware of this on the info leaflet / consent form.

Good luck with the research - it's a very interesting project.

Dr Dawn Leeming

Deputy chair School Research Ethics Panel

School of Human & Health Sciences

University of Huddersfield, Queensgate, Huddersfield

HD1 3DH: Tel: +44 (0) 1484 473545; fax: +44 (0) 1484 473760

APPENDIX 12: Amendments to Proposal

THE UNIVERSITY OF HUDDERSFIELD
School of Human and Health Sciences – School Research Ethics Panel

Applicant Name: Themba Dlamini
Title of study: Exploring end of life care among community-dwelling African-Caribbean PLWD and family caregivers

	Amendments required	**Please explain below how you are addressing the required amendments.** Please refer to any revisions you have made to documents (if appropriate), indicating page & line numbers.[13]
Researcher(s) details	Tim Dlamini u1163916	
Supervisor(s) details	Dr Alex Bridger Dr Sarah Kendal Professor Nigel King	
Aim / objectives		
Methodology		
Permissions for study	Please provide evidence of written permission from senior management at [redacted], alongside the information you have sent to the organisation about their contribution and protection of participants and the organisation.	Find attached an email from [redacted] confirming their support.
Access to participants		
Confidentiality		
Anonymity		
Psychological support for participants	Please consider the risks of distress and your strategy for supporting participants in both the individual and focus group interviews. Given that this is an extremely sensitive area we would see the risk of distress as more than a 'remote likelihood'.	The researcher is aware that asking people questions about their views, knowledge, attitudes or life experiences, particularly related to "sensitive" phenomena such as the end of life may generate emotional responses. To prevent this, I will take great care in planning the research so that the participants' well-being, dignity, privacy, beliefs, and

[13] There is no need to amend and resubmit your SREP application form.

		cultural values are respected throughout the interviews. -Data collection in both phases of the study will begin with less sensitive questions to ease and relax the participants before getting onto questions about participants' experiences of dementia care and related end of life care. I will use my experience of working dementia care to communicate sensitively with PLWD and family carers. I will so adopt Krueger and Casey (2000)[14] focus group introductory statement to build rapport and ensure all participants are relaxed before beginning the interview process. -Throughout the research, I will be mindful of the terminology I use and how I present questions to avoid evoking painful memories that may cause distress to participants. -Where a participant displays distressed behaviour (e.g., tearfulness, shouting, withdrawal or other non-verbal indications of being unsettled); I will briefly stop the interview process and check whether the participant/s is fine. King and Horrocks (2010, p.58)[15] warn 'what you [researcher] should certainly not do is decide to terminate the interview without consulting the participant immediately'. -I will give the participant/s time to calm down (give reassurance and support as appropriate at that time) and will resume the interview process once I am certain the participant/s is ready. Participants will have to express that they are happy to continue verbally. -Should they continue to show signs of distress or discomfort; I will give them a choice to either continue with the interview on a later date or withdraw their participation completely. -Every effort will be made to ensure that participants are protected from harm as result of their participation - [redacted] has its support system in place which the researcher

[14] Krueger, R & Casey, M.A. (2000) Focus Groups: A Practical Guide for Applied Research (3rd Edition). Thousand Oaks, CA: Sage.

[15] King, N. & Horrocks C. (2010) Interviews in Qualitative Research, London: Sage Publications.

		will access should there be concerns regarding participants' and researcher's safety.
Data Storage		
Researcher safety/support (attach complete University Risk Analysis and Management form)	Please clarify where the interviews will take place and ensure this is clear on the information to participants.	All interviews (focus group and individual interviews with a family/carer) will be completed in a secure and safe office at [redacted] day centre-this has been discussed and agreed (see attached letter). However, an option to conduct individual or group interviews (more than one family member) at home will be accepted on the participant/s request. For the researcher's safety, I will: 1. Make contacts with the School's admin to log down interview times (start and finish). 2. I will also keep a charged mobile phone all the times and will ensure that close research students have my contact details. I will arrange that they check on me if I do not call them back or confirm the end of the interview (times to be determined by interview times). 3. I will also send an email to my supervisors to let them know how the interview went. (Risk Analysis Management form attached)
Information sheet	Check all participant information, letters and consent forms for grammatical and spelling errors. Please present the information in a more user-friendly format. If you want to use research terminology that may not be used on a day-to-day basis by your participants (e.g., consent form, confidentiality) please explain the terms and what it involves for the participant, or use alternative terms 'kept private', / 'sign a form saying you agree to.'. Also please explain what you mean by the end-of-life care & explain how the sensitive nature of the subject will be managed including what support is in place if they do decide to be involved.	Documents now all checked for grammatical and spelling errors as suggested by SREP. Layman's terms have now been used in participants' documents (information sheet, consent forms, and invitation leaflets) in substitute of complex research terminology. Information has been presented in short, direct and straightforward sentences to help participants to understand the aims and objectives of the project to decide their participation freely. In this research, end of life care (EoLC) refers to the support given to a person with advanced, progressive, incurable illness (e.g., dementia and cancer) to live as well as possible until they die. It involves the management of pain and other symptoms (palliative care) and the provision of psychological, social, spiritual and

	At various points in your documentation, you refer to 'family carers'. Please consider whether this is the most appropriate phrase if some informal carers are not necessarily family members. Please amend all documents (not just info sheet) or alternatively provide justification for focusing only on family members	practical support to the dying person. This type of care enables the supportive and EoL care needs of both the patient and his/her family to be identified and met throughout the last phase of life and into the bereavement phase (Department of Health, 2008)[16]. The title 'carer' has a broad meaning, but generally refers to paid professional carers, home helps, home care workers, volunteers and all paid care workers engaged under a contract of service. In this context, a 'family carer' is someone who is providing a significant ongoing level of unpaid care to a family member or friend who needs that care due to their dementia. Family carers generally have an emotional relationship and legal responsibility for the person for whom they are caring (Alzheimer's Society, 2014)[17]Moreover, their role may include management of the persons care, welfare and social needs. This study acknowledges this role and aims to explore family carers' lived experience of dementia care and related end of life care. What is it like to be a caregiver to a Black African-Caribbean person with dementia in the context of future EoLC? The research aims to gain an understanding of family carers' experience as lived not formal carers' experiences.
Consent form	Say if they agree that they need to tick each section as well as sign the bottom of the page. *Consent is being asked from 3 parties, the PWD, the gatekeeper	**Consent forms have been amended**: participants requested to tick each box and sign the bottom of the page if they agree. -The family/carer will be informed about the research (passive consent) and will be requested to send a slip back **ONLY** if they wish their relative not to participate (opt-out). Due to the vulnerability of this participant group, **it is an integral aspect of the research that** family/carer are notified about the research and participation of the cared for. However, in a situation where a person with dementia gives consent, but a family member expresses concern about their relative's participation in the study, the person with dementia's wish to participate will be respected

[16] Department of Health (2008) End of Life care strategy.
[17] Alzheimer's Society (2014) Dementia UK: 2014 edition.

	and the family/carer. Please clarify if all three are required to consent - what will you do if two out of the three parties consent? If you require three-way consent for the PLWD, you need a separate alternatively worded consent form for the family/carer and the gatekeeper for each individual participant.	provisions of the Mental Capacity Act will be followed. The gatekeeper will also be informed of such a situation, and written assent will then be obtained from them. ***2 Party Consent on each phase:** -Phase 1 (Focus Group with PLWD): Gate keeper's consent ([redacted] management) and participants (PLWD). -Phase 2 (Individual interviews with carers): Consent to be sought from gatekeeper [redacted] and family/carer (current or previous carers who attend the 'caring and coping with loss in dementia' session at [redacted] -Gatekeeper Consent Form attached
Letters		
Questionnaire		
Interview schedule		
Debrief	Participant and researcher debrief needs elaborating	Debriefing will occur immediately after interviews (detailed Distress Protocol to be followed) -I will ensure that all participants are given a full and clear explanation of procedures and the outcomes of the interviews. This will allow me to identify any harm or indication of psychological distress so participants will be promptly directed to internal [redacted] or external support (24 HR Helpline services) for psychological help. -A list of helpful numbers will also be provided to participants for later use (attached). -Participants will be given the researcher and supervisors contact information for any questions or comments about the research they may later have (King & Horrocks, 2010). -Participants will be informed about their ethical right to withdraw their data from the study and that if they wish to do so, they will

	Researcher debriefing	have to **only** do so before the 'writing up' stage of the research process. In summery the participant debriefing session will (see distress protocol) 1. Ensure that participants leave with a positive feeling about the research. 2. Look out for signs of distress and sensitively approach the participant. I will ask the participant how they feel about the study and their participation as a way of identifying any harm. 3. Make the purpose of the study clear and give participants time to reflect on their participation which in turn will be an opportunity for me to notice any signs or indication of psychological harm. 4. Explain considerately how and why the study is being undertaken and offer participants the choice to request an abridged report at the completion of the study. If the researcher experiences any personal distress because of an appointment with a participant/s or after interviews, he will discuss the incident with his supervisors at the earliest convenience for support.
Dissemination of results		
Other issues		
Where an application is to be made to NHS Research Ethics Committee		
All documentation has been read by supervisor (where applicable)		

Signed:

_____T. Dlamini_____
(SREP Applicant – electronic signature acceptable)

Date: _____10/03/2016_____

Additional comments by reviewers: (You are not required to address these issues in order for SREP to approve your application. However, their consideration is likely to improve the ethical conduct of your research further.)
• You could consider providing an option for individual or group interview when there is more than one carer. **A consideration for group interviews was addressed in the methods section** • It is complicated to allow participants to withdraw after focus group data has been collected. Please consider how this will be done and if necessary, amend the information sheet. (Information sheet amended participants informed that once they contribute to the focus group discussion it would not be possible to withdraw their data, however, their words will not be used in the write up of the findings). • Could you use a more friendly/ available photo? **Original photo on study leaflet changed to a friendlier one** • You could consider further how revisiting of consent will be managed in the focus group setting.

Kt/SREP_/Amendments _Form/SeLeroy1

APPENDIX 13: Loosely framed Focus Interview schedule

Experiences, views and perceptions on end-of-life care	**Views on advance care planning (ACP)**	**The experience of living with dementia**
What is a good end of life care? What is important at the end of life? **Prompts**: who is expected to provide the care) Choice and place of death Preferred place of death and why? **Prompts:** -Dying at home -at hospital -at a hospice -care home environment What is important to you at the EoL? How would you like to look after at the EoL? Why? Concerns?	From your experience of living with dementia/memory problems, what are your future plans? What comes to your thoughts when you think about the EoL? Prompts: Knowledge and understandings How can communication be facilitated between family and the person with dementia at an early stage? How and when would you like a discussion about future care? Who should initiate these conversations? Significance?	**What is it like to live with dementia?** **Prompts:** -Cultural Experiences -Social life -Health and wellbeing -support networks -independent living Support arrangements -Views on formal care support services -Views on support from family/friends -Expectations of care
Awareness of services	**Overall views around ACP, ethics?**	**Coping with memory loss** **How is it like to live with dementia?**
What, if anything comes to your mind when you think about your future care? Closing remarks: How did you feel about your participation in this discussion?	Views on Medication at the EoL -pain management -wishes/hopes -Choices/preferences/hopes at the EoL?	Care experiences If there is anything you would like to recommend the care you have had, what would it be? -What is important to you -Choices/wishes -Living well with dementia If there is anything you would not recommend about the care you have had, what would it be? -Cultural underpinnings -Barriers to quality care General views about dementia care and related EoLC

APPENDIX 14: How focus groups with PLWD were conducted

Welcome

- Introducing myself as a research student and request participants to introduce themselves (ice breaker).
- Give a brief overview of the aims of the project
- Provide a brief outline for ground rules, ensure participant written consent obtained and signpost participants to take refreshments provided.
- As consent has been sought, advice all participants Dictaphone would be recording and ensure they agree with that.
- Remind all the participants about confidentiality
- Allow time for everyone to settle and set a relaxed ambience
- Encourage participants to feel free to express their experiences as everything they say is equally valuable
- Remind participants of the importance of allowing each person to talk at a time such that everyone's voice is captured and taped clearly during the discussion
- Opening with a general question, avoid emotionally charged questions at the onset of the discussion

During the discussion

- Avoid interrupting participants. I am not a participant! Just moderate/encourage/stir
- When necessary, tactfully interrupt and direct the discussion in keeping with the project aims
- Never use judgmental remarks during the discussion such 'you're correct.'
- or 'that's sound good' etc.
- Make use of nonverbal/body language, smiles, nodding, facial expressions to encourage participants to share their experiences/perceptions/views
- Be aware some PLWD may stand up [confused/disorientated] and offer reassurance as required
- Without adding my views/perceptions, where appropriate, probe for depth and detail (e.g., 'Can you explain that more, give us an example of that please, can you clarify/explain what you mean about…'
- Be aware that there may be 'quiet participants'- encourage them to speak by saying your experiences in this topic are important, what are your thoughts about ….'
- When one participant is more talkative, consider saying 'it looks like you have really told us more about your experiences, is there anybody with the same experience?

Towards the end of the focus group discussion

- We seem to have discussed a lot of this about …have we missed anything here? Is there anybody who wants to add or explain something?

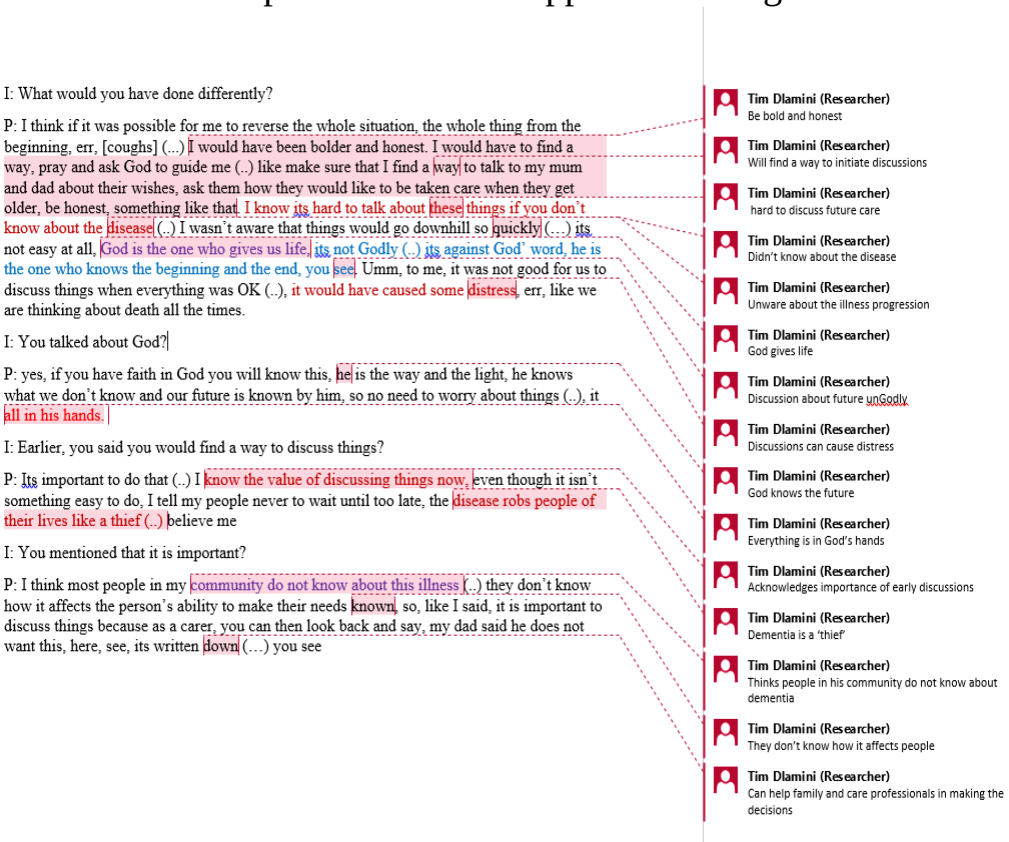
Closing the discussion

- Ask participants' if they have any questions and encourage them to feel free to ask. Signpost them to the telephone numbers should they wish to contact me
- Thank all participants and inform them the Dictaphone is being turned off

- Let participants know that I will not be leaving immediately. Those who want to stay behind can do so. Switch discussion to different topic areas to identify any distress or harm
- Debrief: talk more generally about what the research aims to explore and reassure participants they have made a valuable contribution by participating in the discussion. Follow distress protocol if needed.

Adapted from Krueger (1998) and Hudson (2003)

APPENDIX 15: Example of a wholistic approach/coding



APPENDIX 16: Audit trail (initial)

AUDIT TRAIL: Example of Initial Coding Template for Bereaved caregivers

1. **Living with uncertainty and change**
   1.1. Facing and dealing with constant change
   1.2. Living in denial: 'It wasn't sinking in.'

1.3. ‘It felt like I was in an island of my own.’
1.4. Living in fear of being a failure by the wider community

2. ‘God knows what he is doing.’
2.1. Finding meaning through prayer
2.2. Believing situation is ‘God’s punishment.’
2.3. Seeing difficulties as being tested by God
2.3.1. Strength and resilience from prayer
2.3.2. Wearing a brave face
2.3.3. Believing nothing can be done
2.3.3.1. ‘God has called him, what else can be done?’
2.4. Succumbing to infinite obligations
2.4.1. ‘Fighting within myself.’

3. Being a caregiver at the EoL
3.1. Evolution of ‘caring identity.’
3.2. ‘I never saw myself as a carer.’
3.3. Cultural beliefs of caregiving
3.3.1. Covering the difficulties up
3.3.1.1. ‘Against own culture to ‘air dirty linen outside.’
3.3.1.2. Living with the fear of being criticised
3.4. A life lived alongside being a caregiver
3.4.1. Feeling the strain but soldiering on
3.4.2. Psychological effects of giving care to a dying relative
3.4.2.1. ‘I felt like I was losing my mind.’
3.4.3. Social impacts of being a caregiver
3.4.3.1. Feeling ‘lonely and physically drained.’
3.4.3.2. ‘I didn’t have a life of my own.’

4. Dealing with loss before physical death
4.1. Emotional aspects of caring to a relative at the EoL
4.2. Facing an unknown future but hoping for the best
4.3. Changing relationships
4.4. Avoiding talking about death

5. Awareness and understanding of dementia
5.1. Seeing dementia as a natural part of being old
5.2. Suffering in silence
5.2.1. Fear of being a failure
5.2.2. Reflecting on the concept of ‘they look after their own.’
5.2.3. Caregiving as a family affair: continuity of filial piety
5.2.3.1. ‘I felt as if I’ve let my parents down.’

6. Experiencing inadequate support
6.1.1. ‘I was just left to get on with it.’
6.1.2. Feeling discriminated: ‘It was like he was a second-class citizen.’
6.1.3. Lack of knowledge of or reluctance to use services
6.1.4. Finding it daunting to navigate the ‘labyrinth’ of the healthcare
6.1.5. ‘Many people struggle without support.’

6.1.6. Community stigma as a barrier

7. Feelings of guilt, isolation & despondency

7.1. Wishing to reverse the situation and discuss relative wishes of care at EoL
7.2. 'People must talk to their loved ones early.'
7.3. Carer wishing to have been informed about illness course early
7.4. Making decisions: conflicting feelings
7.5. Negative perceptions of life support
7.5.1. 'why should your relative go through that torture.'

8. End of life care experiences

8.1. Valuing the dying person's privacy, dignity and comfort
8.2. Experiences of hospital care versus hospice care
8.3. Being with the dying relative 'to the end.'
8.4. Anticipating for comfort and 'peace' for the dying relative
8.5. Facing difficult end of life care decisions
8.6. Knowing the wishes of the dying person beforehand
8.7. Experience with services
8.7.1. Being listened to and involved in discussions
8.7.2. Coordinating many services arduous and stressful
8.7.3. Feelings of being 'left out by the system.'

APPENDIX 17: Example of Audit Trail (Final)Template for Bereaved caregivers.

1. LIVING WITH UNCERTAINTY AND CONTINUOUS CHANGE

1.1.Facing the change

1.2.Living in denial: ‘It wasn’t sinking in.’

1.3.‘I felt like I was on an island alone.’

1.4.Fear of being a failure

2. GOD KNOWS WHAT HE IS DOING

2.1.Negotiating meaning through prayer

2.2.‘God is punishing us.’

2.3.Wearing a brave face

3. SUFFERING IN SILENCE

3.1.Experiencing hopelessness and anger

3.2.‘I was responsible for everything.’

4. EXPERIENCING LOSS BEFORE DEATH

4.1.Loss of control

4.2.Dignity and comfort

5. AT THE CROSSROAD

5.1.Looking back with regret

5.2.Realising some lost opportunities