Title: Exploring the Lived Experience of Dementia in Ghana

Thesis submitted in accordance with the requirements of
the University of Stirling for the Degree of Doctor of
Philosophy by

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Abstract:

Title: Exploring the lived experience of dementia in Ghana.

Objective: The aim of this study is to generate an understanding of the lived experiences of dementia in Ghana from the perspectives of people with dementia and their paid (prayer camp staff and healthcare professionals) and unpaid / family carers.

Background: Ghana is one of the upper middle-income countries in the Sub-Saharan African (SSA) region. Dementia is a growing problem for the country as its relatively young population begins to age and the proportion of older people with dementia grows. Culturally, dementia is framed as a spiritual illness or deviance and with a lack of widespread and easily accessible mental health medical system in Ghana, dementia care in the country is dominated by family-based care. This has significant consequences for people with dementia both at home and when accessing the two main non-family care spaces – prayer camps and psychiatric hospitals. However, there is little research exploring the lived experience of dementia in Ghana.

Method: A purposeful sampling method was used to recruit forty-six participants comprising of four participant groups - people with dementia, their family carers, prayer camp staff and healthcare professionals for this study. The study employed focus group and semi-structured interview techniques in order to elicit the participants' understanding and experiences of living with dementia. Data were analysed using thematic analysis (Sundler *et al.*, 2019; Braun and Clarke 2006). This was based on van Manen's (1990) hermeneutic phenomenological analysis with the aim of trying to make sense of what it means to live with dementia.

Findings: The findings were structured and described using van Manen's (1990) hermeneutic phenomenological lifeworld perspectives – lived body, lived relation, lived time and lived space. The lifeworld is the lived or existential world as experienced in our everyday life (Dahlberg and Dahlberg, 2020). The findings indicate that dementia brings about changes and challenges to people with dementia's experience of their lifeworld existentials and this affects their own and their carers' shared experience of the lifeworld. It was also found that, religion, as one of the key social institutions, shapes the cultural understandings of dementia and therefore the meanings attributed to people's lived experience of dementia in

Ghana. Religion therefore remains crucial in the lives of families of people with dementia and can be simply something to hold on to amid the storm of the condition. Evidence shows that the socio-cultural understanding and the growing medicalisation of dementia in the country complement each other. People’s understandings of and responses to dementia were found to be changing.

The thesis concludes with recommendations for practice and policy development and ideas for future research.

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AD	Alzheimer’s Disease
ATR	African Traditional Religion
CJSW	Criminal Justice Social Worker
CPN	Community Psychiatric Nurse
ER -	Eastern Region
FTD	Frontotemporal dementia
GAR	Greater Accra Region
GHS	Ghana Health Service
GUEP	General University Ethics Panel
GSS	Ghana Statistical Service
LAC	Lunatic Asylum Act
LBD	Lewy body Dementia
LMICs	Lower- and Middle-Income countries
MHA	Mental Health Act
MHD	Mental Health Decree
MHN	Mental Health Nurse
MPC	Mohab Prayer Camp
ƆPC	Ɔgyam Prayer Camp
NHIS	National Health Insurance Scheme
NRCD	National Redemption Council Decree
PA	Physician Assistant
PH1	Psychiatric Hospital 1
PH2	Psychiatric Hospital 2.
SSA	Sub-Saharan Africa
SSNIT	Social Security and National Insurance Trust

SSW	Senior Support Worker
SuW	Support Worker
SW	Social Worker
TDO	Training and Development Officer
UNWPP	United Nations World Population Prospects
VaD	Vascular Dementia
WHO	World Health Organisation

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Chapter 1: Introduction

1.1: Overview of the problem this thesis addresses

People are now living longer, and increased longevity is one of humanity's greatest achievements in recent times (United Nations Population Fund, 2011a). Evidence suggests that people are now living longer than before because of improved nutrition, sanitation, medical advances, healthcare, education and economic well-being (Maharaj, 2013; Tawiah, 2013). Several studies (Lloyd-Sherlock, 2000; Beard and Petitot, 2010; Economic, 2010; Mba, 2010) have shown that population ageing is progressing fastest in the low- and middle-income countries (LMICs). Currently, only Japan has over 30% of its population aged 60 years and older. It is, however, estimated that, by 2050, 64 countries in the world will join Japan with an older population of more than 30% (Cosco *et al.*, 2015). However, while population ageing remains a success story, it is also a public health challenge worldwide (Uhlenberg, 2009; United Nations Population Fund, 2011; Benna and Garba, 2016).

The Sub-Saharan African region (SSA including Ghana) has a relatively youthful population, but projections suggest that, in the future, older people will constitute a proportionally larger share of the total population. As people live longer in SSA, the health profile of its population is likely to change as many chronic illnesses such as diabetes, stroke, hypertension, cancer and dementia increase rapidly with age (Maharaj, 2013; Mazaheri *et al.*, 2013; Dosu *et al.,* 2014). As health deteriorates with advancing age, frailty and disability become more frequent and there will be an increased demand for healthcare. The shift in the health profile of the population will have considerable implications for health service provision and resource allocation.

Aikins and colleagues (2015) and Mba (2010) predict that chronic non-communicable diseases are going to be the largest cause of death in the world by 2025 and the LMICs of Africa, Asia and Latin America will experience the biggest impact of this rise in chronic diseases. It is estimated that, of the 55 million adults aged 60 years and older worldwide, only 1.3 million lived in Africa in 2013 (Guerchet *et al.*, 2013; Mazaheri *et al.*, 2013) and this figure is projected to rise to 5.05 million by 2050 (Guerchet *et al.*, 2017). It is also estimated that 2.13 million people were living with dementia in SSA in 2015 and this number will reach 3.48 million by 2030 and 7.62 million by 2050 (Maharaj, 2013; Mazaheri *et al.*, 2013; Tawiah, 2013).

The SSA region is experiencing high mortality and fertility rates and is heavily burdened by infectious diseases. However, the region's population continues to age and a rise in non-communicable diseases is inevitable. Currently, dementia is a relatively minor problem in Ghana (Agyeman *et al.*, 2019; Spittel *et al*., 2021); however, as the population ages, dementia, alongside other non-communicable diseases associated with ageing, will become a growing problem for the country. With no known cure or preventative intervention, Mavrodaris *et al*. (2013) predict that dementia and cognitive impairments are set to be one of the biggest public health challenges in SSA in the 21st century. However, there is a paucity of information on dementia and dementia care in the sub-region in general and in Ghana in particular about what it is like to live with dementia. Available evidence suggests that most published studies on dementia, including the lived experience of dementia, have been carried out in more developed countries, with the few being conducted in LMICs where published research is focusing mainly on prevalence (Gureje *et al.*, 2006; George-Carey *et al.*, 2012; Mavrodaris *et al.*, 2013; Brooke and Ojo, 2020) but not necessarily on the lived experience of dementia (Clare *et al.*, 2008 ; Brittain *et al.*, 2010 ; Baumgardner and Mayo, 2021). Steeman *et al.* (2007) argue that having insights into what people with dementia experience, especially during the early stages of the illness, is necessary in order to ensure effective care provision, as well as helping healthcare practitioners to adapt their care practices to adequately meet the needs of the people with dementia that they care for (Gerhardt, 1990). Having insights into what people with dementia experience has been found to provide opportunities for people with dementia to make their views and wishes known to their families and healthcare professionals prior to them losing the capacity to do so (Steeman *et al.*, 2007).

This thesis, therefore, seeks to explore the lived experience of dementia in Ghana among people living with dementia, their family carers, and paid and unpaid carers. Using the phenomenological understanding of the lifeworld, the thesis will explore the experience of dementia in terms of how people with dementia and carers experience living with the condition. Thus, exploring the subjective experiences of people with dementia and their paid and unpaid carers will help to improve the understanding of dementia, and people's perception of and attitude towards people with dementia and their paid and unpaid carers in Ghana (Lawrence *et al.*, 2011; Samba *et al.*, 2016).

1.1.1: The research aims and objectives

The main aim of the study is to generate an understanding of the lived experiences of dementia in Ghana, from the perspectives of people with dementia, their family members / unpaid and paid carers.

Using the four lifeworld existentials (lived body, live time, lived space, lived relationships) (van Manen 1990) to frame the analysis, this thesis will explore the following research questions:

- What is it like to live with dementia in Ghana?
- What is it like to be an unpaid carer for a person with dementia in Ghana?
- How do people with dementia and their carers understand dementia and what social and cultural resources do they use to do so?
- What are the perspectives of paid staff and professionals caring for people with dementia in Ghana?

1.2: Background to Ghana – Introduction

This section provides a brief introduction and overview of Ghana, one of the most fascinating countries in the African continent with a unique place in history as the first black African country to emerge from colonial rule in 1957. The location of Ghana within SSA, the political history, population, ethnic groupings, culture and religious aspects of the Ghanaian culture, are discussed to help readers to understand the wider context of the research presented in this thesis.

Ghana is centrally located within the West African sub-region. Covering a total land area of 238,537 square kilometres (92,075 square miles), Ghana is bounded by three Francophone countries – la Côte d'Ivoire on the west, Burkina Faso on the north, Republic of Togo on the east and the Atlantic Ocean coastline on the south. Politically, Ghana's contact with the outside world began in the late fifteenth Century with the arrival of the Portuguese on its shores. Over time, the British ultimately became the dominant power, ruling the country for over a century. Ghana became independent in March 1957, making it the first SSA country to gain independence.

Ghana attained a Republican status in 1960. Prior to independence, Ghana was called the Gold Coast because of the abundance of its gold reserves. As an independent state, Ghana underwent five coup d'états interspersed with short periods of civilian rule within its first 24 years and returned to civilian rule in 1992. Ghana has since been ruled under a democratic government and has remained democratic to date. The country is now one of the most peaceful nations on the African continent (Heaton and Darkwah, 2011). Politically, what sets Ghana apart is the peaceful inter-party transitions. Thus, political parties have respected their constitutional term limits and accepted electoral losses by their immediate successors.

With an estimated population of 31 million (Tawiah, 2013; Ghana Statistical Service {GSS} 2021), Ghana has more than 60 languages and dialects spoken across the country. Of these six, Twi, Fante, Akuapem, Ga, Ewe and Mole-Dagomba are taught and examined in Ghanaian schools. Administratively, the country is divided into 16 regions with each region having its own regional capital. Accra is the capital city of Ghana, with Kumasi and Takoradi being the second and third largest cities, respectively. Ghana has diverse ethnic groups. Apart from immigrants, most people in Ghana belong to, or are at least part of, a tribal system. The country has five main ethnic tribal communities: the Akans, Ga-Adangmes (consisting of two ethnic groups – the Ga and the Adangme), the Ewes, the Gonjas, and the Mole-Dagbanis. The Akans constitute the biggest tribe, with nearly half (49%) of the Ghanaian population speaking the Akan language (Twi) (Mba, 2010). The Akan has several dialects with Asante, Fanti and Akuapem Twi and the Bono being the dominant ones. Each of these has several dialects and sub-dialects within it. The second largest tribe, Mole-Dagbani, forms about 16% of the total population. This is followed by the Ewes, who make up about 13%, the Ga-Adangme being 8% and the smallest group, the Gonjas, forms about 4% of the entire population of the country (GSS, 2013).

Culturally, the extended family system is the commonest form of family in Ghana (Dzramedo *et al.*, 2018). In this family type, several adults share the responsibilities of teaching, training and punishing children (Dzramedo *et al*., 2018). The extended family can consist of a group of close relatives from either the maternal or paternal line, or a social arrangement in which an individual has an extensive reciprocal duty, obligations and responsibilities to relations outside the immediate (nuclear) family (Dzramedo et al., 2018). Inter-generational living arrangements are commonplace in

Ghana, with older people, including people with dementia, living together in extended households (Aboderin, 2006; Mba, 2010; Dzramedo *et al*., 2018). Through this type of living arrangement, older people and people with dementia receive support and care from their family members and significant others. However, due to the rapid socio-cultural changes, rural-urban migration by the youth for reasons such as employment, pursuance of higher or further education, and improved social statuses of women in the workforce, the traditional role of caring for older people, including those with dementia, in Ghana has been diminishing in recent years (Geest, 2016; Aboderin, 2006).

Another important cultural domain that influences the care and support of older people and people with dementia is religion. Religion is relevant to most Ghanaians because it touches on every aspect of the lives of people in Ghana including thinking, political organisations, economic and social lives (Addai *et al*., 2013). The Ghanaian traditional religious beliefs, values and practices form a strong force on people's patterns of life and social interactions (Opoku *et al.,* 2018). With regard to religion, three major traditions – Islam, Christianity and African Traditional Religions (ATR) – exist in Ghana. There also exist varieties or sub-groups within each of these broad categories (Omenyo, 2011a). The largest religious group, Christianity, constitutes 71.2%, Islam (Muslims) forming 17.5%, ATR and 'none' each accounting for just a little over 5% and 'other' representing approximately 1% (Asamoah et al., 2014; White, 2015; Arias *et al*., 2016).

With Ghana operating a pluralistic medical system, religion is and has been one of the traditional medical systems and has operated side by side with biomedicine or scientific medicine for a long time (Tsey, 1997; Tabi *et al.*, 2006; Amzat and Razum, 2014). Amzat and Razum (2014) argue that religion, as a traditional medical model, is a source of life protection and healing from all forms of illness and adversities. A growing number of faith-based healers believe that there is no disease beyond the power of God to cure (Amzat and Razum, 2014, p 11). People's search for spiritual intervention is often performed at the personal level, or most times through consultation with religious leaders such as pastors/priests and prophets/prophetesses.

Religion and religious groups have provided support and services including faith healing and clergy support to the under-resourced psychiatric and mental health system in Ghana (Arias *et al.*, 2016; Osafo, 2016). Consequently, some frontline roles of some religious bodies have been recommending collaborative networks with biomedicine (Asamoah *et al*., 2014; Read, 2019). However, the lack of space for spiritual issues in mental healthcare provision, for instance, have often led to faith healers and the clergy perceiving healthcare professionals as ignorant about religious and spiritual matters related to health (Kpobi *et al.*, 2019). Biomedicine has also been found to have disrespected religious leaders' views on the role of spirituality in mental health and the healing process (Tabi *et al*., 2006; Kpobi and Swartz, 2019). Options in medical care, however, exist and the interaction of the pluralistic systems of healthcare in Ghana may be complimentary, competitive or conflicting (Read, 2019).

Despite the apparent tensions and conflicts between them, traditional/faith healing and biomedicine remain two key healthcare providers for physical and mental healthcare provision in the country. The apparent tensions between the two systems of healthcare result from a number of factors. Firstly, traditional medical practices are mostly not amenable to science and seem to be less advanced than biomedicine (Amzat and Razum, 2014). Secondly, people's continual reliance on traditional medicine seems to inform its recognition as part of the healthcare institutions in the country (Amzat and Razum, 2014). The recognition of traditional medicine is also due to the fact that, in most parts of the country, access to biomedical care is limited (Tabi *et al*., 2006; Kpobi and Swartz, 2019). Thus, traditional medicine seems to be the closest and easily accessible healthcare system for the under-served or resourced communities in Ghana (Tsey, 1997).

The health sector in Ghana is both public and private. The public sector is run by the Ghana Health Service (GHS). Ghana has five teaching hospitals (Korle-Bu, Accra; Komfo-Anokye, Kumasi; Tamale; Cape Coast; and Ho Teaching Hospitals), all of which are based at the regional capitals. They provide tertiary care and training for doctors. In addition, there are three state-owned psychiatric hospitals – Accra, Pantang, and Cape Coast Psychiatric Hospitals. All the three psychiatric hospitals are located in the southern part of the country, and this makes accessibility to psychiatric services in Ghana very difficult and uneven. In addition, there are four private psychiatric hospitals – two in Kumasi and two in Accra in Ghana. All three state-owned psychiatric hospitals provide 1,322 beds in total, and the private ones provide outpatient services only. In terms of mental health or old age psychiatry services, Ghana has only 18 psychiatrists (while the UK, with a population of about 60 million, has 6000), 19 psychologists and 72 community mental health officers (WHO-Ghana, 2013).

Several studies (Edwards, 2014; Arias *et al.*, 2016; Ofori-Atta *et al.*, 2018) have shown that Ghanaian families affected by mental or psychiatric illnesses, including dementia, are more likely to send their relatives to traditional medical practitioners, faith healers or prayer camps when seeking a cure. Thus, a family with a relative with a psychiatric problem may be more prepared to invest a lot of time and resources on private rather than public sector health treatment to find a cure for their relative. It is not surprising that some patients would seek help from traditional sources, not only because of their cultural or religious beliefs but also because traditional healers are easily accessible and inexpensive compared with psychiatric hospitals (Ewusi-Mensah, 2001; Ofori-Atta *et al*., 2010; Read and Doku, 2012). Quinn (2007) also noted significant differences between people's attitude towards mental or psychiatric illnesses in rural and urban centres of Ghana. He found that the urban inhabitants had greater beliefs in the biomedical understandings of mental or psychiatric illnesses than their rural counterparts. People in the rural areas were found to prefer help from traditional than biomedical interventions. Also, people in rural areas were more likely to believe that spiritual factors were mainly responsible for psychiatric illnesses. People's perceptions, local understanding and cultural beliefs about dementia and mental health conditions, as well as the terms used to described them, can be used interchangeably due in part to the similarity in the psychological and behavioural symptoms associated with both dementia and mental illnesses.

Economically, income levels in Ghana for both formal and informal (private or self-employed) sector workers are generally low and this affects the social security contributions and earnings on retirement or at older age (Geest *et al*., 2004; Geest, 2016). The formal employment within the public and private sectors constitutes about 13% of the working population, while informal employment within the private sector makes up 86.1% (UNFP, 2012). This makes the informal sector the most important part of the Ghanaian economy. Almost all monetary and non-monetary inflows to older people in Ghanaian households come from families and relatives or personal and non-governmental organisations, including churches and HelpAge Ghana (WHO-Ghana, 2013).

Ghana has no welfare system, neither is there a universal income security system in place for older people. The country's Social Security and National Insurance Trust (SSNIT) provides insurance for formal (government and private) sector employees. Approximately 65-70% of the active labour force in Ghana are engaged in the informal sector activities and do not make any contributions towards their old age pension (Agyepong and Adjei, 2007). As a result, the majority of older people in Ghana have no state pension and are therefore dependent on their families and their own resources generated through properties, assets or proceeds from their farms (if they possessed these during their working-age years*)* (Agbényiga and Huang, 2012)*.* This can and does affect the care and support older people and people with dementia receive, as it can leave their families unable to afford to pay privately for care or unable to provide care themselves with any support (Aboderin, 2004; Aboderin, 2006; Geest, 2016).

1.2.1: Structure of the Thesis

Chapters 2 and 3 review the existing literature on dementia and people's understanding of the illness as well as their experience of living with it. Chapter 2 describes the concepts in the existing literature relating to the context of dementia and dementia care in different contexts and care settings. There are three dementia care settings in Ghana – the home, prayer camps and psychiatric hospitals – and each is described in this chapter. Prayer camp care practices and explanations for the rapid growth of prayer camps in Ghana are also discussed. The chapter ends by adding a supplementary literature review summing up the published work since original literature review was completed. Chapter 3 discusses population ageing and what it means to be 'old' within the Ghanaian context. The concept of ageing and social change and its implication on the care for people with dementia are also discussed here. Additionally, the extended and nuclear family systems and how the elements of social change have impacted on care provision for people with dementia are discussed. The chapter ends with a supplementary literature review summarising some published works since completion of the original literature review.

Chapter 4 presents the theoretical framework of the study. The first section provides the philosophical background and evolution of phenomenology. While the focus is on the two main phenomenological traditions, namely the Husserlian and Heideggerian approaches, the work of two other influential contributors to phenomenology, van Manen and Gadamer, whose works have further developed these two original traditions, are discussed. The second part of the chapter examines the key concepts of phenomenological lifeworld, its existential elements and their usefulness to this project. The final third of the chapter discusses the disruption of the lifeworld in illness. The conclusion summarises the significance and rationale for choosing this approach for this thesis. Chapter 5 discusses the research methods. Included in the chapter are the study design, sampling and recruitment of participants, data collection and ethical considerations of the study. The chapter describes the process of translating all the interviews conducted in Twi (a Ghanaian local language) to English, transcribing them and analysing the data. It highlights the challenges encountered during this process and makes recommendations for researchers whose work involves translation and data transcription. Ethical and reflexive dimensions that arose from this study are also discussed in this chapter. Chapter 6 provides a pen picture of the study participants including brief characteristics of them, their relationships and, where relevant, experience of caring for or working with people with dementia. A brief introduction to the two key institutions of care for people with dementia, prayer camps and the psychiatric hospitals, is also provided. Chapters 7 to 9 present the findings. Across these three chapters, the focus is on lived experience of dementia, understanding or conceptualisation of dementia and the institutional and structural response to dementia within the Ghanaian context. In chapter 7, the altered embodiment of people with dementia and how they and their carers experienced this changed lived body on a day-to-day basis is examined. This includes discussions about how the symptoms of dementia disrupted the lived body of those affected by the condition and, in so doing, brought their bodies into conscious reflection. Chapter 8 discusses, from participants' perspectives, how dementia was understood within the Ghanaian context. The biological, cultural, spiritual and religious understandings of dementia are explored under this chapter. The third and final findings chapter, chapter 9 examines the institutional and structural responses to dementia in Ghana.

Chapter 10 is the discussion chapter and brings together findings from across the thesis. The chapter examines the changing experience of people with dementia's lifeworld due to the illness. The chapter then discusses my position on the biomedical model of dementia in Ghana. Chapter 11 provides conclusions, personal reflections on the research process. The research aims/objectives were revisited, and how the research questions were answered or objectives were met was discussed. The chapter concludes by considering the study's implication for policy and practice including recommendations for future research study.

Chapter 2: Literature Review 1

The context of care for people with dementia in Ghana

2.1: Introduction

Dementia is a growing problem for Ghana as its relatively young population begins to age and the proportion of older people with dementia grows (Tawiah, 2013). Within both the dominance of a cultural framing of dementia as spiritual deviance and lack of a widespread and easily accessible mental healthcare system, dementia care in Ghana is dominated by family-based care. This has significant consequences for people with dementia, both at home and when accessing the two other care spaces – prayer camps and psychiatric hospitals for people with dementia. This chapter focuses on the different definitions and conceptualisations of care. The chapter covers the evolution of care from a traditional point of view, where parents care for their children, through to caring for other vulnerable groups of people including people with dementia by paid and unpaid carers. The chapter also discusses people's motivation for providing care - paid and unpaid care provision, and inter-generational living arrangements and other dementia care settings for people with dementia. This includes two key institutions – prayer camp and psychiatric hospitals, where people with dementia are often cared for.

2.2: Literature review methodology

Traditionally, research studies begin with a review of the existing literature in the field. Using a narrative literature review methodology, which Theile and Beall (2024) define as an analysis of scientific information on a specific topic, this review sets out the context for this research study and also reveals gaps in existing knowledge that the study intends to fill (Byrne, 2016).

Rationale for choosing a narrative literature review

A narrative literature review was used to provide a summary, assessment and interpretation of the existing literature and thus provide up-to-date knowledge related to the research topic, the lived experience of dementia in Ghana. Another rationale for the choice of narrative literature review was that it offers breadth of literature coverage and flexibility to deal with evolving knowledge and concepts (Byrne, 2016) and allows researchers to present their own perspective on the topic being studied (Theile and Beall, 2024).

Mining the literature

The search process for this narrative literature review was performed on five databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, PubMed, Web of Science and Google Scholar. Keywords used in the searches included “dementia”, “memory loss”, “dementia in Ghana”, “dementia in Africa” “lived experience of dementia”, “lived body”, “corporeality”, “lived relation”, “relationality”. In addition to these, a manual search for additional studies was performed using references cited in the original articles.

The searches yielded numerous articles that related to the thesis topic. Decisions were then made about which articles to include and which ones to exclude. An initial review of abstracts was undertaken to exclude articles that were unrelated to the thesis topic. Those articles remaining were read in full and included in the review, where they provided useful information about the experience of dementia in Ghana (Theile and Beall, 2024). Thus, all the articles were reviewed and those that had relevance to and could help address the research questions were selected. Contacts was also made with some researchers who had worked or were still working on older age and mental health-related studies in Ghana for studies known to them. Thus, a four-stage literature search was undertaken: an electronic search of databases; review of abstracts and full texts of articles in relation to research questions; follow-up search of reference lists of journals in the selected sample of articles; and emailing researchers requesting published works by them and any relevant articles that are personally known to them.

The literature review helped in identifying the gaps in my own reading and knowledge. The review was also helpful as I made sense of the increasing volume of original publications in the field of dementia in Ghana, SSA and across the world. After completing the searches and review of articles, I realised that the relevant literature that could provide valuable insights into the research topic being studied covered a wide range of issues. I then decided to split the literature review chapter into two in order to manage the data. The first of the two chapters covers the meaning of care, why people care; paid and unpaid aspects of care provision and the various settings in which care is provided to people with dementia in Ghana. The second half of the literature review chapter considers the ageing population, and ageing policies; the family systems in the country; dementia and its prevalence, social change and its implications on care for older people and people with dementia in Ghana.

2.3: Meaning of care

Most human beings have experienced care that occurs naturally within the family structure, while some may have experienced care by paid carers. It is reasonable to expect that the perception of care can differ depending on each individual's situation, their previous experience and the awareness of their specific condition. It is thus of great importance that the processes and implications of receiving care become clearer and more specified in order to gain a comprehensive understanding of what it means to care (Lundgren and Berg, 2011). A considerable amount of research has discussed and attempted to define the term 'care' and 'caring'. However, while a great deal is known about care (Geest *et al*., 2004; Heenan, 2000; Rytterstrom *et al*., 2013; Sanuade and Boatemaa, 2015; Phillips 2007; Geest 2002), not enough is understood about care in different contexts.

Care is an integral part of human nature and natural behaviour and the process of being cared for is an essential part of human existence. To care for someone is a natural pattern of human response and behaviour and all humans are, at some time in their lives, dependent on being cared for, or take some responsibility for the care of others (Phillips, 2007). The term 'care' is very complex to define as it has a multi-faceted meaning. The meaning of care or caring has been a subject of debate amongst a variety of disciplines and professional bodies including psychology, social work, sociology, epidemiology, policymakers, social scientists and other health and allied-health professionals (Mensah, 1994; Lundgren and Berg, 2011). Caring for someone depends on different cultural values, basic motivations, the beliefs of the person that is giving the care and the person that is being cared for. The meaning of caring involves a mutually emotional response, concern for the situation of the other, and includes feelings of concern, fondness and affection (Lundgren and Berg, 2011).

Focusing on the bodywork aspect of care, Twigg (2000) and Twigg *et al.* (2011) talked about working directly on the bodies of others. This involves direct, hands-on activities, handling, assessing and manipulating bodies, and goes on to explain caring as an intervention that includes medical, therapeutic, pleasurable, aesthetic, erotic, hygienic and symbolic. She identifies caring as an activity that encompasses a range of practitioners including doctors, nurses, care workers, hairdressers, beauticians, masseurs, and undertakers (Twigg, 2000). However, variations exist in the caring work that each of these practitioners does.

2.3.1: Care as a functional and moral and spiritual activity

Several alternative definitions have been provided to explain the term ‘care’ from functional, moral and spiritual perspectives. From a moral standpoint, care involves a disposition or concern for others or another (Fine, 2007a). Tronto (1993) offered this definition of care: “On the most general level we suggest caring be viewed as a species activity that includes everything we do to maintain, continue and repair our “world” so that we can live in it as well as possible. That world includes our bodies, ourselves and our environment, all of which we seek to interweave in a complex, life-sustaining web” (cited in Lachman, 2012 p 113). Watson’s model of care requires carers to look at the uniqueness of the individual they care for and proposes that carers should make every effort to preserve the dignity of those they care for.

Litwin and Auslander (1990) however, have a slightly different perspective on care. To them, ‘care’ is only when support is needed because of ill-health or functional limitation. From functional perspectives, care is a form of work that takes place as an activity of providing practical assistance to another, the actions of which involve physical provision of support to another over time (Fine, 2007b). Cronqvist *et al.* (2004) provide further clarity on the meaning of ‘care’ by distinguishing between ‘caring about’ and ‘caring for’. ‘Caring about’ relates to a moral obligation for people to care about others on moral grounds. In ‘care about’, people care because they know what is morally good to do in a caring situation, and those who give care have a genuine concern about the well-being of those they care for in terms of care-receivers’ feelings, beliefs and insights of their vulnerabilities (Lundgren and Berg, 2011). ‘Caring for’, on the other hand, is task-oriented and often assigned to and controlled by others including employers, superiors and physicians. It can be considered as a moral obligation to fulfil work responsibilities (Lundgren and Berg, 2011; Marschall, 2014). Usually, the ‘care for’ type of care is provided as a formal activity by those who provide it, highlighting the fact that the organisations that care practitioners work for usually provide guidelines concerning practical, technical and medical assessments of individuals needing care.

2.3.2: Family care as a tradition

Care is a personal service that requires the presence of a carer. Usually, a carer carries out a physical task for the person they are caring for, though ‘passive caring’ may just involve being available in case assistance is required (Himmelweit, 2006). Care is fundamental to an individual’s identity as it plays an important role in our societal interactions and relationships (Phillips, 2007). Traditionally, care is connected to parents or adults giving care or help to their children (Marschall, 2014). However, in contemporary societies, studies have focused on caring for different vulnerable groups of people including children in formal care settings (such as foster care, adoption or residential care), people with learning and physical disabilities, people with sensory impairments, older people and people with dementia or mental health issues.

In a health and social care setting, care can be seen from a familial context and others outside of the family, which may include friends, neighbours and paid caregivers (Geest, 2002; Sanuade and Boatemaa, 2015). Against this background, it is evident that care is no longer regarded solely as a familial concern and the responsibility of women at home to be undertaken for love or duty and without pay (Fine, 2007a). The way care is provided to and understood by members of the society is often judged by the society within which people find themselves.

Like families, the state has a moral obligation to ensure that adequate health and welfare services are provided to meet the needs of its citizens (Geest, 2016; Dzramedo *et al*., 2018). However, differences and similarities exist between the functional acts and the practice of care for children and older people with disabilities, including dementia. Caring for children can be seen as a process of a child growing to become an independent individual, who would one day take over the caring responsibilities and care for themselves. However, caring for older people with disabilities including dementia could be constructed as a process or functional act of managing the decline of older people's abilities, with little or no hope of them being able to independently care for themselves again in the future. As Cronqvist *et al.* (2004), Rytterstrom *et al.* (2013) and Jaastad *et al*. (2022) argue, caring for both children and adults has different moral investments that determine the meanings associated with care activities and their relative value within societies. Additionally, sex differences in caregiving exist for both men and women.

In Ghana, care for older people and people with dementia is provided mainly by four groups of people – unpaid care through families, friends and neighbours; the state through nurses, doctors and other healthcare professionals; private healthcare providers, including religious organisations such as Roman Catholic and Seventh Day Adventists Missions; and, finally, voluntary sector organisations through non-governmental organisations (NGOs) such as HelpAge Ghana. Even within the unpaid care provision, not all unpaid care is given by kin in Ghana, as some families rely on intermittent volunteers whose care services are often organised through charitable religious organisations. However, unlike kin who may not have a choice when becoming carers (Mensah, 1994; Sanuade and Boatemaa, 2015), volunteer carers provide care by choice and their presence in the lives of older people and people with dementia may be temporary or intermittent. However, in this thesis, the focus is on unpaid family care provision.

2.3.3: Gender and society's role expectations

Naturally, the differences between the sexes arise from biological and anatomical factors, and these differences become associated with role differentiation pervasive throughout cultures (Akotia and Anum, 2015). These role differentiations are mostly observed in reproductive and caregiving functions and the nurture of newborns and children in households (Akotia and Anum, 2015). As Fuwa (2004) found in the study on cross-national comparisons of the household division of labour across 22 countries, the gender-role approach posits that men and women are socialised to conform to socially constructed roles. In Ghana, as in other cultures, gender inequality still persists and household works are mostly undertaken by women (Ampofo, 2001; Fuwa, 2004; Akotia and Anum, 2015). Examining the influence of education on gender role ideology in Ghana, Akotia and Anum (2012) found that males, when compared with females, were more likely to be 'traditional' and less likely to be ‘modern’ in their gender role perceptions. Unlike some cultures such as the Scandinavian and other countries, where women have achieved more egalitarian conditions and may be able to negotiate the division of household work with their male counterparts (Fuwa, 2004), Ghanaian women mostly perform the ‘core’, traditionally feminine tasks while men concentrate on more episodic or discretionary housework tasks (Beales, 2000; Akotia and Anum, 2015; Safdar *et al.*, 2015). For instance, childcare, the first experience of caregiving, has traditionally been the occupation of females in Ghana and almost every society across the world (Janevic and Connell, 2001; Sanuade and Boatemaa, 2015). Care by women is a cultural expectation as well as a cognitive model. Chafetz and Chafetz, (2006) provide an explanation for this and argue that, often, girls are socialised to be concerned about others and incorporate within their sense of self a basis for empathy that is different from that of boys. However, Ter Meulen and Wright (2012) contend that caregiving is not necessarily due to the anatomical differences between boys and girls per se, rather it is a function of early childcare that is traditionally being done by women (Akotia and Anum, 2015).

Traditionally and culturally, men in Ghana (as in most societies) are expected to be breadwinners for their families and have often worked outside the home (Fuwa, 2004; Akotia and Anum, 2015). Often, boys are socialised to be men who work out of the home to provide financial resources for the family, while girls are socialised to express concern for others and to be submissive (Kramer and Kipnis, 1995; Fuwa, 2004) and Ghana is no exception to these (Sanuade and Boatemaa, 2015). Against this background, Ghanaian men have not been expected to be daily providers of intimate care for disabled members of their families (Akotia and Anum, 2015; Geest, 2016).

Gender inequality in Ghana is an outcome of a combination of different factors such as socialisation practices, social structures and weak efforts at addressing cultural practices that do not favour women in general (Akotia and Anum, 2015). The social system in Ghana is, therefore, a mechanism that creates a model that places males and females in superordinate and subordinate positions. In Ghana, as in most cultures, care, especially intimate care provision, for people with dementia in particular and others who need care in general have and continue to remain the women’s role (Ampofo, 2001; Akotia and Anum, 2015; Sanuade and Boatemaa, 2015; Geest, 2016b).

2.4: Why do people care?

A number of studies (Himmelweit, 2006; Fine, 2007; Ter Meulen and Wright, 2012) have documented reasons why people care for others in whatever setting or situation they may be in. The purpose for providing care, in most cases, defines the reason why the care is needed. For instance, patients in hospital settings receive medical care because of their ill-health or an accident. For those in social care settings, care is provided because of people’s inability to undertake some or all activities of daily living including personal care, housework, shopping, financial management among others *(*Bunkers, 2004; Bursell and Mayers, 2010; Cronqvist *et al*., 2004; Phillips, 2007).

While people can choose whether or not to care for older members of their families, caring for children in most countries is a legal or statutory duty for parents. Thus, parents have parental responsibilities towards their children, and their failure to do so (or if they neglect the children) can lead to removal of the children from their parents (Phillips 2007). This is different for adults. As Heenan (2000) argues, caregiving patterns depend on particular set of cultural expectations and norms. In Ghana, families try to arrange care for their older members themselves, as getting outside help to care for one’s older relative(s) can be considered an admission of failure, as there appears to be a sense of pride and a strong cultural expectation in being able to look after one’s own family members (Sanuade and Boatemaa, 2015; Geest, 2016b). Drawing on Ungerson’s (1987) work on care, Phillips (2007) echoed that care takes place because of a complex mixture of love and moral obligation, what Ungerson described as “compulsory altruism”. Heenan (2000) adds that, amongst other things, people do care for older members of their household or community as they see care as natural and not something they would question. However, perceptions and notions of care provision in Ghana are gradually changing as, due to globalisation and migration, people are now increasingly moving from rural to urban areas, resulting in fragmentation of families (Geest *et al*., 2004). Geest (2016) has, therefore, questioned the nature and extent to which care is being provided in contemporary times as well as the future of family care provision in Ghana. However, despite the effect of social change, many families continue to care for their older relatives, including those with dementia, in Ghana.

Several studies (Cheung and Kwan, 2009; From *et al*., 2009; Heenan, 2000; Phillips 2007; Geest, 2002) have also identified reciprocity of care as a major theme, explaining why people do care especially for their older members in society. In his study of ‘Respect and reciprocity; care for elderly people in rural Ghana’, Geest (2002) found the activities of caring in Ghana to be largely defined culturally and varied among different cultures. He found that the only way to figure out what care in a particular setting means is by listening to those who are directly involved in it and also by observing their actions. In addition, Geest (2002) found that, in Ghana, the young care for their older parents as a means of reciprocal filial piety, an act of respect and responsibilities that children should carry towards their parents and grandparents (Geest *et al.,* 2004; Geest, 2016). Geest (2002) argues that, in Ghana, children like to care for their older parents and members of their families and communities as they see their caring responsibility as a means of returning or ‘paying back’ their parents for the care or help they received from them in the early stages of their life (Cheung and Kwan, 2009; From *et al*., 2009). Ter Meulen and Wright (2012) refer to this form of care, where able-bodied members of a family may willingly support their older and other vulnerable members within the context of mutual obligation, as ‘family solidarity’.

Yeh and Bedford (2003) identified reciprocal filial piety to be beneficial to an individual’s development, as it enhances their interpersonal relationships and allows people to emotionally and spiritually attend to their parents out of gratitude for their child-rearing efforts (Cheung and Kwan, 2009). In contrast, Antonucci and Wong (2010) maintain that reciprocal filial piety is an authoritarian concept. For them, the concept is a way of suppressing children’s own wishes as, often, they would have to comply with their parents’ wishes because of their seniority in perhaps physical, financial or social terms, or perhaps as a means of maintaining one’s parents' reputation (Geest *et al*., 2004; Geest, 2016).

2.4.1: Paid and unpaid care provision to people with dementia

Care provision to people with dementia in Ghana has largely remained within the family (Sanuade and Boatemaa, 2015; Geest, 2016). Common caring activities for people with dementia, who have needed help from others, included getting food, assistance with bathing, washing clothes, assisting with toileting, provision of social support or companionship and financial support, among others. Geest, a Dutch anthropologist (Geest, 2016), also identified organisation of a befitting funeral when an older person dies as one of the most important types of care in the Ghanaian society. Geest (2016) notes that the Ghanaian culture believes in glorifying and giving the dead a good send-off, as this shows the valuable roles the person played in their lifetime as well as the legacy they have left behind. Often, people with high social status such as politicians, religious leaders and royals, or those who hold chieftaincy positions, are believed to deserve and be given befitting funerals.

Modifying Himmelweit (2006) definition, here informal caregiving or care work is considered to be the provision of unpaid personal services to meet the physical, mental and emotional needs that allow a dependent person to function at a socially determined acceptable level of capability, comfort, and safety. Dependants include all children (before they are legal adults), all those who are either temporarily or permanently ill, or physically and/or mentally disabled, and some older people.

Studies across disciplines have shown that the majority of unpaid family care work is done by women, but this is largely ignored when development policies and programmes are crafted Coe (2016), even though women are increasingly their target population. Caring for someone with dementia in Ghana may not necessarily differ from the traditional care of assisting someone with personal care tasks, for example washing, dressing, feeding, toileting and other aspects of activities of daily living. People with dementia may need care and support from carers to live safely and independently and to maintain themselves at home.

Several studies (Heenan, 2000; Apt, 2007; Börsch-Supan, 2012; Marschall, 2014) have described the physical and emotional burden of unpaid care in relation to dementia care generally to be very high. The most physically demanding tasks cited in the literature include lifting the dependent person, helping him or her to the toilet, or turning them over in bed, and further household tasks such as extra laundry due to incontinence and travelling to and from the hospital (Clarke *et al.*, 1993; Heenan, 2000; Litwin and Attias-Donfut, 2009). These burdens can be particularly heavy in the provision of unpaid care to people with dementia who, in addition to personal care provision, may need round-the-clock support and supervision to ensure their safety and security both at home and in the community. Additionally, family care for someone with a long-term progressive condition like dementia may be experienced as an increasingly burdensome activity. In some cases, the unpaid carer may feel trapped in their caring role as they may have no means of escape. This can negatively affect carers' mental health and emotional well-being and potentially lead to a loss of sense of identity, both for the carer and the cared for (Beard, 2004; Ter Meulen and Wright, 2012). For instance, the relationship and roles between husband-wife or daughter-mother may change to carer-cared for a certain type of relationship, and both the carer and the cared for may find adjusting to their new situation very frustrating.

Summarily, this sub-theme has discussed the concept of care and identified the centrality of care in the life of humanity. It is noted that care binds families, friends and communities together (Bergman *et al*., 2016; Geest *et al*., 2004; Mensah, 1994; Phillips, 2007) and that individuals and societal understandings of care differ from one society to another due to differences in people's personal experiences, history, geography and the different dimensions within which the care takes place (Phillips, 2007). Despite changes in occupational patterns globally, in Ghana and most LMICs childcare and care for older people and people with disabilities largely remains the women's responsibility. It is concluded that, in most cultures, men do not necessarily provide and are not expected to provide intimate care – although, in some situations, childless men may be caring for their wives when they are severely or chronically ill (Kramer and Kipnis, 1995; Botsford *et al*., 2011).

2.5: Dementia care settings in Ghana

In general, care provision in Ghana takes place mainly in three different care settings: the home, prayer camps and psychiatric hospitals. Mostly, older people, including those with dementia, are cared for in their own or family homes. However, they may be placed in or admitted to prayer camps and psychiatric hospitals if their care at home becomes untenable due in part to extreme carers' stress or inability to manage the person with dementia's behaviour at home. People with dementia may also be placed in care settings other than the home if their families believe or interpret manifestation of the symptoms of their dementia as signs of madness, or

label them as being a witch. The concept of witchcraft is explored more later in the thesis.
This section examines the main settings that older people and people with dementia in Ghana inhabit, are cared for and manage their everyday activities. It considers the three main care settings: the home, the psychiatric hospital and the prayer camps. While most older people and people with dementia live and are cared for in their own homes, dementia care is also provided in two other care spaces – prayer camps or medical facilities such as psychiatric hospitals. Each of these settings reflects specific ways of understanding dementia within Ghana.

Phenomenologically, Førsund *et al*. (2018) described these sites as lived (spaces) and refer to them as one's encounter with an environing world; a world of places, things and situations that have meaning for living and, consequently, for health. Lived space, therefore, refers to the meaning of space in relation to the experiences of living with dementia (Førsund *et al.*, 2018). All spaces are 'lived', but different groups of people have different experiences to these spaces depending on their life Circumstances, including illnesses such as dementia. With dementia, people may lose confidence in themselves and their environment and may, thus, curtail some of their previously enjoyed social and outdoor activities like visiting friends and families, attending funerals and church services (Aboderin, 2004; Dekkers, 2011). Discussing the lived body/lived space in illness, Phinney and Chesla (2003) described people with dementia getting lost in the world of space, which showed up in people with dementia getting lost when they are outside their homes. Although this rarely happened, people with dementia often lived with the sense that it could happen to them anytime, especially if they did not pay particular attention, as familiar spaces no longer seemed familiar to them. Living with such constraints could increase the risk of social isolation and loneliness in people with dementia.

Understanding how people with dementia experience the spatial dimensions of their day-to-day experiences of living with the condition is therefore important. This is necessary to both enable supportive living environments and create communities that compensate for the fading abilities of persons with dementia and allow them to maintain a meaningful life (Førsund *et al.*, 2018). However, while lived space is important for people's identity and the meaningful activities they could engage in

(Mahomed and Pretorius, 2022), little to no studies have attempted to explore this within the SSA in general and Ghana in particular.

2.5.1: The home as a site of care for people with dementia

The home is a crucial site in the construction and maintenance of one's identity in later life (Rowles, 1983; Cristoforetti *et al.*, 2011). The home is primarily a lived space in which older people, including those with dementia, live and interact with others. People with dementia follow their own rules and values based on their personal frame of reference in their homes. However, due to the home being intersubjective, people with dementia share the home spaces with others and, as a result, their taken-for-granted understandings may not necessarily show up to conscious reflection. However, the onset of dementia can bring such pre-subjective experiences into relief or consciousness, or as particular places with specific meanings attached to them. The home is also a place where older people and people with dementia may be in control of and have their freedom of self-expression. The home is, thus, a lived space characterised by feelings of belonging, tranquillity and close personal relationships that can offer support and care to older people and people with dementia (Verbeek *et al.*, 2009; Dekkers, 2011). These feelings are expressed as deep and extremely important for people with dementia (Norlyk *et al.*, 2013; Førsund *et al.*, 2018). Other meanings attached to the home can include it being a place of refuge for people with dementia from a threatening world outside, or a place of privacy, where people are able to let down their guard to relax, and where people are released from the constraints of showing the face that our culture obliges us to present to the world (Rowles, 1983, p 2000).

In Ghana, as in most LMICs, the home is the primary site for dementia care, as most people with dementia live and are being cared for in the community due in part to lack of institutional care (Dekkers, 2011; Ofori-Atta *et al.*, 2018b; Mahomed and Pretorius, 2022). It is a place where people with dementia spend the most time. However, the home space can become disrupted in times of ill-health, and this can destabilise the meaning of the home for both the people with dementia and their family carers (Rowles, 2000). Like many degenerative illnesses, in changing the lives of people with dementia. Dementia will also change people's experience of the home as a lived space, in more or less significant ways.

Once older people develop dementia, they may consider the limits of their lived body, which entails continuous reorganisation of their everyday routines (Ayouch, 2008; Førsund *et al.*, 2018). Dementia may also modify how people with dementia perform their former every day, taken-for-granted activities of daily living (ADLs) like washing, showering and cooking and other ADLs, as they may no longer be able to do them due to their illness, disability or frailty. Thus, ADLs may become more challenging or even impossible for older and people with dementia to undertake independently because of their deteriorating physical or cognitive abilities, or both. However, sometimes, older people and people with dementia in Ghana may be unable to sustain themselves or be sustained in their own homes by their families. This may happen when the person with dementia appears to be increasingly difficult to be cared for or managed at home by their families. This may be due in part to changes in their personality resulting from the illness, which can often be interpreted by their family members and others as ‘madness’ or signs of being a witch.

For people with dementia who may be living at home with their families, the home can be experienced as a prison-like space, or a place of entrapment, as some may be restricted from moving beyond the home or find themselves limited to the home. In extreme cases, some people with dementia may be physically restrained by their families by locking them up, thus preventing them from going out on their own. This may be due to the fear that people with dementia may be unable to find their way back home and get lost as a result. Locking people with dementia up in rooms by families could result in them becoming increasingly socially isolated as their contact with others and the outside world could be curtailed (Norlyk *et al*., 2013; Førsund *et al.*, 2018). Dementia can, therefore, lead to changed experiences of the home for people with dementia from its essential construction as a place of safety and refuge to a prison-like place.

People with dementia may have a good relationship with their families at the home space, as most of them are in inter-generational living arrangements and share spaces intersubjectively (Aboderin, 2006; Geest, 2016). However, people with dementia may find their experience of the home to be disrupted by dementia. Symptoms of dementia could impact on their ability to undertake ADLs, resulting in them becoming dependent on their family carers, whilst carers may find their caring role to becoming increasingly stressful and difficult as they deal with people with dementia’s cognitive, functional and behavioural changes. This can affect the reciprocal relationship between carers and people with dementia that they care for. Where family carers perceive people with dementia to be at risk of escape from home and potentially getting lost in the community, they may provide their relatives with dementia with a 24-hour care and support to meet their care and safety needs, albeit people with dementia may perceive the home environment as a place of confinement. People with dementia can also become socially isolated and disconnected from friends and the wider society.

2.5.2: Prayer camps as sites for dementia/mental healthcare

The existence of a dual healthcare delivery system and the use of either traditional or biomedical systems, or both, have had a significant effect on Ghanaian health practices (Tabi *et al.,* 2006a). In addition, the Ghanaian history of strong family and religious bonds has impacted the choices made by individuals seeking healthcare services. The proliferation of faith-based, charismatic churches across Ghana has led to most of them establishing residential centres in the form of prayer camps in the country. The prayer camps are often facilities run by faith or Christian organisations that house people seeking, or who are seen to need, spiritual treatment or protection against evil spirit /forces (Arias *et al.*, 2016). Prayer camps can also serve as community institutions and spaces of spiritual retreat for Ghanaians. People attend these camps for a variety of reasons including seeking success in businesses and marriage, good health, fertility and protection against their enemies, deliverance from evil spirits and healing from physical and spiritual illnesses (Taylor, 2016).

In Ghana, prayer camp leaders often advertise themselves and their activities on national radio, television and other social media sites, often with inscriptions that are catchy and appealing to the general population. One prayer camp, for instance, has “to set free those held captive by Satan through a ministry of fasting and prayer” as its mission statement. The interpretation that prayer camps are able to heal anyone under the bondage of the devil, be it physical, social, material or spiritual, can be very attractive to many who want their lives changed in these areas of their lives. Prayer camps and their leaders hold a place of major cultural significance within

Ghana, and they are not a niche, marginalised or radical group of people (Ofori-Atta *et al.*, 2018).

Several hundreds of prayer camps are operated by various Christian organisations across the country, usually by the ‘one-man-church’ leaders. The camp sites provide sacred spaces and homes for people with dementia and other psychiatric illnesses, as well as people facing socio-economic issues, for example with marriage or businesses (Arias *et al.*, 2016). Prayer camps are usually staffed with prophets and prophetesses, who often establish the camps themselves and set themselves up as chief healers or spiritual leaders, pastors, elders, caretakers and camp administrators (Arias *et al.,* 2016).

A prophet/prophetess is an individual believed to be supernaturally equipped to communicate the mind, will and intentions of God, as well as forewarn and offer guidance and directions to individuals or the church (Dominian, 1983).

Prayer camps are often run with the assistance of male caretakers due in part to the challenging nature of behaviours some people with mental illnesses can display. These caretakers provide personal care, for example provide food, bathe, clean and counselling services, to people with dementia and other residents (Taylor, 2014). However, most of these camps are under-resourced, lacking adequate shelters, bedding and decent sanitation facilities (Tabi *et al.*, 2006; Hindley *et al.*, 2016), despite the important roles they play in the lives of many people, both Christians and non-Christians alike.

Most prayer camps have an on-site sanatorium, which is the home for people with mental illnesses and neurological conditions including dementia, psychosis, depression, epilepsy, bipolar disorder and substance abuse issues (Ae-Ngibise *et al.*, 2010; Edwards, 2014). Additionally, people from all walks of life with different socio-cultural, religious and educational backgrounds visit and gather at prayer camps on a regular basis to seek God’s divine guidance, retreat from challenges of daily life and be in the presence of spiritually-gifted men of God *(Ae-Ngibise et al.*, 2010; Read, 2012; Read and Doku, 2012). Apart from the spiritual healing, people with many social, psychological, emotional and physical health issues attend the camps for psycho-social and spiritual interventions. The camp leaders often adopt a variety of practices, some of which can violate human rights, to help them run the centres, as explored further in the next section.

2.5.3: Prayer camps' practices for mental health treatment

Prayer camps employ several practices as part of their diagnosis, treatment and management of mental illnesses. Some notable practices at prayer camps include fasting, prayer and chaining. Fasting is a religious practice, practised amongst Christians and Muslims. Most prayer camps observe this on a regular basis and fast for a variety of reasons. These include being closer to God, humbling oneself to God, or as a way of expressing one's grief for sins he or she has committed. During fasting, people abstain from food and drink for a specific period of time. It can last for a few hours, days or weeks. In prayer camps, this practice can be coercive, as people with mental illness can be asked by the spiritual leaders to fast as it is perceived to be an important part of the healing or treatment process (Abbo, 2011; Ofori-Atta *et al.*, 2018b). While the person suffering from the illness can fast themselves, others, including members of their families, can also fast on their behalf (Taylor, 2016).

The practice of prayer is a significant observance at prayer camps. It involves a range of activities used in conjunction with fasting, to exorcise demons or evil spirits from people believed to be demon-possessed (Kpobi and Swartz, 2019), bewitched (Onyinah, 2002) or cursed, possibly leading to a person developing dementia (Bursell and Mayers, 2010a). Prayer is also believed to be used to identify the mental illness, its causes and treatment (Gyimah *et al.*, 2022).

Most prayer camps are characterised by chaining. People with psychiatric illnesses perceived to be violent, aggressive, displaying challenging behaviours or perceived to be running away may be chained to trees, pillars, cement blocks or heavy objects that may found in the compound of the camp (Onyinah, 2002; Edwards, 2014; Arias *et al.*, 2016). It is argued that chaining as a practice is used to prevent people with behavioural issues from running away, causing harm to themselves or others. Several studies (Ae-Ngibise *et al*., 2010; Coleman, 2019; Taylor, 2016) have investigated treatments to people with psychiatric illnesses in prayer camps. Participants from these studies, in their explanation for chaining people at the camps, have argued that they do so due to a lack of sufficient human resources to supervise people with mental illness; because of the lack of physical structures such as walls or fences around the camps; and to stop people from running away (Minas and Diatri, 2008). It is further argued that recovering escaped people with mental illnesses or dementia could be a difficult thing to do, regardless of the location of the camp, so chaining reduces the risk of people with dementia and other psychiatric illnesses running away (Ofori-Atta *et al.*, 2018).

The prayer camps are also characterised by ‘deliverance’ practices as a means to free people from evil spirits, witches, demons and ancestral curses and diseases. Read (2019) and Onyinah (2002) found that it is believed that anyone in Ghana, whether Christian or not, could be a witch, demon-possessed or inherit ancestral curses. It is culturally believed that people need to be delivered from these spirits before they could be free (Onyinah 2002). Deliverances are major activities of prayer camps and are usually performed through such practices as fasting, prayers and sometimes exorcism. Before deliverance sessions, the spiritual leader would ask those needing deliverance to come forward or stand in front of the congregation. The spiritual leader would then interview the person suffering from the mental illness or their families, or any person needing to be delivered, to gather some background information about them. They would then instruct the congregation to sing, often accompanied by musical instruments and clapping. The spiritual leader would pray and give instructions to the congregation to pray, too. They would say some words or phrases like “break” (bubu-break), “bind” (kyekyere), “burn with the fire of God” (*Onyankopɔn egya nhye wo*) repeatedly to rebuke the witches and evil spirits. The spiritual leaders may lay their hands on the person being delivered, who may fall to the ground sobbing, groaning or shouting (Onyinah, 2002, 2004; Asamoah *et al.* 2014). The people believed to be demon-possessed are thought to have received their deliverance and be clear of evil spirits after their deliverance session.

2.5.4: Explanation for rapid growth of prayer camps

One area in which witchcraft accusation is well-rooted in Ghana, SSA and other cultures around the world is in the health domain. This belief about witchcraft is very entrenched and a fundamental part of the Ghanaian religious and social culture (Geest, 2002; Agyapong, 2020). Such religious beliefs and values are perpetuated by the stories people hear every day, including personal testimonies grounded on the belief that Ghanaians constantly live in the presence of supernatural realities. It is common to find witchcrafts, occult money and their associated evils being shown in Ghanaian and African films (Agyapong, 2020). Often, taken-for-granted stories of witches attempting to visit their relations abroad by travelling on spiritual aircrafts and getting them deported, or witches bringing happy marriages to ruin through barrenness and impotence, are commonplace (Adinkrah, 2019; Oluwole, 1995). Such a visible presence of discourses relating to ‘spirits’ or ‘witches’ lead to there being an explanation for negative life events, and that the means of eliminating such influences is through religious rituals, Christian prayers or sometimes a combination of resources to achieve their goals (Koning, 2013).

Prosperity, both in the spiritual and material sense, remains a major theme in contemporary Ghanaian and African Christianity (Omenyo, 2011). Thus, contemporary Christianity shares the supernatural worldview associated with traditional religion in which evil powers are held responsible for the problems that people face in life, including the failure to prosper materially (Onyinah, 2002b; Brooke and Ojo, 2020). For certain denominations, responses to the demands for diagnosis, healing, exorcism and deliverance of people from these supernatural or evil powers are adopted by many healing or prayer camps in the country. What both the pastors or prophets, and those who attend these healing centres, have in common is the belief that supernatural powers, with witchcraft as the most single suspect, are the cause of their problems and misfortunes. They claim to possess the ability to heal the sick, especially those with mental or psychiatric illnesses, and solve the multiplicity of socio-economic issues and other challenges that people face; they have now become centres of attraction for solving human problems.

Summarily, there is limited access to psychiatric treatment in Ghana due in part to inadequate human and material resources. The belief in supernatural powers is deeply ingrained in Ghanaian culture and it is believed that supernatural illnesses can only be cured through the power of God. Consequently, spiritual care, rather than biomedical care practices, plays a much more significant role in the care of people with dementia when compared to other Western countries. Reviewing the literature, several studies (Edwards, 2014; Arias *et al.*, 2016; Hindley *et al.*, 2016; Kpobi and Swartz, 2019) have revealed that people with mental illnesses and their families often consult spiritualists, pastors and prophets, witchdoctors and other traditional healers as their first port of call instead of seeking biomedical help. The religious culture in Ghana means that spiritual care based on religious constructions of dementia, such as witchcraft and curses, is a significant part of dementia care practice in Ghana.

2.6: The biomedical care system

In Ghana, the biomedical care system includes the government-operated and financed delivery systems with medical care provided at hospitals, health centres, clinics, health posts and maternity homes (Ewusi-Mensah, 2001; Tabi *et al*., 2006). Some quasi-government-operated health services, including those provided by the army, the police and some large firms and corporations for their employees, also exist. There are also private healthcare services provided by religious missions such as the Catholic Mission, the Presbyterian Church and the Seventh Day Adventist Church. The government supports these missions' health services financially (Ewusi-Mensah, 2001).

The first to bring biomedicine to Ghana, the then Gold Coast, were the Christian missionaries and missionary societies from Europe in the 19th century. They were "almost the sole providers of modern medicine until after World War I" (Ampomah Gyamfuah *et al.*, 2015). In Ghana, the biomedical system is officially managed by the Ministry of Health, which provides medical care, mental healthcare and other health services in the country (Tabi, 1994). The Ministry of Health supervises the medical system as well as the control of drugs, scientific research and professional qualifications of medical personnel in Ghana.

2.6.1: Psychiatric care for dementia

This section discusses the development of psychiatric care in Ghana from the colonial era to date, as well as the limited accessibility to psychiatric services in Ghana. As previously mentioned, there are three state-owned psychiatric hospitals in Ghana, two of which are based in the GAR. Psychiatric care provides an alternative to traditional healthcare; however, it is beset with a number of challenges thus making patronage of psychiatric care services more difficult for most people with psychiatric problems (Tabi *et al*., 2006).

Firstly, medical technology is not advanced – or, in some cases, missing altogether – in many health centres in most African countries including Ghana (Tsey, 1997; Tabi *et al., 2006)*. As a result, medical laboratories may be ill-equipped, and this can make establishing accurate cause-effect relationships in dementia and many psychiatric diseases challenging (Secker, 2013). The result is that health professionals may rely on guesswork to try and establish the proper diagnosis of many illnesses including dementia (Albert *et al.*, 2011). Secondly, several studies (Tsey, 1997; Mbwambo *et al.*, 2007; Moshabela *et al.*, 2017) have argued that the belief in a mystical cause of diseases takes over when biomedical personnel fail in giving a proper diagnosis and treatment of illnesses. Thirdly, following on from the above, for most Ghanaians, the easiest thing for them to do is to find the "witch" who caused the illness or misfortune. Brooke and Ojo (2020) found that, in SSA, older women are mostly perceived to be witches within the neighbourhood and so can easily be blamed for the cause of illnesses and misfortunes. It is, therefore, no wonder that most families with people with psychiatric conditions seek help from traditional sources, not only because of the cultural or religious beliefs but also because of ease of access or inexpensive access to traditional healing services in the communities where people live (Ewusi-Mensah, 2001; Ibrahim *et al.*, 2016; Ofori-Atta *et al.*, 2018).

2.6.2: Historical overview and evolution of mental healthcare in Ghana

In the early 19th century, people suffering from mental illnesses in Ghana (then Gold Coast) were usually kept in prisons (Ewusi-Mensah, 2001). Before this time, psychiatric patients were left on their own to fend for themselves or were sent to traditional healers (Ewusi-Mensah, 2001; Ibrahim *et al.*, 2016). In 1888, the then Governor, Sir Griffith Edwards, passed the Lunatic Asylum Ordinance (LAO), which provided statutory backing for the institutionalisation of mental health patients. The purpose of the LAO was to curb the situation where people with mental illnesses "were seen roaming on the streets in towns and villages causing damage to properties and sometimes inflicting harm on people" (Asare, 2010, p 1).

Following the LAO's enactment, people who were perceived to be suffering from mental illness were put in prison in the capital city, Accra. Special prisons with harsh conditions were established, and people with mental illnesses were put under strict restrictions. People with mental illnesses were to be confined to institutional care, as they were seen as social outcasts who were needed to be removed from mainstream society into institutions (Asare, 2010). Mental illnesses were treated as a crime and a specialised prison was set up for people suffering from mental illnesses, but not necessarily curing them of their illnesses. It was not uncommon at that time for patients suffering from mental illnesses to be unceremoniously removed from the hospital by their relatives in order to consult a traditional or spiritual healer. This was because of a widely held belief that psychiatric illnesses were caused by supernatural evil forces that could be banished by traditional medicine (Asare, 2010; Walker and Osei, 2017).

This special prison became full and could no longer admit more patients. Therefore, in 1906, the Accra Psychiatric Hospital ("The Lunatic Asylum"), the first of its kind in West Africa, was built by the British Empire (Adu-Gyamfi, 2017). Until 1950, there were no substantive psychiatrists. In 1963, the Ghana Medical School began offering undergraduate courses in psychiatry. Until then, psychiatric doctors were sent abroad to pursue studies in psychiatric medicine. The LAO operated until 1972, when the Mental Health Act was passed by the National Redemption Council (NRC). Under the NRC government, in 1972, the Mental Health Decree (MHD) of the (NRC) Decree 30 (NRCD 30) was enacted. This law was an improvement of the LAO, although it maintained some elements of it. Similar to the 1888 Act, the MHD placed emphasis on institutional care to the detriment of providing mental care in primary healthcare settings. In the Act, the NRCD 30 gave way for the abuse of people's freedom and liberties, as people with mental health issues were not deemed sane enough to enjoy basic human rights (Walker and Osei, 2017). Additionally, people with psychiatric illnesses were not sufficiently protected by the law against unnecessary admission. Furthermore, under the Act, serious mistreatments of people with mental disorders took place with some people being locked away in institutions for many years (Ewusi-Mensah, 2001; Walker and Osei, 2017). However, under the MHD, the NRCD 30 was never fully implemented (Adu-Gyamfi, 2017; Walker and Osei, 2017).

In 2012, the mental health law in Ghana was revised. The new act, the Mental Health Act (MHA) 846, established the Mental Health Board. The Board performs several functions including taking responsibility for the policy formulation, and regulation and enforcement, whilst a mental health programme within the Ghana Health Service would be responsible for the implementation of public mental health services. The MHA was passed, as the 1972 legislation was felt to be out of date and no longer fell within the practices of mental healthcare. One of the focuses of the MHA 846 was to improve access to care for people with mental illnesses, the challenges poor and vulnerable people face, safeguarding human rights, and promoting participation in the restoration and recovery of mental illness (Ofori-Atta *et al.*,2010; Walker and Osei, 2017). The MHA 846 also made provision for the integration and regulation of spiritual and traditional mental health practices in Ghana, and the decentralisation of mental healthcare, as well as placing emphasis on community rather than institutional care *(*Asamoah *et al.*, 2014; Taylor, 2016). This was the first time that mental health was regarded as a public health issue and people with mental health issues had their human rights protected (Adu-Gyamfi, 2017). However, this did not seem to be fully operational, as people with psychiatric illnesses continue to be chained in prayer camps and other such facilities (Ofori-Atta *et al.*, 2018). Also, inadequate community-based formal mental health services mean that faith-based (prayer camps) and traditional healers continue to be a major/main or a popular avenue for mental health treatment (Walker and Osei, 2017).

Dementia is not strictly a mental health condition, and dementia and its treatment are not specifically mentioned in the MHA 846, despite the improvement the Act made to the treatment of mental health in the country (Walker and Osei, 2017). The MHA 846 talked generally about treatment specifically for older people with mental health or mental disorder. Section 66 sub-sections 1 and 2 of the Act state that “the aged who require treatment for mental disorder shall be accommodated separately and are entitled to free physical treatment in accordance with age exemption policy. Special provision shall be made for the accommodation of the aged whose conduct may at any time be harmful to them or other aged patients” (Walker and Osei, 2017, p 30). Given the lack of awareness of dementia and the societal beliefs about both dementia and mental illnesses being spiritual illnesses caused by supernatural/evil forces, people suffering from dementia and mental health issues are all treated in the same facilities, mainly in psychiatric hospitals or prayer camps.

2.7: Summary and Conclusion

Publicly funded medical facilities that can provide high-quality dementia care are rare in Ghana. As previously highlighted, all the three state-owned psychiatric hospitals are located in the southern part of the country, which makes access to formal psychiatric care and services very limited. While both physical and human resources relating to psychiatrists and other healthcare professionals in the field of psychiatry are woefully inadequate, faith-based centres in the form of prayer camps form an important part of the infrastructure for dementia care based on a different conceptualisation of dementia – as a spiritual ailment associated with the spiritual deficiencies of the person. This conceptualisation of dementia requires faith-based healing centralised on religious figures and delivered through religiously defined spaces such as prayer camps (Koduah *et al.*, 2019). Prayer camps are believed to be able to cure mental and other illnesses thought to be caused by evil spirits, and the prayer camps rely heavily on divine revelation as a means of diagnosing and treating mental disorders. Using Christian practices such as fasting, prayers and exorcism, prayer camps are believed to be able to set free people believed to be demon-possessed, or people being attacked by demons. Thus, the religious-based beliefs around dementia in Ghana construct dementia as a spiritual illness requiring spiritual care often at prayer camps, which are symbolic places where such spiritual care takes place.

2.7.1: Summary of published work since completion of original literature review

Several studies published since the original literature review have explored the views of dementia by different stakeholders including healthcare providers, professionals, and members of the general public in SSA. These include a study in rural Kenya (Musyimi *et al.,* 2021), research with students and the general population in Ghana (Spittel *et al*; 2021) and family caregivers' experience of dementia in South Africa (Mahomed and Pretorius, 2022).

Musyimi *et al.* (2021) explored the perceptions of dementia and dementia care across the three stakeholder groups: healthcare providers, professionals and the general public (38 participants altogether) mentioned above. The study employed a focus group discussion method and found a general lack of knowledge of dementia amongst all the three stakeholder groups and an ill-equipped healthcare system, both leading to stigma which was manifested in the form of patchy diagnostic pathways and neglect and abuse of people with dementia. However, as the study utilised a small group of participants from one rural region in Kenya, its findings may not reflect the opinions of people living in the urban regions of the country.

In another recent study, Spittel and colleagues (2021) conducted research on dementia awareness in SSA with special reference to Ghana. The study aimed to ascertain participants' familiarity with dementia in the country. A total of 1,137 people comprising students and members of the general community (churches and villages) were surveyed between 2015 and 2017. The findings showed that 9.3% of students had little awareness of dementia, while 32% of members of the community showed greater dementia awareness. Also, approximately half (45%) of those surveyed believed in witchcraft being the cause of dementia, with 57% indicating they were afraid of potentially being harmed by witchcraft. Furthermore, the study found no significant difference between participants' age, gender or whether they were rural and urban dwellers regarding their belief in witchcraft. One critique of Spittel *et al.'*s work was that, while the sample size was relatively large, it was not clear which or how many districts or regions the study took place. It is likely that the study was limited to a few districts or regions of Ghana and, given the variety of cultural differences and belief systems within and across the country, it could well be that the views captured in the study represented a very limited view that is not in line with the general population.

Another work published after the original literature review was carried out in South Africa by Mahomed and Pretorius (2022). In this study, a sample of 30 participants were interviewed using semi-structured interviews. New insights from the findings showed that there appears to be a shift in perception away from a cultural and spiritual paradigm of dementia and a lack of pressure to conform to community conceptualisations of dementia among individual family caregivers. Further, caregivers did not feel emotionally supported and reported a lack of assistance with their daily practical demands. Additionally, before receiving a diagnosis, family caregivers might be viewed as the perpetrators of abuse and/or neglect against their family members with dementia, instead of individuals with dementia being stigmatised by the community due to their behavioural symptoms, as commonly reported in caregiving literature. Similar to studies highlighted above and others across most LMICs, a lack of awareness of dementia at the outset affected South African caregivers' ability to make sense of what was actually happening to their relatives with dementia. Other findings included caregivers sacrificing their ambitions and aspirations, sometimes leaving their jobs or avoiding their leisure pursuits or social engagements owing to their caring responsibilities. Some caregivers avoided social events due to feeling guilty, anxious or stressed from managing their relative with dementia's dementia-related behaviours in public, or the fear of leaving them alone at home.

Findings that have emerged from the published works since the original literature review have led to new insights regarding dementia and dementia care provision in Ghana in particular and SSA in general. It is significant to note that, while witchcraft and other spiritual-related beliefs about the cause of dementia and other psychiatric illnesses in the literature remain unchanged, there appears to be a shift in the perception of dementia away from this cultural/spiritual paradigm in some countries including South Africa (Mahomed and Pretorius, 2022). Secondly, the lack of knowledge and awareness of dementia remains an issue in most SSA countries (Brooke and Ojo, 2020; Musyimi *et al.*, 2021) including Ghana (Spittel *et al*., 2021) and, in some countries, people's age, level of education, religion and gender do not appear to change their perceptions and views about what causes dementia (Musyimi *et al.*, 2021). Another new insight gained from the published works since the last literature review was that there are no significant differences in people's belief in witchcraft being one of the key causes of dementia in SSA. Thus, age, gender or rural or urban living did not make any difference in participants' beliefs in witchcraft being one of the key the causes of dementia. Another new and relevant knowledge discovered since the last literature review was that, in some communities in SSA, dementia is not necessarily a stigmatised condition due to the symptoms people with dementia might display. Instead, family carers of people with dementia are often viewed as perpetrators of abuse or neglect before people with dementia receive their diagnosis of dementia.

What is new and relevant to my study following review of published work since commencement of the literature review is that, while the display of behaviours such as hallucinations and socially inappropriate conduct by people with dementia are perceived as spiritual phenomena such as witchcraft or evil-possessed; most carers in Mohamed and Pretorius' (2022) study did not concur with these spiritual perceptions held by their communities. Neither did they feel any pressure to conform to the cultural beliefs held by the larger community.

Chapter 3 - Literature Review 2

Ageing and Dementia in Ghana

3.1: Introduction

The youthful Ghanaian population to date has meant that the older population does not appear to feature in the country's national policies, or at least little consideration is given to the older and ageing population (Tawiah, 2013; Kwankye and Cofie, 2015a). However, projections of Ghana's population have suggested that its structure will likely change dramatically, and the country will experience an increasingly high growth of the numbers of its older people. Ghana's ageing population will likely have major and far-reaching implications given its widespread poverty, changing household and family structure due to modernisation, urbanisation and migration, the heavy burden of communicable diseases and an inadequate healthcare system (Aikins *et al*., 2015). However, the Ghanaian government does not seem to have adequately focused its attention on the older and ageing population, despite a review of the burden of chronic diseases (de-Graft Aikins *et al.,* 2010; Apt, 2012) that had found dementia and other age-related diseases to be among the top ten causes of death in the country (Kwankye and Cofie, 2015a). In addition, while dementia appears to be a relatively minor problem in Ghana, several studies (Guerchet *et al*., 2013; Maharaj, 2013; Mazaheri *et al*., 2013) have predicted that it will become a growing problem in SSA, including Ghana, as their population ages. The increasing prevalence of dementia and the complexity of it, as well as other chronic diseases as the population grows older, means that the pressure on the health system and health and social care will become problematic given the lack of human and material resources available to meet the needs of the growing population in Ghana.

This chapter, therefore, seeks to discuss population ageing, what it means to be old in Ghana, ageing and social change, the context of family and family systems in Ghana, dementia, its prevalence and socio-cultural context.

3.1.1: Organisation of chapter

The literature review chapter is divided into two sections, with each looking at a different aspect of the thesis. The first chapter (Chapter 2) seeks to examine the concept of care, types or models of care, formal and informal care provision, and different care settings, namely the home, prayer camps and the hospital within which dementia care is provided. The second chapter (Chapter 3) discusses Ghana as a country, its ageing population highlighting the challenges associated with this rapid increase in its ageing population, social change resulting from urbanisation, migration and globalisation, and how these have affected the traditional family structure, role and its ability to care for older people, including those with dementia. Some challenges facing older people in Ghana, dementia, its prevalence and sub-types, as well as cultural understandings within the Ghanaian context, are explained. A brief discussion of stigma and its impacts on ageing, people with dementia and their carers is held.

3.2: Population ageing in Ghana

The 2000 Population and Housing Census Report (PHCR) of Ghana showed that the proportion of the country's population aged 60 years and older formed 5.3% of the population. This figure was an increase of 4% from the 1984 report (Ghana Statistical Service {GSS}, 2013). In 2010, the total number of people aged 60 years and older had increased to 6.7% (GSS, 2013). The 2010 figure is projected to rise further to more than double, to 14% by 2050 (Kwankye and Cofie, 2015). However, neither population ageing nor dementia has been considered a public health priority by the Ghanaian government and policy-makers (Kwankye and Cofie, 2015) and, although dementia is projected to become a big problem for Ghana in the future (Agyeman *et al.*, 2019; Spittel *et al.*, 2021), the country is not adequately prepared for it at this stage (Kwankye, 2013; Kwankye and Cofie, 2015). Instead of dementia and other age-related diseases, the government and policymakers have been focusing their attention on policy initiatives that affect the segments of the population, particularly the youth.

According to the 2010 PHCR, nearly 50% (49.5%) of the country's population was under 20 years and 25% of the population was reported to be aged between 20 and 35 years (Kwankye, 2013; Tawiah, 2013; Kwankye and Cofie, 2015). The youth population appears to be of critical importance to and has remained at the top of the government's priorities (Tawiah, 2013). It is evident from the above statistics that the older population makes up a small proportion of the overall population of Ghana and this might partly account for the ageing population remaining a low priority in Ghana, as in other LMICs (Lloyd-Sherlock, 2000; United Nations Population Fund, 2011; Kwankye, 2013). In addition, appropriate systems to collect essential data for accurate demographic estimates and projections on ageing are lacking (Tawiah, 2013). This might account for why the government has been focusing its attention on using the available resources to address the demographic challenges and health issues that affect the youthful population who are in the majority.

In summary, the older and ageing population of Ghana seems to have been largely ignored or excluded, as more emphasis and policies are placed on the younger generation who constitute the bulk of the population. The youthful population has meant that older people, including those with dementia, do not often feature much in national policies.

3.2.1: What it means to be old in Ghana

There is no standard definition of what it means to be 'old' in Ghana. With life expectancy in Ghana being as low as 62 years, people who grow past this landmark are regarded as 'older people'. Geest, an anthropologist in his study of older people in the Kwaku Tafo area of Ghana, used different concepts to describe what 'being old' meant within the Ghanaian context (Geest, 2016). Geest referred to an older person as '*Opanin*', which literally means an adult, matured person, a 'tired' body as opposed to '*akwadaa',* child or '*ababunu'* youth, someone between 15 and 35 years of age as defined in Ghana Youth Policy (Gyampo, 2012). For many, the main marker for age is physical, with frailty and debility more significant than numerical age per se. People in the civil service – including teachers, police and medical personnel – tend to use the compulsory retirement age of 60 as the definition of old age (Gyampo, 2012). However, very few people are employed in the civil service and have an opportunity to retire (Tawiah, 2013; Araujo de Carvalho *et al.*, 2015).

The 2000 Ghana census showed that 54% of older people live in urban centres (GSS, 2013; Tawiah, 2013). The report further showed that older people living in the rural areas, compared to their urban-dwelling counterparts, are disadvantaged due to the inadequate provision of basic infrastructural amenities, sanitation facilities, and safe and portable drinking water (Darkwa, 2000; Dosu *et al*., 2014). Kwankye and Cofie (2015) noted that an inadequate provision of basic amenities creates extra burdens for carers of older people, as they may have to provide alternative means such as digging their own boreholes to ensure a regular water supply. Over two thirds (68.2%) of older people are classified as young-old (60–74 years) and approximately one in ten (9.6%) is very old (85 years and over) (GSS 2014; Kwankye and Cofie, 2015). Also, older women compared to their male counterparts suffer more from extreme poverty, discrimination and abuse due in part to the latter mostly having lower levels of education as well as the cultural restrictions, for instance childcare responsibilities, that are imposed on them by society (Brooke and Ojo, 2020).

Culturally, older people in Ghana must be met with respect, fear and deference by the youth due to age and silence (Brown, 1990; Geest, Mul and Vermeulen, 2004). Geest (2016; 2006) argue that, often, older people have acquired a wealth of experience and accumulated more wisdom than the younger generations. Geest (2002) found that the young were eager to receive advice from the older people in society because of the older people's wisdom and life experiences. Traditionally, older persons act as master craftsmen, handle arbitrations and settle disputes in the communities (Tawiah, 2013). Geest (2002) further identified that older people often know the history of their respective towns and families and that the young enjoyed tapping the wisdom and historical knowledge from them. Through these activities, older people reduce the level of social unrest, civil strife and encourage community development. Thus, older people in Ghana are respected for such roles that they play in society (Geest, 1998, 2002). However, Ajatnoah-Gyadu (2004) notes that some older people are suspected to possess harmful occult powers, something that the youth can be fearful of, as it is believed that curses or negative pronouncements from older people can cause misfortunes in the lives of the young.

Also, older people, especially women, may be suspected of being witches and may, therefore, be more feared by the young and old alike because of the harm witches are believed to be able to cause in people's lives (Mkhonto and Hanssen, 2018; Brooke and Ojo, 2020). Ajatnoah-Gyadu (2004), therefore, argued that the young may fear and obey older people to avoid potential harm that witches can do to them, or receive negative pronouncements such as curses, but instead receive good advice and blessings from older people. The Ghanaian cultural beliefs about witchcraft, its association with dementia and how these impact on the people with dementia, their family carers and others who care for or work with them, will be discussed in more detail later in the chapter.

3.2.2. Regional Ageing Policy

In Africa, the African Union (AU) has taken the lead role in ageing and social protection issues. In 2006, the AU held a conference at Livingstone, Malawi to examine new ways to tackle poverty and promote the human rights of the poorest in Africa. The conference emphasised that political will was the driving force for long-term investment in social protection programmes. The Livingstone conference defined social protection as “a range of protective public actions carried out by the State and others in response to unacceptable levels of vulnerability and poverty, and which seek to guarantee relief from destitution for those sections of the population who for reasons beyond their control are not able to provide for themselves” (Kazeze, 2008 p 46).

Old age and ageing have been described as invisible in most policy dialogues in Africa (Kalasa, 2001). Lomazzi *et al.* (2014) maintain that the Millennium Development Goal (MDG), the overarching framework for international development priorities, specifically targets children, youth and women, but no reference was made to older people. Consequently, older people are less likely to be covered in any policy document or benefit from any targeted development support. Kalasa (2001) argued that the African continent focuses on urgent and pressing demographic problems including rapid population growth, as shown in high youth populations, and unemployment, infant and child mortality rates, excessive urban expansion and maternal mortality. Owing to these, African governments have been focusing their attention on investing their limited resources on the long-term productive potential of the youth, thereby according to older people low priority in their national development policies and programmes (Kalasa, 2001).

3.2.3: National Policies on Ageing

As population ageing continues to present challenges and opportunities worldwide, actions are required by national governments and policymakers to try and address these challenges while creating opportunities for active and healthy ageing in their respective countries (United Nations Population Fund, 2011). Ghana has a few national policy documents and social protection programmes and projects that provide for the needs of older people in the country.

Ghana has, over the years, implemented several social protection programmes and strategies, such as the Social Security and National Insurance Trust (SSNIT), the Livelihood Empowerment Against Poverty (LEAP) Programme and the National Social Protection Strategy (NSPS) that are aimed at reducing poverty. However, it is difficult to sustain several of these programmes (LEAP and NSPS) because the majority of the population is living in abject poverty (Abebrese, 2011). This has contributed to making social security programmes in Ghana weak (Owusu and Baidoo, 2020).

3.2.4. Social Protection in Old Age in Ghana

Paragraphs 48 and 53 of the Marid International Plan of Action on Ageing (MIPAA) stress the need to reduce poverty among older persons and providing sufficient income for all older persons, paying particular attention to socially and economically disadvantaged groups (including people with dementia) (Sidorenko and Walker, 2004). These objectives are supported by the UN Charter of Human Rights and UN Convention on the Rights of Persons with Disabilities. However, Prince *et al.* (2008) argue that social protection in old age depends upon a complex interaction of health, living arrangements, family support, sources and levels of income. Carvalho and colleagues (2014), in their study of ‘Informing evidence-based policies for ageing and health in Ghana’, found that older people’s healthcare needs were not adequately met due to low health insurance coverage in older Ghanaians, although insurance is free for those aged 70 and older. The WHO’s SAGE study (in Ghana) on global ageing and adult health found that health insurance coverage for people aged 60 and over were below 50%. Moreover, older Ghanaians were found to lack an understanding of conveying the message of chronic diseases and the need for them to receiving ongoing treatment for these. It was noted that this was partly due to their (older people's) belief system and health practices (Kowal *et al*., 2011).

i) National Health Insurance Scheme

The policy objective is that, within the next five years, every resident of Ghana shall belong to a health insurance scheme that adequately covers him or her against the need to pay at the point of service use in order to obtain access to a defined package of acceptable quality of health service (Barimah and Mensah, 2013). It is compulsory for every person living in Ghana to belong to a health insurance scheme. Every person living in Ghana shall contribute according to the principle of ability to pay in order to enjoy a package of health services covering over 95% of diseases afflicting Ghanaians.

The formal sector shall contribute 2.5% of their 17.5% Social Security and National Insurance Trust (SSNIT) contributions, whereas the informal sector shall contribute at least 72,000 Ghana Cedis per annum. In addition to the funding of the scheme by the contribution of persons working in the formal and the informal sectors of the economy, the government has put in place a framework for mobilising additional funds to support the implementation of the scheme. The government has instituted by law a 2.5% National Health Insurance Levy payable on selected goods and services. Funds raised from this source shall be used to subsidise the contributions of the underprivileged segment of the society and to pay for the contributions for the core poor and other vulnerable groups.

The benefit package of the NHIS includes general out-patient services, in-patient services, oral healthcare, eye care, emergencies and maternity care (such as pre-natal care, normal delivery, and some complicated deliveries). Diseases covered, among others, include malaria, diarrhoea, upper respiratory tract infections, skin diseases, hypertension, asthma, and diabetes. About 95% of all common health problems in Ghana are covered with specified minimum benefit packages to members. Some services (such as HIV antiretroviral drugs, hearing aids, dentures, and VIP accommodations) are excluded from the health benefit package. As of December 2009, some 14.1 million Ghanaians, or 60.1% of the total national population of 23.4 million, had registered for the NHIS (Barimah and Mensah, 2013).

ii) The Social Security and National Insurance Trust (SSNIT)

The right to adequate social security for older people is enshrined in human rights, and international labour standards include the right to a social security pension (Hokenstad and Roberts, 2011; Chitonge, 2012). Providing people with adequate and reliable sources of income security throughout their old age is, therefore, essential. However, in SSA including Ghana, owing to the high proportion of informal employment, only 8.4% of the labour force contributes to pension insurance and earns rights to a contributory pension, compared with 34.0% in Asia and the Pacific, 47.4% in North Africa, 89.2% in Western Europe and 98.5% in North America (United Nations, 2015).

Thus, for most older people in Ghana, old age income security is a real challenge. Ghana has two main types of Social Security Schemes for its older people – 'CAP 30' and the Social Security and National Insurance Trust (SSNIT). The CAP 30 was established by the British Colonial Government for the Pensionable Officers in the Civil Service and the Members of the Armed Forces in the Former British West African Colonies. Set up under the CAP 30 Pension Ordinance of 1946, only Pensionable Officers and African Civil Servants who joined the service before January 1972 were covered. In 1972, the SSNIT (the Pension Scheme) was established by the NRD 127 and amended by the Social Security Law 1991, PNDC 247. This contributory scheme covered workers in the formal and informal sectors (Agyepong and Adjei, 2007). In Ghana, about 70% of the population work in the non-formal sector of the economy (Agyepong and Adjei, 2007), make no contributions towards the old age pension scheme and receive no old age pension in their old age. This partly explains why pension cover in Ghana, like most LMICs, is low despite the important roles pension plays as an income source to the less affluent groups of the population (United Nations, 2015). Also, like many countries across LMICs, pensions coverage for women in Ghana is lower than that of their male counterparts. Less than 8% of the working age has some form of legal coverage (United Nations, 2015). In Ghana, women largely work in informal employment, and this reflects their lower participation in the labour market. Until recently, most women received very low or no formal education. This made it difficult for most women to enter the labour market. Petty trading is a very common means of establishing oneself in the informal economy. People can start this type of business with little capital and one does not necessarily require formal education, previous experience or a particular skill set to start. In short, there is free entry, it is not capital intensive, and people can sell on the street, at bus/coach stations or anywhere they believe they can get good patronage. With most women working as self-employed or working in the agricultural or other sectors with no careers in formal employment, this would affect their ability to contribute to the social security fund.

Adei and colleagues (2015) found pension coverage in Ghana to be as low as 7.6%, which is significantly lower than the regional average of 26.2%. The majority of older people in Ghana work in the informal economy, including working in the agricultural sector, as artisans and other self-employed businesses and so did not contribute to the SSNIT fund. To ensure income security for those who work in the informal economy, Article 37 (6) of Ghana's 1992 Constitution explicitly mandates the government to ensure that contributory schemes are instituted and maintained in order to guarantee economic security for the self-employed (Adei *et al*., 2015; Agyepong and Adjei, 2007). Consequently, the government in Ghana set up a pension scheme, the Informal Sector Fund of the SSNIT, in 2005 so that those working in the informal sector could make some contributions towards their old age pension. Freiku (2011) indicated that, between 2005 and October 2011, membership of the fund rose from 6,577 to 90,913 (cited in Adei *et al*., 2015). In addition, the LEAP fund provides income to the aged in Ghana, although the percentage of beneficiaries of this income source is low, at about 1.1% (Adésínà, 2009; Adei *et al*., 2015).

iii) Livelihood Empowerment Against Poverty (LEAP)

In addition to the NHIS, people aged 65 and older who are poor have LEAP. LEAP is a Ghana government social cash transfer programme which provides cash and health insurance to extremely poor households across the country to alleviate short-term poverty and encourage long-term human capital development (Handa and Park, 2012). LEAP started on a trial phase in March 2008 and then began expanding gradually in 2009 and 2010. Five years after it was launched, LEAP had reached over 71, 000 households across the country. LEAP is fully funded from the government of Ghana’s general revenues and one’s eligibility is based on poverty and having a household member in at least one of three demographic categories: single parent with orphan or vulnerable child, elderly poor, or person with extreme disability unable to work (Handa and Park, 2012). Beneficiaries of the LEAP programme receive two-monthly payments through the national postal service agency. However, the majority of older people in Ghana continue to live without adequate protection coverage, which means that older people's fundamental human rights to social security may only partially be realised, or not at all (Adésínà, 2009; Chitonge, 2012).

Nationally, the Ghana government policy documents SSNIT, on ageing, upholds Ghanaian families as the proper site for the care of senior citizens (Tawiah, 2013; Kwankye and Cofie, 2015a). Successive governments in Ghana have, since the 1990s, explicitly advocated against old age homes (Geest *et al*., 2004b). The state constructs its draft Aged Policy around a traditional, idealised Ghanaian family and highlights the expense, foreign-ness, and inappropriateness of other countries' approaches (Kalasa, 2001). Instead, state resources in Ghana seem to be concentrated on the futures of the young (Adua *et al*., 2017). Geest (2016) argued that the approach of focusing on the needs of the youth seems to ignore the plight of the aged in Ghana and presents the government as needing to do little to support its senior citizens.

3.3: Ageing, social change and its implication on people with dementia

Despite the number and percentage of older people growing faster than any other age group in Ghana, the country continues to lack the capacity to address the challenges associated with this demographic shift (Mba, 2010; Kwankye and Cofie, 2015b). Rapid social change in Ghana within the past few decades has also exacerbated the plight of older people and people with dementia's situation in the country. Several studies (Geest *et al*., 2004; Benna and Garba, 2016; Cobbinah *et al*., 2016; Coe, 2017) identified urbanisation, migration, Westernisation and industrialisation as some of the main agents of social change and which have had significant impacts on the care and support older people and people with dementia in Ghana receive.

3.3.1: Urbanisation

The world is becoming increasingly urbanised and the United Nations Department of Economic and Social Affairs, Population Division [UNDESA/PD] (2012) estimates that about 54% of the world's population is living in urban areas (Cobbinah *et al*., 2016). This trend is expected to continue to nearly 70% by 2050 with increasing concentration in urban Africa and Asia (Cobbinah *et al*., 2016; Leeson, 2018).

Within the past three decades, Ghana has become increasingly urbanised (Cobbinah *et al*., 2016, Ardayfio-Schandorf, 2012) with nearly 51% of its population residing in urban localities (GSS 2014). With as low as 9.4% of Ghana's population living in urban centres in the three major cities of Accra, Kumasi and Takoradi in 1931, the trend has increased significantly with the proportion of urbanisation increased to 13.9%, 28%, 31.3% and 51% in 1948, 1970, 1984 and 2000, respectively (GSS, 2013). The most recent census, GPHC (2021), indicates that the urban population has increased from 50.9% in 2010 to 56.8% in 2021, with almost half (47.8%) of the increase recorded in only two (Ashanti and Greater Accra) out of the 16 regional capitals (GSS, 2021). Thus, the proportion of the population that is urban varies across the regions, with the highest in Greater Accra (91.7%) and lowest in Upper East Region (25.4%). Also, of the 16 regions across the country, seven are urbanised with more than half of the population in those regions living in urban areas (GSS, 2021).

Urbanisation often results in family dispersal, as the older and the younger populations may no longer live together in the same dwelling due to the younger population often migrating to urban centres in and across the country (Geest *et al*., 2004; Coe, 2017). Additionally, the traditional family support system that had mostly been available to older people in the country (Aboderin, 2006; Geest, 2016) is gradually decreasing as the younger population, now living in urbanised areas, may be unable to be physically present to care for the older members of their families.

3.3.2: Migration

As another aspect of social change, migration, both internal (rural-urban and urban-rural) and international (trans-national) migration is one of the challenges facing older people and people with dementia care in Ghana (Coe, 2016, 2017). Several studies (Geest *et al*., 2004a; Coe, 2016, 2017a) have highlighted that the out-migration of Ghanaians to Europe and the United States of America is due in part to the rapidly growing sectors in healthcare and social care services in these countries. The growth of these sectors has provided opportunities, especially for female migrants, resulting in the influx of the youth travelling abroad to work in these sectors. However, internal migration, especially the rural-urban type, is more prevalent in the country. Similar to the out-migration, the youth mostly constitute the bulk of the migrants, as this type of migration is less costly and cumbersome in its preparation (Geest *et al*., 2004; Coe, 2017).

Migration has affected both the size and growth of the population (Geest *et al*., 2004b; Coe, 2017). Several studies (Aboderin, 2004; Geest *et al*., 2004; Coe, 2017) have explored the linkages between migration and the care of the frail and older people, and identified that older people are often left behind with little or no familial care and support due to the migration of the younger population into urban centres of the country. Coe (2017) also identified that some rural areas of Ghana are now unsuitable for modern agriculture, and this had partly contributed to the youth out-migrating to the cities. Coe (2017) further described that some rural areas in Ghana are becoming almost exclusively 'older people's settlements'. While some migrants may be physically present to provide care to their older relatives whom they left behind, they may indirectly provide care through remittances and distance communication (including emotional support) rather than through daily, practical care activities (Geest *at al*., 2004a; Coe, 2016; Geest, 2016).

3.3.3: Modernisation/Westernisation

One other significant factor of social change in Ghana is the adoption of the 'modern/Western' lifestyle along with demographic shifts. According to Divale and Seda (2001), modernisation occurs "when a more dominant and complex society comes into sustained contact with a less complex society and the former exerts an influence for change in the latter. Some of the change is involuntary, such as the influence of technology and more complex social organization imposed by the dominant culture, and some of the changes are voluntary, such as changes in role expectations and material culture desired by the members of the less complex society. When the differences in complexity between the two cultures are great the results can be psychologically traumatic" (p 151-152).

Modernisation, coupled with urbanisation and migration, means that young people in Ghana are increasingly moving into urban centres, where they would more likely find jobs that match their skills set and experience (Poku-Boansi, 2021). Also, as part of the modernisation process, the sizes and structure of modern Ghanaian families show that they are gradually shifting away from extended to nuclear families (Owusu and Baidoo, 2020). The implication of this is that filial piety is increasingly being weakened and so older people in the country are no longer able to depend on their children and grandchildren or receiving the same level of material and practical care and support as much as they would have done a few decades ago. Thus, within the past few decades, the duty of the young, especially of adult children, to provide support to their aged parents, which is enshrined in the customary moral code and encapsulated in the proverb ‘‘When your elders take care of you while you cut your teeth, you must in turn take care of them while they are losing theirs’’ (Apt, 2012) is being weakened. As Cheung and Kwan (2009) argue, modernisation alienates people from their natal families and localities so that their productive potential is realised in jobs away from their original homes, which lessens the practicality of filial piety. Modernisation has, therefore, brought about changes in the Ghanaian social structures and people’s aspirations, which has, in effect, weakened people’s acceptance of the norms of filial piety and its obligations (Aboderin, 2004a) on the part of children and grandchildren. The above-described social change agents, namely urbanisation, migration, modernisation and Westernisation, have affected the social structures and roles of families and thus the young people’s ability to continue to care for their older relatives.

In summary, the number of older people making up the population in Ghana has been rapidly increasing over the years. The changes in the older people profile and family structure have exerted much pressure on family members’ ability to adequately care for their older relatives. Unlike diseases such as HIV/AIDs, malaria and hypertension, population ageing and dementia have not, as yet, been recognised as a public health priority.

Rapid social change resulting from urbanisation, migration, globalisation and Westernisation taking place in Ghana is slowly weakening the family’s ability to fully and adequately honour its filial piety obligations to care for its older relatives. This is manifested in the reduction of sizes, compositions and declining structures of families in both rural and urban areas.

With no proper and effective care policies for older people, the family remains the main provider of care services to its members that are needing help – whether young or old. Two types of family systems – extended and conjugal/nuclear – are identified in Ghana, as in most sub-Saharan African countries. The next section discusses these family systems.

3.4: The context of family in Ghana

As one of the oldest and important social institutions, the family is the most fundamental unit of all societies in the world (Apt, 2012). Families are usually the major source of basic necessities of life and health, love and tenderness, adequate food, place and time for rest, clothing and sanitation (Apt, 2012). Families in Ghana, as in SSA and cultures elsewhere, are responsible for the care and upbringing of all their members. Families define the social and moral norms and safeguard both material and spiritual customs and traditions, as well as providing role models preparing the way for adulthood (Aboderin, 2004; Dzramedo *et al.*, 2018; Owusu and Baidoo, 2020).

The family is not an easy concept to define in general terms. One of the definitions of the family is Murdock's (1949), "The family is a social group characterized by common residence, economic cooperation, and reproduction. It includes adults of both sexes, at least two of whom maintain a socially approved sexual relationship, and one or more children, own or adopted, of the sexually cohabiting adults" (p 1). Most of the literature on family types have focused on the nuclear family and the extended family (Spiro, 1954; Dzramedo et al., 2018). What constitute a family and types of families in Ghana and their distinguishing features are discussed in the sections that follow.

3.4.1: Introduction to family systems in Ghana

In Ghana, families vary in their structures, sizes and roles. Family members may not necessarily stay under one roof. Within the Ghanaian context, a family is a group of persons linked by kinship connections, with the older members taking care of the younger ones (Ardayfio-Schandorf 2001). Families are usually headed by family heads, who are the leaders of their respective families. They are responsible for organising family meetings to discuss and resolve issues between members of the family, organising family events such as funerals, or discussing matters relating to the welfare of its members (Dzramedo *et al.,* 2018). This may include caring for its sick and disabled members and making financial contributions to support its members in need. This may include older people and people with dementia.

Within the Ghanaian social structure, familism is recognised. This is the practice whereby the needs of the family as a whole are more important than those of the individual members (Chee and Levkoff, 2001.; Tuomola *et al*., 2016). Similar to Asian and other cultures, the Ghanaian family expects that its problems be kept within it rather than publicise them. Tuomola *et al*. (2016) used the metaphor ‘face-saving’ to refer to this practice, while the Akans of Ghana express it thus “matters within families aren’t like clothes to be washed and dry out for the whole world to see” (Owusu and Baidoo, 2020, p 209). Culturally, the Ghanaian family believes that seeking external help, for instance to care for its older members, may upset the family cohesion. The reason being that there is the fear of stigmatisation amongst most Ghanaians and their families to disclose certain information about themselves. They may be reluctant to disclose information relating neuro-psychiatric or mental illnesses such as dementia or ‘madness’ or epilepsy, or behaviours that they consider inappropriate and disgraceful to the family’s reputation. It could also be anything that the family can be labelled with, for instance drunkenness or prostitution. This ‘face-saving’ culture of the Ghanaian society results in the person with dementia or their families feeling reluctant to disclose their condition if they are affected by certain illnesses including dementia. This prevents families from seeking help and early intervention, as they may not want to discuss their condition with the family, let alone approach formal services for diagnosis and treatment (Chee and Levkoff 2001).

As already noted, due to the modernisation process, the extended family system is changing and ties between family members are becoming looser. Conversely, the nuclear families are becoming increasingly common in Ghana and the number of households are gradually reducing (Bernard *et al.*, 2001; Aboderin, 2004).

Culturally, Ghanaians tend to revere and arrange their lives around the extended family. While some people still desire to have many children and large family sizes, most families in Ghana are increasingly having fewer children, resulting in the reduction of sizes of modern families. This is partly due to the fact that most Ghanaian couples are wanting an improved quality of life for their families and that the economic situation is making it increasingly difficult to bring up or care for large families (Sanuade and Boatemaa, 2015).

There are two main family systems in Ghana – the matrilineal and patrilineal. Both systems share many things in common; however, the difference exists in the way of inheritance, e.g. those who succeed the dead and how the bequeathed properties or estates are shared. In the matrilineal system, sons often inherit their maternal uncles, whereas sons inherit their fathers in the patrilineal system. Another common characteristic of both systems is the practice of filial piety (Kyei-Arthur and Codjoe, 2021).

3.4.2: The extended family system

The extended family system is the commonest form of family in Ghana. In this family type, several adults share the roles and responsibilities of teaching, training and punishing children. The extended family can be looked at from two perspectives: i) it consists of a group of close relatives along either male or female line and ii) a social arrangement, in which an individual has extensive reciprocal duties, obligations and responsibilities to relations outside the immediate (nuclear) family (Dzramedo *et al.*, 2018).

Darkwa (2000) described the extended family unit to mean all persons whose lineage is traceable to a particular ancestral home. Thus, the extended family is made up of oneself, parents, siblings, nephews, nieces, cousins, grandparents, and great-grandparents (whether living or dead) (Darkwa, 2000b; Geest, 2016; Dzramedo *et al*., 2018). Culturally, every family has a family home and all persons whose roots are traceable to the family home are considered members of the extended family. It is expected of members of the family to participate in almost all activities and events, including performance of rituals such as marriage, funerals and naming ceremonies (Darkwa, 2000b; Oheneba-Sakyi and Takyi, 2006).

The extended family type is based on the compound style of living, where a house is built usually by a prominent member of the extended family and the rooms are shared among members of the family (Agyemang *et al*., 2018). Often referred to as family houses, this type of living arrangement is gradually dying out, more especially in the urban areas due to what Agyemang *et al.* (2018) referred to as multi-habitation living, “a situation in which people who do not consider themselves as one household share a living space that is clearly not designed for multi-family purposes” (p 897). It is common to now find houses being occupied by different households and sharing common facilities in multi-habitation houses, often referred to as compound houses – this might be used synonymously with multi-habitation houses.

Members of extended families are obliged to help the family members who are in need of money or other forms of support, including social and emotional support. A member of the family might, for instance, come and ask for financial help to set up their own business or pay their school fees. Additionally, the upbringing of children is not the responsibility of only the biological parents but also all adult members of the family. Furthermore, traditionally, older people within the families, and who may be living in the same household, take part in rearing their grandchildren and ensuring that they receive good moral values and adhere to cultural and societal norms. This means, there are almost always children and young people around to assist older relatives of the family in a variety of ways or tasks (Dzramedo *et al.*, 2018). This includes fetching something or running errands for them, preparing meals and assisting with shopping and other domestic tasks, including laundry. One of the main expectations from children and young people is to reciprocate the care and support their parents and grandparents provided them when they were young. This reciprocity of care for older people is gradually dying out as a result of rapid social change, with implications on modern families within Ghana and globally (Dosu *et al.*, 2014; Geest, 2016). As Geest (2016) explains, the principle of reciprocity describes the non-market exchange of gifts or labour, where a return is expected. The reciprocal relationship is such that having looked after their children well, it is an expectation of parents that their children, in turn, will look after them in their old age when they need help and support (Geest, 2016). The principles of filial piety and reciprocity in relation to caregiving to older members of Ghanaian families are discussed under care provision in Chapter 2.

The Akans (the largest group and most commonly spoken local language) of Ghana often use this metaphor of solidarity *“praeɛ wɔ hɔ yi, sɛ wo yi baako a na ebuo, wo ka bɔ mu a emmu, enti sɛ yɛn nyinaa yɛ baako a na ɛyɛ*” to express the value of oneness, unity, the spirit of collectivism and mutuality amongst its members. This metaphor literally means that ‘it is easier to break a bundle of a broom if you take them one by one than if you tried to break the whole bundle together at the same time’ (put simply, ‘united we stand, divided we fall’) to express the importance of unity and mutual support in Ghanaian families. Such cultural values partly explain why families usually come together to try and resolve socio-cultural, financial and health issues such as divorce and illnesses that any member of the extended family may be facing. It is a common practice for most Ghanaian families to come together to discuss and share responsibilities collectively amongst their members, when the family or a member of it is in crisis, for instance when one is seriously ill and death is imminent (Akotia and Anum, 2015).

In summary, the family structures in Ghana are gradually shifting from extended to the nuclear families, and the perception of the youth acting as ‘social security’ for the older members of the family is weakening (Aboderin, 2004; 2006) due in part to economic pressures and modernisation leading to the desire of families to have fewer children (Dzramedo *et al.,* 2018).

3.4.3: The nuclear family system

Some sociologists and anthropologists consider the nuclear family as the most basic form of social organisation (Geest, 2016; Dzramedo *et al*., 2018; Owusu and Baidoo, 2020). In contrast to the extended family, the nuclear or conjugal family unit is a family group consisting of the two parents and their child or children. Differences in definitions, however, exist. Some definitions allow for only the biological children that are full-blood siblings and consider adopted or half and step siblings a part of the immediate family, but others allow for a stepparent and any mix of dependent children, including stepchildren and adopted children (Puig *et al., 2008; McCann et al.*, 2012).

Like the extended families, members of the nuclear families provide the same practical, emotional and financial support to their older parents. Furthermore, Heelan (2000) and Brodaty and Donkin (2009) identified that African-Americans are more strongly attached with traditional values and view their caring role as being setting an example to children, teaching religious or spiritual beliefs, and family teachings rather than individualistic caregiving systems. The increasing transformation of the traditional extended family system gradually giving way to nuclear families has affected the inter-generational living arrangement and, thus, the care and support extended families hitherto provided to their older members of the family.

In conclusion, the structure and roles of families, in both the extended and nuclear families, are changing due to rapid social change in Ghana. Many young people are migrating to urban areas and, in some cases, abroad in search of jobs, for a better quality of life or for educational purposes. The implication of this is that older people, and people with dementia, are being left in the villages and cities without care. Another implication is that the cultural norm of filial piety obligation, with its expectation of children taking care of their older parents and grandparents when they are no longer able to care for themselves, is losing its value and gradually dying out due to migration, modernisation, globalisation and urbanisation. This affects the care and support younger members of families are able to provide to the older relatives who need help. More recently, care agencies are being set up to care for older people and people with dementia who need care, but whose children may be unable to provide direct care due to the agents of social change discussed above in section 3.2.0. In most cases, these services are paid for by the care recipients' families (Coe, 2016, 2018).

3.5: Dementia – Introduction

Dementia has become a global, regional and national public health issue and is now considered a health priority in most countries across the world. As a chronic degenerative disorder for which its aetiology remains largely unknown, the characteristic features of dementia include memory loss that disrupts daily life; challenges in planning or solving problems; difficulty completing familiar tasks at home, at work or at leisure; confusion with time or place; trouble understanding visual images and spatial relationships (Kalaria *et al.*, 2008; Guerchet *et al.*, 2013). Other characteristics include misplacing things and losing the ability to retrace steps; decreased or poor judgement; withdrawal from work or social activities; and changes in mood and personality (Guerchet *et al.*, 2009; Kalula and Petros, 2011; Mavrodaris, Powell and Thorogood, 2013). What is clear is that dementia is an age-related illness that mostly affects older people (60 years and older) (Longdon *et al.*, 2013), although it can occur much earlier than this.

The sections that follow cover the definition and presentation of dementia and its incidence and prevalence at global, regional and national levels. The understanding of dementia is also considered from within the socio-cultural context of SSA and Ghana specifically.

3.5.1. Definition and presentation

In recognition of the contemporary use of the term and situated within a biomedical framework, the International Classification of Disease (ICD) -10 defined dementia as: *"a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. The syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain"* (National Collaborating Centre for Mental Health (Great Britain) *et al.*, 2007 p 67). Chapman (2006) adds that, as a syndrome, dementia is caused by numerous underlying diseases associated with varied cognitive, emotional and behavioural malfunctioning with the four main subtypes, namely Alzheimer's disease (AD), Vascular dementia (VaD), Frontotemporal dementia (FTD) and Lewy body dementia (LBD), accounting for about 90% of all dementia cases (Magnus, 2009; Economic, 2010; Yusuf *et al.*, 2011; Great Britain *et al.* (2007).

From a clinical or medical perspective, dementia can be described as a group of progressive neuro-degenerative brain disorders which are characterised by a deterioration in people's intellectual, mental and physical functioning abilities resulting in disability and eventually death. Recognising its multiple dimensions, the World Health Organization (WHO) describes dementia as a chronic illness that occurs from the interplay of genetic, environmental, and behavioural factors, and has severe adverse influences on social and physical activities and on the quality of life of an affected person. George-Carey *et al.* (2012) note that the deterioration in cognitive function is commonly accompanied by a decline in emotional control, social behaviour or motivation. Dementia is more common in older people. However, in a small proportion of cases, an early onset of the illness can occur at any stage of adulthood (Wawrziczny *et al.*, 2016).

The traditional biomedical conceptualisation of dementia as a neurological impairment has led to the development of drug therapies to alleviate the symptoms, and cognitive rehabilitation interventions to maximise cognitive capabilities (Ineichen, 1998; Great Britain *et al.*, 2007; Yusuf *et al.*, 2011). However, it is increasingly recognised that the clinical manifestation of dementia cannot be fully explained by the neurological deficits alone, and that psychosocial factors largely influence the experience of dementia illnesses. For instance, unmet emotional needs and ‘malignant social contexts’ have been identified as important contributing factors to mood disorders, behavioural problems, and ‘excess disability’ commonly manifested in dementia (Kitwood, 1997).

American psychiatrist, George Engel, introduced the bio-psycho-social model of health in the mid-1970s. Engel argued that the traditional medical model was fundamentally limited in its scope and ability to provide practitioners with the rounded evidence-base necessary for clinical decision-making (Engel, 1977 cited in Ghaemi, 2009). Engel put forward the idea that health was better viewed through interconnected systems of biological (focus on disease), psychological (thoughts, emotions, feelings with a focus on psychological testing and measurement) and sociological (the person’s social context) spectrums, and that the ‘disruptive effects of (psychiatric) illness’ are an interplay within and between these fields (Engel, 1977 in Ghaemi, 2009, p 3). Drawing on from Engel’s (1977) critique of the traditional biomedical model of disease and using the term “bio-psycho-social approach” in the treatment of diseases, Keady *et al.* (2012) argued that, to understand and respond adequately to people’s symptoms, medical professionals must attend to the biological, psychological and social aspects of dementia simultaneously. The socio-psychological approach presents an understanding of the impact of relatives and caregivers on the self-image of the person with dementia and on his or her capability of expressing his or her current insight. However, a socio-psychological perspective may disregard both the actual disablement due to brain damage and psychological mechanisms that might reduce the person’s ability to gain insight (Robertsson *et al*., 2007). As the model claims, in the words of its founder Engel (and also Kitwood, 1990), “all three levels, biological, psychological, and social must be taken into account in every health care task”. No single illness, patient or condition can be reduced to any one aspect. They are all, more or less equally, relevant, in all cases, at all times (Ghaemi, 2009, p 3).

3.5.2: Prevalence of dementia in Sub-Saharan Africa (SSA)

The UN World Population Prospects 2015 Revision reports that the total population of the world in 2015 was 7.3 billion, of which 1.2 billion (16%) lives in Africa. Africa was said to have the highest rate of population growth among the major areas of the world, with a growth rate of 2.55% per annum between 2010 and 2015. It is estimated that 1.3 of the 2.4 billion people projected to be added to the global population by 2050 will be added in Africa (United Nations, 2022).

The SSA region is currently undergoing a demographic and epidemiological transition, and the growth of the population will lead to more chronic illnesses, including dementia, in the region (Paddick *et al.*, 2013; Samba *et al.*, 2016). However, whilst several population-based studies have been carried out on dementia in more developed countries to try to better understand the epidemiology of the dementia epidemic, only a few studies have been conducted in less developed countries. Examples of such studies in SSA have included Nigeria (Yusuf *et al.*, 2011b; Samba *et al.*, 2016), Benin (Guerchet *et al.*, 2009, 2009; Paraïso *et al.*, 2011); Tanzania (Longdon *et al.*, 2013; Mushi *et al.*, 2014), Congo (Samba *et al.*, 2016) and the Republic of South Africa (Kalula and Petros, 2011). These studies are predominantly focused on prevalence, and there have been relatively few studies compared with similar studies in the USA and Western Europe.

In a systematic review of 10 published epidemiological studies on dementia and its forms in SSA, George-Carey and colleagues (2012) found the prevalence of Alzheimer’s disease at age 60 to be 1%, and this figure rose to 2% at age 70. Similarly, in the Indianapolis-Ibadan Dementia Project (IIPD) in Nigeria, Guerchet *et al*. (2009) found the prevalence rate of dementia to be 2.3% compared to 6% and 8% in Europe and the United States, respectively. Apart from Alzheimer's and vascular dementia, little is known about the prevalence and distribution of the other sub-types of the illness in the SSA region including Ghana (George-Carey *et al.*, 2012b; Brooke and Ojo, 2020a).

With no known cure or preventative intervention, coupled with the faster pace at which its older population is growing, dementia and cognitive impairment are set to be one of the biggest public health challenges in SSA in the 21st century (Kalula and Petros, 2011; Mavrodaris, Powell and Thorogood, 2013; Brooke and Ojo, 2020a).

3.5.3: Socio-cultural context of dementia in Ghana

As indicated above, the population of older people in Ghana is growing faster than its high-income country counterparts. However, there is paucity of research in dementia, especially in the areas of prevalence, impact and care. Therefore, both quantitative and qualitative types of study, particularly the latter to find out people with dementia and their carers' experiences of living with and caring for dementia in Ghana, are lacking. This may be due in part to the general lack of awareness of dementia and the stigma associated with it in Ghana. To date, Ghanaians (and in SSA in general) may perceive dementia and older people who show dementia-like symptoms as being mad, a witch, or evil-possessed (Geest, 2002; Secker, 2013; Brooke and Ojo, 2020). Research reports that this often results in people with dementia being socially excluded and, in some cases, may be subjected to all sorts of inhuman treatment including beatings, flogging, forced fasting or even death (Read and Doku, 2012; Akotia *et al.*, 2014; Edwards, 2014).

Another concern identified in the literature reviewed was that family members often hide or feel reluctant to report manifestations of the illness (Ineichen, 1998) and would thus not seek medical intervention. This is a serious and common challenge in most LMICs, including SSA (Guerchet *et al.*, 2013; Samba *et al.*, 2016; Spittel *et al.*, 2021).

Research on mental health in Ghana has demonstrated that families of people with mental health issues or disabilities often do not visit their relatives with mental health or may give wrong contact details so they cannot be reached or located by healthcare professionals if they need to (Ssengooba, 2012). In an extreme instance, a 75-year-old woman lived in a psychiatric hospital for more than 30 years because her family did not come to pick her up due to the stigmatising and discriminatory nature of the illness, both within the health sector and in the community (Uwakwe, 2000; Edwards, 2014). Mental health problems are commonly stigmatised around the world and often lead to efforts to conceal the illness on the part of the person living with the problem and their families. A survey of mental healthcare consumers in the US by Link *et al*. (2001) illustrates this point. The study reported that the majority of the healthcare consumers stated they did attempt to conceal their disorder for fear that disclosure would precipitate unfavourable treatment towards them (Link *et al*., 2001).

Several studies conducted within the SSA have shown that mental or psychiatric illnesses including dementia are a taboo subject and that they attract stigma when they are talked about. Amuyunzu-Nyamongo (2013) found that people in Nigeria responded to people with mental illness with fear, anger and avoidance and the term 'depression' was not culturally acceptable in Uganda. Evidence suggests that general prejudice, lack of education and fear are contributory factors to the stigma that is linked to mental health or illnesses in SSA (Jack *et a*l., 2015; Read and Doku, 2012). The social stigma associated with mental health or psychiatric illness in SSA means that there is a high tendency for people suffering from such a condition and their families to hide it (Carless and Douglas, 2008; Barke *et a*l., 2011), what Amuyunzu-Nyamongo (2013) referred to as a 'silent epidemic'*.* Similarly, other studies (Quinn, 2007; Read and Doku, 2012) have found stigma to have negative impact on the level of care and support offered to people experiencing psychiatric illness and their families in Ghana.

In most African cultures, dementia has no name, although the symptoms are recognised and attributed (Faure-Delage *et al.*, 2012). Faure-Delage *et al.* (2012) identified that, in SSA, socio-behavioural disorders associated with progressive deterioration of mental functions were not recognised as being pathological. Rather, they are experienced by families as harmful, intentional and carried out by someone whose role is, by definition, to protect the clan. When dementia occurs, older people lose the valuable qualities expected of them, such as being sources of information and training and facilitating the transmission of knowledge to the youth. Dementia is perceived to be caused by the invisible or supernatural forces that cause mental illnesses (Quinn, 2007; Barke *et al.*, 2011; Faure-Delage *et al.*, 2012). Dementia would, therefore, be considered in the same way as mental health conditions in Ghana.

Added to the above challenges, the Ghana healthcare system lacks the requisite human and material resources and is unprepared to handle its ageing population and age-related illnesses, including dementia. For instance, Ghana has only three state-owned psychiatric hospitals, namely Ankaful, Pantang and Accra psychiatric hospitals, all located in the southern part of the country – Ankaful in the Central region and the other two in Accra. Altogether, the three hospitals have about 1,322 beds, with one of the hospitals having a children's ward consisting of 15 beds (Roberts *et al*., 2014). The combined human resource capacity for all the hospitals amounts to 1,887, including 18 psychiatrists, 31 non-psychiatric medical doctors, 21 social workers, 4 occupational therapists, 19 psychologists, 1,256 nurses and 546 other workers (including health assistants and other auxiliary staff) (Arias *et a*l., 2016; Roberts *et al*., 2014).

Such levels of resource allocation towards mental health services reflect the political apathy towards mental health as a priority public health concern in Ghana (Barke *et al.,* 2011b; Arias *et al*., 2016). This, combined with widespread stigma, impedes the progress of mental health and mental healthcare in the country. Consequently, faith-based institutions, mainly prayer camps and traditional healers, remain the major sources of help-seeking for psychiatric illnesses in the country. This is partly due to their accessibility and the belief that psychiatric illnesses are caused by evil spirits, thus requiring spiritual intervention. An in-depth discussion of the causality, care and treatment of dementia and other psychiatric illnesses in Ghana is held in Chapter 2.

3.5.4: Stigma associated with old age and dementia

As in many other cultures, stigma is a serious problem affecting people with dementia, mental illness and other cognitively impaired people in Ghana. Thornicroft (2008) defined stigma as a mark or sign of disgrace usually eliciting negative attitudes to its bearer. If attached to a person with a mental disorder or dementia, it can lead to negative discrimination. Considering the scale of stigma in societies, Thornicroft (2008) argued that there is no country, society or culture in the world in which people with a mental health diagnosis are considered to have the same value and be accepted as people who do not have mental illness. He illustrated that, each year, approaching 30% of the population worldwide has some form of mental illness and that at least two thirds of those affected receive no treatment (Thornicroft, 2008). People with psychiatric illnesses may feel unable or unwilling to disclose their condition or seek help due to fear of stigma.

Stigma has been found to produce three related problems: a lack of knowledge (ignorance and misinformation); negative attitudes (prejudice); and excluding or avoiding (discrimination). When these problems are combined, they produce a powerful force for social exclusion (Lyons and Ziviani, 1995; Thornicroft, 2008;

Secker, 2013). Stigma also affects the carers of people with dementia, as well as faith-based or church institutions and healthcare professionals who work with people with mental illnesses in Ghana. Feeling stigmatised can impact negatively on people's self-esteem, their relationship with others, and can lead to social rejection or neglect, as well as influencing people's access to care and treatment services (Barke *et al*., 2011). Stigmatisation of mental illness including dementia often leads to efforts by families to conceal the illness either by people with dementia themselves or their family carers. A survey of people with mental health issues by Link *et al*. (2001) in the USA illustrates this point. The study reported that the majority of people with mental health issues stated they did attempt to conceal their disorder for fear that disclosure would precipitate unfavourable treatment towards them (Link and Phelan, 2001; Link *et al.*, 2001). People with serious psychiatric illnesses have been found to believe that others would devalue and reject them. In Link *et al.'s* (2001) study, people with mental illnesses found it threatening and disheartening to believe that they had developed an illness that others were afraid of.

On a personal level, any person who is conscious of his/her potential stigma marker may take certain evasive actions to avoid the perceived negative consequences of the stigma. Evidence from high-income countries suggests that stigma can stem from anybody, including professionals (Link and Phelan, 2001). It is evidenced that both the general public and healthcare providers might stigmatise older adults with psychiatric disorders (De Mendonça Lima *et al.*, 2003).

The chaining of people with mental illness is commonplace in countries in SSA, especially in remote rural communities where psychiatric services are scarce (Asher *et al.*, 2017). This suggests that responses to the mental illness of a family member are influenced by social norms regarding how best to control mental illness, which are, in turn, informed by historical, cultural, and symbolic practices. Such social norms become the accepted, and even expected practices in response to mental illness, and therefore will not evoke widespread protest, particularly at the community level (Cross, 2004; Bartlett, 2012).

In other studies (Joachim and Acorn, 2000; Dinos *et al.*, 2004; Secker, 2013; Bamford *et al.*, 2018), fear of stigma and its associated rejection by family and others resulted in people with dementia and their families choosing to conceal their illness.

Similar studies in Ghana reported perceiving mental health and related illnesses as a taboo and not a subject to talk about in public (Quinn, 2007; Kyei *et al.*, 2014). Due to the stigmatising nature of mental/psychiatric illnesses in Ghana, a psychiatrist described the first psychiatric service that was established at Kumasi Teaching Hospitals as a "Headache Clinic" (Donkor and Andrews, 2011).

In their study of the beliefs and community responses to mental health in Ghana, Quinn (2007) found that many family carers of people with mental illnesses were worried about stigma and the negative attitudes from society and extended family members, although some supportive attitudes were also reported. It is also common for parents in Ghana, especially older women, to be accused of witchcraft and being the cause of their children's psychiatric illnesses (Secker, 2013; Ibrahim *et al.*, 2016). Such accusations often result in a breakdown in families, rejection and abandonment of people with psychiatric illnesses, including dementia, by their families and the wider society. Older people, including those with dementia accused of witchcraft, may be subjected to all kinds of inhuman treatment such as beatings and, in some cases, murder.

3.6: Role of relevant organisations in caring for older people

In fighting against poverty and human rights abuses, governments, especially in LMICs, mount several strategies, such as to permit non-governmental organisations (NGOs) to contribute towards abuse and poverty reductions (Agbényiga and Huang, 2012). Forkuor and Agyemang (2018) outline the benefits of NGOs in Ghana to include taking responsibility for the needs of local people in terms of poverty and abuse reduction. NGOs are also less susceptible to political manipulation, unlike public sector policies. NGOs encourage the involvement of the poor and are able to access areas that are often neglected by the government (Gorman, 2002).

Two major NGOs in Ghana that help to protect and support older people are HelpAge Ghana and Basic Needs. HelpAge Ghana (HAG) was established in Ghana in the late 1990s. Adopted under its umbrella mission, HelpAge International (HAI), HAG's mission is, "To work with and for disadvantaged older people worldwide to achieve a long-lasting improvement in the quality of their lives" (Beales, 2000). Basic Needs (Adei *et al.*, 2015), HelpAge Ghana (Agbényiga and Huang, 2012), Alzheimer's Disease and Related Association of Ghana (ARDAG) and other non-governmental organisations and advocacy groups help in creating public awareness of dementia and other psychiatric illnesses that people can experience due to ageing. HAG has been improving the lives of older people and people with dementia by supporting their empowerment, promote equality and seeking to end discrimination against them (Forkuor and Agyemang, 2018).

HelpAge Ghana has successfully advocated and lobbied the government for national healthcare policies and Older People’s Day. The centre provides on-site and outreach healthcare programmes. HelpAge Ghana organises events for older people. The people at Osu Day Centre in Accra attended a two-day conference on Dementia and its effects on the Aged and Caregivers hosted by CAAA. It has also engaged in fundraising, network building and raising social awareness about the living conditions of older people in the country. Another NGO is Basic Needs Foundation.

3.7: Summary of theme

This section of the chapter has considered dementia as an age-related illness whose aetiology remains unknown, although age, sex and genetic factors are identified as contributory factors. Dementia causes disability in those it affects, and this can disrupt the affected person’s ability to remember and/or undertake activities of daily living. The loss of cognitive and occupational abilities often results in the person with dementia becoming increasingly dependent on others for their care and support. The four main sub-types of dementia are: Alzheimer's dementia, vascular dementia, frontotemporal dementia and Lewi-body dementia. It was noted that few studies on the illness have been conducted in the sub-Saharan African region, and information on dementia in Ghana remains limited.

The life expectancy of people living in Ghana is relatively low. However, people under 60 years and older remain vulnerable to dementia due to possible early onset of the illness. The cultural beliefs about dementia and other psychiatric illnesses being caused by supernatural forces or evil spirits have contributed to society not regarding dementia as a public health issue, hence accord dementia a low priority amongst other health issues in the country. Additionally, Ghana lacks the appropriate human and infrastructure, and material resources needed to manage the ageing population and associated age-related illness including dementia. Finally, the chapter has examined the concept of stigma and its implication on dementia and mental healthcare in Ghana. Stigma was found to affect people with mental health and other psychiatric illnesses of every country, society and culture all the world over. It often leads to exclusion and rejection of people with psychiatric illnesses by families and the wider society. Stigma could also affect the self-esteem, quality of life and health outcomes of people with dementia and other psychiatric/mental health issues and their families, as they are more likely to avoid making contact with others altogether or seek help for fear of disclosure of information about their condition.

3.7.1: Summary of published work since completion of original literature review

New gerontological and dementia studies articles about dementia in Ghana have been published recently, these include research on what it means to grow older in contemporary Ghana (Issahaku, 2022) and experiences of living with dementia in Kintampo, in rural Ghana (Agyeman *et al.*, 2019a). Exploring what growing older means in contemporary Ghana, Issahaku (2022), interviewed 23 older people from the Northern and Greater Accra Regions with different genders, ageing experiences, occupational and educational backgrounds and living in rural or urban centres. The study revealed that people's priorities, roles and responsibilities change as they grow older, have children and grandchildren as do others' expectations of them. Older people were found to be peace builders, dispute resolution or community problem-solvers and 'teachers' of history from experience. Additionally, older people were characterised by the challenges of physical and cognitive decline, loss of influence and increased dependency due in part to their deteriorating health or loss of strength, income and work, among others. These findings are in line with the existing literature on older people in SSA.

Findings from several other studies on dementia and dementia care in Ghana (and SSA) have shown a lack of awareness and knowledge of dementia (Brooke and Ojo, 2020; Spittel *et al.*, 2021), the right training and support system for carers (Spittel *et al;* 2021; Adedeji *et al.*, 2022) and a change to family and household approach type of care provision to people with dementia owing to changing demographics, culture and migration (Adedeji *et al.*, 2022). Consistent with existing literature, the lack of awareness and dementia have, in most cases, resulted in stigmatisation, discrimination and/or exclusion of people with dementia and their carers from society (Brooke and Ojo, 2020). On the other hand, family and household-based approach to care provision in Ghana has now evolved alternatives to institutionalised care by engaging paid and non-family personal care provision to people with dementia (Issahaku, 2022).

With in-depth interviews conducted on 28 people with dementia and their family carers, Agyemang and colleagues (2019) explored the socio-cultural beliefs, understandings, perceptions and behaviours relating to living with dementia in the Kintampo area of Ghana. The study found the perception of stigma to be non-existent as participants associated the symptoms of dementia and cognitive impairments with the inexorable bodily decline experienced by older people. Consequently, participants understood dementia or cognitive decline to be a characteristic of the normal ageing process. Another significant finding from the study was that care provision to people with dementia in Ghana was largely accepted by carers as a filial piety. Caring for people with dementia was largely shared among female members of the family usually in large compound households. The study however took place in only one out of the over two hundred districts in the country and therefore may not have reflected the views of the larger Ghanaian populace.

Chapter 4: Theoretical framework - Phenomenology

4.1. Introduction

The purpose of this thesis is to develop a contextual understanding of people with dementia and their family carers' perceptions and lived experiences in Ghana. A phenomenological approach would therefore facilitate understanding of participants' beliefs, thoughts, attitudes and assumptions towards dementia and dementia care provision. As Mapp (2008) assert, only those who have experienced phenomena can communicate them to the outside world. Because the study aimed to construct a rich understanding of participants' experience of dementia, hermeneutic phenomenology, which explores the meaning of lived experience and the contextual forces that shape it (Mapp, 2008) was chosen. This was chosen over descriptive phenomenological approach as it recognises the importance of context, for instance lived space, in helping to fully understand participants' experiences of living with dementia as well as the inability of 'bracketing' my personal experiences of the phenomenon being investigated to the fore. Using phenomenology would therefore help to answer questions of meaning in understanding the experience from those who have experienced it. Detailed description and significance of the use of phenomenology as a theoretical framework for this thesis are provided below.

Like many illnesses and diseases, the biomedical model has been the dominant paradigm for understanding dementia in Western societies (Lyman, 1989; Bond, 1992; Beard et al., 2009). In this model, the patient's story is used in the diagnostic process and psychiatry labels the symptoms as dementia. Due to the dominance of this paradigm, health professionals have come to hold a monopoly on perceptions of dementia and other diseases and illnesses (Estes and Binney, 1989; Miller et al., 1992). However, when health professionals work in partnership with people with dementia, the person's story becomes the focus of the therapeutic relationship (Estes and Binney, 1989). This therapeutic relationship allows the person's story to be heard. Consequently, Crowe (2000) suggests that nursing's focus should be on their patients' experience rather than the psychiatric diagnosis with which the experience is attributed (p. 588).

A great deal can be learnt about aspects of people's lived experiences from listening to their stories through a phenomenological lens. This can enhance our understandings of what it means to live with dementia; how people go about making sense of their experiences; the factors that influence their lived experience; and the meanings that are attached to living with dementia within the Ghanaian context. Phenomenology has been employed across various health studies whose goals have been to understand the meanings of people's experiences of living with or caring for a variety of illnesses including dementia (Siriopoulos, Brown and Wright, 1999; Butcher *et al*., 2001; Phinney and Chesla, 2003; Galvin, Todres and Richardson, 2005; Todres and Galvin, 2006); depression (Allan and Dixon, 2009), multiple sclerosis (Toombs, 1988; 1995; van der Meide *et al*., 2018) and cystic fibrosis (Jessup and Parkinson, 2010). Similarly, this thesis will use a phenomenological lens to understand the lived experience of people with dementia, their family carers and members of the two key institutions that care for people with dementia in Ghana.

The chapter is structured into three sections. The first section provides the philosophical background and evolution of phenomenology. Here the focus is on the two main phenomenological traditions – the Husserlian and Heideggerian approaches, although other influential contributors such as van Manen and Gadamer whose works have further developed these two traditions will be discussed. The key concepts of the phenomenological lifeworld, its existential elements and their usefulness to this project are then discussed. The final third of the chapter discusses the disruption of the lifeworld in illness and the chapter concludes by summarising the significance or rationale for the approach taken in the thesis.

4.1.1: Philosophical background of phenomenology – from Husserl to van Manen

From a philosophical perspective, phenomenology helps researchers to explore and understand everyday experiences without pre-supposing knowledge of those experiences. Husserl is credited with starting the phenomenological movement in the early twentieth century with the publication of his book – *Ideas: General Introduction to Pure Phenomenology* (Bynum and Varpio, 2018). Since then various phenomenologists have re-theorised his approach to phenomenology. For instance, the descriptive tradition that originated from the writings of Husserl has been further developed by Merleau-Ponty while Heidegger and Gadamer developed the interpretative (hermeneutic) approach.

The word phenomenology is derived from two Greek words “phenomenon” and “logos”, with the latter translated as “the science of” consciousness (Bradbury-Jones et al., 2009). Phenomenology therefore means ‘the science of phenomenon’. According to Willis *et al.* (2016) ‘phenomenon’ refers to things (objects) as they appear in human consciousness as opposed to reality. Thus, a phenomenon involves how things appear in our experience or the way we experience things and the meanings that they have in our experience.

Phenomenology studies the structure of various types of experience that determine our understanding of phenomena; ranging from perception, thought, memory, imagination, emotion, desire and volition to bodily awareness, embodied action and social activity including linguistic activity (de Witt and Ploeg, 2006; Rich *et al.*, 2013a; van Manen, 2017). Phenomenological study therefore describes lived experiences where people’s consciousness is present. Lived experience is the starting point or central question of phenomenology and our experience in this context, refers to something that happens to us and not necessarily an accumulated evidence or knowledge mastered by us (Mapp, 2008). Heidegger explains that during practical activities like walking along, hammering a nail or speaking our native tongue we are not explicitly conscious of our habitual patterns of action (McConnell-Henry *et al*., 2009). Our conscious experiences consist of passive and active experiences. The passive experiences include our vision and hearing whereas the active experiences involve activities such as walking, driving, hammering a nail or kicking a ball (Smith, 2004). As such our orientation to phenomena focuses on the action itself, rather than the habitual movements or practices that this orientation is dependent upon.

As an approach to research, Husserlian approaches to phenomenology describe the essence of a phenomenon from the perspective of those who have experienced it (Carel, 2011; Neubaue*r et al*., 2019; Svenaeus, 2001). As Dahlberg (2006) explains, the essence or structure is what makes the phenomenon to be that very phenomenon. Thus, the essence or structure illuminates the essential characteristics of the phenomenon without which it would not be that phenomenon (p 11). Essence concerns itself with the basic, implicit, taken for granted shared understandings that come to mean that we know what we know but this can be 'hidden' from our conscious attention. This is a particularly useful lens to apply to this study of health and illness states such as how illness re-makes habitual, ready-to-hand experiences by bringing these understandings that may be hidden from our conscious reflections into relief thus rendering them visible to conscious reflection.

4.1.2: Transcendental (descriptive) and hermeneutic phenomenology

The German philosopher and founder of phenomenology, Edmund Husserl (1859-1938) defined phenomenology as 'the science of pure consciousness'. To Husserl, phenomenology as a discipline seeks to describe the manner in which the world is constituted and experienced through conscious acts (Dowling, 2007; van Manen, 2017). In his German phrase '*Zu den Sachen Selbst'*, Husserl's conceptual framework of phenomenology carries dual meaning of 'to the things themselves' and 'let's get down to what matters' (van Manen, 1997; Dowling, 2007). Husserl's phenomenology relates to the way that knowledge comes into being in consciousness and is seen as the rigorous human science of all conceivable transcendental phenomena (Adams and van Manen, 2008). Phenomenology proposes to describe instead of explaining a phenomenon or searching for its causal relations. As Mapp (2008) puts it, phenomenology focuses on 'the very things' as they manifest themselves (Carel, 2011; Lopez and Willis, 2004). Defining the concept of phenomenology as a discipline, Langdridge (2007) holds that the aim of phenomenology is to focus on people's perceptions of the world in which they live and what it means to them; the focus is on people's lived experience. Phenomenology seeks to turn to the world of experience by taking into account that before any objective reality, there is a subject who experiences it. Before any objectivity, there is a pre-given world and before any knowledge there is a life on which it is based (Lopez and Willis, 2004). In support of Lopez and Willis, Dartigues (1973) asserts that any knowledge has its origin in experience which is pre-reflective. To understand the reality of a phenomenon is to understand the phenomenon as it is lived by a person (Mapp, 2008). Lived experience, for Husserl, is a dimension of being that had yet to be discovered.

Central to Husserl’s approach to phenomenology and its use as a research methodology is bracketing, reduction or ‘epoche’. This is the process to temporarily suspend the researcher’s existing personal biases, beliefs, pre-conceptions and assumptions about the phenomenon in order to get straight to the “pure and unencumbered vision of what it essentially is” (Allan and Dixon, 2009 p 866). Husserl believed that to reveal the essential components of an experience, researchers must shed all their prior knowledge about the phenomena being investigated so as to prevent their personal biases and pre-conceptions from unduly influencing the findings (Dowling, 2007a; McConnell-Henry *et al*., 2009). This enables the researcher to present the phenomenon exactly as a person experiences it. Using the example of pain, McCance and Mcilfatrick (2008) explain that the clinical nurse or researcher, according to Husserl’s approach, must not impose their knowledge of pain on the patient but rather allow them to express their own experience of pain as lived by them.

4.1.3. Heideggerian (interpretive or hermeneutic) phenomenology

Another prominent phenomenology scholar who modified and built on the work of Husserl was Martin Heidegger. Heidegger challenged some of Husserl’s assumptions regarding how phenomenology could guide meaningful enquiry (Lopez and Willis 2004). Heidegger’s phenomenology adopted a more interpretive or hermeneutic research tradition. Miles *et al.* (2013) viewed Heideggerian phenomenology as an extension of Husserl’s original ideas by adding meaning and interpretation to descriptions without the notion of bracketing. Heidegger did not believe that getting to know and describing the experience of individuals was enough. Instead, he stressed on the importance of knowing how people come to experience phenomena in the way they do. Heidegger considered that the primary focus of philosophy was on the nature of existence (ontology), while Husserl focused on the nature of knowledge (epistemology). Heidegger believed that understanding phenomenon requires both description and interpretation and this could be achieved through hermeneutics.

The root for the word ‘hermeneutics’ lies in the Greek verb *hermeneuein* , generally translated ‘to interpret’ and the noun *hermeneia*, ‘interpretation’ (Chang and Horrocks, 2008, p 384). The concept refers to the messenger of God – Hermes - who is associated with the function of transmuting what is beyond human understanding into a form that human intelligence can grasp. Various forms of the word ‘hermeneutics’ suggest the process of bringing a thing or situation from unintelligibility to understanding (Chang and Horrocks, 2008 p 384). Hermeneutics has a long tradition as an academic practice, for example in the discipline of theology through the interpretation of biblical texts (Austgard, 2012, p. 19). As a methodology hermeneutic phenomenology increases sensitivity to humans’ ways of being-in-the-world (Dreyfus, 1991) rather than providing theory for generalisation or prediction of phenomena. Hermeneutics goes beyond mere description of core concepts and essences to look for meanings that are embedded in common life practices. For Sloan and Bowe (2014) hermeneutics refers to the interpretation of text or language by an observer and can be used as a methodology or an enhancement of phenomenology. Spielgelberg (1976) described hermeneutics as a process and method for bringing out and making manifest what is normally hidden in human experience and human relations (Lopez and Willis, 2004). Hermeneutic inquiry therefore focuses on what humans experience rather that what they consciously know (Solomon, 1987). Heidegger therefore maintains that an observer or researcher cannot remove him or herself from the process of essence identification as he or she exists with the phenomena and the essences. He argues that researchers’ presuppositions or expert knowledge invaluably guide the research inquiry and thus make the research a meaningful undertaking (Lopez and Willis, 2004).

In contrast to Husserl, Heidegger emphasised that it is impossible to rid the mind of the background of understandings that has led the researcher to consider the topic being researched in the first instance (Geanellos, 2000). Geanellos (2000) further argues that it is the researcher’s knowledge base that leads to specific ideas about how the inquiry needs to proceed and therefore cannot be bracketed. Thus, the research literature is what leads the researcher to the realisation that research is needed in an area that is under-studied.

Heidegger described three-fold fore-structures upon which all interpretation is grounded. This consists of:

- fore-having – we come to a situation with practical familiarity, that is with background practices from our world that make interpretation possible.

- A fore-sight - because of our background we have a point of view from which we make interpretation and
- A fore-conception – because of our background we have some expectations of what we might anticipate in an interpretation (Plager, 1994). These forestructures link understanding with interpretation. Understanding allows us to be involved in our daily activities as meaningful events.

Heidegger emphasises the usefulness of researcher's foreknowledge, pre-understanding or fore-structures (van Manen 1990) as these aid the understanding of the phenomena as well as providing the foundation upon which hermeneutic phenomenological interpretation is based. Mackey (2005) explained our forestructures to mean what we understand or know in advance of interpretation; and Benner (1985) used the term to mean the 'context-dependent knowledge', opinions and experiences which researchers and participants bring to the research study. Some transcendental phenomenologists such as Husserl and Todres (Todres *et al*., 2007) have however, warned against the risks of the researcher imposing their own interpretation onto participants' story and potentially understanding that story within the context of their own experiences.

Some hermeneutic philosophers including Heidegger, Gadamer and Ricouer argue that we are embedded in the world of language and social relationships (Austgard, 2012; Laverty, 2003) and that "the meaning of phenomenological description as a method lies in its interpretation" (Heidegger 1962, p 37 cited in Geanellos, 2000). Interpretation constitutes an inevitable and basic structure of our being-in-the-world (Geanellos, 2000) and some phenomenologists argue that it is central to unveil the hidden meanings of phenomena and that we transition from actual experience to a second-hand explication through translation and interpretation (Friesen *et al*., 2016).

4.1.4. Contributions of other phenomenologists and methodologists

The works of Hans-Georg Gadamer and Max van Manen have contributed to the use of phenomenology as a research methodology rather than as a philosophy.

i) Gadamerian hermeneutic phenomenology

Another influential figure who contributed to phenomenology through further development of Heidegger's ontological structure of understanding was Hans-Georg

Gadamer (1900 - 2002) (Austgard, 2012; Dowling, 2007b; Rolfe, 2015). Gadamer believed that phenomenological interpretation does not revolve around the texts alone, but the researcher doing the interpretation and his or her interaction with the world are all crucial to understanding the phenomena being investigated (Austgard, 2012; Fleming *et al*., 2003). Gadamer posit that all understanding includes interpretation, and all interpretation is essentially verbal (Rolfe, 2015 p 145). He emphasised the importance of language in understanding phenomena and explained language to include everything handed down to us right from the very day we are born into a family, society, culture and tradition. Gadamer argued that the researcher is embedded in the social, cultural and historical world and that this 'situatedness' needs to be considered when interpreting the text (Gadamer, 2004).

Gadamer's concept indicates that the meanings that the researcher arrives at in interpretive research are a blend of the meanings articulated by both the research participant and researcher within the focus of the study. He used the metaphor "fusion of horizons" to explain this act of inter-subjectivity, understanding and interpretation (Debesay *et al.*, 2008). The horizon to which Gadamer referred to is the background of various assumptions, ideas, meanings and experiences that one has in living. Rolfe (2015) recognises that one's interaction with another in an act of understanding and getting to know each other, is based on a personal horizon of experiences and meanings. This means that the act of interpretation is always bounded by the separate and intersecting horizons of human beings - both researcher and the research participant (Geanellos, 2000). This means that there could be more than one interpretation of the narratives depending on the focus of the research. Geanellos (2000) argues that no one true meaning can be produced by any interpretive study, but the meanings that are stated in the research findings must be logical and plausible within the study framework and that these must reflect the realities of the study participants (Debesay *et al.*, 2008; Fleming *et al.,* 2003).

Another key concept Gadamer used to answer the question of 'how is understanding possible in 'being' is the hermeneutic circle.

ii) Max van Manen and hermeneutic phenomenology

More recently, van Manen further developed the hermeneutic approach to phenomenology. It is through language such as the language of the interview which provides the means through which a person’s lived experience becomes meaningful as data (Langdridge 2007).

To understand phenomenology hermeneutically, van Manen (1997) suggests that researchers move through a ‘hermeneutic circle’; a process of understanding a text by moving between part of the text and the whole of the text to establish the truth by discovering the phenomena and interpreting them (Langdridge, 2007, van Manen 1997). Schutz started a shift from phenomenology as a research philosophy to phenomenology as a research methodology (Schutz, 1967) and van Manen’s approach to phenomenology developed this further. According to van Manen, phenomenology formatively informs, reforms, transforms, performs and pre-forms the relations between being and practice (van Manen, 2007). In contrast to early philosophers, van Manen (1997) provides specific guidelines for using phenomenology as research methodology within human science research and many health care professionals including nurses have used these guidelines to conduct studies of lived experiences of patients, families and nurses themselves (Adams and van Manen, 2008). van Manen’s use of the phenomenological lifeworld and its division into four existential elements; lived body, lived space, lived time and lived relation have become particularly useful in the study of illness and its lived experience. Reflecting this use, van Manen’s (1990) lifeworld existentials and their use in this thesis to investigate the lifeworld of people with dementia within Ghana are now discussed in more detail.

Unlike Husserlian phenomenology that requires researchers to bracket their own preconceptions, hermeneutic phenomenology acknowledges and accepts the reasonability of researchers bringing their own personal biases, beliefs, values and the whole practical “situatedness” into the interpretation of people’s experiences (Seah and Wilson, 2011). Hermeneutic phenomenology was therefore adopted as a methodology for this study as it acknowledged and accepted my attitudes, beliefs, values, ethnicity and cultural background all of which helped to shape the interpretation of the study. Additionally, hermeneutic phenomenology does not only focus on human experience but also helps us to understand the everyday subjective experience of living with dementia within the Ghanaian context.

Concerned with the understanding and interpretation of “what is it like to live with dementia in Ghana” van Manen’s lifeworld existentials provides a holistic perspective as they describe and interpret the question the study seeks to answer within a historical, socio-cultural and language context of people with dementia (Eriksen *et al.*, 2022) in Ghana. Using a hermeneutic phenomenological approach allows dementia experience (which is personal, subjective and complex) to be interpreted thoroughly to unveil the richness of the essences of living with dementia. The experience of living with dementia in Ghana was influenced by a number of factors including the cultural and religious understanding of the causality of dementia, the relationship between people with dementia and their carers, how families and others responded to people after developing dementia and the level of social support that people with dementia received. As Heidegger posits, one cannot understand the lived experience of a person in isolation from the person’s interaction with the world, instead the person and their world should be seen as co-constituting each other (Eriksen *et al.*, 2022).

4.2: The lifeworld and its existentials: Introduction and meaning

The lifeworld approach originates from the writings of Husserl. To understand the meaning of our lived experiences several authors (Benner, 2000; Rich *et al.,* 2013) advise us to be aware of our lifeworld, our bodily being-in-the-world and how we interact with others (Carel, 2011). The lifeworld attempts to question the ‘whats’ of those meaningful relationships. Husserl identified the ‘whats’ of our relationships in lifeworld to include embodiment, inter-subjectivity, mood, temporality and spatiality which were referred to as the constituents of the lifeworld (Dowling, 2007; Todres *et al.*, 2007). Heidegger, van Manen, Merleau-Ponty and other phenomenologists further developed Husserl’s consideration of these dimensions of the lifeworld.

The concept of lifeworld is about the world as it is immediately experienced (van Manen, 1997). It is the everyday world in which we live and experience naturally and pre-reflectively through our daily interactions and activities (Rich *et al.*, 2013; van Manen, 2002). The term denotes the subjective nature of our everyday life. As Laverty (2003) explains, our lifeworld and world of lived experience is what we experience before we have begun to label or conceptualise it. In the lifeworld, each person experiences a phenomenon such as illness from individual, social, perceptual and practical perspectives in a way that is both similar to other's experiences of the illness and yet different and even unique for each individual (Lin, 2013). The lifeworld is thus the horizon of our everyday experience and the domain of life in which 'things' become meaningful to us' (Rich *et al.*, 2013, p 500).

Edmund Husserl discusses two fundamental ways in which we come to understand the lifeworld - our natural attitude and our reflective attitude (Husserl, 1936/1970 cited in Rich *et al.,* 2013). As Husserl explains, our natural attitude to life occurs pre-scientifically and prior to theorisation while the reflective attitude to life occurs subsequent to and draws upon, the natural attitude (Rich *et al*., 2013).

These Husserlian conceptualisations of our lifeworld were later developed and theorised by Max van Manen as existential elements constituting the lifeworld.

To understand and explore the lifeworld, van Manen (Dowling, 2007; van Manen, 1990; 2017) has used the notion of lifeworld existentials to include lived body, lived relations, lived time and lived space. Although each of these existentials offers different points of focus, they are not sharply separable; rather, they are interwoven and interact with one another in the exploration of the lifeworld. Here each is discussed in turn with reflections in their usefulness as a method for analysing the data collected in this research.

4.2.1: Corporeality (Lived body)

To Rich *et al.* (2013), lived body refers to our physical, corporeal bodies as well as their bodily presence in our everyday lives and includes all that we feel, reveal, conceal and share through our lived body. Rich and colleagues explain that we are always present in the world through our body and that it is through our lived body that we communicate, feel, interact and experience the world (Rich *et al*., 2013 p 501). Using the metaphor of the hammer, Heidegger provides three interrelated modes of our involvement or engagement with equipment or practical activity that we have in our day-to-day life. He referred to these as 'ready-to-hand', 'unready-to-hand' and 'present-at-hand'. He explains that in the ready-to-hand mode of engagement, equipment and practical activities function smoothly and transparently. At this point, the person involved is in an absorbed manner so that the equipment is for the most part unnoticed (Plager, 1994). We hammer a nail into a wall without thinking about the actions required to make this possible. For instance, when a family is healthy and life goes along well, relations within it are often smooth and transparent. However, when some sort of breakdown occurs in the smooth functioning of the equipment or activities, we encounter the unready-to-hand mode. Here, the equipment and its functioning become conspicuous to the user. In the healthy family example above, when a family member is diagnosed with dementia the smooth activities of the family may be disrupted. In much the same way, the hammer becomes more present because it no longer facilitates the smooth functioning of hammering a nail. Such bringing of the body into relief can also be shaped through social and cultural understandings. In some families, some members may become full time carers and lose their jobs as a result. In different ways, whether physiologically, or through social or cultural dimensions the activities dependent on the experience of the lived body become disrupted.

When we are afflicted by an illness our experience of the lived body alters. In his work on chronic illness and its conceptualisation as a particular type of disruptive event, Bury (1982) discusses the disruptive nature of illness on our bodies. During illnesses the structures of our everyday life and forms of knowledge that underpin them become disrupted in a process Bury (1982) described as ‘biographical disruption’. Bury noted that illness brings people – individuals, families and the wider social networks face-to-face with the character of their relationships in a stark form and this often disrupts the normal rules of everyday life, such as reciprocity and mutual support of those affected by the illness (Beard *et al.*, 2009; Bury, 1982; Toombs, 1995b).

Experience of illnesses shape situations of those affected and cause them to learn new definitions of themselves and would most often, relinquish old ones (Beard *et al.*, 2009; Bury, 1982; Toombs, 1995, 1988). Toombs (1995) uses the example of her own experience of living with multiple sclerosis to explicate how the illness, in affecting her corporeal body disrupted her lived body as an existential element of her lifeworld. Expressing the disabling nature of her illness (multiple sclerosis), Toombs stated “at one time or another my illness has affected my ability to see, to feel to move, to hear, to stand up, to sit up, to walk, to control my bowels and my bladder and to maintain my balance. Some abilities such as sensing the position of a limb, I have lost abruptly and then slowly regained. Some such as clearsighted vision in one or the other eye, I have lost and regained numerous times. Other physical capacities have disappeared and never returned” (1995a p 11-13). Experiencing multiple sclerosis, an incurable, progressive disabling disease of the central nervous system, Toombs (1995) indicated how her physical capabilities altered in a number of ways following diagnosis of her illness.

4.2.2: Relationality (Inter-subjectivity / Sociality)

Another dimension of the lifeworld concept is relationality which relates to how we are in a world with others. As humans, we cannot be understood without reference to how our lives take place within a social world (Petherbridge, 2019). Relationality means that we exist with others in an understanding way or, as Merleau-Ponty (1962) puts it, we are part of an embodied world: others are always taken into account in some way – even ignoring someone is a form of taking into account (Petherbridge, 2019). How we relate to others or others' relations with us such as being kind, friendly, hostile or violent can humanise or dehumanise us (Petherbridge, 2019) and such relationships can alter our lifeworld at any given time (Svenaeus, 2000).

Bury (1982) identified another aspect of our lived relations that involves how and where we are in our culture and traditional beliefs and how we carry these beliefs forward and differentiate ourselves from others either consciously or unconsciously. To fully describe and understand the quality of an illness as it is lived, we need to understand what it means to us both interpersonally and culturally (Beard *et al*., 2009; Bury, 1982; Reynolds, 2010; Toombs, 1995a). Phinney and Chelsla (2003) explain that within Western cultures, everything known about the pathology of dementia points to it being a disease of the brain and that it is commonly thought of as a devastating disease which affects people from the neck up and where the body of those affected body is tragically spared.

In Ghana, unlike the West and other parts of the world where dementia is considered a biomedical condition, there is a cultural understanding of dementia as a form of spiritual illness relating to witchcraft, curses and madness. As a result, when compared to the biomedical knowledge of dementia, there are significant gaps in the knowledge of dementia as a lived condition (Brooke and Ojo, 2020; Cohen *et al*., 2016; Crampton, 2013). These supernatural, superstitious, and cultural explanations of dementia including belief in witchcraft, curses and madness among others are all lived relation existentials that help us understand how dementia is conceptualised within Ghanaian (and SSA) contexts.

4.2.3: Temporality (Lived time)

Temporality refers to the continuities and discontinuities of time as it is humanly experienced (Nyga and Johansson, 2001; Toombs, 1990). The existential of lived time can be understood as time as we experience it. It is composed of our subjective understanding of time as opposed to the more objective or "factual" time, and it refers to the ways in which we experience our world on a temporal level (Rich *et al.*, 2013). Heidegger emphasised the notion of temporality, taken to mean the horizon of all possibilities of 'being' or existence which make sense to us in terms of time – past, present and future. For Heidegger, temporality is the basic existential of existence which provides context for understanding all 'being' (McConnell-Henry *et al.*, 2009). We live with time in many ways. As Nyga and Johansson explain, "We can have the feeling of a number of possible futures – the feeling of possibility; or we may feel the anxiety or depression of our future closing down, limiting the possibilities of living forward if we are inflicted with diseases" (Nyga and Johansson, 2001 p 91).

Illnesses such as dementia are also experienced in what Toombs (1995) described as 'temporal experiencing'. Toombs (1995) notes that during illnesses we experience time as 'gearing towards the future'; although our actions are normally in the present, we anticipate what is to come. However, dementia disrupts such taken for granted experiences of lived time, in which the future remains open and accessible to us. Losing physical and cognitive abilities due to dementia can make it increasingly difficult for those affected by the illness and their families to continue to strive towards future goals (Toombs, 1995).

4.2.4: Spatiality (Lived Space)

According to Rich *et al.* (2013) spatiality refers to "our environing world; a world of places and things that have meaning to our living" (p 501). The experience of space is pre-verbal, in contrast to objective accounts of space which focuses on mathematical, 'objective' or scientific descriptions of space, for example its length,

depth, size or height. Our experience of lived space is therefore described as “felt space” (Førsund *et al*., 2018a; Norlyk *et al*., 2013).
Lived space explores both the way in which the space we find ourselves in can affect the way we feel and conversely, how the way we feel can affect the way we experience a particular space (Rich *et al*., 2013, p 501). Benner (2000) contends that we exist in relation to what is over there in terms of spatial distance or closeness. However, neither the distance nor the closeness of something is primarily meaningful to us in its quantitative measurement such as its metres and centimetres (Førsund *et al*., 2018b; Norlyk *et al.,* 2013). Instead, things and situations can be close to or distant away from us in terms of their significance in our daily lives. For example, when sick in bed and in pain, our world may shrink to the immediate environment of our room. In this mood, we may become particularly focused on the view outside the window of a dark parking space or a group of trees (Beard *et al.,* 2009; Rich *et al.,* 2013; Toombs, 1995a). Things in our environing world do not have simple, explicit meanings, instead, they can have a number of potential meanings depending on where they fit into our lives at that particular moment (Olausson *et al.,* 2013). Our spatial experiences involve how things appear to us in terms of their closeness to or distance away from us as well as the meanings and understandings we have on them within such the space (Mapp, 2008; Neubauer *et al*., 2019; Todres *et al*., 2007).

Illness changes our experiences of lived space. In illness, our lived space often constricts in the sense that our range of possible actions can be severely restricted or narrowed. Our functional space, for example, can suddenly assume an unusually problematic nature and some taken-for-granted things that we could easily do prior to becoming ill may need to be adjusted (Carel, 2011; Toombs, 1988, 1995). When we are affected by stroke for example, we may have to rearrange our physical environment and this may include changing the arrangement of the furniture in our living room, putting a stairlift in to help us negotiate stairs in the house or we may have to move house as our previous one may no longer suitably meet our housing needs (Toombs, 1988, 1995).

In summary, the concepts of phenomenology, the lifeworld and its four existentials– lived body, lived relations, lived time and lived space as proposed by van Manen and how these can be disrupted when we are affected by illness have been explored. It is noted that in illness our sense of certainty and the confidence that we have in our bodies can become deeply disturbed and the things that we once took-for-granted, for instance, our brain's ability to continue to work as before can suddenly be thrown into question. Moreover, illness affects our values and sense of what is important to us in life and the limitations in our bodies due to illness can affects our existence and most fundamental sense of being-in-the-world (Carel 2007, 2010; Schwartz 2019; Toombs 1998).

As Merleau-Ponty (1962) points out, our lifeworld is determined by our bodily movements and perceptions (McConnell-Henry *et al.*, 2009). Often, we are not necessarily aware of this experience and lifeworld fundamentally encompasses the pre-reflective mode of our being-in-the-world. By turning our attention to a particular experience, we achieve reflective awareness of it (van Manen, 1997). Phenomenology describes how we experience things through our conscious acts.

4.3. Impact of illness on the experience of the lifeworld

Phenomenologically, illness changes our body and its functions. It affects our way of being-in-the-world and the meaning of our experience. When viewed through a phenomenological lens, illness is experienced not so much as a specific breakdown in the mechanical functioning of the biological body but more fundamentally as a disintegration of one's world (Toombs, 1988b p 207). She adds that illness-as-lived is a disruption of the lived body rather than as a dysfunction of the biological body (Toombs, 1988b). Using the example of migraine headache Toombs explicates how an illness can disrupt body as lived. According to her, when we experience a migraine headache it is not simply having a pain in our head but also the difficulty, we can have concentrating on what we are reading (Toombs, 1988 p 207-208).

In ill-health, our bodies that we once took-for-granted can come to the forefront of our attention as an object of contemplation that is thematised as a problem (Schwartz, 2019). Thus, illness often destabilizes the structure of our experience and the nature of our being-in-the-world. In illness we become more aware of our bodies as they become dysfunctional in some way (Crossley, 1997). Leder (1990) maintains that in illness our bodies become absent in action, describing it as 'dys-appearance' of the body and a process of objectification in illness by Carel and Toombs (Toombs, 1988a; Carel, 2011a). Thus, rather than seamlessly functioning to accomplish tasks

and goals, the body in illness can disrupt our plans and make some actions impossible for us to undertake (Toombs, 1988a, 1995b; Frank, 2001).
The negative and limiting aspects of illness cause our attention to be focused back towards our own body as an object. Thus, in illness our taken-for-granted attitude towards our body as we expect it to perform every day, habitual movements, to be pain-free or to allow us to concentrate becomes disrupted (Toombs, 1988a; Carel, 2011b; Schwartz, 2019). Carel (2013) explains that changes in our embodied experience lead to what she termed a "sense of bodily doubt" which she described occurring when we can no longer take our body's capacity for granted. Thus, in our 'bodily doubt' we focus on our present incapacities that are cut off from our future goals.

When affected by dementia, the things or activities that people once took-for-granted now become their achievements and the changes resulting from these bodily doubts can have significant effects on their being-in-the-world. As Leder explains people often interpret symptoms of illnesses as a problem caused by many things including their job, a product of a moral or religious failing and that it is only when they come to interpret the symptom via medical categories as symptomatic of a physical or psychiatric dysfunction that they attempt to seek help from the doctor (Leder, 1990). Also in illness, our sense of certainty, feeling of confidence, familiarity, continuity and people's future plans all of which depend on our bodily capabilities become limited. Illness affects one or a combination of the lifeworld existentials (lived body, lived relation, lived time and lived space) described above. For instance, people's temporal sense – values and sense of what matters to them in life and the negative impacts of these changes can affect their existence and fundamental sense of being-in-the-world (Carel 2007, 2010; Schwartz 2019; Toombs 1998). With our attention often withdrawn from the world and being focused on our bodies when we are ill, we may become isolated from others who may detach themselves from both our physical and social environments while maintaining their connection to the 'healthy' world (Schwartz 2019; Carel 2007, 2008). Illness can also affect people's lived relations as they may be unable to participate in shared activities within their lifeworld – at home, work and / or in the community. This can restrict their life thus resulting in social isolation and loneliness. Ill people may lose friendship due in part to changes in their past reciprocity as they may no longer be able to visit or meet friends and acquaintances which hitherto were taken-for-granted activities. Added to this is stigmatisation associated with some illness / diseases such as dementia and mental health issues. These and other stigmatised conditions could lead to the ill person becoming isolated because the experience of feeling stigmatised alone sets the ill person apart from others.

Using interviews and participant observation in a study of nine people with mild and moderate dementia, Phinney and Chesla (2003) asked participants to undertake some activities of daily living. They found that participants experienced “being slow” as their illness had caused disruption to their embodied skills and they were no longer able to drive or dress, activities which they had hitherto taken-for-granted. Phinney and Chesla (2003) also identified that participants experienced what they described as “being lost” as participants had lost their way-finding abilities and got lost in unfamiliar places as a consequence.

In a similar study carried out in a long-term care home of people with dementia in the Ontario area of Canada, Kontos (2004) utilised participant observation with residents in the home while they went about their day-to-day activities. The aim of Kontos’ study was to see how people with dementia interacted within their lifeworlds. She found that in spite of loss of cognitive abilities of participants, their concerns for appearance, social etiquette and caring were intact. Her conclusion was that participants had awareness of their lifeworld despite their cognitive deficits (Kontos, 2004). Spatiality constricts in the sense that the range of possible actions becomes severely circumscribed. In spatiality, our functional space can assume an unproblematic nature. Objects which we were able to easily grasp may now be regarded as "restrictive potentialities" for the body (Toombs, 1995). For example, for people with dementia, remembering to undertake certain basic activities of daily living may represent constant reminders from others because of their inability to recall how these activities, which previously were taken-for-granted, are performed (Toombs, 1988; Suddick *et al.*, 2021). Dementia therefore disrupts the mind, body and self and the relationships of people affected by the condition with others. Such disruptions will take specific forms given the economic, social and cultural settings in which people with dementia live and receive care within Ghana.

4.3.1. Conclusion of chapter

This chapter has focused on phenomenology from two major approaches – transcendental and hermeneutic – highlighting on the similarities and differences between them. It has considered the concept of lifeworld and its existentials – lived body, lived relation, lived time and lived space, and their usefulness in the study of chronic illnesses such as dementia. Using a hermeneutic phenomenological approach, studies in the field of dementia (Carel, 2011; Phinney and Chesla, 2003) and other neurological conditions such as multiple sclerosis (Toombs, 1995, 1988) have described the symptoms of these illnesses as causing disruption to the affected persons' lifeworld. For instance, participants lost their functional abilities due to, in the case of dementia, forgetfulness resulting from failure of their brain / mind to remind or direct their corporeal body towards accomplishing the intended tasks (Phinney and Chesla, 2003).

While these studies were conducted in the western countries where the pathology of dementia is medicalised as a disease of the brain, this understanding may not necessarily reflect the Ghanaian perspective where this study is being conducted. As a culture, people in Ghana tend to believe that dementia is a spiritual illness resulting from witchcraft or madness as discussed in detail in chapter 3 suggesting a very different lived experience for people with dementia there. The lifeworld of people with dementia in Ghana is (like everywhere else) determined by the existential elements of lived body, space, time and relation. This thesis explores these existentials in order to help deepen understanding of how dementia is experienced in the Ghanaian context.

Given little attention has been paid to studying the lived experiences dementia in Ghana (Agyeman *et al.*, 2019; Spittel *et al.*;2021) as well as the disruption the illness can cause to people affected by the illness's lifeworld, there is a need for research to explore what it is like for people to live with dementia within the Ghanaian context. By undertaking research in this field, attention can then be paid to lived experiences of families affected by dementia and thus their needs and concerns could be highlighted and addressed to ensure a better care and improved quality of life for people affected by dementia. I hope this thesis will make a contribution to help fill the knowledge gap in subjective experience of dementia in Ghana in particular and sub-Saharan African in general.

Chapter 5 – Research Methods and Methodology

5.1. Introduction

The chapter is divided into three parts: aims and objectives, methods, and interviews. The first part outlines the research aims and objectives of the study, which seeks to understand what it is like to live with dementia. The second part examines the research methods used in the study. Under this, the sampling procedures, including the inclusion and exclusion criteria, participants' recruitment, data collection strategies, translation and transcription of the data, are discussed. In order to generate data to explore what it is like to live with dementia, semi-structured interviews and focus group discussion techniques were employed and are discussed below. The last section focuses on ethical issues including gaining consent from participants, confidentiality and anonymity, and some reflections of the chapter.

This chapter reveals the importance of using focus groups and semi-structured interviews in helping people with dementia narrating their stories about what it was like for them to live with dementia in Ghana. As argued in Chapter 4, hermeneutic phenomenological methodology best suits the study of people with dementia and their carers in their lifeworld. Using this methodological approach enables an exploration of the ways in which people with dementia and their carers shared their everyday taken-for-granted experiences of living with dementia and how dementia has changed their lifeworld. Evidence suggests that a phenomenological approach using the lifeworld allows researchers to see things in a manner that enriches their understanding of the 'lived experience' of the participants (Meyer *et al*., 2016). Moreover, a phenomenological approach allows the essence of participants' experience to emerge from the data and highlights what makes an experience unique to each individual (Ritchie, *et al*., 2014).

5.1.1. The study setting

The study was undertaken within the Greater Accra and Eastern Regions (GAR and ER) of Ghana. The GAR with its capital, Accra, is located in the south-eastern part of the country with an estimated population of 5 million people (GSS, 2019). GAR was chosen due to it being the home of two of the three state-owned psychiatric hospitals – PH1 and PH2 in Ghana. The other psychiatric hospital, Ankaful, is in the Central region. Most mental health and psychiatric-related illnesses are diagnosed in these two hospitals in Accra. Patients at PH1 and PH2 travel from all over the country and surrounding countries including Togo, Côte d'Ivoire, Benin, Burkina Faso and Nigeria for treatment of their psychiatric illnesses (Fournier, 2011). On an ordinary day at the PH1 alone, around 100 to 400 outpatients could be seen, ten patients are admitted, and nine patients are discharged from the hospital wards (Fournier, 2011).

The ER borders the GAR in the south. With a population of approximately 3.2 million (GSS, 2019), the region houses some of the biggest prayer camps in the country (Arias *et al.*, 2016). The location of the psychiatric hospitals, the concentration of healthcare professionals in psychiatry, people with dementia and their carers, and the two regions being the home for some of the biggest prayer camps in the country made them the most appropriate sites for the study.

The study took place in three different settings or sites: the home, the prayer camps and the psychiatric hospitals. The rationale for the choice of sites has been discussed in the literature section of this thesis. People with dementia and their carers were mostly interviewed at their homes, while the focus group discussions were held at the prayer camp and psychiatric hospitals sites, respectively.

5.1.2. Research aims and objectives

The main aim of the study is to generate an understanding of the lived experiences of dementia in Ghana, from the perspectives of people with dementia, their family members and paid and unpaid carers.

Using the four lifeworld existentials (lived body, lived time, lived space, lived relationships) (van Manen 1990) to frame the analysis, this thesis will explore the following research questions:

- What is it like to live with dementia in Ghana?
- What is it like to be an unpaid carer for a person with dementia in Ghana?
- How do people with dementia and their carers understand dementia and what social and cultural resources do they use to do so?

- What are the perspectives of paid staff and professionals caring for people with dementia in Ghana?

van Manen’s (1990) hermeneutic phenomenological approach was chosen for interpretation purposes as this can be used to answer the ontological question of ‘what is it like to live with dementia or care for people with dementia’. There is an acknowledgement that carers did not refer to themselves as ‘carers’, but the term carer is here used to refer to both paid and unpaid carers to describe those who cared for people with dementia in the study. This included unpaid family carers, one live-in paid carer, and staff in the two key institutions (hospital and prayer camps) who cared for people with dementia in a paid capacity.

5.2. Research methodology

Hermeneutic phenomenology reveals the richness of lived experience. In a hermeneutic phenomenological methodological study, the researcher, study participants and interpreters are collectively referred to as participants because of the philosophical assumptions that they all share the same precognitive background with the same preunderstanding or primordial understanding of the everyday world and how they are situated in it (Chang and Horrocks, 2008, p 386).

Participants were engaged in semi-structured, face-to-face shared interviews and focus group discussions with the aim of eliciting experiential narrative data from participants as they lived as people with dementia or carers of people with dementia. In-depth interviews and focus groups were employed to collect the data because they provide opportunity to learn about the “lived experience” through the eyes and language of those living the phenomenon (Seah and Wilson, 2011). These interview techniques also portray the participants’ realities as they relate to the experience, as well as providing participants the liberty to explain and elaborate on their first-hand experiences, thus developing a rich base of data (Storli *et al.*, 2008; Seah and Wilson, 2011; Arkles *et al.*, 2018).

5.2.1. Sampling method

The study employed a purposive sampling technique to select participants. Purposive sampling is a non-random method of obtaining a small group of people with a specific characteristic useful in naturalistic or qualitative research (Robinson, 2014a; Palinkas *et al.*, 2015). Study participants were identified and selected based on their knowledge or experience (Robinson, 2014b; Palinkas *et al.*, 2015) of living with dementia or caring for people with dementia. The selection of each of the participant groups is explained in the sections below.

5.2.2 Access and recruitment

Two healthcare professionals from PH2 acted as recruitment gatekeepers for people with dementia and their family carers, while participants from the two key institutions who took part in the study were contacted through arrangements with their heads or training and development officers. Access and recruitment processes for each of the four participant groups are discussed below.

My initial attempts to contact the PH1 and PH2 were unsuccessful. The purpose of the attempted contacts was twofold: i) to ask for details of key figures or research and development officers of the institutions to discuss my intention to carry out a study there and ii) to seek their permission to do so. The discussion was also meant to seek the possibility and willingness of the hospitals acting as research gatekeepers to access potential participants for the study.

Following unsuccessful attempts, I asked a colleague of mine in Ghana for help to visit the hospitals in person to discuss their intentions to undertake research there and other preparatory tasks, including visiting some prayer camps on my behalf. Following the colleague’s visits, both hospitals agreed to take part in principle. Two Training and Development Officers (TDOs), each from the hospitals’ Research Teams, agreed for their contacts details to be passed on to me. Follow-up contacts were made by me to discuss the project with the TDOs in more detail. The discussion included the institutions’ expectations, requirements and protocols for researchers. In addition, copies of formal and ethical approval letters from the University of Stirling were requested by the TDOs. These were to confirm my studentship at the University and that ethical approval had been granted for the study. Furthermore, PH2 asked me to provide an undertaking letter agreeing to share the key findings with them upon completion of the study (see Appendices 1, 2, 3 and 4 for copies of ethics approval letter, Letters requesting permission to undertake research in PH1 and PH2 and a letter of undertaking to share findings of study respectively).

i) People with dementia and their family carers

Two hospital-based mental health nurses (MHNs) who worked at PH2 acted as recruitment gatekeepers. With the MHNs' knowledge of the exclusion and inclusion criteria of the study, potentially suitable participants were identified by the MHNs from a list of patients with a diagnosis of dementia or cognitive impairment. The list was provided by the TDO of PH2. Having identified potential participants, the MHNs made initial phone calls to introduce the project to them, sharing information about the study and asking if they wished to take part. Agreement was obtained from potential participants who showed interest for their contact details to be passed on to me for a follow-up and to further discuss the project. Upon receipt of potential participants' contact details, I made follow-up calls to see if they still wished to take part. A total of 13 families with people with dementia were contacted, of which three families declined to take part. I provided further information and more detailed explanation to those who wished to take part in the study. Of these, seven people with dementia and 16 carers took part.

Inclusion and exclusion criteria

The following inclusion criteria were used in selecting the study participants:

i) People with a diagnosis of dementia or cognitive impairment. People with cognitive impairment were recruited, as I anticipated some difficulty in getting a sufficient sample size of participants with formal diagnosis of dementia for the study. However, all participants did have a formal diagnosis of dementia.

ii) Participants should be at least 50 years or older.

iii) There should be no evidence of verbal communication difficulties (as lack of it could serve as a barrier to the consent process and interviewing).

The exclusion criteria were as follows

i) People with no formal diagnosis of dementia or cognitive impairment.

ii) People with more advanced dementia who were no longer able to consent to take part in the study.

iii) People who lacked verbal communication skills.

The tables below set out the demographics of the participants, their names having been replaced by pseudonyms.

Table 5.1: Demographics of people with dementia:

Names (Pseudonym)	Age	Sex	Type of dementia	№ of years since diagnosis	Previous occupation/ job title	People with dementia contacted
Gladys	58	Female	Unspecified	2	Petty trader/ farmer	Interviewed
Emma	80	Female	Vascular	4	Undisclosed	Interviewed
Simon	73	Male	Alzheimer’s	3	Civil servant	Interviewed
MayLiz	69	Female	Vascular	5	Petty trader, seamstress, farmer	Interviewed
Mag	60	Female	Vascular	3	Petty trader	Interviewed
Mansa	65	Female	Alzheimer's	4	Petty trader	Interviewed but stopped shortly afterwards
Adjoa	65	Female	Vascular	6	Undisclosed	Interviewed

Table 5.2: Characteristics of carers of people with dementia:

Pseudonym	Sex	Occupation	Type of caring	Relationship with cared for
Geo	Male	Unpaid carer	Part time	Mother
Xiana	Female	Paid carer	Full time	Paid employee
Danny	Male	Unpaid carer	Part time	Grandma
Joymo	Female	Unpaid carer	Part time	Mother
Pepdon	Female	Unpaid carer	Part time	Mother
Irenekor	Female	Unpaid carer	Part time	Mother
Gracem	Female	Unpaid carer	Full time	Husband
Bea	Female	Unpaid carer	Part time	Father
Marygya	Female	Unpaid carer	Part time	Sister
Rosemary	Female	Unpaid carer	Part time	Mother

Sarasa	Female	Unpaid carer	Part time	Mother
Maryako	Female	Unpaid carer	Full time	Mother
Esi	Female	Unpaid carer	Part time	Mother
Tomadze	Male	Unpaid carer	Full time	Father
Tinaboa	Female	Unpaid carer	Part time	Father-in-law
Lizzy	Female	Unpaid carer	Part time	Mother

Arrangements were made to interview participants who agreed to take part at venues or sites of their choice, mostly in the participants' own homes. Details of participants who took part in the study are provided in Chapter 6. I had aimed at obtaining between 10 and 15 people with dementia and their families. Interviewing seven people with dementia and 16 carers of people with dementia meant I achieved the number of participants I wished to interview. Deciding on the sample size of research study depends on the type of the epistemology and methodology of the study, as well as the ethics of study (Sandelowski and Barroso, 2003). The sample size was found to be appropriate for this study, as phenomenological research is focused on engaging in in-depth interviews with participants. Having reviewed qualitative research and phenomenological studies, I continued to interview participants until I reached theoretical saturation, where no new concepts were emerging from the interviews (Sandelowski and Barroso, 2003; DiCicco-Bloom and Crabtree, 2006).

ii) Healthcare professionals

Study participants from the two hospitals were recruited through TDOs of their respective institutions. The TDOs informed their colleagues about the project through their social media platforms and by word of mouth. Those who showed interest were given copies of the invitation letters and information sheets (Appendices 9 and 11 respectively) so that they could learn more about the project and decide whether they would still want to take part. TDOs finally confirmed the number of participants who agreed to participate with me. Dates and times were then arranged for the focus group discussions to take place. Table 5.3 below outlines the characteristics of healthcare professionals from both hospitals who took part in the study.

Table 5.3: Characteristics of healthcare professionals:

Names (Pseudonym)	Sex	Occupation	Years of experience	Place of work
Akugya	Female	CPN	5	PH2
Maame	Female	CPN	7	PH2
Barima	Male	SW	2	PH2
Petan	Male	MHN	5	PH2
Adwoku	Female	Psychiatrist	8	PH2
Milla	Female	CPN	5	PH2
Kyeiba	Male	PA	11	PH2
Alexyline	Female	Psychologist	12	PH1
Mikoansa	Male	T&DO	8	PH1
Lawalma	Female	MHN	4	PH1
Maryan	Female	MHN	10	PH1
Rosebu	Female	MHN	7	PH1
Efuamen	Female	MHN	6	PH1
Chrisom	Male	CJSW	Undisclosed	PH1
Esinamow	Female	CPN	3	PH1

PH1 – Psychiatric Hospital 1
PH2 – Psychiatric Hospital 2
CPN – Community Psychiatric Nurse
TDO – Training & Development Officer
MHN – Mental Health Nurse
CJSW – Criminal Justice Social Worker
PA – Physician Assistant (Prescriber)
SW – Social Worker

iii) Prayer camp staff

I identified and approached four prayer camps. One of them declined to take part and another did not meet the criteria for the study as there were no residential facilities where people with dementia and other psychiatric conditions could stay and be cared for, and the leaders had no lived experience of dementia. The remaining two prayer camps, Mohab and Ɔgyam in the ER and GAR, respectively, agreed to take part.

In total, there were nine participants across the two prayer camps who took part in the study. This consisted of one prophet, one prophetess, one reverend minister and six senior carers. Table 5.4 below outlines the demographics of the prayer camp participants.

Table 5.4: Prayer camp participant descriptors.

Name (Pseudonym)	Sex	Occupation	Prayer camp
Nateye	Male	SSW	MPC
Kwadame	Male	SSW	MPC
Hamasa	Male	Reverend Minister	MPC
Charlietof	Male	Pastor	MPC
Jessegya	Male	SSW	MPC
Stefano	Male	SSW	ƆPC
Tommyas	Male	SSW	ƆPC
Williezor	Male	SuW	ƆPC
Profedem	Female	Prophetess	ƆPC

MPC – Mohab Prayer Camp
ƆPC – Ɔgyam Prayer Camp.
SSW – Senior Support Worker
SuW – Support Worker

Participants at ƆPC were recruited directly through their prophetess. At MPC, the participants were recruited through the camp's secretary after gaining approval from the prophet and head of the camp. During my first visit to the camps, copies of the information sheets and focus group invitation letters (Appendices 8 and 11) and were shared with the secretary and the prophetess to be distributed to those who might be interested in the study. This was after the heads of the camps had agreed for the study to be undertaken there. We agreed that I would phone them within the week for an update and then arranged a suitable date for the focus group discussion.

5.3. Research methods

Two qualitative research methods of enquiry were used to collect data for this study. For people with dementia and their carers, semi-structured interviews were deemed the most appropriate research methods as they allow participants to voice their thoughts, tell their own stories and talk at their own pace (Miles and Huberman,1994). For healthcare professionals and prayer camp staff, focus group discussions were used. This method allowed me to know more about the experiences and challenges these group of participants faced in caring for people with dementia and their families.

5.3.1: Semi-structured interviews

The study employed semi-structured interviews with open-ended questions with people with dementia and their family carers. I used this interview method as I wanted to gain a deeper understanding of each participant and their lifeworld (Bajramovic *et al*., 2004; Lambert and Loiselle, 2008). This method allowed this participant group to provide answers to the research questions posed in their own terms and in ways that they thought and used language (Qu and Dumay, 2011). Semi-structured interviews enabled the researcher to have prepared questions that were identified by guided themes/topics and, thus, provided an opportunity to complement more specifics with the main questions such as ‘What do you mean by that?’, ‘Can you give me an example of that?’ (Appendix 14). These advantages made the semi-structured interview a more suitable method for this research.

5.3.2: Focus group discussions

According to Sagoe (2012), focus groups consist of a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research. This interview technique was used with healthcare professionals and prayer camp staff working in the hospitals and prayer camps, respectively. Focus groups were chosen due to their advantage of being a well-suited method for exploring people’s subjective experiences and attitudes (Lambert and Loiselle, 2008; Bradbury-Jones *et al.*, 2009). This method also provided study participants the opportunity to share their thoughts, experiences and ideas on caring for or working with people with dementia and their families (Sagoe, 2012). Additionally, focus groups have been useful in studies where existing knowledge of a subject was inadequate and elaboration of pertinent issues was required (Powell and Single, 1996). Furthermore, focus groups were a particularly good choice of method for this study as their purpose was to elicit participants’ understandings, opinions and views within the socio-cultural context (Wilkinson, 1998) of Ghana.

A focus group method was, therefore, deemed a more suitable research technique for studying the lived experience of dementia in Ghana because it could help the researcher gain insight from individuals’ lived experience about the shared (inter-subjective) elements of dementia experience, and how these experiences shaped and were shaped by the social, cultural and medical discourses or practices within the Ghanaian society and culture. As the study aimed to obtain data from different groups, the researcher decided to use homogenous groups of participants (Wong, 2008), prayer camp and healthcare staff in separate group discussions. The inclusion of medical and prayer camp discussions reflects the different practices in relation to dementia care in Ghana. It was felt essential that dementia would be better discussed by people with similar backgrounds and experience, because participants' sense of "everyone is in the same boat" was particularly important to facilitate disclosures (Wong, 2008). Thus, focus groups provided participants the opportunity to talk freely and share their experiences as they had a lot in common (Hollis *et al*., 2002; Lambert and Loiselle, 2008).

5.4 The interview setting

It is crucial to consider the social context within which interviews take place prior to interviewing participants. I ensured that participants were interviewed at places and settings that they felt secure, relaxed and comfortable to share their private and potentially upsetting information with me. All people with dementia and their carers were interviewed at home, except for one person with dementia. Two carers – Pepdon and Irenekor – were also interviewed at the psychiatric hospital on the day their mother, Aggie, was attending her monthly health review.

People with dementia were offered the choice of being interviewed alone or with a member of their family present. Several studies (Cort *et al*., 2004; Peters *et al*., 2008; Taylor and de Vocht, 2011) recommend including carers when interviewing people with life-threatening illnesses. This is because carers' experiences and relationships can influence how the course of the illness is negotiated by those they care for. My experience of interviewing people with dementia in Ghana was similar to Taylor and de Vocht (2011). People with dementia, except one, preferred their family carers to sit in their interviews. One advantage of having carers sitting in the interviews of people with dementia was to enable the carers to provide emotional support to people with dementia if required and, thus, enable them to narrate their stories as best they could. However, where a spouse or family carer sat in the interview, they were asked not to interrupt people with dementia's storytelling, albeit they could fill in any detail(s) or help with any word-finding difficulty that people with dementia might experience. During the interview, most people with dementia deflected some questions to their family carers, who they perhaps felt knew more about their situation than they themselves. On occasions, family carers interjected and disagreed with their relative with dementia, either verbally or through non-verbal means, such as shaking their heads or making a gesture to indicate their disagreement. Where a carer verbally interjected, I reminded them to only assist if their relative with dementia was, for instance, struggling with word-finding but not to interrupt or argue with them. However, gestures made by carers to indicate their disagreement with their relative with dementia were recorded in my fieldwork diary/note. Sometimes, I took the opportunity during such disagreements to probe the subject matter further.

As indicated above, with the exception of Pepdon and Irenekor, all other carers were interviewed at home. For both people with dementia and their family carers, interviews could be upsetting and some needed time and support before continuing. Where people became upset, they were given space to settle. I later checked on them to see if they wished to continue and, without exception, all carers expressed a desire to continue the interview. For some carers, this was the first opportunity they had to talk about their experiences and situation (Carlsson e*t al*., 2007), whilst others described the process as therapeutic as it offered them an opportunity to express or share their views and the challenges they were facing in their caring role.

5.4.1: Data collection

A total of 46 participants, namely 17 males and 29 females, took part in the study. Of these, 17 were interviewed in English and the remaining 29 in Twi. Details of these are provided in Table 5.5 below. The 15 healthcare professionals comprised of social service workers, psychologist, psychiatrist, physician assistant (prescriber), community psychiatric and mental health nurses with various years of experience (Table 5.3). Of the nine participants from the two prayer camps, only one was a female (prophetess and head of the prayer camp), the remaining eight being all males. According to staff, the male dominance in this area of work was due to the fact that some people with dementia and other psychiatric illnesses can be quite challenging in their behaviours, which often requires people who are physically strong to look after them.

Table 5.5: № of participants and language(s) used in interviews.

Group of participants	№ of males	№ of females	Total №	Interviews in English	Interviews in Twi
People with dementia	1	6	7	1	6
Unpaid	3	12	16	1	15
Paid carer	0	1			
Healthcare professionals	5	10	15	15	0
Prayer camp staff	8	1	9	0	9
Total participants	17	30	46	17	30

5.4.2: The interview process

The two interview processes – semi-structured and focus group – employed to recruit participants for the study are discussed below:

i) Semi-structured interviews with people with dementia and their family carers

People with dementia and their carers were contacted the day of their interview to ascertain if they still wished to take part in the study. All confirmed they would. Each interview began with an introduction and seeking people with dementia and their carers' consent before interviews commenced.

Interviewing people with dementia

Each interview with people with dementia commenced using questions such as, "When did you first notice something was wrong with your memory?", "Who did you tell and why?". While such interview questions helped in touching upon the life histories of people with dementia, including their journey to and through diagnosis to living with dementia, prompts such as, "Tell me more about it", "Can you explain a bit more?", "What do you mean by that?" and "Can you give me examples?" were used to ensure that all aspects of the data required were collected. I listened attentively to what participants talked about, while focusing on participants sharing their experiences in their own words (DiCicco-Bloom and Crabtree, 2006).

People with dementia were encouraged to describe their situations and experiences from the time they recognised that something was ‘wrong’ with their memory and what impact this has had on their day-to-day living. This included their contact with others such as family members, friends, neighbours and healthcare professionals. Interviews with people with dementia lasted between five minutes and just a little over an hour. A copy of the interview scheduled / topic guide is provided in Appendix 14.

Interviews with family carers and one paid carer

Family carers of people with dementia were interviewed separately from those they cared for, the aim being to get a deeper knowledge and understanding of the people with dementia’s life as well as a holistic view of their family life with dementia (Taylor and de Vocht, 2011). Family carers were asked what their perception of dementia was, ‘what the first signs were’ that made them think that ‘something was wrong’ with their relative with dementia’s memory, what their pre-dementia lives were like, and to describe their experiences as they lived with dementia. They were encouraged to describe their feelings and thoughts and how they responded to situations that they came across on a day-to-day basis.

For both people with dementia and their family carers, small talk and debrief sessions were held with them at the end of each interview. This allowed me to avoid ending interviews with participants abruptly. I also kept a reflective diary to record my observations, thoughts about techniques used, feelings, opinions of participants and ideas about the interviews during and immediately after each interview. These were used to enhance the information gained from the interviews. All the interviews were audio-recorded, and all participants’ details and personal information were anonymised to protect their confidentiality (Digby *et al*., 2016).

ii) Focus groups discussions with healthcare professionals and prayer camp staff

Each focus group session began with basic introductions, clarifying terms, completing consent forms, clarifying issues of confidentiality, clearly defining the topic to be discussed and the process that would occur in the group (Then *et al*., 2014). Name tags were used, with participants’ first names written on them so that I could address participants by their first names both for documentation and transcription purposes. Permission to audio-record sessions was requested from and approved by participants before beginning each discussion session (Kitzinger, 1995; Then *et al.*, 2014). The audiotape (digital voice recorder) was positioned in the middle of the group to ensure that participants' voices were properly captured. Each group discussion ended by thanking participants for their assistance in helping me gain some insights into the topic under discussion. I provided participants the opportunity to ask any questions or leave comments. The focus group discussion sessions were guided by the topic guides (Appendix 15).

5.4.3. Choice of use of language

All study participants were offered the choice of using either Twi or English language, depending on which language they felt more comfortable with and wished to be interviewed in. While it was felt participants could speak in at least one or both languages, provision was made for an interpreter service for potential participant(s) who could not, or did not wish to, speak either of those two languages. However, the interpreter service was not needed, as participants spoke Twi (of which I was a native speaker myself) or English. All healthcare professionals, plus one carer and one person with dementia, spoke English, while the rest of the participants, including all the prayer camp staff, were interviewed in Twi. This was their preferred language choice.

5.5: Ethical considerations/issues

Ethical approval was obtained from the University of Stirling's General University Ethics Panel (GUEP). A copy of the approval letter can be found at Appendix 1. People with dementia and their carers can be considered to be vulnerable, and dementia affects a person's life, their independence, identity and autonomy (Pesonen *et al.*, 2011). Dementia can thus pose significant physical, emotional and financial challenges to the families with people with dementia (Buescher and Grando, 2009). Consequently, I ensured that research participants understood the nature of what was being asked of them and that they were aware of the risks and benefits of the study, as well as their right to withdraw at any time. Ethical issues addressed in the study included informed consent, confidentiality and anonymity, as well as addressing any potentially distressing issues that could arise from the interviews.

5.5.1. Obtaining informed consent

Ethically, research participants would need to consent to or withdraw from taking part in research studies. Consent involves having enough understanding and the will to agree or withdraw from something (Alderson and Goodey, 1998), and obtaining informed consent from research participants was central to any research activity (Hellstrom *et al.*, 2007). All research participants were provided with sufficient information about the study to enable them to make informed decisions about whether or not they would like to take part (Sutton *et al.*, 2003). Information provided included the nature and purpose of the research, duration of interviews and the potential impact of the findings for participants. Participants' consent was based on the premise that they were capable of making free and voluntary conscious decisions based on the adequate information provided them about the study (Pesonen *et al*., 2011). For people with dementia, I drew on Dewing's (2007) guidance for a 'process consent' method.

i) Dementia and process consent

The process consent method involves seeing consent as a process and gaining people with dementia's consent each time they take part rather than just once (Hellstrom *et al.*, 2007). Dewing (2007) developed and used this method with residents with dementia in a care home. Dewing suggested that the initial consent of people with dementia should be revisited and re-established on every occasion, or within the same occasion, due to the variable capacity of people with dementia (Dewing, 2007; Hellstrom *et al.*, 2007). Dewing's process consent has been recommended and widely used to support people with dementia to give informed consent within dementia research and outlines the process researchers should follow to gain process consent from people with dementia. This process is summarised in the table below:

Table 5.6 The process consent method (based on Dewing, 2007)

1. *Background and preparation.* Gaining permission to approach a person from staff or carers. This means consent for access before thinking about consent for the study. Finding out about the person's biography. How does the person present themselves when in a state of well-being?
2. *Establishing basis for consent*. During this stage, the researcher is primarily establishing the basis for capacity for consent and how this has been achieved. Things to

consider include the person’s usual self-presentation, the person’s usual level of ill or well-being. How a reduction in well-being can be triggered. How a decrease in well-being can be recognised. What behaviour/conversation may indicate psychotherapeutic need? How does this person usually consent to activities within their day-to-day life?
3. *Initial Consent*. At this point, the researcher should feel confident to seek initial consent, i.e. situation specific consent. The exact method will vary according to the individual and may involve showing them props such as recording equipment. Researchers should record how consent was given.
4. *Ongoing consent monitoring.* Here, the focus is on ensuring that the initial consent is revisited and re-established on every occasion. This highlights the concept of consent representing a process. It is important to remember that consent is both transitory and situational. One way to increase robustness of process is to ask someone else to sit in and act as a validator. It is also important to make a note of the participant’s well-being state at the end of every encounter.
5. *Feedback and support.* It may be necessary to feed back to carers or relatives. However, this needs to be considered carefully due to issues of confidentiality. Discussion with other members of the research team is important.

Apart from the initial verbal consent given to healthcare professionals by people with dementia and their family carers confirming their agreement to be contacted by me about the study, I re-sought people with dementia’s verbal consent during the follow-up calls and by written and verbal consent on the day of interview (Appendix 12). This multi-stage consent process was beneficial in providing participants several opportunities to consider and reconsider their wish to either take part in the study or refuse to do so, as well as giving them sufficient time to make a more informed decision about their participation (Hellstrom *et al.*, 2007). For participants who were either unable to read or write, or had difficulty reading the information sheet, I read and translated the information sheet for them, to ensure that they understood the information and what the project was all about prior to deciding whether or not they would wish to continue their participation.

All the participants with dementia were able to and did sign a written consent form, except for one person who thumb-printed to indicate their agreement to take part in the study before interviews commenced. I was confident that the people with dementia who took part were able to provide informed consent.

The literatures presented on consent were mainly from the Western, predominantly White and English-speaking countries, and Western ideas and tools have been used throughout the ethics section. This was because, while section 68 sub-sections 1-8 of the Mental Health Act (2012) of Ghana make provision for ‘competence, capacity and guardianship’ where a person is deemed to lack capacity (Walker and Osei, 2017), it is uncommon to find people who have been assessed as lacking capacity in Ghana. This may be due in part to the stigma around psychiatric illnesses, lack of human resources such as psychiatrists and other health professionals to carry out diagnosis, as well as the cost involved in carrying out such capacity assessments. I, therefore, had to rely on the established protocols for gaining consent from people with dementia based on Western ideas and tools.

5.5.2. Obtaining informed consent for all the other participants

All other participants were assumed to have capacity unless it was clearly indicated otherwise (Asare, 2010; Walker and Osei, 2017). All participants demonstrated their ability to understand the research process and were provided information including information sheets and invitation letters and all gave their consent before the start of interviews. Consent forms were signed and dated by participants to indicate their agreement to take part in the study before interviews commenced (Appendices 12 and 13).

5.5.3. Confidentiality and anonymity

Protecting research participants’ confidentiality and anonymity is essential to ensuring the safety and the quality of information that participants provide (Hellstrom *et al.*, 2007). Wiles *et al*. (2006.) defined confidentiality as ‘spoken or written in confidence, charged with secrets, while defining anonymity as ‘of unknown name, of unknown authorship*’* (p 3). While participants had already read about their rights to privacy and confidentiality from the participant information sheets, I ensured that these were reiterated to them before the interviews and focus group discussions began. For participants who had difficulty reading or writing, their rights to privacy and confidentiality were explained to them in Twi. All participants were made aware of the possibility of me breaching confidentiality if information shared or disclosed indicated harm to themselves or others. Participants were also advised that, under such circumstances, the local adult or child protection procedures would be followed, and the issue(s) would be reported to the appropriate or relevant authorities for investigation. Participants were assured that I would discuss any follow-up actions within them before this took place. However, no issues were raised that necessitated a breach of confidentiality.

5.5.4. Seeking local ethical approval

Apart from the University of Stirling's ethical approval, local ethical requirements needed to be met. The two healthcare institutions confirmed their acceptance of the University of Stirling's ethical approval. Consequently, no further ethical approval was required after these. However, as indicated above, PH2 requested an undertaking from me to share the study findings with them (see Appendix 4) after completion, although the findings can be accessed by all participating groups.

5.5.5. Potential for distress during interviews

Aware of the potential distress associated with interviewing participants about the emotive issues around dementia and living with dementia, I was vigilant to any signs of distress participants might display during interviews and focus group discussion sessions. With my background as a social worker, I had been trained to be able to spot these signs and to support the emotional well-being of participants, should they become upset or distressed during interviews. Arrangements were therefore made with the health professionals at the psychiatric hospitals to provide some emotional or therapeutic support to distressed participants, if required.

For instance, a situation arose where a 65-year-old woman with dementia, Mansah, became upset when narrating her experience of living with dementia. I offered to cease the interview, to which she agreed. Both the CPN who accompanied me to interview the family, and I provided some emotional support to Mansa until she advised she was OK. However, she would neither want to continue nor rearrange the interview at a future date. It was suggested to the family to seek further professional input if they felt the need for this. The CPN provided them with a telephone number to contact should they feel the need to do so.

5.6. Translation and transcription of data

The existing body of literature recognises the important role that translators in qualitative research play in bringing the translated data as close to the meanings of the original data as possible during translation (Bashiruddin, 2013; Ho *et al*., 2019). Preparing bilingual data for analysis is a part of methodology and, hence, should be discussed in more detail than it currently is. It is also a cultural issue, because translation involves converting ideas expressed in one language for one social group to another language for another social group, which entails a process of cultural decoding (Torop, 2002). As Halai (2015) argues, interviews are not just words spoken at a certain time in response to a social situation; rather, they are embedded in the culture of the place and, as a result, when translating, one must keep the target social group/reader in mind. In this case, I had the advantage as I belonged to the same culture as the research participants. Hence, I did not have to translate for the culture as well. However, I did consider the target reader(s) the entire time, who could be from any part of the world, and hence tried to make the translations understandable for the general reader(s) (Torop, 2002; Halai, 2015).

As shown in Table 5.5, most of the interviews were conducted in the local (Twi) language. I listened to the audio in Twi while transcribing the interviews into English. The differences in the two languages – from data collection through to interpretation and analysis – have presented some challenges.

All the participants could speak Twi very well. I was fluent in the Twi language myself as a native speaker. I, therefore, played multiple roles, for example a researcher/translator or interpreter and author, something I consider as an advantage. Given my cultural background, I realised at the interview stage that some of the words and phrases used could not be translated directly into English. The Twi word '*sɛbe*', for instance, does not have direct translation into English. While such words and phrases did not present challenges to me during data collection, I found some to be more challenging during the translation and transcription phases.

To overcome these challenges, I consulted a colleague with a good background in socio-linguistic competence, advanced level education in Twi and a University degree in Linguistics, for help to deal with the translational challenges. Regmi *et al*. (2010) recommend that qualitative research interpreters and translators should have a background and well-established links to the ethnic group involved in the study. Being a native speaker of the Twi language and having a similar background as the study participants, it was felt appropriate to translate from Twi into English myself. It was felt that using a non-native speaker or an outsider to translate the data could have complicated the meanings and experiences participants ascribed to dementia, as certain gestures and non-verbal communication cues could have been missed, thus risking the quality and richness of the data.

5.6.1. Data transcription

Transcription is an important first step in and central to the data analysis process (Clark *et al.*, 2017). It is the process of producing a valid written record of an interview (Clark *et al*., 2017, p 1753) and involves the close observation of data through repeated careful listening. It is the representation of what is preserved from the audio-recorder or taped speech. Transcribing the data from this study was slow and it took several months to transcribe the entire interviews and focus group discussions that were conducted in Twi. It took an average of an hour to at least five hours to transcribe an hour of talk (interview) and even more in the case of focus group discussions. This was because I listened to the interviews several times before transcribing them. Firstly, all the 29 interviews conducted in Twi were translated into English and then transcribed. I listened to the audiotape and typed them up. The accuracy of all the transcribed data was verified while I was listening and re-listening to the audiotape. Spellings were checked for errors and corrections were made to ensure that misspellings were changed, and correct words used where necessary before using them as quotes.

On reflection, I found that cross-cultural studies, where interviews conducted in a target language are translated into another (English), to be time-consuming. They can also require a good level of understanding of the target language. I recommend that cross-cultural researchers have good linguistic skills and need to be conversant in the target language. I would also recommend that translators be familiar with the content or subject area involved in the source material. As Torop (2002) concludes, translators' familiarity with English language contributes to the translation quality and this is better for concepts with which translators had more familiarity.

5.7. Data analysis and interpretation

Analysing the data is one of the most important steps in the research process, as it assists in making sense of the data. Data analysis began with coding.

i) Coding

Coding is one of the significant steps taken during analysis in order to organise and make sense of textual data. Data analysis began by developing a coding framework to code the transcribed data. This was to ensure consistency in the use of the codes throughout the process across all participants (Joffe and Yardley, 2004; Saldana, 2013). The coding framework was to help sort out the data into manageable and meaningful parts, as well as enabling the identification of the need for developing new codes when necessary (Allan *et al.,* 2009).

Coding began by reading and re-reading all the transcribed texts, now in English, several times in an effort to understand the meanings in the data. I made notes about potential themes and sub-themes in the form of words, phrases and sentences at the margins of the printed, textual material (data). This was an iterative process – moving backwards and forwards and was done manually. Creswell (2007) and Creswell (2012a) described this procedure, of fragmenting and classifying text to form explanations and comprehensive themes in the data, as coding. As I went through the transcripts, the most important ideas or concepts in the data were identified and shaped into codes.

To make the data easier to handle, I used NVivo 11 for organising the data, developing analytical structure, identifying the emerging trends from the text materials and building themes. At the initial or descriptive coding stage, five parent nodes and 86 child nodes were identified. Words and phrases in the text that corresponded with the phenomenon (lived experience of dementia) that showed key ideas or views of participants were highlighted and coded when reading the text line-by-line. Initial impressions of the codes were written at the margins of the printed transcripts. This provided initial interpretations.

The parent nodes included experiences, perception of dementia, challenges, ways of coping and perceived solutions, while the child nodes comprised of, for example, loss of familial roles, loss of jobs, finances, witchcraft, ‘madness’, curses, forgetfulness, spirituality, and support. Family, government and others were also identified. I discussed the codes with my academic supervisors and different opinions were reconciled prior to progressing further with the analysis. It was felt that the original process of coding was not working well and, following further discussions with my academic supervisors, it was agreed that van Manen’s lifeworld existentials, namely lived body, lived relations, lived time and lived space, could be used to structure the coding framework.

After coding a few transcripts using the new structure under van Manen’s (1990) construct, the lived body had much value (in both sources and references in NVivo), whereas lived time and lived space had fewer codes. Under the lived body, I found themes such as “mad”, “madness”, “*w’abɔdam*” (he is mad), “abnormal” or “not normal” and “forgetfulness” coming up again and again as I read through the transcripts. It was felt that those themes could lead to some interesting insights. More analytical codes were added to the next level of the coding process to include mental health, dementia and spirituality as they emerged from the data. These had more connections with and significance to the broader literature and research questions than the simple descriptive codes that I initially assigned. Coding was found to be a thoughtful process that helped generate themes and elicit meanings.

Table 5.7

Examples from the interview texts			
Facts about events having significance	The person’s way of expressing what the situation meant	The person’s way of coping with and adjusting to the situation	Creation of themes
What I am experiencing now wasn't a problem then. Everything started getting worse after the stroke. As I sit now, I still feel the numbness in my hands.	“*I am not like how I was created by God anymore.”*	*“As for my attendance at church services, I manage to go even if I need to crawl to get there.”*	Losing one’s identity (lived bodily change)
A sense of feeling of loss of self/control	*“At first, I used to go and fetch water myself but can’t do that now.”*	*“I noted something was wrong in my physical body.”*	Loss of independence

	"I am no longer able to do my own laundry now."		
Forgetting what was happening or being in denial of deteriorating memory.	*"I can't deny I forget things. Even yourself, you do forget."*	*"So, if anyone is telling you that I am insane or trying to disgrace me, I'm not accepting it."*	Lived body failing (cognitively/ forgetfulness)

Adapted from (Holst and Hallberg, 2003).

ii) Analysis

The data were analysed using thematic analysis. Braun and Clarke (2006) define thematic analysis as a method for identifying, analysing and reporting patterns (themes) within data (p 6). Thematic data analysis was chosen due in part to it being a flexible process that enables data to be explored in an efficient manner. Thus, as an inductive approach, thematic analysis is not tied to any specific epistemological approach (Sundler *et al.*, 2019). This study also benefited from thematic analysis as it seeks to describe common practices and shared meanings that are intended to reveal, enhance and extend one's understanding of dementia as it is lived, but not to generate or build upon any theories (Darbyshire *et al.*, 1999; Ironside, 2006).

In interpreting and analysing thematically and phenomenologically, Heidegger emphasises the usefulness of the researcher's foreknowledge (pre-understanding) (Parson, 20101; Smythe *et al*., 2008a) or fore-structures (van Manen 1990), as it aids understanding of the phenomena being studied. My pre-understanding also provided a foundation upon which the hermeneutic phenomenological interpretation was based (van Manen, 2017). van Manen (1990) advocates for hermeneutic phenomenological reflection based on thematic analysis; however, he does not specify how data is to be managed in the process. van Manen suggested a structure of human science research that focused on lived experience. The structure comprised of six steps (see table below), of which stages three to six are of particular value to my data analysis.

Table 5.8 van Manen’s (1990) Methodical Structure of Human Science Research.

1. Turning to a phenomenon which seriously interests us and commits us to the world. Setting out to make sense of a certain aspect of human existence.
2. Investigating experience as we live it rather than as we conceptualise it. Looking at the world by re-awakening the basic experience of the world. The researcher stands in the fullness of life and actively explores the category of lived experience in all its modalities and aspects.
3. Reflecting on the essential themes which characterise the phenomenon. Reflective grasping of what it is that renders this or that particular experience its special significance.
4. Describing the phenomenon through the act of writing and re-writing. To do research in a phenomenological sense is always a bringing to speech of something through the act of writing.
5. Maintaining a strong and oriented pedagogical relation to the phenomenon. The researcher must remain strongly oriented to the fundamental question and avoid becoming side tracked
6. Balancing the research context by considering parts and whole. The researcher must not lose sight of the entirety of the question being addressed.

van Manen (2017) posits that the description of methodology and features of human research should enable the reader to select or invent a research method that is appropriate for their own research questions. I therefore decided how best to perform the thematic analysis based on van Manen’s methodical structure of human science research above. Using the concept of a hermeneutic circle to better understand the text, I kept moving between parts and the whole texts to reveal the hidden layers of meanings of the text (Crist and Tanner, 2003; Crowther *et al.*, 2016). I ensured that any discrepancies in the interpretation were clarified, while I continued to explore themes that cut across the interview texts such as religion, spirituality and stigma. As a researcher, my responsibility here was to make sense of the data collected during fieldwork by exploring and interpreting them. Direct quotes or excerpts from participants’ accounts were used to enhance analysis of the data (see Table 5.7). Thus, I referred to the original data quoting verbatim participants’ words to assist in revealing how words were expressed in participants’ own words rather than mine. However, as Holst and Hallberg (2003) argued, the meanings that people give to their behaviours do not only involve what they think but also what the interpreter or researcher thinks of what those individuals have done. Interpretation of the data involved making sense of what participants had said and the meanings that were made out of them.

The final set of themes that emerged from the data were structured around the lifeworld existentials of the lived body, lived relation, lived time and lived space. These are discussed in detailed in the findings chapters (Chapters 7 to 9).

5.8. Data management

The interview and focus group data were stored on a password-protected laptop provided for that purpose in a locked cabinet at the University of Stirling. All the stored audio data have been transcribed and personal details of participants have been anonymised within the transcripts to protect participants' identity and privacy. The audio recordings will be destroyed at the end of the project, while the anonymised data will be kept for a minimum of ten years as per the University's data protection process.

5.9 Methodological reflections

Here, I make reflections on some of the methods and methodological limitations and challenges encountered.

i) Sampling

Although sample sizes are important in qualitative research, large sample sizes are not necessary in phenomenological enquiries (Carel, 2011). Large sample sizes in phenomenological studies can preclude the details of the lived experience of the phenomenological inquiry. Instead, what is important in a phenomenological study is having a sample size that captures a full range of the lived experience of the phenomenon being investigated (Mapp, 2008). This study design covered a wide range of participants (four participant groups) with a wide range of experiences, and from participants with different professional backgrounds. This gave me rich and detailed information for the study. I, however, hereby discuss some of the limitations of this study. Firstly, while the study aimed to access as wide a range of experiences as possible within the sampled group, men compared with women with dementia were under-represented. It was my expectation during the initial study design that I would interview almost an equal number of men and women with dementia.

However, as shown in Table 5.1 above, of the seven people with dementia interviewed, only one was a male. In the list of participants provided to me by the recruitment gatekeeper, the number of women with dementia outweighed the number of men. Therefore, I knew it was not likely that I would interview an equal number of men and women with dementia. However, while an ideal number of men (3) agreed to take part in the study, two withdrew on the day they were supposed to be interviewed due to them being unwell. They also did not want to reschedule the interview. Given this limitation, the lived experience of men with dementia still remains an important area for further study.

Secondly, accessing participants, particularly families with people with dementia, and prayer camps proved to be difficult. Although the hospitals identified a large number of potential people with dementia and their family carers, a little over half of the people identified either showed no interest, failed to respond to phone calls, or gave excuses such as bereavement and, thus, refused to take part in the study.

ii) Potential sample bias – socio-economic status of study participants

During the recruitment process, participants in the Greater Accra Region (GAR) were more likely to enter the study than their non-GAR counterparts. Apart from staff from MPC in the Eastern Region (ER) that took part in the study, all other participants were recruited from the GAR. Thus, people with dementia, their family carers and healthcare professionals were over-represented relative to the general population in the two regions (ER and GAR). Those living in and around GAR were more likely to access psychiatric services, for instance, getting dementia diagnosis, attending regular monthly health review appointments or occasionally receiving home visits by CPNs than their counterparts living in the ER and other regions due in part to distance. This greater access to health services for people with dementia is likely to significantly impact their perceptions of the condition. It would be important in future research to engage with people from the ER to understand more about the differences in experiences with healthcare and perceptions of dementia.

The demographic and socio-economic characteristics of people with dementia in the study revealed that women relative to men were mostly either engaged in farming (subsistence), self-employment and petty trading, selling often second-hand clothing or engaged in dressmaking. The only man with dementia who took part in the study was a retired civil service who worked in a government department. Further, the women with dementia had relatively lower educational attainment and were in low-paid jobs compared to their male counterpart. Because there were more women with dementia than men in my study, and the man and the women were on low incomes, the research does not provide a full understanding of the experiences of men or the experiences of people with higher economic status with dementia. Further, those that were included were less likely to access formal health services due to their low economic status and so there is a lack of knowledge about access to and engagement with formal health services across the thesis.

iii) Withdrawing from study/discontinuing interview

Additionally, interviewing people with dementia who appeared to have more advanced dementia dropped out of the study as they were not able to consent to be interviewed. Mansa, for instance, started the interview but became upset and distressed and discontinued approximately five minutes into the interview. Mansa provided consent for the data from the short segment of the interview she undertook.

A number of prayer camps visited also refused to take part. It transpired that the government of Ghana at the time had embarked on reviewing prayer camps' activities owing to some human rights concerns or abuses that were reported to be going on in some of the prayer camps. As a result, some prayer camps suspected me to be an agent of the government and so did not want to be interviewed.

5.10: Summary

This study has used semi-structured interviews and focus group discussion techniques. Combining these two interviewing techniques is a particular strength of the study, as the sample designed through them captured as wide a range of experiences of people with dementia and their paid and unpaid carers as possible. While there were problems of participants either withdrawing from the study, stopping the interview a few minutes after its commencement, or prospective participants refusing to take part, the amount of data collected through these approaches enabled me to gain access to rich sources of information regarding participants' lived experience of dementia.

Some reflections

Under this section, I discuss some ethical, reflexive and translational concerns faced in this study.

i) Ethical issues

It is important to consider concerns that arose from the study which aimed at people with dementia and their carers narrating their stories about the illness – how to live with or care for someone with dementia. Telling stories about people's personal lives can and did cause some psychological or emotional harm to participants due in part to the sensitive nature of such stories. Interviewing or accessing participants' views on such emotive subject can often be a distressing experience. Most people with dementia and their family carers found accessing such deeply personal information to be distressing, with some even becoming tearful and upset during interviews. I found some of these difficult to deal with myself. One person with dementia, who found the narrative of her experience to be too upsetting, discontinued the interview. The person with dementia in question and their family were offered support and were signposted to services if they needed further emotional support.

ii) Reflexive

Undertaking this research, including writing up the thesis, has indeed been a journey of learning and 'discovery' for me. In the introductory chapter, I discussed that Ghana has wide linguistic and cultural diversities and this can make it difficult for outsiders to value and understand its cultural practices. However, considering myself as an insider, my understanding, cultural awareness and the sensitivity of the local issues impacted on my communication and interaction with participants. This was made easier as I shared a similar culture with the study participants. As an insider doing research with a study group to whom I belong, I had the advantage of being able to use the knowledge of the participants to gain more intimate insights into their opinions and views on living with dementia in Ghana. I understood participants' colloquialisms, idiomatic expressions and non-verbal communication cues, especially body language, gestures and some facial expressions. These understandings were due to my foreknowledge of the Ghanaian culture. Further, my status as an insider was helpful in overcoming some of the difficulties that arose from both verbal and non-verbal communication practices. For instance, it was relatively easier to communicate effectively with the research participants in terms of interpretating their speech, tone, body language, facial expressions, gestures and assumptions shared by participants regarding the context and purpose of the study (Abugre, 2018). Some of the gestures, for instance, would have been difficult for a non-Ghanaian researcher to have comprehended. Despite perceiving myself as an insider, my dilemma was that if I gave in too much to the culture, for instance beliefs around witchcraft and madness as causality of dementia, I would lose credibility with the source culture. Achieving a balance was, therefore, a very difficult and challenging thing for me.

In many respects, I considered myself an outsider as I did not particularly feel I belonged to the participant groups I interviewed, neither did some of the participants perceive me as an insider. My position as a doctoral candidate and an outsider appeared somewhat suspicious to some of the prayer camp staff. For instance, one of the prayer camp staff perceived me as an ‘information seeker’ who wanted to gather information for the government, which was at the time investigating some of the prayer camps’ activities in the country. However, other participants respected my status as an outsider and treated me as such. For instance, while all participants were made aware of their rights to withdraw from the interview at any point, some felt it was disrespectful for them to do that to someone coming from abroad to undertake such a project.

I was also mindful of my reasons and aspirations for carrying out the study. It became clear to me during the interviews with people with dementia and their family carers that issues regarding privacy and confidentiality were arguably Western concepts that have a different cultural meaning within the Ghanaian society. For instance, some participants apparently waived these rights by allowing other family members to be near them so that they could hear whatever was being discussed without questioning. It was, however, difficult to gauge how receptive some participants with dementia would have been to the study in the absence of their family members given the communal nature of Ghanaian culture. It was, therefore, questionable whether these Western socio-cultural moral constructs fit in within the Ghanaian cultures since the beliefs, ethical values and cultural norms differed significantly. This was most noticeable when considering the requirements for informed consent, namely disclosure, privacy, confidentiality and autonomy. Matters of privacy, confidentiality and autonomy in cross-cultural research such as this can be complex. This, therefore, raises the question of whether ethical principles are universal across cultural groups, or whether they are relative to a particular setting or culture. As indicated above, most participants believed that withdrawing from the research study would indicate being disrespectful to me, and so did not think it was a good idea to end their participation without informing me of their reason(s) for doing so.

iii) Translational issues

It is also important to discuss the translational issues that arose from the study. I kept a reflective journal throughout the fieldwork. As I wrote my reflective journal, I took note of some words and issues of translation that I would face during the translation process. I reflected on and analysed the data in the reflective journal by self-examination based on my thoughts and actions as a researcher.

I present here some of the challenges I faced translating the research data from one language (Twi) to another (English). Reflecting on this, I think of the process as multi-layered, complex and problematic (Xian, 2008). As shown above, 29 participants were interviewed in Twi, while the remaining 17 participants could speak Twi well along with English. As I am fluent in both Twi and English languages, I had assumed that translating the data from Twi to English would be a simple procedure. However, my assumption soon faded when I started to engage in the process.

I played several roles here – as a researcher/translator and interpreter, which I found to be an advantage as I did not have to hire the services of translators (and/or interpreters during fieldwork). Thus, many researchers who cannot speak the language of the research participants would have hired interpreters or translators. As Temple (2005) identified, some researchers tend to ignore study participants who do not speak English; however, this can be marginalising and discriminatory. Participants were allowed to use any language, as long as they were able to tell stories of their experience and make meaning out of them and were comfortable and confident in doing so.

Some Twi words did not have a close equivalent in English; therefore, to capture and represent the meaning became an ongoing problem. I felt that the translation was 'almost accurate' in representation if the meaning was conveyed from the perspective of the participants. As a researcher, I had learnt that I had to continuously look for threads that would help me understand the participants' stories and how they could be situated in their local contexts. I had to constantly make decisions about the cultural meanings that language carries and evaluate the degree to which the two different worlds were the same (Xian, 2008). If words were translated literally, they would become meaningless; hence, a lot of thinking was involved to situate the words in a way that would be comprehensible to international readers. As suggested by Xian (2008), I focused on contextual meaning rather than verbal meaning and took a 'meaning-based approach' to translation (Marschan-Piekkari and Reis 2004). This approach was employed so that the stories told and interpreted by the participants in Twi were embedded in the social reality in which they lived their lives. Therefore, the construction of stories and their translations in English was a joint construction.

Chapter 6: Pen Pictures

6.1: Introduction

In this chapter I introduce the participants I interviewed and details of the nature and characteristics of people with dementia, their family carers and their family relationships. Details of prayer camp staff and healthcare professionals are also provided. I have provided a table detailing the number of participants in the study, their roles and experience of working with dementia in chapter 5. The chapter concludes with brief information of the two prayer camps that took part in the study and some reflections from fieldwork.

6.1.1. People with dementia and their carers

This section provides details of people with dementia and their relationships with their family carers, the length of time of their diagnosis, who provided care to people with dementia and whether or not they were receiving any treatment following their dementia diagnosis.

6.1.2. Emma and her carers - Danny, Joymo and Xiana

Emma was an 80-year-old woman with vascular dementia. Emma's dementia symptoms started to appear in 2013, three years after suffering a mini stroke. She lived at home with her full time, paid carer, Xiana and her unpaid carer and grandson, Danny. She was also cared for by her daughter Joymo who lived nearby and was in frequent contact, visiting most days and calling her regularly if she could not visit. Danny was Joymo's son. Xiana helped Joymo and Danny with their general care duties.

Emma was aware that her memory was declining, and this was affecting her relationships. She could no longer remember her grandson Danny's name or how he related to her. Emma frequently experienced visual and auditory hallucinations. She claimed to be hearing or seeing people in her room who were not there. She was incontinent which she regarded as a big problem. Joymo often took Emma to her hospital appointments including monthly health reviews.

6.1.3. Simon and his carers - Tomadze and Tinaboa

Simon was a 73-year-old pensioner with Alzheimer's dementia. He had suffered dementia for 3 years. Simon lived at home with his younger son Tomadze, daughter-in-law Tinaboa and her husband. Tinaboa was Simon's older son's wife. Noting the difficulties caused by his dementia, Simon tried to be mindful of his increasing forgetfulness by giving up the responsibility for collecting his pension from the bank to Tomadze. Simon was receiving treatment from the psychiatric hospital. Simon forgot his relationship with Tomadze and often referred to him as his (Simon) younger brother.

Tomadze was Simon's main carer and cared for Simon full time. He was assisted by Tinaboa. Simon was often locked up in the room by his family who feared that he would get lost if he went out. However, Simon felt he could find his way back home if he did go out walking on his own and asked to be set 'free'. There was tension between Simon and his family as a result.

6.1.4. Adjoa and her carers – Marygya and Rosemary

Adjoa was 65 years old and had suffered vascular dementia for 6 years. She previously lived in the UK with her partner but was brought to Ghana after developing dementia. In Ghana, Adjoa lived with her daughter Rosemary and her husband. Rosemary was Adjoa's main carer. She worked full time and was available mostly in the evenings and at weekends. Adjoa's sister Marygya lived many miles away but visited almost every day to provide care during the day. She often took Adjoa for her hospital appointments and monthly health reviews.

6.1.5. Mag and carer Geo

Suffering vascular dementia for 3 years, Mag was diagnosed with dementia at the age of 57 years. She was a divorcee and a mother of four. She lived at home with her son, Geo who was her main carer. A petty trader selling different things in the local market, Mag stopped working as she was becoming increasingly forgetful and was losing money from the daily sales due to her dementia. Consequently. Mag's family asked her to 'retire' from working. Mag suffered a mini stroke before she was diagnosed with dementia. The stroke affected her speech and mobility. She became more forgetful and could not remember some of her friends' names.

Mag also had a history of experiencing bodily sensations and ‘turning and twisting’ which was believed to be associated with evil spirits. Mag’s family stopped visiting or calling her since developing dementia. She received treatment from the psychiatric hospital. She was meant to go for a monthly health review; however, she was apprehensive of this and so attended two-monthly. Her family would buy her medication from the local pharmacies on months she did not attend her monthly review.

6.1.6. MayLiz and carer Lizzy

A 69-year-old MayLiz had a diagnosis of vascular dementia and had lived with it for 5 years at the time of the interview. She lived at home with her husband in the village where they farmed. She had some insight into her condition. She realised that her dementia had affected her relationship and communication with her husband. She was a mother of eight children. Enjoying her work as a seamstress and second-hand clothes seller, MayLiz gave up work following her dementia as she was becoming increasingly forgetful and finding it difficult to sew for her customers. MayLiz was receiving treatment and consistently attended her monthly health reviews. Lizzy supported MayLiz to attend these appointments.

Lizzy was MayLiz’s daughter and main carer. She spoke about some tensions in the family following Mayliz’s diagnosis of dementia. She shared that her siblings would neither answer her phone calls nor visit their mother even when she came to Accra where most of them lived. This was due in part to their perception about people with dementia being witches.

6.1.7. Ish and carer Bea

Bea was the main carer for her father Ish. She worked full time and was assisted in caring for Ish by her two siblings and mother with whom she lived at home. Ish was a 60-year-old man with Alzheimer’s dementia. He had lived with dementia for 5 years. He withdrew from the study.

6.1.8: Gladys and her carer, Esi

Gladys was 58 years old when she was diagnosed with an unspecified dementia. She had been diagnosed with dementia 2 years prior to her interview. A mother of four, Gladys worked as a seamstress and petty trader selling some second-hand goods until developing dementia in her late 50s. In addition, and likely related to her dementia, Gladys suffered auditory hallucination claiming to be hearing voices of people who were not there threatening to harm her. Gladys would leave the house when she heard these voices.

At the time of the interview, Gladys had moved home from a village to join her family and was seeking to start a new life in Accra. While in Accra, Gladys lived with her daughter Esi who was her main carer. Gladys attended church and would never miss her monthly health reviews.

6.1.9. Max and carer Gracem

Gracem was a pensioner and main carer for her husband, Max. She lived at home together with Max and their youngest daughter. The couple had 10 children. Gracem ran her own business in town but gave up her job to take up full-time unpaid job caring for Max. Diagnosed with vascular dementia, Max was 85 years old. He had lived with dementia for approximately 8 years at the time of the interview. He was receiving treatment and attended monthly health reviews at the hospital. He withdrew from the interview.

6.1.10. Mansa and carers - Sarasa & Maryako

Mansa was 65-year-old lady with dementia. She had lived with dementia for 4 years. She lived at home with Sarasa and her children. Mansa neither recognised where she lived nor her grandchildren and often accused them of theft. Mansa was a petty trader and seamstress but gave up work due to her dementia.

Mansa was a mother of five children (all girls) three of whom died suddenly. Mansa was cared for by her two surviving adult children, Sarasa and Maryako. Sarasa was the younger of the two surviving children of Mansa. Maryako lived away but visited Mansa regularly to provide care and support. Mansa was receiving treatment and attended monthly health reviews at the hospital.

6.1.11. Aggie and carers – Pepdon and Irenekor

Pepdon and Irenekor were the main carers for their 58-year-old mother Aggie. Aggie had suffered (unspecified) dementia for 3 years. She was a divorcee and a mother of four. Aggie's family initially sought help from a prayer camp before she was formally diagnosed with dementia. Aggie also suffered bouts of incontinence in addition to her dementia. She withdrew from the interview.

6.2: Dementia care workers / sites in Ghana

This section discusses the two key institutions – prayer camp and psychiatric hospitals in which people with dementia were cared for by paid professionals. The details of staff at the psychiatric hospitals and the prayer camps are described in tables 5.3 and 5.4 in chapter 5 above. In both prayer camps I was able to engage with spiritual staff and care staff. However, the pen pictures of the prayer camp staff were not included in this chapter due to concerns around anonymity. Similarly, I engaged with both junior and senior members of staff at the psychiatric hospitals.

6.2.1 The Prayer Camps

The two prayer camps MPC and ƆPC took part in the study. MPC was headed by a prophet while ƆPC was headed by a prophetess (female). A prophet / prophetess is an individual believed to be supernaturally equipped to communicate the mind, will and intentions of God as well as forewarn and offer guidance and / or directions to individuals or the church (Dominian, 1983). The prophets(ess) were assisted by carers who provided direct hands-on care and support to the people with dementia and people with similar psychiatric conditions.

Prayer camp support workers (carers)

The care support workers provided day-to-day, practical, hands-on tasks such as assisting residents with personal care including bathing, medication administration and feeding, especially those were unable to do so independently. They also ensured that people with dementia who were perceived to be violent or aggressive in their behaviours were chained for fear that they might harm themselves or others. Chaining was also used as a means of stopping people from absconding from the camps.

6.2.2 MPC

MPC is a Christian organisation whose mission is to “set free those held in captive by Satan through a ministry of fasting and prayer”. It is located in the rural area of the ER of Ghana. It is about an hour’s drive from Accra. People with all kinds of medical conditions and different socio-cultural backgrounds could go there to rekindle their relationship with God, often through fasting and prayers or Bible study. While people could go there on their own, others could be sent there by their friends or relatives to seek cure / healing from the spiritual leader of the camp for illnesses believed to be physical or spiritual in origin. As such, while the camp primarily served religious functions, they fulfil a number of care functions for people living with conditions like dementia.

MPC is a community in itself. The camp has a prophet who has his own villa. In addition, there are several residential facilities which house the support staff, residents and others who would require accommodation on a short, medium or long stay basis depending on the length of time required to address their issues for which they attended the camp. This can range from an overnight, a week, fortnight, month or could even be years (Ofori-Atta *et al.*, 2018).

MPC was headed by a prophet who gave approval for the focus group discussion to take place. However, he himself did not take part in the study.

6.2.3: ƆPC

Located in the Achimota Forest in Accra, ƆPC was one of the two prayer camps which took part in the study. The Achimota Forest houses several prayer centres and people visit the forest daily for prayers. ƆPC initially had residential facilities for people with dementia and other psychiatric illnesses and others who needed various forms of support. However, most of the residential facilities had just been demolished by the government at the time of the interview as ƆPC had allegedly encroached on the government's reserved forest land, ƆPC was left with only a small housing facility where the prophetess and her support staff lived. ƆPC was therefore operating an 'open door system' where people could come and go as and when they wished. At the time of the interview, ƆPC had no residents on site but they had prior experience of working with and caring for people with dementia and other psychiatric conditions. Thus, people with psychiatric and other chronic illnesses and their families were coming for prayers and returning home on the same day.

6.3 The Psychiatric Hospitals

As indicated in earlier section, both PH1 and PH2 are located in Accra. Both hospitals were interviewed to gain information on dementia, staff experience of working with families with people with dementia and the challenges the dementia and mental health system face. The hospitals offer in-patient and outpatient services, limited counselling and therapy and clinical training for doctors, psychologists and psychiatric nurses. Additionally, they offer primary health care, reproductive and child health services and HIV counselling services (Fournier, 2011).

Chapter 7. Findings 1- The lived experience of dementia in Ghana

7.1. Introduction to findings chapter

Like many chronic diseases, dementia alters people's embodiment, their experience of the lived body and its place within their lifeworld (Benner, 2000; Crossley, 2007). Dementia leads to changes in people's sense of the lived body (Toombs, 1988, 1995b; Phinney and Chesla, 2003). This first of the findings chapters examines how the symptoms of dementia disrupted the lived body of those affected by the condition and, in so doing, brought the body into conscious reflection (Leder, 1990; Crossley, 2007; Carel, 2011).

Findings from this study show that people with dementia experienced memory loss, which caused a variety of difficulties within their lifeworld. Three phenomena in which changes to the lived body were experienced are discussed. Firstly, the lived experience of forgetfulness is not just a cognitive symptom; its highly disruptive lived experience, ranging from people with dementia forgetting names of people, places, events/rituals among others, is discussed. Secondly, how people with dementia experienced disruptions to a range of specific biological or bodily functions resulting from the disease, which are highly visible in rendering the lived body visible in dementia, are discussed. Thirdly, people with dementia experiencing the world as becoming confusing, frightening and distressing through hallucination and other distressing experiences, and all experiences which fundamentally alter the ability to perceive and experience the world, is discussed. In sum, these will illustrate how the lived body changes for people with dementia in Ghana.

The first master theme considers the lived experience of forgetting, and three different dimensions of forgetfulness and its impacts on people's embodiment emerge: forgetting/hiding/losing things, forgetting people and their relationships, and losing skills. The second master theme, namely failing biological or bodily functions, discusses the failing physiological body through changes in two key biological/bodily functions – the lived experience of incontinence and the body becoming an increasing barrier to activities. The third master theme, namely experiencing dementia as a form of sensory disturbance, discusses how people with dementia

come to experience the changing world as it presents to their sensations – hallucinations leading to people becoming frightened, distressed and confused.
I draw on the interview data from all the different groups of participants to illustrate the points raised in the findings chapters. The chapter will be concluded by summarising how these various themes contribute to the experience of the lived body in dementia in Ghana.

7.1.1 Master theme 1: Lived experience of forgetting

Forgetfulness is a common experience in life and has many expressions and even more causes (Ballard, 2010). As Patil (2021) maintains, people forget if they permanently or temporarily lose their ability to recall or recognise something learnt earlier. This master theme is about the lived experience of forgetfulness; forgetting things, places, people and how to do things; and how these were manifested in their everyday life. Drawing on data from the interviews, this master theme illustrates these different dimensions of forgetfulness.

7.1.2. Sub-theme 1: Forgetting/losing/hiding things

This theme talks about people with dementia forgetting/losing/hiding things including facts, rituals, information and words. People with dementia forgot what these things were and where they were. When participants were asked to describe their experiences of forgetting, several of them told stories about what it was like at the beginning, when they first noticed that something was wrong with their own memory or their relative with dementia’s memory.

Reflecting on her experience of forgetting, MayLiz talked about losing her memory as she was no longer remembering things, as illustrated in the following statement:

As for me, I am becoming increasingly forgetful. Sometimes, I would be holding my phone (in my hand) and will be looking for it at the same time. I’ll keep looking for it until someone tells me “Is that not what you are holding” before I realised or come back to my senses.

Similarly, Emma recalled having difficulties or troubles remembering and finding things after putting them somewhere. She states:

As for my memory, it's not quite right. I may put or hide my shoes somewhere and will be looking for them – then it becomes a case. Little, little things like that.

Both MayLiz and Emma acknowledged that their memories were declining as they were becoming more forgetful. They realised that they were not remembering simple things that they would have required no effort to remember prior to developing dementia. They noted that some information about things was not always available to them. Here, both the phone and the shoes disappeared from MayLiz and Emma's conscious perception as they forgot what and where these objects were, as well as what their purposes were. Thus, the phone and the shoes ceased to be 'ready to hand' and became 'present to hand'. The phone and the shoes revealed themselves to MayLiz and Emma through their strangeness.

Gladys also talked about her experience of becoming increasingly forgetful in this statement:

I have become more forgetful now. But I don't have to worry about it so much so that I'd begin to think I can no longer live in this world or life is no longer worth living, that I am worthless or something like that. No, it shouldn't be like that. I have to encourage myself and know that in all things God is able.

Gladys acknowledged being forgetful, but her experience of forgetfulness differed from other participants with dementia. While most people with dementia, including Gladys, admitted to having impaired memories, she claimed that she was not all that forgetful because God reminded her of things and so did not forget as much. She had a positive outlook and was hopeful and believed that God could do the unexpected thing in her life by improving her deteriorating memory. She remarked:

He (God) is my reminder and reminds me of things, so I don't forget too much. All the time, He causes me to remember what I would need to know, or I want to remember.

Gladys' comments suggest that she was hopeful that her deteriorating memory would improve. In addition to forgetting names of people, places, events and date of birth, most people with dementia I interviewed lost or hid items and, in some cases, struggled to locate or remember where they put them.

Another carer, Bea, spoke about her father, Ish, forgetting words and rituals during her wedding ceremony. She stated:

I think it (dementia) started on the day I was having my wedding, that was 2014. But then we didn't know what was actually wrong because, you know, when you take the bride to the church, they would ask you, the father, who brought her here? Who gave her to this man (bridegroom)? And the type of answers he gave, everybody was like Ah! All of us were like, we didn't know what actually the problem was! I think that was the first time the problem started but we didn't know. So, it was later on we realised that was the problem with him.

She explained that Ish forgot the correct words to use to respond appropriately to questions posed him during her wedding. As the father of the bride, Ish forgot his role and the rituals he needed to perform on that day as the tradition demanded of him. He neither recalled what he was supposed to say and say it appropriately, nor the ritual fathers perform when giving their daughter out in marriage. Forgetting what to say or do on such occasion made people question Ish's memory. This shows that forgetting has wider social consequences to include family rituals, such as a wedding as in Ish's case. This demonstrates that forgetting is more than just recall. It is also about forgetting social structures, concepts and expectations. Ish's family sought medical help after the event. What was common about forgetfulness was the participants' realisation that people with dementia were forgetting, but this was more than just forgetfulness in the everyday sense of the word forgetting. Forgetfulness was understood as becoming a problem.

Simon, a 73-year-old man, also admitted to forgetting things. He explained:

Oh! boss actually, as for forgetfulness, it's everywhere. I can't deny that I don't forget things. Even you yourself, you do forget, so, that one if they are telling you that I am insane or trying to disgrace me with it, I'm not accepting it. Me, I'm not mad.

Simon admitted to being forgetful. However, the quotation presented above demonstrates his resistance to being labelled by his family as a ‘mad’ person, something he clearly refused to accept. Explaining his forgetfulness, his son Tomadze shared that Simon was evicted from his previous house, which is the reason why they took him into their family home. However, he (Simon) had forgotten about it. Tomadze expressed:

We got a call that his landlord had evicted him. He had overstayed there, but the day we brought him here, he himself was intoxicated so he did not know what happened. He was sleeping in front of someone’s house (at the gate) when we went to collect him.

Tomadze explained the circumstances around Simon’s eviction to include his dementia, forgetful and drinking behaviours. He went on to say that Simon was still going to sleep in front of the house. Simon had forgotten that he had been evicted and was no longer living there but kept going there. Tomadze added:

We used to stop him from going there and kept reminding him that his landlord had evicted him, that’s why we had brought him here, so he shouldn’t go.

By moving from a familiar home environment to a new, unfamiliar home (son and family’s) might have caused Simon to lose emotional attachment of the familiarity of his old house. In addition to Simon forgetting that he was no longer living at his old address, Simon had also forgotten that he had retired and was a pensioner. He repeatedly said he was working and getting paid every month during the interview. He said:

I am still working. I work with GS Commission.

Simon authorised his son Tomadze to collect his pension from the bank on his behalf. He might have interpreted his monthly pension money to mean that he was still working and getting monthly salaries. In summary, this sub-theme has considered forgetfulness from different dimensions, including forgetting to remember where items were kept to forgetting events and rituals, among others.

7.1.3. Sub-theme 2: Forgetting places

As human beings, we continually dwell in the world of the familiar and the unfamiliar and remembering keeps us grounded in the familiar, which keeps us connected to our world (Parsons-Suhl *et al.*, 2008). However, most people with dementia can lose connection to what had been familiar places. This theme discusses people with dementia forgetting and losing connection with their worlds and getting lost as a result due to not being able to recognise familiar environments, including their homes.

Sarasa spoke about her mother Mansa not able to recognise their house after returning home following an outing. She stated:

Yesterday, for instance, we went out. When we came back, she was confused and could not recognise our house. She asked, 'Is this our house?' She will tell you, 'I don't even know where I am' and I would ask her 'Who am I to you? If you see me as your daughter, then you are in your daughter's house.'

Mansa lost her sense of direction and connection of relationship with her environment. She lost the cherished and emotional attachment of the home and the community due to being forgetful and confused. Non-recognition of the house due to forgetfulness led to Mansa getting lost at times. While Mansa might have found her experience of forgetfulness to be frustrating, her family were worried about leaving Mansa on her own as they feared she might get lost.

Similarly, Gracem shared her experience of Max getting lost in the community when out and about on his own. She informed:

Sometimes he goes out and doesn't come back home. Last time, he got lost at Community 1 (one of the suburbs in the city where he lived). Some people were reporting that someone went out and is lost and that they had found him.

Both Max and Mansa were reportedly found to be roaming about in the community without them knowing where they were or where they were going to. Losing their sense of "being-at-home and being in-the-community" (Cristoforetti *et al.*, 2011; Mahomed and Pretorius, 2022), both Mansa and Max got lost in their respective communities that had been shaped over time. This suggests that Mansa and Max might have lost their sense of connectedness to the places that were known to them. Thus, places which should have been very familiar to them became unfamiliar due to dementia. Forgetting where Max and Mansa lived meant that the world around them had become so unfamiliar that they were neither able to recognise nor recall the environmental cues or landmarks necessary to help them locate their houses. Mansa did not only forget where she lived, she also could not recall the name of the town where her grandson lived. Maryako shared:

She (Mansa) said she was going to her grandson in the village. Her grandson actually lives in a different town, but she could not remember the name of that village, but she had lived in that village before.

Mansa decided to visit her grandson in the village where both of them previously lived. She forgot the name of the village. She had also forgotten that her grandson had moved out of the village. Mansa could not recall the name of the village where her grandson was currently living and so mentioned the name of a different village to the driver. She was taken to a wrong village or destination and could not find her grandson as a result. She eventually got lost. Maryako explained:

The driver took her round the whole village but could not find him (grandson) and so took her back to a Radio Station in Accra to report her missing. We went to collect her after hearing the announcement.

Mansa forgot the period of time when her grandson used to live in the village where they both lived. She was supposed to be familiar with the town as she herself had lived there before, but appeared to have found herself in an unfamiliar environment due to dementia. As she appeared frustrated and confused, the driver took her back to a radio station in Accra, where she was reported missing. Mansa's family upon hearing the announcement went to collect her.

Mansa and Max's families provided them with round-the-clock support and supervision to minimise the risk of them getting lost again in the future. Gracem explained:

Sometimes, I would want to go somewhere but cannot leave him on his own. Sometimes, when I travel, I am not here physically but all my mind will be at home. I keep asking myself, is the man there? Is he at home? Is he lost? Or what?

While Mansa’s family ensured there was someone there to supervise her at all times, Max’s family took turns to look after him or would lock him up on occasion when no one was available to look after him.

In summary, forgetting places was one of the dimensions of forgetfulness, which resulted in people with dementia not remembering where they lived or had lived before and getting lost as a consequence. In some cases, carers of people with dementia imposed restrictions on their relative with dementia, by either providing them with a 24-hour care or locking them up in the house due to the fear of people with dementia getting lost if allowed out on their own. This restricted people with dementia’s use of space both physically and socially, resulting in them becoming socially isolated and lonely.

7.1.4. Sub-theme 3: Forgetting the world of tasks – losing skills

Some participants reported that the beginning of their experience of dementia was marked by the awareness that people with dementia were no longer remembering to do a wide range of tasks and activities. Eventually, this included some basic, everyday activities such as bathing, brushing teeth, going for shopping or preparing a meal, all of which were part of their daily routine.

Irene, a carer, talked about her experience of Aggie losing her ability to take a bath or brushing her teeth:

Sometimes, when you take her to the bathroom to assist her bathe, you tell her to bathe, and she can't bathe herself. I have to bathe her because she can't bathe herself properly. Even if you tell her to brush her teeth, she will hold the brush, put it in her mouth, will be standing there and wouldn’t know what to do. Sometimes, I have to take the brush from her and demonstrate to her how to brush her teeth before she can remember and then start doing it herself.

Like most participants with dementia, Aggie once did these activities without having to stop and think about them beforehand. However, when she began forgetting to do these everyday taken-for-granted activities and when this happened on more than one occasion, her family became conscious of the fact that something was wrong.

Maryako also spoke about Mansa losing her ability to shop independently in the following statement:

At the beginning (of her dementia), she could go to the shop but would forget what she wanted to buy when she got there. She would be standing there and if they asked her what she wanted she was unable to tell them. The shop assistant would repeatedly ask her, "Auntie, what do you want to buy?" but she would be unable to say and leave and come home – forgot about the things she wanted to buy and what they are for. Consequently, Mansa would come home with nothing.

A petty trader, Mansa forgot her shopping – buying and selling skills. She could not recall what item(s) she wanted to buy when she went to the shop. She would then leave the shop, come home empty-handed and tell her family that she had forgotten what she wanted to buy, as per Maryako's quote below:

When she comes (home), she would tell me, Afua, when they asked me what I was there to buy I couldn't tell them and because I (Maryako) didn't want that to continue, I would tell her, "Mama, when you go tell them you want to buy, say tomatoes." Once I have told her that, she would then go back and buy it.

Once prompted, Mansa would return to the shop, but this time would remember exactly what item(s) she wanted to buy. On other occasions, Mansa would forget to take her change after paying for items. Maryako shared:

If she went to buy something from the shop, she was not taking her change (balance). Some of the people (shop assistants) were giving her back her change but others wouldn't.

Money is an element of people's everyday experience that became increasingly difficult to manage. Due to forgetfulness, Mansa was neither able to identify nor recognise the local currency and its value, as indicated in Maryako’s statement below:

“How much money is this?” and I (Maryako) said “Eh auntie, don’t you know what this is or recognise how much is this?” So, I started taking her through the currency all over again.

Mansa gave up her job as a petty trader due to not being able to transact business due in part to being forgetful and losing her concept of money, an activity that she once took for granted. By losing her ability to handle money and transacting business, this was one way by which Mansa lost her taken-for-granted ways of interacting with her world.

Another participant, MayLiz, who prided herself in her ability to sew and work for long hours, gave up her jobs as a seamstress following her dementia. She explained:

Just before the illness I could work for long hours, especially around Christmas. I could work from morning till cock crow. I would go to bed for a few hours and then start again in the morning because everyone needed their clothes for the Christmas.

Both MayLiz and her family realised that she was struggling to sew for her customers. She and her family saw her as changing, but they were not sure what was causing this. MayLiz was no longer able to do things the same way as she used to. Consequently, her family asked her to stop her job as a seamstress, which she did.

Similarly, Ish lost his abilities and skills in carrying out his job as a secretary, which was once a taken-for-granted activity. Describing him as the family’s secretary as he often used the typewriting machine to do some administrative works that the family needed, Bea explained:

Before we saw it became serious, if you gave him an application letter, he would write it for you; resignation or excuse letter, he would write it for you. He had been writing our letters for us. So, when we started monitoring him and we saw when you *give him a letter to write and he can't write, I said hmm, things are not right. He can't remember any more. He said "Ah, how can I write it?"*

Ish's family identified that something was wrong with him due to his inability to undertake one of his once taken-for-granted activities – typing, using the typewriting machine. Not only was Ish not able to use the typewriting machine, but he did not recognise it, its purpose and its usage. Thus, the typewriting machine, as an example of a routine object, ceased to be ready-to-hand and, instead, it became present-to-hand, visible because of its sudden unfamiliarity.

Summarily, memories for the above-discussed participants – Aggie, Mansa, MayLiz and Ish – were unreliable, as the participants were no longer able to engage in everyday, mundane tasks such as shopping, brushing teeth or using the typewriter independently and without help from others.

7.1.5. Sub-theme 4: Forgetting people

People with dementia did not only forget things, name of things or skills in doing things, they also forgot people, as well as what their relationships with others were. This theme, namely forgetting people, discusses the dimensions through which people with dementia forgot people, from forgetting names of people to forgetting who they were and what their relationships with others were. Relating to forgetting names of people, Emma and Simon could neither remember the names nor what the relationship they had with their family carers were. When Emma was asked who Danny was and what relationship she had with him was, she replied:

That's my daughter Joymo, but as for this one (pointed to Danny) I don't know him. When I came to this house he was already here. Didn't I come to meet you?

In contrast, Simon recognised Tomadze as a member of his family but as a brother rather than a son, as illustrated in this quote:

When I came (referring to the day he moved in with his sons and family) I met this young boy who is my junior brother.

Both Emma and Simon's ability to remain connected to their families, as they had always been, was challenged by their inability to remember the relationships they had with their family carers, Danny and Tomadze, respectively. Emma seemed to have recognised her grandson and carer Danny, but as a 'stranger', someone whom she only met in the house when she moved in. However, for Simon, Tomadze was a family member, a brother but not a son. Forgetting was not just about forgetting the names of Danny and Tomadze, it was also about forgetting who they were as people and the magnitude of this – what it meant for Danny and Tomadze to suddenly become unfamiliar to Emma and Simon, respectively. For Emma, Danny was not her grandson anymore, he was a stranger. For Simon, Tomadze was a brother, but not a son anymore. The magnitude of these changes was a central disruption to Emma and Simon's lifeworld.

Becoming carers meant that both the leisure and work patterns of Danny and Tomadze were affected by Emma and Simon's behaviour and daily care, which may have affected Danny and Tomadze's everyday routines as well as the families'. As carers, Danny and Tomadze juggled their caring roles with other responsibilities, including paid work. Thus, both Danny and Tomadze and Emma and Simon may have to adapt to more changes in their lives following their dementia.

Apart from forgetting names and relationships, people with dementia also forgot about the bodily cues such as the voice of people who were familiar to them. Bea cited an example where Ish could not recognise the voice of people who were familiar to him. She explained:

When someone called him (Ish), the people he used to call every day, he would now ask "Please who is this? Can you please remind me who you are? I've forgotten, please who is this?" But these people always called him, but when it (forgetfulness) became a little bit serious, the same voice would call him, and he would ask "Who am I talking to?"

Bea noticed that Ish was becoming more forgetful, as he repeatedly asked people who were familiar to him to tell him their names when they called him. Remembering the names and voices of close relatives and others was a struggle for Ish and this was no longer Ish's everyday tip-of-the-tongue experience. Ish now required prompting to either remember the names or recognise voices of people he knew well before developing dementia.

7.1.6 Summary of master theme

It was apparent from the data that people with dementia had different experiences of forgetfulness. These ranged from forgetting their relations with others, places where they lived, how to undertake some activities of daily living, what objects were, where they were or what they were used for. Thus, memory loss caused disruptions to people with dementia’s taken-for-granted, practical, everyday activity of remembering. Thus, remembering what was once automatic for people with dementia did not occur as it once did. Instead, in dementia, people with dementia’s lived body and being-in-the-world changed as they had to think reflectively about remembering.

In conclusion, forgetting is more than just recall. It creates a profound disjuncture in the lived experience of dementia that prevents people with dementia’s taken-for-granted being-in-the-world. In dementia, people with dementia’s lifeworld became full of objects, people, places and events that were no longer recognisable for what they or their purposes were. Applying Heidegger’s crucial discovery of the hammer, the clothes, shoes and mobile phone discussed above, were no longer noticed or understood by people with dementia as clothes, shoes or mobile phone. Thus, their practical everyday activities ceased, and they were seen by people with dementia as “objects with isolable properties and characteristics” (Dotov *et al.*, 2010). People with dementia’s experience of the previously ready-to-hand entities – the clothes, shoes and mobile phone – changed and may have experienced them as failing to serve their function appropriately. People with dementia’s world, therefore, became full of confusion as the objects, spaces and relationships did not only become unfamiliar but also made no sense to them. The objects – clothes, shoes and mobile phone – no longer possessed a ready-to-hand orientation but disappeared from people with dementia’s conscious perceptions and revealed themselves to people with dementia through their strangeness as something that were merely there (Smythe and Spence, 2020). Forgetting, therefore, affected all the domains of people with dementia’s lifeworld and fundamentally disrupted their taken-for-granted mode of inhabiting it.

7.2. Master theme 2: Failing biological or bodily functions

The lived body experience of dementia is more than just memory. Dementia also causes bodily changes or dysfunctions in those affected by it. Dementia is not just a cognitive disorder – it also affects all aspects of the lived body. According to Drew Leder (1990), our bodies dys-appear in illness – that is to say, that our bodies fail us when we are experiencing pain, discomfort or disease. As a result, the body can be brought into relief as a conscious entity (Groven and Zeiler, 2018).

This theme sheds light on how the physiological bodily changes affected people with dementia's everyday experience of being-in-the-world, which was usually fraught with difficulty. It focuses on how changes to biological functions bring a person's dementia into relief by disrupting the physiological body's ability to inhabit the world. Some people with dementia were more aware of these bodily changes as their "*bodies were no longer normal*". How people with dementia experienced these biological/bodily changes and the impacts these had on their lived bodies following the illness are discussed in this section under two sub-themes: the lived bodily experience of incontinence (losing one's ability to control their bowel and/or bladder) and the lived body as a barrier to activities.

7.2.1. Sub-theme 1: The lived bodily experience of incontinence

Through dementia, people may lose their ability to control their bladder and bowel, resulting in incontinence (Cassells and Watt, 2003; Cole and Drennan, 2019), something which may have been a taken-for-granted skill prior to developing dementia. Incontinence is one of the dimensions in which the physical changes happening in dementia reveal themselves to people with dementia (Cole and Drennan, 2019). Prevalence figures of incontinence based on a summary of the current best evidence, published in the World Health Organization Second Consultation on Incontinence, estimated that between 10% and 40% of older women and between 6% and 20% of older men (over 65 years) living in the community have urinary incontinence (Hunskaar *et al.*, 2000). While age is not a causative factor of incontinence, both urinary and faecal incontinence have been found to be associated with ageing (Roe and Doll, 2000) and, subsequently, dementia (Cole and Drennan, 2019).

People affected by dementia may lose their ability to control their bladder and bowels leading to incontinence (Cole and Drennan, 2019). This sub-theme considers people with dementia's experience of incontinence resulting from dysfunctioning of their bodies due to dementia.

Emma and Aggie experienced incontinence. Emma had insight into her situation and expressed this in the quotation below:

My only thing (problem) is my illness. It is my only worry. Sometimes, I become urinary incontinent. I am ill. It's not normal. I am no longer normal. As for me I don't know but it isn't something I have experienced before. I think I need someone to check that for me.

Emma was aware she had lost control over her body through incontinence and expressed how worrying this experience was for her. However, Aggie had no insight into her incontinence. Irene shed light on how Aggie's bodily dysfunction manifested through incontinence. She explained:

Sometimes, if she (Aggie) wants to go to the toilet she can't or won't tell you. It doesn't matter whether it is day or night. She will defecate on herself, and you have to clean her up. She won't tell you if she wants to urinate.

Like Emma, Aggie now needed help initially with prompting and, later, physical assistance to use or go to the toilet in time to avoid becoming incontinent. Irene further shared that:

Sometimes, she may attempt to stand up and when you ask her, she won't say anything, before you realise, she has already urinated on herself. So, you have to ask her all the time whether she needs the toilet or something like that.

With incontinence, the daily living situations for both Emma and Aggie were uncertain. They could no longer trust their bodies' need for toileting as they could be incontinent at any time. Their bodies ceased to be absent, and their physiological functions were undependable as their bowels and bladders often gave way, resulting in incontinence, and they had to wear incontinent pads to reduce leakage for their dignity and self-respect. They may have found incontinence to be abnormal, socially unacceptable, disgraceful and stigmatising. They also became socially isolated, as their families were not taking them out socialising for fear that they could be incontinent at any time. Incontinence, thus, had a public consequence and this featured heavily as a disruptive lived experience for both Emma and Aggie. Thus, being incontinent appeared to have made their daily living situations uncertain and more difficult to plan, for instance they and their families needed to ensure that there were toilets wherever they planned to go.

In summary, dementia altered the physiological functions that are a necessary part of the lived body of people with dementia. Incontinence is one of the ways in which this occurred. In incontinence, people with dementia could not control their basic bodily functions and worried about it. Incontinence was experienced by people with dementia as a stigmatising condition affecting their interaction with others, for instance going out and socialising with others. It made people with dementia's body dysappear, because it meant they could not trust their own bodies and so had to manage it and worried about it because it was stigmatising to them.

7.2.2. Sub-theme 2: Changes to the body as a barrier to activity

As Bury puts it, in chronic illness such as dementia, the structures of people's everyday life and the forms of knowledge that underpin them, including the normal rules of reciprocity and mutual support, become disrupted (Bury, 1982). In everyday life, we often undertake activities of daily living such as walking, fetching water, using the toilet and many other activities or occupations pre-reflectively, without thinking about them (Phinney and Chesla, 2003a; Toombs, 1988). In dementia, people lose these physical capabilities and occupations, which alters their experience of living with the illness.

This sub-theme discusses how people with dementia's body became visible by not working properly in a variety of different forms of activity. People with dementia's body no longer did things as easily as they wanted it to. Rather, their body acted as an obstacle to their needs or wish to undertake activities in their taken-for-granted manner. The findings showed that some people with dementia's body was no longer able to do, or understand how to do, some basic everyday activities such as walking.

For instance, Mag, felt her *life was not like how it was before* because dementia had caused changes to her lived body. She explained:

Things have changed in my life. Things aren't like before. If I am walking, I tend to bend. Sometimes too I tend to twist round and round ("me twa me ho"). I also feel some numbness in my limbs. I get panic attacks with no apparent reasons. It appears there are some veils covering my eyes. My eyes aren't like they were before. I can see but can't see properly.

Walking as a basic task or taken-for-granted activity now faces challenges. Realising changes in her body through dementia, Mag was no longer able to walk upright; instead, she was bending and twisting when walking. Mag's lived body was no longer taken-for-granted as she took time and care when walking. She was observed to be pausing when talking during the interview. This suggests that Mag was perhaps trying to remember what to say, how to say it, or get the words she wanted to say right. This slowed down the flow of communication with Mag throughout the interview.

In her attempt to find meaning and make sense of her illness, Mag drew on her statement, *"I am not like how I was created by God anymore".* She suffered a stroke and was paralysed for a few months. Mag's functional abilities improved after a period of hospitalisation and she started walking again, albeit bending when walking.

Mag's sense-making and response to dementia (and stroke prior to this) was due in part to her cultural identity. In Ghana, like in other cultures across the world, people look askance at people with any form of disability. Mag previously walked upright to work and other places every day, undertaking mundane tasks such going to church. However, she lost her mobility and memory following the stroke and, subsequently, dementia. She realised that, in her belief, she was no longer the same person that God created. Her apparent disfigured body made her feel embarrassed as she simply lost her memory and upright posture when walking. With a decrease in her balance and confidence in walking, Mag felt her sense of embodiment had changed – her mobility had reduced and now she was walking more slowly than before. These changes in Mag's lived body affected her interests in and motivation to attend social events, or to socialise with others other than members of her household and her church community. Mag reported feeling unhappy and occasionally getting panic attacks as a result of her condition. She eloquently remarked:

When I sit down and reflect, I get worried that I am not like I was before. Some people grow old and would still be strong and healthy, but at the moment I am no longer able to go to the market or out with my friends. I am not happy because things have changed in my life and things aren't like before. I get panic attacks with no apparent reason.

Gladys also experienced similar changes to her lived body through felt sensation – bodily pain, feeling abnormal and feverish as exemplified in her statement below:

I noted something was wrong in my physical body. I would feel feverish and my whole body would be aching. I realised that my body was not functioning as well as before. That is still ongoing in my body. I can lie down quietly and wouldn't care about anything. I can be overly quiet. I don't feel like talking. I wouldn't bother about anything that goes on around me. It is unreal finding myself lying here all day. I myself understood what I was going through.

Gladys went on to explain her response to her altered lived bodily experience thus:

I wouldn't feel 'normal', that was why I went to PH2 (hospital) just to find out what was exactly causing that. I thought if they tested my blood and urine, the results could help the doctors find out what the cause of the illness was.

Gladys was aware that her body was changing and longed for the life that was being lost. She wanted her body to be functioning well, both physically and mentally. She wished to be able to live life as before (to be normal – to pre-reflectively inhabit the lifeworld, prior to the disruptions now being faced). However, the pain Gladys experienced overtook the bodily sensation and took her attention away from her world, as this shifted her focus inward toward the source of the pain. The pain destroyed Gladys' lifeworld. She would become weak, feel powerless and lack control and ability to act. With the pain, it became increasingly hard for Gladys to focus on anything else but the pain. She would not be her usual self. She would then want to lie down quietly and not care about anything. She concluded that her body was not '*normal*' as she felt a vague sense that her life was changing, but she struggles to understand/comprehend it. Gladys might have longed for the ability to, and thought about being able to, care for herself and other things around her, which would have, perhaps, hampered her in living a normal life.

i) Summary of theme

Dementia makes the lived body dysappear – it reveals itself both through its bodily dysfunctions and its ability to take part in habitual and taken-for-granted activities in the lifeworld. In dementia, the body loses self and agency as it can no longer do things. People with dementia lost their ability to complete everyday tasks and were reliant on others for help to accomplish most activities of daily living.

With dementia, some objects – clothes, shoes and, mobile phone – became unrecognisable and were no longer presented to people with dementia as clothes or mobile phone. In people with dementia's perceptions, these items appeared to be foreign objects, as they couldn't recognise them for what they were or their purpose. In Heidegger's terms, these objects were no longer ready-to-hand; rather, they had become present-to-hand, as their ready-to-hand orientation to people with dementia had been destroyed in dementia.

7.3 Master theme 3: Experiencing dementia as a form of sensory disturbance – seeing and voice-hearing

This master theme discusses changes that are caused to people with dementia's sensory bodies and their understanding of the world as it presents to their perception of it. Hallucinations are false perceptions experienced in the absence of external sensory stimuli (Abdelsalam, 2017, p 122). They are extremely complex and individualised experiences that are not always pathologic and may involve visual (seeing), auditory (hearing), tactile and somatic sensations (Scarmeas *et al.*, 2005; Renouf *et al.*, 2018). However, this theme focuses on visual and auditory hallucinations as these were the common ones reported by study participants. Burns *et al.* (1990) provided distinction between auditory and visual hallucinations.

With visual hallucinations, people experiencing them report seeing something or someone in the absence of an external stimulus, or they may be observed to be interacting with a non-existent person or object. In contrast, people report hearing voices in the absence of an external stimulus, or they may be observed to be clearly engaging in a dialogue while no one else is present in the case of auditory hallucinations (p 77). Hallucinations are often associated with people with dementia (Haddad and Benbow, 1992; Scarmeas *et al.*, 2005; Renouf *et al.*, 2018) and other psychiatric conditions.

Findings showed that some people with dementia experienced distorted visual and auditory hallucinations as part of the lived bodily experience of dementia. Gladys and Emma experienced seeing things and hearing voices as part of their dementia symptoms. Gladys shared her experience of hearing voices in the following statement:

As for the challenges I am going through, I can hear some voices in my ears. Sometimes, I hear a voice saying to me, "you will die, you will die". Other times I'd hear something like, "something is happening, something is happening, ehhee!" That is the voice that I often hear. Sometimes too, something will tell me, I will kill you, I will kill you! but I have to rebuke that because some of the voices like this I don't accept them – I'd rather rebuke them. When that happens, I will be leaving the house because that spirit is not from God. Yes, it is not from God.

Gladys felt a series of distressing emotions including fear, terror and sadness when hearing these frightening and threatening words. Buccheri *et al.* (2007), in their study of delusion and hallucination as part of the symptoms experienced by people with dementia, found that of the 27 people who experienced auditory hallucination, 65% of them experienced what they described as 'command hallucinations', in which the voices people with dementia heard were threatening to hurt them (44%) or were telling them to hurt others (21%). The voices Gladys heard, therefore, were not uncommon behaviour in dementia.

Danny and Xiana, carers, also talked about their experience of Emma perceiving to be seeing people and hearing voices. Danny stated:

It (dementia) started by her perceiving to be seeing people. She would be telling you people are coming or sitting beside her and she wouldn't be able to sleep. All of a *sudden, she would run to and call you. The very week that it started, she never rested.*

Xiana added:

If she (Emma) is watching TV in the bedroom, she would say that there are people in there. She would suddenly leave and come to the living room with the bedsheet. She would say the same about the radio programmes, that people are talking to her. If she hears a little noise in the room, she will come to the living room pretending to leave the people there, meanwhile there will be nobody there.

Danny and Xiana found Emma's hallucinatory experiences to be one of the first signs that made them think that something was wrong with her memory. The statements above imply that Gladys and Emma were convinced that their experiences of auditory and visual hallucinations were real. The visual and auditory hallucinatory experiences appeared so frustrating, distressing and disruptive to both Emma and Gladys that they were unable to focus or concentrate on anything else. They would simply immediately leave their environment as a way of escape and to seek comfort, security and safety elsewhere. Emma would stop watching TV or listening to the radio and run to her carers in the living room for comfort and reassurance. However, despite the carers' reassurances, they were unable to convince Emma that that the voices and people were unreal – there was no one in the bedroom. This result was comparable to Ng *et al*. (2012), who found hallucinatory experiences to be disturbing and frightening for those experiencing hearing voices. While Gladys would obey the commands of the voices and leave the house, she would keep her voice-hearing experience to herself and would not tell anyone about it. She explains:

When that was happening to me, I did not tell anyone. I resorted to prayers continuously. I was going to church regularly and put all my trust in God, because I know the God I worship is the only One who can fight this 'big' fight and redeem me from such problems. If you have God, you have all things, so I put all my burdens and cares on God for He alone could do it for me. So, it wasn't a case of telling people of my problems but to leave all my burdens to God. I kept praying as I knew it was only God who could help me with my problems. That's why!

People with dementia also used cultural interpretations to make sense of hallucinations. Gladys' experience of hallucinations was shaped by her religion, which provided the resources used to make sense of this distressing experience. She found solace in God and was hopeful that she could overcome the (evil) spirits being witnessed by praying to God. Attending church regularly and praying continuously suggests that Gladys' faith in and relationship with God increased during this time. She thus understood her auditory hallucinatory experience within the framework of religious beliefs, providing a means to interpret and make meaning from her sensory challenges.

It would also seem that Gladys did not want to tell anyone about her experience because of the stigma attached to dementia and other psychiatric conditions in Ghana. This finding is consistent with Barke *et al*.'s (2011) study, which found that mental and other psychiatric illnesses are stigmatising conditions and that these seriously affect patients and their relatives, as well as institutions and healthcare personnel working with persons with mental illnesses and their families. This might account for why Gladys kept her hallucinatory experience to herself.

7.3.1. Summary of master theme 3

Hallucinations create lived experiences that reshape the lived body and the lifeworld of people with dementia. Hallucinations were one of the major symptoms people with dementia in this study experienced. Hallucinations create lived experiences that reshaped the lived body and the lifeworld by making the lifeworld confusing and disturbing, shaped by sights and sounds that were not real but could be perceived to be real. Hallucinatory experiences shared by participants have highlighted the day-to-day struggles of people with dementia and their family carers. The findings show that not only people with dementia struggled with the voices but also, they and their carers had to bear the consequences resulting from these experiences. This included Gladys and Emma having to leave their immediate environments because of their fear and distress. This meant stopping things they enjoyed doing like watching the TV and running to places where they could find comfort, security and reassurance.

While hallucinatory experiences of hearing voices and seeing people were not real, it was hard for people with dementia who experienced hallucination as part of their dementia symptoms to accept it as unreal – they felt they were real. Seeing and voice-hearing experiences had a psychological and emotional impact in the form of fear, terror, distress and poor night sleep on people with dementia. In both situations, the people and voices Emma and Gladys claimed to have heard controlled their thoughts, feelings and actions. They, however, seemed to have coped with their experiences through the resources available to them then – Emma running to her carers and Gladys praying to God for help, each of which seemed to have helped them distance themselves from the voices and the people.

7.4.: Summary of chapter

The chapter has considered how dementia altered the lived body existential of the lifeworld of people with dementia. Forgetfulness, as narrated by participants, took different dimensions. For some participants, forgetfulness was about them no longer remembering names of people – friends and family members, names of places and/or events. Moving beyond simple recall, forgetfulness also meant losing the underlying structure of everyday life, defined through basic mundane tasks and the embodied abilities based upon them, such as bathing/showering, brushing teeth, cooking or doing laundry. For such once taken-for-granted skills, people with dementia now required lots of efforts, prompts and sometimes physical assistance from carers to undertake them. Thus, in dementia, the lived body forgets – it does not remember the names of people, places and objects, neither is it able to pre-reflectively understand nor comprehend other people. These experiences change people's sense of the lived body and the wider lifeworlds of people with dementia and their carers.

Roles and responsibilities of each of the people with dementia and their carers changed. Parents (who were once carers) became the cared-for persons due to their altered lived body following their dementia. They lost their independence to perform some activities of daily living such as having a bath, brushing one's teeth or losing skills, including use of a typewriting machine. For other participants, dementia affected their basic physiological or biological functions upon which the lived body was grounded. Incontinence was one prominent way in which a deteriorating material body is brought into relief/dys-appears, for instance people with dementia losing their ability to control their bladder and bowels and contributing to the feelings of people with dementia living in an unreliable or untrusted body, which contributed to their insecurity in social settings. Some people with dementia and their families chose to retract from their social network, causing them to be socially isolated. Experiences of incontinence were also found to be embarrassing, shameful and stigmatising, as families either did not want to talk about it or could not do that so very easily. This was because people with dementia's social opportunities became limited to mostly members of their household.

For people with dementia, the positive self-images that they had built for themselves for so many years became disrupted in dementia. This led to people with dementia losing the skills and abilities to do things they once valued and enjoyed as beings with autonomy and agency, able to act in and on the world themselves. Instead, people with dementia's disordered bodies led them to become dependent on others to meet their needs for some of their previously taken-for-granted activities of daily living.

In conclusion, this chapter has explored some of the major changes that dementia brings to people with dementia's experience of the lived body. Phenomenology provides a full account of the existing and modified world of people with dementia, and we can see what the illness has taken away when we compare people with dementia's old healthy world/body and our new world (Carel, 2007, 2011a). Ordinarily, the lived body is experienced as a unity within the lifeworld (Toombs, 1988b; Phinney and Chesla, 2003). However, this unity breaks down in dementia as the body starts to break down in its ability to live in the world. In dementia, people lost the activities they enjoyed well, as those activities were no longer possible because of their dementia. Thus, the body in dementia dysappears and people with dementia lose their ability to complete the most basic, everyday tasks such as remembering things or completing activities of daily living which were previously taken-for-granted, habitual and everyday activities. People with dementia became more forgetful and reliant on others to prompt and/or support them to complete tasks.

The lived body in dementia also meant that people with dementia experienced changes in their social practices and settings. People with dementia's social world was transformed by dementia, and people with dementia had difficulty maintaining the social world as they were no longer able to participate in most shared activities such as work and other community-based activities. In dementia, reciprocity was lost as people with dementia sometimes withdrew from social situations which may compromise or embarrass them (Charmaz, 1983). For instance, people with dementia with incontinence issues were not going out as much as they would have liked owing to the embarrassment and stigma associated with incontinence. People with dementia's autonomy and independence were also compromised or modified, which required people with dementia and their carers to adapt and change to in order to accommodate the 'new life' of people with dementia. Dementia, therefore, becomes both a social and personal issue which defines the relationship of people with dementia in their lifeworld. As people, we experience illness primarily as a disruption of our lived body rather than as a dysfunction of biological body (Toombs 1988). Phenomenological methodology, therefore, allows the expression of these disrupted lived bodily experiences and enables us to develop a better understanding of the experience of illness.

Chapter 8 Findings 2 - Understanding dementia in Ghana

8.1. Introduction:

As Kleinman maintains, an illness comprises the way that the sick person, members of the family and the wider social network perceive, interpret, live with and respond to symptoms and disability (Kleinman 1988, p 3-4 cited in Sagbakken *et al;* 2020). Poveda (2003) recommends that any attempt at a wider understanding of dementia must involve an analysis of dementia in several socio-cultural contexts for everyone who is affected by it.

To get a better understanding of dementia from within the Ghanaian cultural context, this chapter examines people with dementia, their family carers, prayer camp staff and healthcare professionals' knowledge of the disease and how they made sense of it. Unlike professional knowledge that is established on scientific and theoretical bases, people with dementia, their family carers and prayer camp staff's knowledge and understanding of dementia differed from that of the healthcare professionals. Thus, people with dementia, their family carers and prayer camp staff's knowledge and understanding of dementia were embedded primarily within the cultural and social constructs, while the healthcare professionals' understandings were mainly based on the scientific/biomedical model or framework. However, healthcare professionals' understandings of dementia were also influenced by socio-cultural context to some extent.

The chapter discusses the study participants' views and understandings of dementia under four master themes: dementia as a normal part of the ageing process, biological origins/understandings of dementia, spiritual and religious explanations of dementia, and dementia resulting from physical/physiological and psycho-social factors. The first master theme, dementia as a biological illness, discusses dementia from a biomedical perspective. Two sub-themes – dementia as a disease and dementia as menopausal symptom – are discussed. The second master theme, dementia as a normal part of the ageing process, talks about participants' prior understanding and changing understanding of dementia. The third master theme, spiritual and religious understandings/explanation of dementia, discusses people with dementia, family carers and prayer camp staff's perception and understanding of dementia as an illness caused by or developed through supernatural phenomena. The final theme discusses psycho-social factors that are perceived to be causing dementia.

8.1.1. Master theme 1: Dementia as a normal part of the ageing process:

Experience of a decline in people's general physical and cognitive health and functioning is expected as people age (Pollitt, 1996). This master theme considers the study participants' views and understanding of ageing as a common factor underlying cognitive symptoms in people with dementia. For some study participants, dementia was just a natural part of the ageing process. Danny, a carer for his grandmother, exemplified this:

I have always been saying that it is part of normal ageing because we lived in the village for a long time, and we lived with older people who had similar experiences. So, for me, had it not been auntie Joymo I didn't know there was an illness called dementia. All I know is, when someone grows old, they become forgetful, although it isn't everyone who experiences this.

Danny recognised that as people, including his grandmother, age, they may "lose their brain" and can thus become more forgetful and confused. He added:

Honestly speaking, Emma isn't the only older person I have come across. I have come across a lot of these, so I know that it's old age. I know most people when they grow up to certain age, their behaviour changes. That is natural, whether you like it or not, it's there.

Danny viewed dementia and its associated behavioural changes to be something normal. However, his perception and understanding of dementia changed after receiving information on it from his auntie Joymo. This is discussed under the 'changing ideas about dementia' section below.

Mag and Gladys held similar views as Danny's before gaining new insight. When asked about what their perceptions and understandings of dementia were, Mag and Gladys felt that dementia was a condition that people get as they age. Gladys related that, during a visit to the hospital, the doctor explained that her forgetfulness was the result of her being older. She illustrated thus:

The doctor said it is when you grow that you realise that… and that as for forgetfulness everyone forgets but you become more forgetful as you age.

Gladys remembered the doctor giving a name to her diagnosis but could not remember this. This suggests to her that the degree of her forgetfulness meant that it was a medical condition (with a diagnosis) and so took on the doctor's view. She became aware that her condition would get worse as she aged or grew older. This seemed to suggest that Gladys simultaneously held, or was told, different understandings of dementia following her visit to the hospital and subsequent diagnosis of dementia.

Speaking from their experience of working with families with dementia, three healthcare professionals – Kyeiba, Milla and Efuamen – also shared their experiences of families with people with dementia they had been working with and others' views and perceptions of dementia. Kyeiba remarked that:

Some think that it is out of old age; that when people grow old, they easily forget things, so they don't really pay attention to the fact that it is a medical condition. They just think it's normal.

Milla added:

I see that the Ghanaian populace see dementia as a… they don't really see it as a medical condition, but they see it as an ageing process.

Further to these, Efuamen remarked thus:

Also, we normally associate memory loss as something normal here in Ghana. When you are aged above 60, they see it to be normal, so they don't normally seek treatment for these things.

The above excerpts are suggestive of the fact that cognitive decline in older people was considered a normal part of ageing by lay people and, therefore, not something for which they would seek healthcare. Other participants understood dementia from the perspective of how their older relatives behaved. These participants highlighted that the people with dementia they cared for behaved like children. When asked what their understanding of dementia was, Profedem, the prophetess, had this to say:

We think that they behave like children, they behave childishly.

Profedem understood that when people grow, they can behave or act in ways similar to their childhood years, expressed locally as *“w’ayɛ sɛ nkwadaa” or “wɔn nneyɔɛ te sɛ nkwadaa”* which translates as “they act as children or behave childishly”. Profedem commented further on her perception of people with dementia sometimes acting or behaving childishly, claiming that the Bible even says so. She expressed this in these words:

The Bible says that when you grow old, you can become like a child. So, if you look at it, they sometimes behave childishly, they do things that you would not normally expect from an adult. Sometimes they act as people with mental health issues; they are not mad per se but can behave childishly because of their age.

When probed further about what sort of things one would not normally expect from an adult, Profedem mentioned things like inability to wash, dress and eat, which some older people including those with dementia would be needing help with as they may be unable to do them independently.

One CPN, Akugya, indicated that they often employ the concept of infantilisation to explain to families what dementia is like. She explained this in the statement below:

We make them understand that the patients have now become like children, so basically you need to guide them, do everything for them, just like you have been doing for children.

While people with dementia, their family carers and prayer camp staff used various local expressions to describe people with dementia appearing to return to their childhood or infantilised behaviours, some healthcare professionals employ the concept to help them explain how dementia is like to help families understand the disease.

In summary, this theme has shown that participants have perceived both memory loss and dementia as a normal part of the ageing process rather than symptoms of a degenerative disease of the brain that worsens over time. Consequently, most families with dementia may not seek medical help until late, even if people with dementia show symptoms of the condition.

8.2. Master theme 1: Biological origins/understandings of dementia

This master theme examines participants' understanding of dementia as a biological illness, either in its own right or as a part of other physiological changes to the body such as menopause. Within the medical model, the causes of ill health are sought in altered functioning in the biology of an organism and, therefore, responses are largely based on physical or pharmacological approaches (Crossley, 2000 cited in Botsford *et al.*, 2011, p 443).

8.2.1 Sub-theme 1 Dementia as a disease

In this sub-theme, participants, mostly healthcare professionals, described dementia as a disease that reflected their personal and professional knowledge and experience from both within their own families and also as professionals working with families with dementia both in the community and hospital settings. In addition to recognising dementia as a biological illness, some healthcare professionals spoke about their experience of people with dementia and their family carers' understanding or conceptualisation of the disease.

Kyeiba, a physician assistant, recognised dementia as a kind of memory loss that affects people's ability to take care of themselves. Explaining his understanding of what dementia is, Kyeiba said:

You see Sir, in old age, a little kind of memory loss will happen somehow, but in dementia, there is what we called global or total malfunction of the brain function. There is a memory loss with people who are growing old. It's just part of old age, and then go to mild memory loss or mild cognitive problems. Those people can take care *of themselves. You need to carry water to the bathroom for them, they bathe, they can dress themselves and do almost everything. Now, for a person with dementia, you would have to hold his hand, put into it food, he eats and the next moment, he tells another person he hasn't eaten.*

Kyeiba differentiated memory loss resulting from natural ageing from that of dementia. He identified that older people experiencing mild cognitive impairment or normal ageing can be forgetful but would still be able to undertake some activities of daily living such as bathing and dressing themselves fairly independently. However, with people with dementia, help would be required to undertake such and many more activities of daily living. Kyeiba understood people with dementia experience dysfunction in many areas of their lives including their cognitive/intellectual and social-interpersonal dysfunction. Kyeiba went on to talk about his experience and understanding of dementia earlier in his career. He eloquently articulated his experience thus:

When I studied to be a prescribing assistant, I started reading about dementia and I got to know that they had personality and mood changes. Whenever this man wanted to say something and he said something other than what he wanted or what he was meant to say and I laughed, I would get a whole lot of bashing from him. He'll beat you up, insult me or do whatever he likes because he wasn't able to say the things that he wanted to say and that I laughed at him.

Kyeiba acknowledged dementia as a psychiatric condition, with personality and mood changes being some of its associated symptoms. At the same time, forgetting and having difficulty calling or remembering the name of items, not knowing what to say and when to say it (language difficulty) were considered evidence of forgetfulness and word-finding difficulty associated with dementia.

During the interview, Kyeiba was asked whether the healthcare professionals were taught about or received training in dementia. He responded in the affirmative. However, he explained that dementia was taught superficially as part of his course; instead, the course focused mainly on other psychiatric conditions. He explained:

They talked more on these pathologies; the schizos, the psychotic disorders, depression, the bi-polars. They talked more on that than the geriatric disorders. I don't know whether it has changed today.

Kyeiba gained more knowledge and understanding of dementia through reading about the condition himself, as well as his experience of working with families with dementia. Kyeba's colleague, Milla, a CPN, confirmed that dementia was part of the nursing curriculum, and it is taught in all nursing training colleges in the country. She stated:

We were taught dementia, everything about it, but then when you come to the field you meet the cases, and you have to apply what you have learnt. And it's when you are working in the field that's when you see the real signs and symptoms the patient is presenting.

Milla's quote suggests that, although she and her colleagues gained some knowledge and skills on dementia, healthcare professionals gained more practical, first-hand experience in the field after their training.

In response to their knowledge and understanding of dementia and what it was like to work with people with dementia, Rosebu (CPN) stated:

They are overly talkative, and you can't really know what they want to say because they sometimes chip in experiences from the old… one particular man on our ward for example, when we are talking about some current issues, he would say bring in something like, somebody died, what happened? This place is cemetery! We are trying to talk about a current issue, but he keeps bringing in the old ones. So, basically their communication is very, very difficult.

Rosebu understood people with dementia to be lacking concentration and that they were difficult people to engage in conversation with. She also understood that people with dementia can easily veer off and talk about irrelevant matters or issues that may not be directly related to the topic being discussed.

A colleague of Rosebu, Esinamow (CPN), had no direct experience working with people with dementia on the ward, but shared personal experience of her grandmother, who had dementia many years before her training to become a nurse. She stated:

I haven't met a patient with dementia on the ward, but my grandmother had dementia. That time I was young, and I didn't even know about it. Doing certain basic things like opening the door, taking a cup to drink water or wearing a dress, she couldn't do it all by herself. Everything had to be done for her. When everyone came around, she couldn't recognise them except one particular son of hers. Also, sometimes, when you are talking to her, her attention is drawn to something else that minute and then I realised that she was sometimes aggressive.

Esinamow understood that people with dementia often lack the ability to undertake most activities of daily living and would often need help with everything. Similar to the man described above by Rosebu, in Esinamow's understanding, people with dementia may have no recognition of people familiar to them, as in the case of her grandmother.

Alexyline, a psychologist, gave a similar account of working with people with dementia on the ward setting. She advised that:

Casting my mind back to the place I used to do night in the ward, most of them (people with dementia) were not oriented so the night… and when the relatives come she would be missing their names. So, there was a need to constantly remind them about where they are and who they are.

She had found people with dementia to be forgetting names of relatives, where and who they were.
In summary, healthcare professionals acknowledged dementia was a progressive medical condition which often starts with an initial mild cognitive impairment. However, the condition can lead to total malfunction of the brain, and this can affect people's cognitive, social and communication skills as well as their ability to complete some activities of daily living such as having a bath. Healthcare professionals' understanding of dementia evolved as it became more biomedical and

as they gained more clinical and scientific knowledge of the illness following their professional training and clinical work experience.

8.2.2 Sub-theme 2. Dementia as a menopausal symptom

One of the most frequent symptoms that participants ascribed to the meaning of dementia was menopause, a term denoting the end of menstrual cycles and the biological ability to reproduce (Brockie, 2008; Berglund, 2018). Several participants linked dementia to menopause as they perceived it as a condition that older women get. The following quotations provide examples of these views' participants shared, explaining their understanding of dementia as a menopausal symptom. Maryako associated her mother's dementia with menopause in the following words:

I knew it (dementia) was menopause because what is happening to my mother, none of my older aunties experienced it and this illness is not common in our family history. Even in our hometown, I know many older people but have never seen any one of them experiencing anything like this before.

Maryako's initial perception and understanding of dementia was attributed to her mother's experience of menopause in her old age. She understood it was normal for some women going through their menopause to be forgetful. Another participant, Profedem, associated menopause with dementia when talking about her perception of what memory problems in old age (dementia) are like. She explained:

Some of them, it is menopause that can cause older people to suffer memory problems. For those with menopausal problems, they may not necessarily act as 'mad' people but can be very challenging at home. Both men and women get menopause, and they behave differently once they get it.

While a number of things were said by Profedem to be the origin of memory loss/dementia (including evil spirits and curses), in menopause it was considered normal for older women to lose their memory. Linking symptoms of menopause to that of dementia (madness), Profedem viewed symptoms of menopause-related type of memory loss (dementia) to be less challenging than behaviours associated with 'madness'. While menopause-related type of forgetfulness is very common in many women, studies have shown that these conditions can be improved through medication hormone replacement therapy, while dementia-type of forgetfulness can cause problems with activities of daily living (Jett, 2006). Additionally, dementia-related type of forgetfulness was found to be rare in mid-life, whereas a menopausal type of forgetfulness is unique to mid-life women (Henderson, 2009).

One healthcare professional, Chrisom, also spoke about his experience of working with families with people with dementia and the general public, whose views and perceptions of dementia were associated with menopause. Chrisom said:

In the rural setting, the perception about adults losing memory, especially females, is kind of associated with what is popularly known as menopause. It's very common in our society to hear people associating dementia with menopause. For adult females, it is very common, so they see nothing more to warrant them even going further to take the patient to the clinics.

The statement from Chrisom above suggests that families and the general public think of forgetfulness as a consequence of the natural process of menopause – not as an illness, but a natural part of the ageing process.

In summary, families of people with dementia associated dementia with menopause. According to healthcare professionals, both the families with people with dementia and the general public shared similar views – perceiving dementia as a form of menopause, a process of ageing that older women usually reach in their old age.

8.2.3 Sub-theme - Changing ideas/understanding about dementia

This theme talks about how people's understanding of dementia changed and, what influences these changes. The theme also discusses at what point in a participant's experience did they stop thinking about dementia as a normal part of the ageing process, perceiving people with dementia as a witch, evil-possessed or behaving childishly, or understanding dementia from other socio-religio-cultural perspectives. Most participants, families with people with dementia and healthcare professionals alike, spoke about such changes of ideas and knowledge about dementia.

Four family carers, Danny, Lizzy, Bea and Maryako, and some healthcare professionals talked about changes in their initial perceptions and understandings of dementia from it being a normal part of ageing or a condition associated with supernatural forces of witchcraft or curses, to it being a medical condition. Danny's initial perception and understanding of dementia changed from it being a natural part of the ageing process to it being an illness:

I have always been saying it is part of normal ageing because we have lived in the village for a long time, and we lived with older people who had similar experiences. So, for me, had it not been auntie Joymo, I didn't know there was an illness called 'dementia'. All I knew was, when someone grows old, they become forgetful, although it isn't everyone who experiences this.

From then on, Danny's perception of dementia being part of the normal ageing process changed to it being a medical condition, a disease. Joymo researched into dementia and shared her knowledge of the disease with him. Having got some insight into the condition, Danny's perception of dementia changed as indicated in the quote above.

Another carer, Lizzy, intimated that she and her family were unsure what dementia was, as stated below:

We weren't sure what it (her dementia) was. Sometimes, you say something to her and later, if you are speaking with her, she would say you never said that or told her anything. We thought her age was a contributory factor. At first when someone got dementia, we thought she was a witch, caught by the gods and confessing their sins.

Lizzy acknowledged MayLiz was becoming increasingly forgetful, sometimes forgetting and leaving food on the cooker or shopping at the local market after shopping. She suspected that something was wrong with MayLiz's memory as she kept denying things she had said in earlier conversations, although Lizzy was unsure exactly what the cause of these symptoms was. Lizzy's perceptions about what might be causing MayLiz' symptoms changed after watching some health educational programmes on TV. She explained:

I often watch health and health-related talks on UTV. There are a series of programmes that we watch on Sundays and dementia has been treated for about five or six times. One doctor who is an expert on dementia explained it, which made me think that it is dementia that my mother has got. It was through the programmes I got to know more about dementia.

Lizzy had already taken MayLiz to hospital for her diagnosis. However, her perception altered after watching the TV programme. She eloquently stated:

I had already taken her to PH2 before the programme, but listening to it changed my understanding of the illness. Because of this, if she does or says something bad, I don't take it personal.

Lizzy's statement above suggests that she became more understanding of MayLiz's condition and more patient when supporting MayLiz, as Lizzy was no longer taking things personal. She understood that what MayLiz was going through was not associated with madness or witchcraft, as previously suspected; rather, it was an illness and so would not take anything she said personal.

Similarly, a TV programme Bea watched also changed her understanding and perception of dementia. She remarked:

I think I was watching a programme on UTV for those who have such problems as my dad's. They were treating a topic on dementia, so that is where I got to know the sickness. The main thing that I understood was that dementia is a sickness. They explained further, I learnt there is no medicine to cure it.

Bea went on to talk about the doctors' explanation about the causes of dementia in these words:

I think the doctors were educating us, if they can treat it, I don't know, but it is a topic on its own for all Ghanaians to know what is meant by the sickness. I think they asked what is the cause and what the doctor said was if someone is having a BP (blood pressure) or diabetes, those are the two things I heard normally cause dementia.

Despite her changed perception of dementia following the TV programme, Bea seemed ambivalent and queried the cause of her father's dementia thus:

I think that was what the doctor said, but my dad is not having a BP; he is not diabetic, so I don't know where his cause is coming from. That was the question I was asking myself, because I have been taking him to hospital, his temperature was OK, the sugar level was also OK, so where from his?

For Bea, none of the possible causes of dementia mentioned by the doctor seemed to fit her father's dementia. Regardless of Ish's formal diagnosis of dementia, it would seem that Bea did not have enough information on dementia or the cause of it, despite her changed understanding of the condition.

Similar to Lizzy and Bea, Maryako's view associating dementia with menopause changed following watching educational programmes on TV about dementia. Maryako explained:

Until recently that I watched some TV programmes discussing memory problems, I believed that memory loss was caused by menopause. I now understand that it isn't. The reason I am saying this is that the teachings and information provided by the doctors increased my understanding on the illness. For instance, the programme showed how the brain can shrink to cause memory problems, so if they have shown this to you on the TV, what else do you need to refute the idea that memory problems aren't caused by menopause?

With her new knowledge and understanding, Maryako now believed that dementia was a brain disease and not a menopausal system, as she had previously thought.

Families with people with dementia's changed understanding of dementia, from it being associated with menopause and/or supernatural forces of witchcraft or a normal part of the ageing process, parallel medical professionals' evolved or changing understanding of dementia following their training and clinical practice.

8.3. Master theme 3: Spiritual and religious understandings of dementia

This master theme and its sub-themes provide examples of the conceptualisation of dementia through supernatural forces such as curses, witchcraft and madness and their effects on living with dementia in Ghana. Some participants perceived these to be important causes of dementia and other psychiatric illnesses for their relatives suffering from these conditions.

8.3.1. Sub-theme 1: Dementia as a form of witchcraft

One way that participants provided an explanation for dementia was through a supernatural belief in witchcraft, locally known as *bayie* – the power to do evil *(bayi bɔne) or* good (*bayi pa*). This sub-theme seeks to unpick witchcraft as a phenomenon associated with the causality of dementia and the impact this can have on the lives of families with dementia in Ghana.

Several participants associated dementia with witchcraft, and the perception that people with dementia are witches came up in a number of the interviews. Talking about his understanding and perception of what dementia was, Williezor intimated:

Sometimes we see some of them like they are witchcraft. We see them as witches and that is what is controlling their lives. This (dementia) is caused by spirits. Some spirits possess them and take over their brains causing them to be forgetful.

Profedem added further:

As for the things that we see, we can't say much, but all that I can say is that it's a spiritual fight that we engage in. It's not just the illness, because whoever comes here possess spirits and it is up to us to fight them and get the person delivered.

Statements provided by Williezor and Profedem imply that evil spirits or witches can take over and control people's brains causing them to be forgetful, lose their memory or develop dementia. This seems to suggest the belief that evil spirits or witches cause people to develop dementia by taking over their brains.

Maryako also talked about her and others' perception of people with dementia as being 'abnormal' people, who do things and behave as witches and wizards, as illustrated in the statement below:

We see them as being abnormal doing their things like witches and wizards. They behave like witches. We all have had such a perception before. In the past, if I saw an older person behaving bizarrely, I assumed or perceived them to be witches.

Being abnormal here suggests an abnormality in idea and behaviours. Thus, people with dementia do things, say things and act in ways that are or can be inappropriate and socially unacceptable. Added to this is a statement by Esinamow sharing her own experience of society's perception of dementia. She informed thus:

Let's say you have an old woman at home, and she starts showing signs and symptoms of dementia, the family members may assume she is a witch, that's why she is acting that way. So, oftentimes they tend to put them in a witch camp and some family members tend to isolate themselves from them, for they assume they are spiritually possessed.

People with dementia were said to be easily presumed by their families as being witches if they began showing signs and symptoms of dementia at home.

8.3.2. Sub-theme 2: Dementia as a form of madness

This sub-theme discusses experiences of behaviours some participants described as 'madness'. Three family carers – Lizzy, Maryako and Gracem – all used the words 'mad', 'madness' and 'abnormal' in their description of what they perceived to be dementia. The following quotations from them indicate their perceptions about dementia and those of others.

Lizzy said this:

Normally, what we say is their minds are destroyed or they are mad. We would also say this man or woman acts bizarrely.

Explaining her perception of dementia further, Maryako associated dementia with madness, as people with dementia talk nonsensically like mad people do. She said:

The words they would say would make no sense, just like some mad people do. They speak exactly like mad people – they have no meaning whatsoever. We perceive it as madness, or we say the person is 'not normal' – you are mad, and you are not normal are the same. Aren't they?

Gracem added her views and perception of her husband’s behaviour following his dementia. She commented thus:

Sometimes, he behaves in such a way that you would perceive him to be abnormal or mad. Sometimes, if someone sees him, they will think his mind doesn’t work.

The terms mad, madness, or not normal were used interchangeably by participants, suggesting that people with dementia behaved, did or said things that were inappropriate, strange or not normal. Gracem went on to talk about her husband Max going out and walking barefooted. She remarked:

Sometimes, he would go out barefooted. If you are not around to see, he would just go out with no regard to his personal presentation and dignity.

She described that Max had never done this in his life before and so would not have done this under normal circumstances.

Some other participants described behaviours they perceived to be abnormal, which included people with dementia talking to themselves or ‘walking-talking’. Based on his behaviour, Bea said this about Ish and anyone else who would be seen as exhibiting similar behaviours:

I see him as abnormal because sometimes you see the person well dressed, but he will be walking-talking. You’d think the person is mad or abnormal because whatever his mind tells him is what he would do. You wouldn’t know what is wrong with him.

Bea’s statement suggests that people may appear nicely dressed but may be suffering mentally, and this can be manifested through their behaviours such as talking to themselves. ‘Walking-talking’ is a phrase often used locally to refer to people who may be engaging in an undefined or aimless walk and be talking to themselves while they walk. It is similar to talking to oneself, but this time the person talks as he/she walks.

Another common symptom mentioned by participants to explain their understanding of dementia or behaviours they found to be abnormal that warrant the term madness were physical aggression or violence. Nateye described people with dementia in the following words:

Sometimes when you give them food, as you are leaving, they will pour the hot food on you. They do so because they don’t know what they are doing. Some can hit you ‘pang’!

The phrase *they do so because they don’t know what they are doing* used here signifies that the patient was ‘out of their mind’ or mad – everyday language used to refer to people suffering from mental health or psychiatric illness. Several local expressions such as ‘*ɛdam*’ (mad or madness), “*ɔbɔdamfoɔ*” (mad person - singular) or “*abɔdamfoɔ”* (plural), “*wabɔ dam”* (he/she is mad), *“ɔnyɛ normal”* (they aren’t normal), “*ne tiri asɛe”* (they have lost their head) or “*n’adwene asɛe”* (their mind is destroyed), and “*ne tiri nni fie”* (they don’t think right) are used to describe dementia as there is no local name for it. These words or phrases are the everyday language used in Ghana to describe people who show signs and symptoms of dementia or demonstrate behaviours associated with mental illness. As indicated above, healthcare professionals knew about dementia as a disease and used the word dementia and some of its sub-types during interviews.

8.3.3: Stigma – outcome of different understandings

Stigma was identified as one of the direct outcomes of the different understandings of dementia shared by participants. People with dementia and other psychiatric illnesses experienced behaviours and attitudes from family and others that were stigmatising. Nateye talked about stigma that people with dementia often faced within their own families and in the wider community. He illustrated:

If one goes into that situation, it looks as if you are rejected by the family. We have some cases where the person recovers here but when they go home, they would be seen differently by their family. They would say he/she is mad. Even when they go to buy from local shops, the way the seller will respond to them or treat them as if they are different from the others.

The notion that people are ‘mad’ and how it is used on people with dementia or mental illnesses is often deeply stigmatising. People with dementia were reportedly rejected or abandoned by their families, especially in hospitals and prayer camps. This increased the risk of people with dementia being socially isolated and lonely. In summary, no local names or words were found for dementia in Ghana; instead, participants used different words, phrases or metaphors to describe dementia, and these were used interchangeably. As awareness of dementia was lacking, displays of psychological/behavioural symptoms by people with dementia were interpreted to be strange, bizarre or abnormal by most participants.

Summary of master theme

Although dementia, mental illnesses and their associated psychological or behavioural symptoms can be socially constructed, they remain stigmatising conditions in Ghana (Ae-Ngibise *et al.*, 2010; Barke *et al.,* 2011), as it is in most cultures across the world (Corrigan *et al.*, 2005; Mkhonto and Hanssen, 2018a). This study identified that family members, the community and the wider society have a tendency to distance themselves from people with dementia, including those suffering from other psychiatric conditions (Secker, 2013; Mkhonto and Hanssen, 2018a; Jacobs *et al.*, 2022).

8.3.4. Sub-theme 3: Dementia associated with curses (duabɔ or nnomee)

Another prominent theme that emerged from the data was cursing, locally known as duabɔ *or nnomee.* The perception about curses causing dementia was believed to be instigated by someone who may have hurt the other (victim) earlier, but which may have been manifested at a later time in their life (Ajatnoah-Gyadu, 2004). Profedem explained that people can be cursed if they wrong others, causing them to develop dementia. She intimated:

As for the curses-type of memory problems, people get it when they wrong someone, or people may have taken them to the shrine to curse them to be forgetful, thus making them behave like children.

Profedem's religious beliefs informed her understanding of dementia. She referred to the Bible to explain further her assertion in the following statement:

The Bible even mentions it in Psalm 109 about many curses and that if one is cursed and is afflicted with an illness as a consequence, the moment you curse that individual, no modern medicine can save him! Do you understand, unless through spiritual means, God!

Williezor, Kwadame and Jessegya also talked about the possibility of developing dementia due to curses. Commenting on this, Williezor stated:

Most of the old people's madness is curses. Some are curses by God; some are curses by fellow human being; for some it can be a family which have sinned or done evil for the past and that person's curses is working in that family.

Kwadame also remarked:

Some people believe that you have wronged or sinned against someone and has been cursed as a result or have stolen someone's items or that kind of thing.

Additionally, Esinamow illuminated how curses resulting from one's bad deeds earlier in life could cause them to develop dementia or mental illness. She intimated thus:

Some people also think that they are being punished for maybe the bad deeds that they did when they were young. That they are being punished for their bad deeds when they were young.

All three participants held the belief that when someone does wrongful acts against another, the former can be cursed by the one who wronged them – the victim. Thus, dementia could be the result of supernatural intervention – that is, punishing or paying someone back for their sinful or harmful deeds from the past or a curse

(Ajatnoah-Gyadu, 2004). Culturally, curses are believed to become operative when a person lives in disobedience to God's word or when they have wronged another in a hurtful or sinful way – in retribution (Ajatnoah-Gyadu, 2004). Williezor's quotation is suggestive of what Ajatnoah-Gyadu (2004) described as a 'generational curse', which he defined as "an un-cleansed iniquity that increases in strength from generation to generation affecting the members of that family and all who come into relationship with that family" (Ajatnoah-Gyadu, 2004, p 398). It is not uncommon for most Ghanaians, Christians and non-Christians alike to believe in this type of curse and its effectiveness in causing chronic and hereditary types of diseases including dementia and other forms of mental disorders within families.

Summary of theme

The cause of dementia is often inseparable from the domain of religious beliefs and cultural practices of Ghanaians. The Ghanaian cultural beliefs recognise the natural causes of diseases, but the traditions teach that personal and communal sins, curses, demons and other forms of supernatural evil could be responsible for the causality of illnesses including dementia and misfortunes that happen to people (Ajatnoah-Gyadu, 2004). Some participants understood dementia to be the result of supernatural intervention, an act of God, or a curse as a payback for sins or harmful deed from the victim's past. Curses could be instigated by a person or God.

8.4. Theme 4 Understanding dementia associated with physiological and psycho-social factors

This theme encompasses the psycho-social factors – the social, cultural and environmental influences believed to affect people's mental health and behaviour resulting in them developing dementia. Moral failure and too much thinking or worrying resulting from emotional traumatic life events that people with dementia experienced are discussed under this theme.

8.4.1. Moral failure - substance abuse associated with dementia

Morality is socially constructed. It involves morally acceptable behaviours or the quality of being in accordance with the standards of good or right conduct (Hulse *et al.*, 2005). However, when one fails to adhere to these good or rightful conducts within society, this can be described as 'moral failure' (Akyeampong, 1995). This section discusses participants' understanding of dementia as a result of excessive drinking, smoking or illicit drug use. When participants were asked about what their knowledge and understanding of dementia was, Kwadame said this:

If someone takes too much alcohol, he or she can get the problem and smoking 'weed' can also bring such things.

In the quotes above, Kwadame was referring to dementia when he used the word 'problem' and the phrase 'such things' to refer to dementia or mental illness as it was the subject of the focus group discussion. Kwadame went on to talk about how early some people can start drinking alcohol or use illicit drugs in their lives and the potential impact these can have on their mental health. He expressed:

As for drinking, they can start a little later at least they get to certain age. But as for the 'weed', some start while still at school through friendship. They will be doing that without their parents knowing this and they will continue to smoke until it gets to a point where things get out of hand – before they realise it will be too late!

As the quote suggests, Kwadame believed that starting smoking or drinking early in life and continuing to do so in excess could impair people's cognition, thus 'be out of their minds', an everyday phrase used to describe people with psychiatric illnesses, including dementia, in Ghana. While, in reality, either excessive drinking, illicit drug use or a combination of these can cause dementia or dementia-like symptoms (Hulse *et al.*, 2005; Rehm *et al.*, 2019), it was the moral failing that participants believed to be the cause of the dementia, but not the physical impact of drugs on people who take them in excess (Akyeampong, 1995).

In a study exploring the socio-cultural dimensions of alcohol use and abuse in Ghana, Akyeampong (1995) summarised the reasons contributing to people's alcohol use and drinking patterns in the country to include the user's experience of pain, broken heart resulting from a breakdown in relationships, job loss/unemployment, or loved ones and the occurrence of misfortunes in one's life. The study identified chronic drinking or alcoholism in people to be the result of supernatural forces of witchcraft or curses (Akyeampong, 1995). However, studies in other cultures (Hulse *et al.*, 2005; Velentza *et al.*, 2019) found that excessive and prolonged use of alcohol and similar substances led to continuous cognitive dysfunction and alcohol-related dementia in their users. In the Ghana culture, alcoholism or excessive use of similar substances causing their users to be ‘out of their minds’ is perceived or considered a moral failure (Akyeampong, 1995).

In summary, an excessive use of alcohol and other illicit substances is believed to cause cognitive impairment, mental illness or dementia in those who abuse them. Excessive and prolonged alcohol use of substances or frequent drunkenness can be considered a moral failure and stigmatising to the individuals involved and their extended families in Ghana (Akyeampong, 1995).

8.4.2. Too much thinking, too much worrying associated with dementia

Another socio-cultural reason participants gave to explain their understanding of dementia was too much worrying or thinking. Sarakom and Maryako talked about the death of Mansa’s three daughters and related this to the cause of her dementia, as per Sarakom’s statement below:

As for me what I see about my mother’s situation is this, we were five girls; it’s now left with my sister and me. The three of us have died. My mum was the one who was taking them from place to place for treatment. So, all the worries and anxieties associated with these bad experiences may have resulted in her developing dementia.

Maryako elaborated further:

I am the oldest child. The one after me died on my mother’s lap. When she was ill, my mother was going back and forth for a long time, so she has gone through a lot of pain and has experienced high levels of anxieties in her life. Those extreme anxieties and bad experiences have all contributed to this problem. Previously, she was very tearful and would be talking to herself, but we have encouraged and advised her, and she now seems to have somehow gotten over it. I think all we’re seeing today are the result of the pain, the anxiety and the bad experiences that she has been through in her life.

Sarakom and Maryako felt Mansa's memory gradually deteriorated after the death of her children and she had never been the same since then.

Lizzy provided a similar account about her mother and grandmother, whose dementia she initially perceived to have been caused by excessive thinking and worrying. She explained:

The issue is that my grandma had a similar problem, but mum's isn't like her mum's dementia. For my grandma, her 25-acre cocoa farm got burnt in the 1983 fire outbreak. She was shocked on seeing the farm and this negatively affected her mental health (ɛna ɛfaa n'adwene mu). But as for my mother, she is the type of person who, if she is worried about something, wouldn't say it and would keep worrying about it. All these have contributed to her dementia.

Lizzy informed that, although her grandmother was still alive as at the time of the interview, she had never been the same person after that traumatic incident several years back. She went on to describe that her mother was a worrier, who often kept things within herself, and Lizzy believed that worrying behaviour could have contributed to her mother's dementia.

Although the two accounts seem to differ in their aetiology, both make the argument that worrying or thinking too much about the incident or something else appears to have resulted in Lizzy's mother and grandmother's dementia. While her grandmother had been shocked and devastated by the fire outbreak, her mother MayLiz may have internalised her worries over a long period of time without sharing them with others or sought professional help to address them. In either case, too much thinking or worrying could have potentially weakened their brain function and predisposed them to developing dementia.

Other participants talked about how difficult social relationships such as having an unfaithful partner, or taking on too much family responsibilities, could lead to excessive or too much worrying (*ɔhaw mmorosoɔ anaa ɔhaw ntrasoɔ*), or thinking too much (*adwendwene dodoɔ or adwendwene ntrasoɔ*).

While Irenekor was unsure exactly what the cause of her mother’s dementia was, she shared that other people held the belief that ‘too much thinking or worrying’ could cause people to develop dementia. She said this:

I don't really understand the cause of my mother’s dementia, but sometimes people say that if you think too much it can cause that. Different people say different things about the cause. So, it's a whole lot!

When Irenekor was asked to explain further what she meant by ‘thinking too much’ because not everyone who ‘thinks too much’ develops dementia, she explained:

They said, if you think too much about something like family issues. For instance, she took care of a lot of the members of her family. If people have problems, they come to her for help. So, some people say that, but as for me I don't really know what causes it.

Irenekor explained that Aggie was caring for and supporting too many people in her family – both nuclear and extended – in diverse ways, including providing financial and practical support and advice.

Another explanation Irenekor gave in response to her understanding of dementia, based on what other people had said, related to dementia being a spiritual illness. She remarked:

Some people including members of our family believed that it was 'spiritual’ so the family said we should take her to prayer camp, so we did. The prophet said he could cure her, but for all the time that she spent there we didn't see any improvement, so we brought her back home.

Irenekor’s statements suggest a multiplicity of the causes of dementia based on others’ perception of it. This included thinking or worrying too much and dementia being a spiritual illness.

Summarily, this sub-theme has considered some of the psychosocial factors that, from a lay participant’s perception, may have contributed to the development of dementia. Key psychosocial factors mentioned included too much thinking or worrying, loss of loved ones or property. It was also routinely believed that dementia could be caused by excessive alcohol use or illicit drug use.

8.5: Conclusion of chapter

In this chapter, people with dementia, their family carers, prayer camp staff and healthcare professionals' understanding and perceptions of dementia in Ghana were discussed. Findings show multiple ways of understanding what dementia is within the Ghanaian context. There are, however, conflicts between the multiple reasons seen in Ghana to understand dementia and these have real effects on people's lifeworlds. People with dementia and their family carers and prayer camp staff understood and perceived dementia from a social-cultural/religious point of view. They attributed the causality of dementia to a number of factors including supernatural and a normal part of the ageing process. The poor awareness of dementia and manifestation of its symptoms caused doubts about the cause of the disease. It is, therefore, not surprising that, in their attempts to clarify the misgivings, people with dementia and their family carers and prayer camps staff developed their own ways of understanding dementia within the Ghanaian cultural context. However, healthcare professionals, following their training in biomedicine, understood dementia as a medical condition. The spiritual beliefs of dementia have evolved in the absence of medical explanations of dementia. Consequently, participants constructed their subjective understanding of dementia, which was largely based on their personal experiences – observations of the symptoms that people with dementia exhibited – as well as participants' own cultural belief system.

As many considered dementia as a normal part of the ageing process, it was not something that they would seek medical care for. For some people with dementia and their families, particular life events such as the loss of a loved one, and too much worrying/thinking emanating from such losses or other family or social relationships, were used to explain the onset of their relative with dementia's disease. This lay participant's interpretation of dementia reflects the Ghanaians' cultural values and beliefs, as well as substantiating the psychosocial causation of dementia.

The study has also shown that despite lay participants' limited knowledge and understanding of dementia, they vaguely knew that, apart from the perceived psycho-social factors causing dementia, the disease was related to brain degeneration. It would seem that although most families recognise changes in their relative with dementia's abnormal, strange or bizarre behaviours, these did not prompt them to seek medical help, as they seemed to have thought such behaviours were inevitably normal because of their relative's age.

It was also evident that dementia awareness (as a biomedical illness with clear set of symptoms, aetiology and prognosis) is being raised in Ghana, for instance through health educational programmes via the media, particularly the TV. However, dementia remains a largely unknown disease to most families and the wider public as a whole. Also, as discussed in the literature review chapter, a lack of human and material resources for psychiatric and geriatric services in Ghana meant that the knowledge of and services for dementia and other psychiatric conditions remain limited and largely inaccessible to most families with dementia. This could possibly delay families' help-seeking behaviours. It suggests that the diagnosis and, subsequently, treatment for dementia would be dependent on the recognition and acceptance of the condition by the families with dementia. This, together with the stigma attached to dementia, could result in families seeking medical help for their relative with dementia by the time their condition had been worsened.

Beliefs regarding what is dementia and the causes of it are often inseparable from the domain of religious beliefs and cultural practices of Ghanaians. While the cultural beliefs of Ghanaians recognise the natural causes of diseases, the traditions teach that personal and communal sins, curses, demons and other forms of supernatural evil could be responsible for illnesses and misfortunes that happen to people (Ajatnoah-Gyadu, 2004). Within Ghanaian culture, it is believed that the effects of suffering from illnesses or misfortunes can be dealt with through the power or work of God that is enacted through the work of some specially anointed individuals – pastors, priests and prophets (Ajatnoah-Gyadu, 2004).

Chapter 9: Findings 3 - Institutional and Cultural Responses to Dementia

9.1: Introduction

The previous chapter examined and discussed people with dementia, their family carers, prayer camp staff and healthcare professionals' knowledge and understanding of dementia and how they came to make sense of the disease. This chapter explores and discusses how the lived experience of dementia is framed and shaped by specific social / cultural institutions within Ghana. In this case I explore the role that contrasting social constructions of the institutions of the family, religion and biomedicine play in shaping differing lived experiences of dementia within Ghana. Through a discussion of two sites - hospitals and prayer camps, I will discuss how these institutions / organisations shape two contrasting constructions of dementia and their associated lived experiences.

Three master themes – the family as a social institution, religion and its role in dementia care, biomedical model of dementia care and stigma and discrimination associated with dementia in Ghana are discussed. The family as a social institution master theme discusses the family's responses to dementia. The second master theme – religion and its role in dementia care comprises of three sub-themes - prayer camps as sites for spiritual care for dementia, religion's role in integrating people with dementia back into the community and religious faith as resource for coping with living with dementia. The third master theme – the biomedical or Western-based model of health care provides descriptions and the significance of the hospitals which took part in the study, the factors contributing to the use of prayer camps and modern medicine and opportunities for collaboration between biomedicine and prayer camps.

Three sites; the home, prayer camps and hospitals were the key sites where people with dementia inhabited and were cared for and the main spaces of importance in the interviews. Although being different, these sites were the key spaces that constituted the lifeworld of dementia in Ghana, and it is through these keys spaces that meanings and experiences associated with dementia come to be understood. The chapter will conclude by bringing together the key points from all the themes relating the family, religious and the modern healthcare systems and how they responded to dementia and dementia care provision in Ghana.

9.1.1. Master theme 1: The family as a social institution

The family is the most fundamental social institution and most people in the world live in family settings or units. All the people with dementia who took part in the study lived at home with their families at the time of the interview. The significance of the home in the lived experience of dementia in Ghana cannot be over-emphasised. The home is an important place which helps people maintain their identity more especially in later life (Rowles, 1983). In Ghana, like elsewhere, the home is a place where most people with dementia and their families spend most of their time together. It is the primary site where most people with dementia in Ghana actually live - most older people and people with dementia live at home with their families in Ghana. The home serves as a refuge where people with dementia can flee to and hide in away from the wider social world should they find it increasingly threatening or unsafe. Another function the home can also serve is a place where people with dementia relate to their families and others in their social world. From the lifeworld perspective the home becomes the primary lived space where the impact of dementia and its symptoms come to make sense to people with dementia and to their families.

Dementia transforms people’s identities and relations thus providing people with dementia and their carers opportunities for reframing their selves and relationships. This master theme discusses how families responded to the changed selves of their relative with dementia following their diagnosis. Thus, as people with dementia’s known selves diminishes due to dementia, the ways their family relate to them may be transformed. This theme will consider how families respond to the changes in the known and familiar selves of their relative with dementia due to the illness. It will involve how families with dementia used the home space, related to each other within their lifeworld as well as adjusted to their changing roles and identities. Three sub-themes - family’s positive (welcoming) response to dementia, negative (unwelcoming) experience of living with dementia and the carers’ sense of their changing roles and identities are discussed.

The positive response to dementia explains how the nuclear (a couple and their dependent children) and extended (a couple, dependent children, nephews, nieces, parents and grandparents) families became more actively involved in the care and support of their relative with dementia following diagnosis. The second sub-theme - people with dementia's negative experience of space (families denied their relative with dementia access to physical and social spaces within the home) while the third sub-theme - carers' sense of changing roles and identities examines how carers' previous roles and identities altered following their relative's dementia diagnosis.

9.1.2: Sub-theme 1: The family's positive response to dementia

This sub-theme examines how families responded to dementia within the lifeworld of their relative with dementia. Some people with dementia experienced positive relationships within the home following their dementia.

Geo recounted his experience of improved relationship with his mother Mag, since her diagnosis of dementia. He explained:

We converse together a lot. For instance, sometimes when I am cooking, I can ask her to come and help. Sometimes, I ask her to make the fire, so she can be active. Sometimes too, if I am preparing 'banku' [*a traditional dish made from maize flour*]*, I ask her to help with stirring it, because she complains about her hand. Any time I am preparing food, I ask her to come and help to keep her active and engaged.*

Geo's quotation suggests that he took up new roles and responsibilities whilst Mag gave up certain roles she previously performed. For instance, Geo started cooking meals which ordinarily he would not do as traditionally and culturally meal preparation is most often a female role and evening meals are mostly prepared by women in the family. Consequently, prior to Mag's dementia, Geo would meet his friends after work instead of coming home to cook. This type of role change is discussed in detail under 'carers' sense of changing roles and identities' sub-theme below.

Geo however stopped having to meet his friends after work. He would rather come home to support and care for Mag. He explained:

Before, I used to go outings with my friends, have fun and things like that but because of her situation, I am very focused on looking after her, so I only keep in touch with my *friends through phone calls - just to see how they are doing. Instead of meeting them after work for a chat/ fun, I now have to come home straight to look after my mum.*

Mag's dementia changed Geo's social world as he withdrew from his wider social network of friends into family life. Thus, Geo's everyday interactions with his friends after work seemed to be of no interest to him anymore. Becoming a carer thus impacted on Geo's wider relationships as he lost friends in order to focus on caring for Mag. The son-mother relationship between Geo and Mag grew to be stronger as a result of this. Thus, the care of Mag became much of his life which replaced other aspects of his life. Caring therefore subsumed and transformed other family relationships / roles.

Geo also expressed an expectation that it was his duty to give care to Mag while she looked forward to receiving care from him. He explained:

In this world, at all costs my mother will age and will have some little, little health problems. So, I must be prepared, be firm, pray and take her to the hospital because I can see that after 45 years of age, I have to make sure that my mother receives regular check-ups to ensure she is healthy. But in our case, my mother was busy to the extent that, she didn't have time for herself, so we couldn't get time to ensure her health care needs were met during her 40s until she got to her 60s only to suffer all these health problems.

Geo's quotation above suggests Ghanaian traditional filial piety - (to be good to take care of, show love, respect and support to one's parents) (Laidlaw *et al.*, 2010a; Zhang, Clarke and Rhynas, 2019). Filial piety is deeply ingrained in the minds of most Ghanaians. Aware of his responsibility as a son and in the cultural context of filial piety, Geo expected and appeared prepared and ready to look after his mother as indicated in his statement. Geo's relationship with Mag became transformed both negatively and positively having assumed the role of carer for his mother. With Mag's physical presence changing as she was becoming increasingly forgetful of simple things / actions and losing her ability to control her bodily functions (due to dementia), she was unable to perform previous roles as a mother / parent. She could no longer meet the expectations of her as a mother which was necessary to maintain her previous relationship with Geo. Thus, Mag's dementia changed her and this change in turn changed her relationship with Geo, not only as a son but also a carer.

Another carer, Esi, talked about engaging and including her mother Gladys in daily activities of living as demonstrated in the quote below:

I always want to engage her because I know that is one thing they (people with dementia) need. They feel belonged and loved and are happy and when we are interacting with them. It's something that helps to improve their condition and so far, I think it's working fine. I think it's working fine like when I'm going to the market I'll say to her as we're going to the market, what are we going to buy? She would then make her own shopping list and give it to me. Sometimes too when I'm going out I take her along, I take her with me.

Other activities Esi did together with Gladys included watching TV, praying and cooking together. She went on to explain how and why she did this. She remarked:

Well, what I did actually was I read up about the condition (dementia), so I knew a lot about it - how to care for people with dementia and all that. So, I was somehow prepared for it. You know when you are faced with the reality that's where the difficulty comes in but at least I was mentally alert for that. So even though it's sometimes stressful, I have ways and means of calming myself down. And it's also good that I'm not always in the house as it's more stressful because there you have to face the person almost the whole day and the whole time and have to tolerate a whole lot of things.

Doing some research on dementia before becoming a carer for her mother seemed to have improved Esi's knowledge and understanding of dementia and thus equipped her with the necessary skills to better cope with caring for her mother. These skills included Esi having to go out working or meeting friends outwith the home environment thus giving her opportunity to focus on something else other than caring. These helped Esi to cope with the stress of caring for her mother and seemingly, ultimately helped improved her everyday interaction and relationship with Gladys. Gladys herself felt a sense of belonging and well-cared for by Esi as she was being included activities in such activities as praying, preparing meals and going shopping together despite her illness. She stated:

When you give birth to children and look after them well, you expect them to look after you too when they grow up and start working. That makes you happy as a parent and I was very confident that my life would not be the same forever and that they would one day look after me.

Gladys was proud of herself as a mother she felt her children were reciprocating the care she provided them when they were young, a cultural expectation for children to care for their aged parents and / or those suffering from chronic illnesses.

Similarly, Gracem observed improvement in Max's nuclear and extended families after developing dementia. She explained:

In fact, my husband's family is good. They are Christians and really understand Christianity, so they don't hold any superstitious beliefs about the cause of his illness. They would rather phone and ask about how he is doing. Even this morning one of them called me and asked, is uncle able to talk? If so, can I talk to him? I told him that he was sleeping. They don't blame me in any way that I am not taking proper care of him and things like that.

While Max was unable to communicate the same way as he did before developing dementia, his extended family maintained regular contact with him by either visiting or phoning to check up on him. Gracem talked further about some of Max's family coming to sit with him as shown in the quote below:

Sometimes I arrange with them to come and look after him (Max) anytime I am travelling. Often, I prepare food, stew and make soup and make sure that everything is there for them, so they do not have to worry about these. Also, while there I will be calling to check up on him.

Some of Max's family members provided sitter service him to allow Gracem have a break from caring and also to be able to visit her own family or attend family events in the other parts of the country. Max's family did not seem to hold the cultural beliefs and perceptions about dementia being a spiritual illness. Rather they maintained relationship with and were more supportive of him following his dementia.

In summary, some families of people with dementia experienced positive relationships following diagnosis of their relatives' dementia. The findings show that some family members became more involved in the care and support of their relatives with dementia by providing practical, emotional and financial support. Families were also found to spend more time with their relative with dementia and engaged them in meaningful activities which helped strengthened the relationship between people with dementia and their families within the home setting. With their physical presence changing as they were becoming increasingly forgetful of simple things / actions and losing their ability to control their bodily functions (due to dementia), people with dementia were no longer able to perform their previous roles as a mother / parent / spouse. Thus, people with dementia's existing relationships became complicated and conflicted with new demands, responsibilities and changes to their relationships demanded by their carers. People with dementia were no longer meet their expectations as mothers/ husbands / spouses which was necessary to maintain their previous relationships with their cared for persons. People with dementia's inability to continue to perform their previous parental / motherly / husband roles resulted in new relationships being developed / constructed between them and their and their carers. This resulted in both people with dementia and their carers' relational identities, for instance as daughter-mother therefore faded. This section has highlighted the impact of culture on how families understood and responded to dementia in Ghana.

9.1.3 Sub-theme 2: People with dementia's negative experience of space

The home space being the primary space is where the majority of people with dementia's life and the majority of their care takes place. As a result, the meanings associated with the home as a space are significant and change and evolve as a direct result of dementia. Despite families' positive responses to dementia highlighted above, some people with dementia's experience of the home space was rather negative. This sub-theme discusses people with dementia and their carers' experience of being in and use of the home space and how these experiences impacted on what they could do or access within the home and in the neighbourhoods.

With dementia, people’s ability to move freely within the home became subjected to restrictions. Simon talked about being restricted physically and socially within the home by his family carers. He said this:

I can’t even go and take air under the mango tree there because all the time, they lock my door without open it. For over one month that I am here, I can’t go anywhere, I can’t go to my friends. I can’t go and walk about or have a chat with anybody. Nobody will come to me because they don’t know that I am here.

Similarly, Gracem spoke about the family restricting Max’s access to the community / neighbourhood by locking the main door to the house. She explained:

Sometimes when we open the door, he would attempt to go out walking about but if we do not agree, he would try and open the door with a knife, a pestle or he would be struggling with whoever tries to stop him from going out. He displayed aggressive and violent behaviour towards the family especially if we tried to stop him leaving the house. He will appear to fight you.

The family relationships located within the home changed following dementia and this led to changing the meanings associated with the home as family-oriented space into a space of restriction / imprisonment. While Simon and Max families locked them up to stop them from going out for walks or to socialise in the community against their will, Mag’s confinement to the house, in contrast, was her own decision. She said this to explain her circumstances:

At first the way I was happy and enjoyed merry making, it's all gone now. I am no more a happy person because of the illness. If my friends told or asked me to go to places with them, I could go but can’t do so now.

Realising she had become more forgetful, Mag appeared less confident in herself to go to places and socialise as she feared she might be unable to find her way back home. Mag’s statement could also suggest that she could not go because of the illness but not necessarily her family stopping her. Mag’s social world therefore shrunk by choice rather than being enforced on her. She however maintained contact with her faith community by attending the church regularly. She explained:

As for my attendance at church services, I manage to go even if I need to crawl to get there. I have had no experience of being treated differently at church since diagnosis.

Mag had strong determination and willingness to attend church suggesting that religion was perhaps helping her to make sense of the difficulties she was experiencing, or she was perhaps using religion as a resource to rely on for comfort and hope. She seemed to enjoy the sense of being part of the church or spiritual community as she appeared to feel welcome but not different from all the others. – no experience of discrimination.

The cultural significance of the church was shown in Gladys' experience of space. She often fled into the church which served as a solace or a place of comfort when she heard the threatening auditory hallucinatory voices.

Simon, Max and Mag felt the sense of being trapped in the home; a place that should have been experienced as a place of safety or refuge had become a prison-like space for them. This was especially expressed by Simon and Max who were confined to the house against their will. Feeling frustrated about their circumstances, Simon said that:

They know that I want to be set free and if I did something wrong, they should take me to the Police Station and lodge their complaint.

Simon was no longer allowed to use other spaces within the home beyond his room, nor was he allowed to socialise with people in his social circle. Believing he had been detained for no apparent reason(s), Simon asked his family to set him free from 'prison'. The home had become a constraining or shrinking space for Simon, Max and Mag as they withdrew from others in their wider social world. For Mag's this social withdrawal was by her own choice while for Simon and Max this was a restriction by their families. Thus, Simon and Max were denied access to other parts of the home, the neighbourhood as well as social opportunities outwith the home. These were things they took-for-granted prior to developing dementia.

Carers also had to deal with the increasingly restrictive controls they place of people's ability to leave the home and engage with the wider world. Tomadze provided an explanation for the family's actions to restrict Simon's freedom to move beyond the home thus:

Sometimes when he goes out, he gets lost and would be searching for him for a long time before we can find him. He himself may not know where he is. Sometimes he calls this place by a different name. If he sits under the tree there, I sit in the corridor and have to constantly keep an eye on him else, he will go out walking about. It is because of this that we have started to lock him up in the room. At first, we were not locking him but because of what he has been doing (going out walking about and getting lost) that's why we decided to lock him up.

Gracem provided similar explanation for restricting Max's access to the community She said this:

Sometimes he goes out and doesn't come back – he gets lost. Last time he got lost at Community 1.

She talked about the family ensuring they lock the main door to the house as Max would attempt leaving the house if they opened it. She asserted*:*

If we open the door, he will attempt to go out walking about and if we don't agree, he will try and open with a knife, pestle or will be struggling with whoever tries to stop him from going out. He will appear to fight me.

Max's family decided to take him to the psychiatric hospital for diagnosis because of his aggressive behaviour. Max's family had described him as a gentle and calm man. His family shared that Max often got lost in the community. Max's family would lock him up in the house in order to further restrain his movement. Both Simon and Max families felt that they were totally responsible for Simon and Max's security and safety. It would seem that Simon and Max's families could not take any risk of anything happening to Simon and Max by allowing them to go out on their own. The families' perceived need to lock Simon and Max up related to the changing experience of the family's relationship. With the risk of Simon and Max getting lost, it would seem that their families could not take any risks of anything happening them by allowing them to go out on their own. Studies have shown that physically restraining people with dementia, people with severe mental health issues or at risk of wandering /getting lost is a common practice in Ghana and other SSA countries (Hughes, 2018; Patel and

Bhui, 2018).The literature shows that chaining, locking people up or physical restraint is the most practiced way of handling aggressive / violent behaviours. Such measures have been found to minimise the risk of people with dementia or violent / aggressive behaviours harming themselves or others or preventing them from wandering and potentially getting lost.

9.1.4: Sub-theme 3: Carers' sense of changing roles and identities

This sub-theme explores changes in the roles and identities of people with dementia and their carers brought about by dementia. Relationships changed significantly in dementia. Some family members assumed the position of carers, a role previously played by their relative with dementia that they were caring for. Irenekor and Pepdon were previously cared for by their mother, Aggie. However, this relationship changed as after Aggie developed dementia, Pepdon and Irenekor became her carers. Irenekor shared her experience of caring for Aggie thus:

Sometimes when I take her to the bathroom, I tell her to bathe, and she can't bathe herself. I have to bathe her. Anytime I take her to the bathroom I have to bathe her because she can't bathe herself properly. Even if I tell her to brush her teeth, she will hold the brush, put it in her mouth, will be standing there and wouldn't know what to do. Sometimes, I have to take the brush from her and demonstrate to her how to brush her teeth before she can remember and then start doing it herself.

Pepdon and Irenekor lost their roles and identities as children who previously were being cared for by Aggie altered. They found themselves having to deal with new, very intimate duties caring for their mother, Aggie to be a new experience. They became Aggies' carers as she appeared to have lost her sense of who she was as a person; Aggie no longer remembered how to perform personal care tasks such as brushing her teeth and Pepdon and Irenekor had to deal with the very intimate care tasks that they may well have never expected to do with their parent. These were new experiences and very different that they ended up having with their parent as a result. Thus, Pepdon and Irenekor's roles and identities changed from being daughters and cared for persons to becoming carers for their mother, Aggie. Pepdon remarked:

In my experience, it is so annoying to live with her. It takes a lot of patience without which you can't live with her.

Irenekor and Pepdon found adjusting to their new ways of life – being carers for their mother to be difficult to cope with. Both expressed frustration when Aggie was unable to follow instructions during personal care provision. Thus required a lot of patience to deal with.

Most participants also acknowledged changes in their own and their relative with dementia's relationships and identities. Esi felt that her mother, Gladys, was different from how she was before developing dementia. She illustrated:

Sometimes you just wish you could have that old person you had before to discuss things with and live as normal as possible, but sometimes it becomes a bit difficult. You raise a topic, and you realise she's not ready to talk or comment about it and it's something else.

Esi seemed to have lost who Gladys was to her as a person as she was no longer able to engage her in meaningful conversations. She had found that Gladys' actions in her world of everyday living had changed. Gladys did not remain the same as before after her dementia and Esi missed having conversations and interactions with Gladys which she took-for-granted prior to Gladys' developing dementia. On the other hand, Gladys' relationships with her friends and church community changed from being reciprocal to being dependent on them for support. She intimated that:

As for my friends, they were those I fellowshipped with in church. They used to visit me. The church members also do visit me from time to time. Some of them even provide some practical help including fetching water for me. Some would help in a variety of practical tasks and some even prepare meals in their homes and bring them to me here. That's very nice of them!

The role of other social structures such as the church and / or prayer camps' relationship with people with dementia also changed. Those institutions took on more caring responsibilities as indicated in the excerpt above. For instance, while church visitations and supporting members of a church can be part of churches' roles and responsibilities, they provided extra practical support including fetching water, preparing and delivering meals to Gladys. Providing such support may have fostered a sense of belongingness and spiritual upliftment for Gladys and other members of the congregation.

In summary, the relationships based on previous family structures become eroded or declined as a person appears to change in front of them. Evidently, the social structures of the families involved altered as the roles and responsibilities of people with dementia and their carers changed. People with dementia also lost their independence to perform most activities of daily living tasks and so became dependent on their families – children and / or spouse and significant others for care and support to meet their changing needs resulting from dementia. The disruption of dementia affected both people with dementia and their paid and unpaid carers. In dementia, people with dementia became incapable of undertaking some basic tasks as well as maintaining their place in the relationship they had with others before afflicted by the illness. The family member (spouse/ children/ son / daughter) took on a new role as carers and would have to reconstruct their own identity within the family.

9.2. Master theme 2: Religion and its role in dementia care

Religion plays a significant role in integrating people with dementia into the community and people's religious faith acted as a resource for coping with dementia. In Ghana religious bodies such as churches and prayer camps served as a resource for helping people with dementia, their paid and unpaid carers and significant others to better cope with living with dementia. This master theme discusses prayer camps as religious entity acting as a site for spiritual care for people with dementia. It discusses religions' roles in caring and supporting people with dementia in the community and how people's religious beliefs and faith in God helped them to better cope with living with dementia. Three sub-themes – prayer camps as sites for dementia care, religion's role in integrating people with dementia into the community and religious faith as a resource for coping with dementia are discussed under this master theme.

9.2.1. Sub-theme 1: Religious care for dementia

As one of the religious care sites where dementia care is provided, prayer camps are seen as sites of healing but people with dementia are kept in (similar justification to asylums but with a religious context). Prayer camps are one of the main providers of mental and other psychiatric illnesses including psychosis, depression, dementia, bipolar and substance abuse issues in Ghana (Arias *et al.*, 2016a; Ibrahim *et al.*, 2016b). As indicated in chapter 3 of the literature review, religious interpretation of dementia in Ghana has included perceiving people with dementia as witches, mad or evil-possessed people. These spiritual interpretations have often required religious / spiritual 'healing' with prayer camps being one of the most important and recognised sites for such treatment and care (Edwards, 2014a; Arias *et al.*, 2016a). This is due in part to the scarcity of formal psychiatric facilities in Ghana.

This sub-theme discusses prayer camps as significant religious spaces for caring for people with dementia and sites where people with psychiatric and other mental illnesses seek help and are cared for. For some families with dementia, prayer camps were the first port of call for help-seeking. For instance, Aggie's family talked about taking her to a prayer camp first before seeking intervention in psychiatric hospital for formal diagnosis and treatment. When Irenekor explained:

We understand she is our mother, but we had to listen to what the family would say and ensure that we do that. The family said we should take her to the prayer camp and so we did. When we went there the prophet said he could cure her and asked us to pay some monies but for all the time she spent there we didn't see any improvement, so we brought her back home

It is not uncommon for families with dementia to believe dementia is a spiritual problem requiring spiritual healing usually at prayer camps. When Aggie started showing sign and symptoms of dementia, her family were unaware of what was exactly happening to her. Aggie's family had multiple perceptions about the cause of what might be happening to her.
Studies by Arias *et al*. (2016) and Ibrahim *et al*. (2019) found that majority of people with mental illnesses in Ghana often seek help from traditional healing including prayer camps. Adwoku, a healthcare professional, shared her experience of relatives sending their loved ones with dementia to prayer camps for religious care as follows:

There are different forms of dementia but most of the people affected can talk about their dead relatives, seeing and hearing from them and all that. Some of them are *taken to prayer camps for a certain period of time because they believe that these are all spiritual problems.*

When discussing what participants meant by dementia being a 'spiritual', illness, they associated dementia with the invocation of evil spirits or forms of possession by evil spirits. When asked for clarity about what Irenekor meant by 'spiritual', she said*,'spiritual' means that someone has invoked some evil spirits on them.*

Believing it to be a spiritual illness, Aggie's family advised her carers Irenekor and Pepdon to take her to a prayer camp. However, after many months with no noticeable changes in Aggie's condition, the family decided to discharge her home and then sought biomedical intervention later. It is also believed that biomedicine treats physical signs but not the spiritual aspect of the illness.

This finding supports Ibrahim *et al.* (2016) work on understanding the pathways that people with mental disorders traversed for psychiatric services in Ghana. The study found that people preferred consulting traditional healers, mostly prayer camps either as their first point of contact in the pathway to biomedical mental health services or as their sole mental health providers in the country. In summary, prayer camps serve as a spiritual refuge for people with dementia and other psychiatric illnesses. The camps are one of the main providers dementia and mental health care in Ghana and families often send their relatives with the psychiatric condition there as they are able to express their fear in witchcraft and seek protection from them at the camps.

9.2.2. Sub-theme 2: Religion and its role in integrating people into the community

Religion and religious institutions provide direct and indirect social / psychological, medical services and physical infrastructure across the country (Pokimica *et al.*, 2012; Addai *et al.,* 2013). Some of the support religious bodies provide have included helping people in their integration into their daily lives. The social support and the psychological buffers that people derive from their religious organizations and faith may be one of the insurances a person can fall on in times of social and economic crisis (Pokimica , 2012).

This sub-theme examines the role that organised religion, religious institutions such as the church and specifically prayer camps play in shaping lived experiences and subsequent social understandings of dementia.

Nateye spoke about the prayer camp treating people with dementia well and making them feel at home when describing the relationship between staff and people with dementia that they cared for. He said this:

Some of them after recovering from here we let them know or we say to them that they can come back. Some of them too they say that when they went home how they were responded to by the environment they don't like so they themselves come and stay here.

Nateye explained that the prayer camp staff often made people with dementia felt at home and so some preferred coming back to stay there after they had been discharged home. He cited an example of a resident who found life at home too difficult to cope with and so decided to return to the camp. He stated that:

He then he said to himself, after all when I was at the prayer camp at least I had something to eat, so he himself gathered some money and came back to stay. We accepted him and told him to get himself involved in whatever we do – when we send him, he should go, if someone needs help, he should help them. He knew how to shave (was a barber) and so we bought him razor blades so that when someone needed to shave their hair, he could shave him and get some money. Now he feels at home.

He went on to explain how the resident in question had no food to eat and no proper place to sleep and so decided to go back to the camp as life there was a lot better than it was at home. He felt isolated and was neglected by his family when he went home, Nateye explained.

Jessegya added that they attended to and interacted well with residents and just joke with them. He stated:

It was the attention that we give them. These people when they come, to be frank, the way we handle them here, we treat them nice, it is different from other places because at least, we have time for them, we play with them, we just joke.

Responses from participants above illuminate the positive relationship staff at prayer camps had with people with dementia who demonstrated non-aggressive, non-violent behaviours. Other participants including Gladys spoke about the support the churches / Christian congregation provided them more especially after developing dementia. She stated:

If I were ill, I would tell the church and my pastor, and some members of the congregation would come and pray for me. They also visited me. They were happier if I went back to church. They can see that by God's grace, I have been well again and all would be happy!

Some people with dementia found religious groups including prayer camps and their activities helpful in addressing the religious / spiritual, health and social issues including stigma that they were facing. these took the form of providing practical and financial support as well as helping people with dementia and mental health issues integrating back into their communities after treatment from the prayer camps.

9.2.3. Sub-theme 3 Religious faith as resource for coping with caring for dementia

This sub-theme considers how some people with dementia and their family carers managed living with dementia through their faith. Maryako' s faith was expressed through prayer. She talked about praying to God and hoped that her mother could be healed of her illness. She said this:

As they keep saying that every day is different, we only pray to God that He, the great physician, who is able to do all things should heal her for us one day. He created us and everything within us; so, He knows our inside-out. We keep praying that God Himself touches her wherever the illness is and heal her for us. It is now a lot better than before.

Maryako' s belief seemingly gave her hope in God's healing power in the cure of her mother's illness one day.

Religious belief and faith in God still featured as a salient theme in participants' resilience. While some participants believed in God's direct intervention or miraculous cure of the dementia afflicting their relative, others hope and faith in God was expressed as a means of resilience – to enable them cope with living with dementia. This was demonstrated by the expression of Marygya who had cared for her sister with dementia Adwoa for a few years. She stated:

God is saying that this is just a temptation but as He is with us, the temptation will soon be over. So, we would have to wait on Him till we are set free from those temptations. If it's a sin we have committed, human as we are, we will continue to sin but if we ask for forgiveness, He will have mercy on us and forgive us. It's all about time, it will definitely pass away.

Marygya found it reassuring that God was with them and that waiting on and praying to Him could helpfully deliver them from what she described as 'temptation'. Like others, Gladys also relied on her religious faith to cope with her diagnosis of dementia. She explained:

He is our healer, helper and redeemer. He is able to do all things and would do it for us. If we have such confidence and strong faith in Him, He will fight for us, and it is true. When we are in suffering, He would take away all our cares and worries, set us free from these and give us peace and comfort. So, as for me, I know that people can say all sort of things to discourage me but, in spite of all these, I know and believe in the God I am following. So, it doesn't bother me much at all.

She relied on the description of faith and hope in God to take away all the cares and worries she faced with her condition. Religion was something that Gladys seemed to have held on to amid the challenges she was going through. She maintained regular church attendance and prayed constantly while asking God to take away the cares of her world. The feelings Gladys expressed above related to religion serving as a coping resource to give her hope for the future. She seemed to have coped and dealt with the stigma associated with her dementia through her faith and belief in God. She intimated that:

The Bible itself has made it clear that when Job went into calamity, his own friends rejected him and accused him that he was suffering because of his sins. So, as for what people will say, as they say, let them say it and give all things to God because He is the one who when we encounter any difficulties or sufferings, tells us that we should not cry for Him but for ourselves.

Accused of being a witch, demon-possessed or a mad person, Gladys refused to accept any of these labels. Her quote suggests that her reliance on God helped her to better cope with living with dementia. It would also seem that spirituality provided Gladys some sense of purpose despite the losses associated with her dementia. It would also seem that Gladys had anticipated that people would be accusing her of being a demon-possessed or mad person as Job's own friends accused him of being the cause of his illness.

Another participant, Marygya shared that knowing Christ had helped her cope with being a carer for her sister with dementia, Adwoa. She informed that:

In my opinion, if one has not known and accepted Christ, things like this can be a headache for them indeed. But God knows everything, so I don't mind what the society says. All God says is what I hope for.

Marygya said this when she was asked what it was like to be a carer for someone with dementia. In Ghana, people can easily accuse family members of being a witch or bewitching their relative with dementia or mental illness. Aware she could be accused of bewitching her sister Adwoa, Marygya' s focused on caring for her sister rather than what others might say about her. She seemed to have coped with her caring role through her faith in Christ. She did not appear to feel stigmatised for being a carer for someone with dementia who may have been perceived as a witch or a mad person.

This theme has considered how participants relied on their spiritual and religious beliefs as a resource to cope with living with dementia. It highlights people's understanding of dementia as a stigmatised condition and how their faith shaped these understandings. Most participants perceived God as an integral part of their social and spiritual support system and related to Him through prayers. Most participants emphasised the impact of spirituality on their caregiving and receiving experience. It was evident that most participants believed that their religious and spiritual beliefs had positive impact on their experience of living with dementia.

9.3: Master theme 3: Experiences and views of healthcare professionals about dementia

The current medical system in Ghana provides medical and mental healthcare which is being managed by the Ministry of Health (MoH). In section 2.5.0 of Chapter 2 the role of government, quasi-government (i.e. the Police, Army, large firms and corporations) and religious missions of the health systems of Ghana were discussed. Three sub-themes are discussed under this master theme: description and significance of biomedicine (psychiatric hospitals), factors contributing to the use of prayer camps and psychiatric hospitals and the opportunities of collaboration between biomedicine and prayer camps.

9.3.1. Descriptions and significance of the hospitals

PH1 and PH2 are two of the main healthcare facilities dedicated to psychiatric care and employ about 80% of the psychiatric workforce in Ghana (Ibrahim *et al*., 2016. They render the major referral psychiatric services and serve a number of people with dementia and others with a variety of mental disorders in the country. Staff working in these hospitals talked about their experience of working with people with dementia and their families both at the hospital wards and in the community settings.

Recounting his experience of working with people with dementia as a nurse and prior to his training to become a physician assistant (prescriber), Kyeiba shared the following:

There were so many times I received 'knocks' from this man. He would call me to come and lace his shoes for him and before I realised, there's a 'knock' on my head and I wouldn't know why he did that. Most of the time his wife would come and say what is wrong, why are you hitting this man? He'd say, he's not doing it well but I don't think that I wasn't doing it right. People with dementia can be extremely angry right now and at the same time be happy in the next moment.

Kyeiba recognised that dementia could change people's mood and behaviour. However, he did not seem to understand why the man he was caring for was hitting him. Rosebu however talked about her experience of caring for people with dementia within the hospital ward in what she described as staff's "headache". She explained thus:

I think you just mentioned our headache because people with dementia are often confused, and you have to basically do everything for them. Sometimes, they would defaecate on themselves and smeared it everywhere. They become babies again!

Rosebu explained that people with dementia could become confused and forget how to do things for themselves, often requiring help from staff with almost everything they need. While people with dementia may need assistance with some activities of daily living, Rosebu's description of them as "become babies again" seems to suggest her lack of awareness, understanding and perhaps training in dementia.

Another everyday experience of working with people with dementia shared by Petan related to people with dementia refusing care from staff as illustrated in his statement below:

I think one of the things I would say is that sometimes they refuse care. They refuse self-care. They think that you're bothering them so when you want to attend to them, it's a hell. Before you get things done for them, you see that you're going through a lot.

Similar to Rosebu's, Petan's statement appears to be stigmatising and provides a very negative understanding and apparent lack of awareness of dementia.

For some healthcare professionals, caring for people with dementia required involving their families in their care and helping them to understand the disease. Milla explained how they involved families in the care of people with dementia thus:

We try to help people with dementia by involving their relatives in their care. We try to have family therapy to help them understand why people with dementia *sometimes behave the way they do. We invite the family, the carer and the patient. We do psychoeducation first, then talk to the wife or carer what they should expect when the patient is relaxing, how they should support the patient in terms of giving medication and then helping the patient to maintain their personal hygiene.*

Family therapy provision often took place both in the community and at the hospitals. Talking about family therapies in the communities, Maame intimated thus:

We go for home visits and if there are special cases we pay particular attention to the special case. So, if they are unable to come, we call them first and tell them when we are coming and when we go, we educate them on the mental health issues. We have to follow up to find out a bit more about special cases.

The 'special cases' used above suggest 'emergency' situations that families with dementia, drug abuse or mental health-related issues including depression or suicidal thoughts could be experiencing. The expectation was for families with people with psychiatric issues to attend the hospitals especially if there was a crisis. However, if they were unable to attend the hospital, they might call the healthcare professionals on the phone who would respond to this by visiting the families at home.

In addition, Akugya spoke about providing family therapies at the hospitals. She explained:

To not inconvenient them, we normally schedule the family therapies to coincide with their monthly health review days, so they don't have to come to us again for those things. So, they are coming for their review, and we will have everything done at once so that they don't have to come another time and spend money.

Providing family therapies and people with dementia's monthly health reviews on the same day suggest that families with dementia could save money and time as attending these sessions separately could cost them more money on transportation and time. However, spending more time attending these sessions on the same day could be tiring for people with dementia. It was also possible for healthcare professionals to attend to more people with dementia at the hospitals than visiting them at homes individually owing to the length of time it could take especially those who are not car drivers and had to rely on public transport for home visit to families.

The focus of other healthcare professionals spatial experience of dementia centred around the challenges they faced at their workplace and the impact these had on the quality of care and work they were able to provide. Adwoku for instance spoke about the lack of financial resources and support especially from the government and how these affected the quality of service or care they could provide. She explained:

Getting funds and all that. The government supports us but mostly the support we get isn't enough. As you can see coming into the hospital, there are a lot of infrastructural works needing done and all that. We're getting little support from the government to renovate the wards, so it is very difficult. If we had support and the government was to help us, I'm sure it would have been well because we talk about it but it's like for now our hands are tied, so the little resources we have, we manage it according to what we can do. So, it's not as if we haven't felt the need, we know we need infrastructure like that, but we just don't have.

Adwoku felt they (healthcare professionals) were unable to provide "total care" to people with dementia due in part to the lack of or insufficient resources they had and with which they worked. This negatively impacted on the care and support they could provide to families with dementia.

Another challenge most healthcare professionals mentioned was breakdown in relations and communication with families after their loved one with dementia was admitted to the hospital. Barima intimated that:

I think one of the challenges we are facing caring for people with dementia is that we hardly come into contact with their relatives. Well, once a while we get in contact with them but at the times we need them most, we don't get them. When you call either their phone is off, their number is changed or they would say, Oh, I don't know him so let me find out from somebody who I think may know him. So that is it! You try to call again, and it doesn't go. The phone is switched off.

Petan went on to add that people with dementia had been left to die in the hospitals owing to some families leaving their relatives with dementia in the hospital for many years with some even dying in the hospital. He illustrated:

I had this issue where we seldom admit demented patients, but we end up nursing dementia in the facility. What do I mean? Some of the patients we admitted have been here for how many number of years now? You can imagine! So, they grow here, they become old here and then die here. These are some of the challenges that we probably have with relatives.

In relation to Petan's statement above, Barima shared an experience where families even refused to answer telephone calls or pretending, they did not know their relative with dementia in the hospital. He remarked thus:

Right now, there is somebody at the ward who needs to be discharged but because the person is suffering from mental illness, the relatives are not coming forth. The other day we called the sister, and she sometimes answers but sometimes she wouldn't. so, we contacted the CPNs in the area and they traced the patient to his family house but then the family members were saying they don't know him. So that's the issue.

Statements from Barima and Petan and other healthcare professionals suggest that most people with dementia and mental illnesses were neglected and rejected by their families and were left in hospitals for long time with some even dying there. Some families either changed their phone numbers so they could no longer be contacted or pretending to not knowing the person with dementia whom they may have taken to the hospital themselves following their illness.

This section has considered healthcare professionals' lived experience of dementia in both the hospital and community settings. Healthcare professionals highlighted a number of issues or factors relating to their work with families with dementia on one hand and the lack of or insufficient resources they had or needed to work with one another. Undoubtedly, these negatively impacted on the quality-of-care healthcare professionals were able to deliver to families with people with dementia. The section has also highlighted the views of some healthcare professionals which appeared to be stigmatising and showed negative understanding, lack of awareness and appropriate training in dementia.

9.3.2: Factors contributing to the use of biomedicine and prayer camps in dementia care

The existence of a dual healthcare delivery systems and the use of either traditional (with special reference to prayer camps / faith-healing) or biomedicine has had a significant effect on healthcare practices in Ghana (Koduah *et al.*, 2019b). Both healthcare professionals and prayer camp staff talked about people with dementia sometimes receiving treatments that were a combination of biomedicine and traditional faith-healing interventions. Adwoku explained why this often happens in her experience of working with families with dementia in the statement below:

My experience so far is that patients usually default their monthly health reviews. The reason is that because the treatment and management of dementia does not really cure the condition, anytime caregivers bring a patient to the hospital their expectation is for the doctor to give them medication that will completely solve the cognitive deficit and all that. And if they don't get that, they feel much isn't done for the patient because when they come, the condition is still the same. So, there is no motivation for them to come.

As Adwoku's account indicates, dementia has, as yet, no cure and families with people with dementia seemed to have lost hope in biomedicine's ability to fully cure dementia after a period of hospital attendance. Families with people with dementia may, therefore, likely tend to faith-based treatment modalities that are based on their faith and beliefs systems as a consequence. An example of this was shown in section 6.1.10 (chapter 6) where Aggie's family first took her to a prayer camp before considering biomedical intervention. Also, often an ill-person in Ghana including those with psychiatric illnesses may choose to disregard the condition and use treatment modalities that is known to them, their family or friends (Koduah *et al;* 2019). Ofori-Atta *et al.*, (2018) identified that many Ghanaians would consult traditional medical practitioners before, during or after receiving biomedical treatment. While these consultations and choice of treatment modalities may be due to cultural reasons, lack of or insufficient information, knowledge and understanding of dementia and its symptoms may have contributed to families with dementia's diminished hope in biomedical interventions.

Some prayer camp staff also believed that the increasing specialisation of biomedicine means that healthcare professionals work according to their respective areas of specialism only, however prayer camps provide both physical and spiritual healing. This was explained by Stefano in the statement below thus:

If you go to the Teaching Hospitals there are eye specialists or psychiatrists, all of whom work according to their specialisms only. Each has specialized in a particular field, so when you consider those who come here, as human beings, we need life so whether one is spirit-possessed or whatever, the word of God can deliver them. So, both physical and spiritual-related illnesses can be dealt with or cured through the word of God or in prayer camps where people can get their deliverance.

Stefano's statement suggests that faith-based system of healthcare focuses on the person as a whole – both the physical and the spiritual aspects of the ill-person while biomedicine tends to disintegrate the person owing to the increasing specialisation of biomedicine. This means that several referrals can be made for just one person (Koduah *et al.*, 2019b). Thus, biomedicine may treat people exclusively according to its norms and may ignore the spiritual or other cultural aspects that helps in providing explanatory models to the many aspects of illnesses in Ghana (Ofori-Atta *et al.*, 2018).

Additionally, it is felt that prayer camps provide cultural / religious / spiritual explanations to psychiatric illnesses including dementia with supernatural mainly witchcraft and other evil powers as the causative agents of such illnesses (Adjorlolo *et al.*, 2018; Agyapong, 2020). These perceptions and explanations appear to be contradictory to the established knowledge of biomedicine, but healthcare professionals were aware of these perceptions and appeared to draw on them to make judgements about treatment of dementia. Adwoku and other healthcare professionals shared their experience of relatives sometimes either taking their loved ones with dementia from the ward to prayer camps temporarily for 'religious or 'spiritual' treatment and bringing them back to the hospital or vice versa. Adwoku said this to indicate their awareness of families visiting prayer camps:

There are different forms of dementia but most of the people affected can talk about their dead relatives, seeing and hearing from them and all that. Some of them are taken to prayer camps for a certain period of time because they believe that these are all spiritual problems.

The above quotation seems to suggest that it is impossible to do away with traditional / faith-based system of healing in the treatment of dementia and other psychiatric illnesses in Ghana. Koduah and colleagues' (2019) in the study *I sometimes Ask Patients to Consider Spiritual Care,* noted that some healthcare professionals in Ghana were mostly in favour of either referring people with psychiatric illnesses to traditional healers or would not prevent them from consulting traditional practitioners if they wished to do so. This finding also supports the result of other studies including (Ae-Ngibise, Cooper, Adiibokah, Akpalu, Lund, Doku, and The MHaPP Research Programme Consor, 2010) which highlighted the immense psychosocial support that many traditional and faith-healers provide.

9.3.3: Opportunities for collaboration between biomedicine and faith / traditional healing practices

Although there appears to be tensions between biomedicine and traditional / faith-based systems of healing in dementia and other psychiatric illnesses, data from this study suggests they rather complement each other and that opportunities for the two systems working together also exist. Some prayer camp staff felt they were already working collaboratively with healthcare professionals as shown in Jessegya's statement below:

As for here we work with nurses from the TQ Hospital. We also have psychiatric doctors who attend to the patients here.

Nateye provided further clarity on Jessegya's statement thus:

So, we do the spiritual side, and they (hospital staff) do the medical side of things. There are times too that people get their deliverance instantly without any medicine. It depends.

The statements above suggest that some prayer camp residents received care and treatment from the biomedical facilities which could be regarded as supplementing the work of the prayer camps. Conversely, some prayer camp staff felt they were able to cure both psychiatric and physical health conditions that hospitals could not cure. Profedem shared this:

There are so many other illnesses including HIV/AIDs that come here for cure so if those with mental health issues stop coming here, it isn't an issue for me at all. Someone with HIV/AIDs went to the hospital and was prescribed HIV/AIDs medication and he continued taking them. It made no difference to his condition, but we healed him through prayer. We have spirits to back that 'spirit'. For instance, there is spirit for Asthma. HIV'AIDs has been in existence from time immemorial. People think it is a recent disease and that people get it through unprotected sex but there are spirits behind HIV/AIDs also. Those HIV/AIDs that are caused by spirit can be easily cured if they seek help from prayer camps but those that are transmitted through sex can take longer but God can help the person with the condition.

Profedem made this statement when she was talking about the government's intensive exercises to close down some of the prayer camps whose activities had been deemed to be unsatisfactory. Although she made references to HIV/AIDs and Asthma, Profedem cited these as examples of diseases other than dementia or psychiatric illnesses that were also believed to be caused by 'spirits' which were being cured through the work of the prayer camps.

Stefano suggested for a collaborative work between biomedicine and the prayer camps. Stefano highlights:

The government must do its part, and the doctors (biomedicine) would play their role. For some people, as soon as they come here, mummy (prophetess) would tell them to go to the hospital for a check-up first after which we would be praying for them. So, if it is spiritual – we would do our part and if physical the doctors would do their part also. So, it's all about collaborative working.

When the causal attribution of dementia was suspected to be both physical, for example following a stroke and supernatural, there was no clear pathway to access dementia and other psychiatric care. Some participants attended a conventional medical facility either before or after consulting a prayer camp and for others prayer camps were their first port of call.

In summary, it is almost impossible to do away with traditional / faith-based healing systems in Ghana (Osafo, 2016; Koduah *et al.*, 2019c) owing to the Ghanaian culture associating dementia and other psychiatric care to be inseparable from the domains of religious beliefs and cultural practices of the country. The traditional / faith-based practitioners know their communities well and so use their local knowledge that resonates with the community's beliefs to provide basic psycho-social and religious / spiritual needs of people with dementia that is most likely absent in biomedical practice

9.4.0. Summary and conclusion of chapter

The home, prayer camps and psychiatric hospitals were three main sites where the study participants lived or worked. It is not uncommon in Ghana for people with a psychiatric illness to be removed from hospital by their family to consult a prayer camps / faith-healing or other form of traditional healing centres. This is partly due to the widely held belief that psychiatric illnesses are caused by supernatural evil forces which can be best banished by traditional / spiritual healers such as prayer camps (Edwards, 2014a; Arias *et al.*, 2016a).

Religious institutions mainly churches, and prayer camps offered practical, emotional and spiritual support to people with dementia through visitations, interaction with others who share the same faith. Some people with dementia were visited by their church members which appeared to be an important source of practical, spiritual and emotional / psychosocial support for them. Prayer camps on the hand offered treated through faith healing camps. The cultural beliefs in witchcraft being part of the causality of dementia have a significant negative impact on relationship between people with dementia, their families and their interaction with the wider society. This wider perception or stigma and its associated stereotypes shape the society's understanding of and relationship with families of people with dementia as well as those who care for them

Evidence from the study suggests that healthcare professionals' views on dementia could be very stigmatising owing to the words and phrases they used to describe people with dementia. Based on those stigmatising views, it would seem that healthcare professionals lacked understanding, awareness and training in dementia and its care. The findings further suggest that prayer camp staff and biomedical healthcare providers appeared to be complementing each other's work or at least were engaging with each other in the care of people with dementia. It was also evident from the study that not only prayer camps staff were referring residents believed to be suffering from physical ailments to hospitals to mental health facilities but also healthcare professionals were visiting to treat people with dementia and other psychiatric illnesses in the prayer camps. Nevertheless, potential challenges to meaningful partnership between the two systems of dementia / mental health care in Ghana was evident owing to differences in the beliefs systems about the causality of dementia and other psychiatric illnesses and their modes of treatments. Thus, while families with people with dementia and prayer camps often complement 'spiritual treatment' with biomedical treatment of dementia, collaboration between healthcare professionals and prayer camps does not seem as easy as it can be commonly assumed given the differences in treatment modalities between the two systems. However, promoting greater understanding rather than maintaining indifferent distances between them may lead to a more successful cooperation and harmonious working relationship between the two systems of dementia care in Ghana.

Chapter 10 Discussion

10.1: Introduction

This thesis has explored Ghanaian people with dementia and their carers' experience of living with dementia, a degenerative and progressive neurological condition and its impact on their carers' lifeworld. The goal of this chapter is to discuss the relevance, significance and implications of the findings of this thesis. Exploring these views is crucial. In the first instance, alongside other sub–Saharan African (SSA) countries there is a paucity of first-hand data on dementia and the lived experience of dementia in Ghana. Secondly, understanding the social dynamics of dementia in a resource-limited country like Ghana is critical for developing effective and appropriate interventions for people with dementia and their carers in the country, as well as the wider SSA region.

This chapter includes discussion on the key contributions this thesis makes to the care and treatment of dementia in Ghana, and the practice and policy implications in terms of service delivery for people with dementia and their families. The lifeworld existentials of van Manen are utilised here to draw out aspects of the lived experience of people with dementia in Ghana.

10.1.1: Key findings from the study

This thesis provides an in-depth, phenomenological presentation of how the various symptoms of dementia are experienced and how they revealed themselves through disruptions to the lived body bringing the body and its place in the lifeworld into conscious reflection.

This study has provided an important contribution to knowledge about stigmatising experiences, attitudes and beliefs about dementia in Ghana, SSA and worldwide. The study highlights the impact of culture on how families understand and respond to dementia in Ghana. Dementia care provision mostly focuses on the socio-cultural causes as well as the symptoms of the condition. The study identifies how in the Ghanaian culture competing understandings of dementia, which can be seen as part of the normal ageing process; as a result of brain disease; spiritual illness resulting from supernatural forces including witchcraft, evil-possession, curses from different agencies including God and fellow human beings, are culturally shaped with profound impacts for its lived experience.

Findings from the study showed that religion, faith and spirituality shape cultural understandings of dementia and therefore the meanings that study participants attributed to the lived experience of dementia in Ghana. Religion and spirituality remained crucial in the lives of families of people with dementia, sometimes simply as something to hold on to amid the storm of the disease. Previous research focused on religion and spirituality as a mechanism to cope with dementia and other chronic illnesses (Bursell and Mayers, 2010; Dalby *et al*., 2012; Baumgardner and Mayo, 2021). Participants' faith in God and valuing that faith sustained most families with dementia and enabled them to cope with living with dementia. Participants held the belief that God was in control and that everything would work out in the end; carers believed that their relative with dementia could be healed by God. Such cultural understandings also adopt wider spiritual or supernatural elements as mechanisms to understand dementia. In Ghana as in other countries in SSA, belief in supernatural forces pervade the minds of many people regardless of their education and professional background. These beliefs also influence interpretation of the biomedical concept of dementia, as known to healthcare professionals who were trained in biomedicine but who also engaged with spiritual models or understandings of the illness (Faure-Delage *et al*., 2012).

10.2: The lifeworld of people with dementia in Ghana

Here findings from the previous three chapters are brought together using the lifeworld existentials to enable a deeper phenomenological understanding of people's experiences of dementia in Ghana. Presenting the findings using the phenomenological structure of the lifeworlds as a means to understand experiences of people with dementia can help both paid and unpaid carers to better understand people with dementia's everyday experiences of living with the condition within Ghanaian context. As Nygard and Borell (2008) assert, when encountering a person with dementia health professionals need to comprehend how the individual experiences the illness.

To enter the lifeworld of human experience and to gain more understanding of how dementia can be experienced by those afflicted by it, a phenomenological approach inspired by the ideas of van Manen (1990, 1997) was adopted in this study. The aim was to gain some insights into participants' understandings of dementia as well as the problems they encountered in their everyday life of living and working with dementia (Galvin and Todres, 2012). It is important to explore these views as the meaning of the bodily changes resulting from dementia can be understood as living with an altered perception of the body and self. With dementia, people with dementia perceived their bodies as unfamiliar and unreliable. Discussions around the dysfunctional bodies in dementia may therefore be crucial in a country like Ghana where there is a paucity of first-hand data on the lived experience of dementia and a pluralistic healthcare system with medical and alternative conceptions of health and illness. An awareness of the inter-relationship between people with dementia and their lifeworld existentials of lived body, lived relations, lived time and lived space will contribute to a better understanding of how bodily experiences after dementia influence the perception living with dementia. Such awareness is essential for healthcare workers when planning treatment and care and preparing dementia patients for their own and their relatives' future life (Gyimah *et al;* 2022).

10.2.1: The lived body in dementia

Everything we do we do with our bodies, when we think, speak, listen, eat, sleep, walk, relax, work and play we 'use' our bodies. Every aspect of our lives is therefore embodied (Phinney and Chesla, 2003; Nettleton and Watson, 1998). This thesis adopts a phenomenological perspective focusing on 'lived body', the idea that human beings and their consciousness are invariably embedded within the body (Nettleton and Watson, 1998).

As indicated in the findings chapters, forgetfulness and incontinence are two key parts of people with dementia's lived body experience. These two phenomena provide exemplars of the changing lived body, which affected people with dementia's ability to interpret the world they lived in. Both forgetfulness and incontinence are fundamental elements of the lived body that people with dementia should have been able to control as part of their taken-for-granted activities, however these became uncontrollable following dementia.

Forgetfulness fundamentally disrupts people with dementia's lifeworld. In dementia people's thinking and ability to recall things, events, rituals or perform activities were challenged as they were no longer able to interpret the world they lived in. Thus, people with dementia's taken-for-granted, everyday activities became disrupted as people with dementia were unable to recall without effort or prompt from others. In the literature, Fuchs (2012) found forgetting to be a common phenomenon in everyday life of people with dementia and up to 55% of older people (65 years or older) in his study complained about being forgetful. With dementia people's bodily dys-appearance removed them from the activities they normally engaged in. This alienated them from their social world and forced them into limited sphere of the body (Gimlin, 2006). In this study, people with dementia's previous lived bodies which were once taken-for-granted and worked well dys-appeared in their immediate awareness thus rendering their bodies visible and unfamiliar to them (Leder, 1990; Phinney, 2002).

Within the findings, some people with dementia described their experience of incontinence as being 'abnormal' and they wished to be able to live lives as before but were unable to do so owing to their malfunctioning bodies. The lived bodily experience of incontinence was embarrassing, shameful and an invasion of people with dementia's privacy. With incontinence, people with dementia had no choice but to disclose (some of) their intimate body parts to others whose assistance they needed to clean themselves up of the mess caused by their failing bodies. People lost their autonomy through incontinence suggesting that a person's body was no longer absent, and its physiological function of urination could no longer be depended on. Incontinence also led to stigma, and this affected families with dementia's social lives. Cassells and Watt (2003) and Cole and Drennan, (2019) investigated incontinence management of people with dementia from the perspectives of their family carers and found it to be a humiliating and embarrassing condition. Through incontinence people with dementia lost control of their bodies leading to what Drennan *et al.* (2019) described as 'loss of social acceptability'. Incontinence limited people with dementia's social life. For instance, a family outing which was previously a taken-for-granted activity now required thinking and planning as families needed to ensure they went to places where they would have access to public toilets.

The image we hold of our bodies will to a greater or lesser extent impact upon how we experience our bodies in everyday life. It may impact upon our sense of self, our degree of confidence in social situations and the nature of our social relationships

(Nettleton and Watson, 1998). Incontinence made people with dementia uncomfortable in social settings. People feared that their altered bodies might undermine how significant others felt about them. This affected people with dementia's willingness to socialise with others. People with dementia made efforts to improve on their social life by wearing incontinence pads to try and bring their perceived dysfunctional bodies in line with their 'ideal' bodies (Drennan *et al.*,2011).

In summary, from a lived body perspective, experiences of forgetfulness and incontinence provide greater insight into the body and people with dementia's involvement in body management practices like recall and bowel / urine management. This thesis has demonstrated that the body is central to our identity. In dementia, people experienced the body as intrusive and limiting. Incontinence and forgetfulness affected people with dementia's relationships with their families and significant others as they were presented as being dependent on others including children, spouse and extended family members to meet their needs for activities of daily living.

10.2.2: Lived relation in dementia

Dementia also affected the lived relations of people with dementia. We seek security and meaning in our everyday lives through our lived relations (Moi *et al.*, 2008) and our relationships are intimately interconnected to all the other lifeworlds (Peacock *et al.*, 2014). People with dementia encountered different types of relationships on their dementia journey and these had an impact on the care and support that they received.

Findings showed that tensions ensued in some families after a member developed dementia. This could be due to the families' perception about the cause of their relatives' dementia and the stigma associated with having someone with dementia in one's family. Such tensions interfered with families' dementia care experience as families' collective responsibility for caring for their members with dementia became the responsibility of a few family carers. Thus, the core value and the strong commitment of the family as a system of support, socialisation and assistance became weakened following dementia. This resulted in increased carers' stress and financial burden on the few who cared for their relative with dementia.

Dementia also led to changing social roles within families. Family carers acquired new or additional roles and responsibilities as they became ‘parents’ and breadwinners for their respective families. The interdependency in familial relationships altered as most parents (now with dementia) became dependent on their children or spouses (as their carers). As indicated in the findings, sons and daughters became carers for their parents with dementia. This was in line with the concepts of reciprocity and filial piety (Cheung and Kwan, 2009; Laidlaw *et al.*, 2010a; Zhang *et al*., 2019) where children are expected to care for their parents when they are no longer able to care for themselves independently due to old age, illness or both (Coe, 2016). Having cared for their children in their childhood years, culturally there is an expectation of children to care for their parents in return when they grow. In the literature, caring for older parents in Ghana (like many parts of the world) is and has been viewed as family’s responsibility for many years. The roles and relationships between parents and their children are regulated by the concept of reciprocity expressed in the Ghanaian language “*sɛ m’ahwɛ wo ama wo se afiri a ɛsɛ wo nso wo hwɛ me ma me deɛ tutuo”.* This literally means “if I have looked after you to grow your teeth, you must (it is your responsibility to) look after me to lose mine”. The concepts of reciprocity and filial piety are practised in many other cultures (Cheung and Kwan, 2009; Laidlaw *et al.*, 2010b; Coe, 2016; Zhang *et al.*, 2019) and in China it is a legal requirement for children to look after their aged parents. However, Benna and Garba (2016) and Cobbinah *et al.* (2016) have found the occurrence of socio-cultural and demographic changes such as rapid urbanisation, influence of western cultural values and migration among others have decreased the capacity and availability of traditional family care and support systems in Ghana (Benna and Garba, 2016b; Cobbinah *et al*., 2016).

Changes to lived relationships also manifested themselves through stigma; the experience of negative feelings towards people with dementia and their carers. Stigmatising labels excluded people with dementia from mainstream activities and services through perceiving people with dementia as witches, mad or evil possessed people (Mkhonto and Hanssen, 2018a; Brooke and Ojo, 2020a; Musyimi *et al.*, 2021; Ocran, 2022). Underpinning these negative images is the belief that in Ghana, people with dementia are perceived to be ‘abnormal’, ‘have no brains’ and therefore incapable of expressing themselves (Quinn, 2007; Ocran, 2022). The current study suggests that people’s response to dementia is being driven by their poor understanding of the condition, in conjunction with cultural beliefs about dementia and its cause, which influence taken-for-granted interpretations of the condition as a lived reality. Beliefs, knowledge and attitudes towards people with dementia and their families are important areas in helping us understand the manifestations of internalised, public and structural stigma and discrimination (Jacobs *et al.*, 2022).

In summary this study has highlighted the impact of culture on how families understood and responded to dementia in Ghana. Dementia care provision mostly focused on the socio-cultural causes as well as the manifestation of the symptoms of the condition. Perceiving people with dementia as witches, mad or evil-possessed was stigmatising and negatively impacted on the care and support people with dementia received.

10.2.3: Lived time in dementia

Dementia also affected families with dementia's present and future possibilities. People with dementia experienced longer time to complete activities of daily living (Baars, 1997; Nyga and Johansson, 2001). People with dementia had difficulties with knowing, remembering and planning when and how to do things or undertake some activities of daily living such as when to take their medication or keeping their health review appointment times. People with dementia were therefore reliant on their carers or significant others with prompts or assistance to undertake their mundane, taken-for-granted activities of daily living. In a study of the experience and management of temporality in Stockholm, Nygard *et al*. (2001) found their participants with dementia to have difficulties with "knowing when" and "how long". Both people with dementia and their family carers realised that something was wrong with their relative with dementia due to the mistakes that people with dementia were making, however they were unaware what the cause was other than, in most cases, attributing it to the normal ageing process. It was also common to find people with dementia's story being jointly lived and jointly told especially where the person with dementia was struggling to narrate their stories about their experience of dementia.

Another finding of participants' experience of lived time related to their hope and faith in God. This was evident through participants' expectation of a miraculous cure for dementia. People who perceived dementia to be a divine punishment (by God), a curse or the devil casting spells were still hoping for a miracle that these might be reversed. This suggests that people with dementia, their carers and prayer camp staff saw the future of dementia differently from their non-dementia counterparts or those who believed in the biomedical model and who held the view that dementia is an irreversible condition. Additionally, people's faith provided them some hope and emotional strength to better cope with the problems and challenges they were facing living with and caring for dementia. Evidence from a study by Jewell *et al., (*2016) on the faith of primary carers of people with dementia in some UK churches indicated that participants' Christian faith helped them to cope with their caring role, albeit some reported experiencing loneliness owing to stigma and the demands of their caring role (Faure-Delage *et al*., 2012).

10.2.4: Lived space in dementia

Changes to the lived body was manifested through the lifeworld existential of lived space with the spaces people with dementia lived in becoming unfamiliar to their bodies following dementia. Svenaeus (2011) described the unfamiliarity of our bodies in illness as unhomelike being-in-the-world. In dementia, our bodies experience the world as being alien or foreign and familiar and unfamiliar environments and spaces can enable or disable us. In the current study, people with dementia became increasingly forgetful with their ability to understand, remember places, events of the past, retaining and retrieving information becoming compromised. The findings show that people with dementia lost connection to what had been familiar places resulting in them getting lost as they were unable to find their way back home.

People with dementia shared home spaces with their families. However, these spaces were experienced differently by people with dementia and their family carers. Some people with dementia had positive experience of the home space facilitated by their feelings of togetherness, always having family around and seldom having to feel lonely or abandoned. The home space thus provided opportunity for people with dementia to be connected and reconnected with others. Two people with dementia who moved in with their families after developing dementia reconnected with them (families) after many years of living away from each other. In addition to being reconnected, people with dementia's security and safety were protected by their families with whom they lived. Previous studies (Norlyk *et al*., 2013; Førsund *et al.*, 2018; Petherbridge, 2019) identified the lived space as an important and supportive environment that creates communities that compensate for the fading capabilities of people with dementia. These findings are in line with current studies where people with dementia felt protected by and reconnected with their families after developing dementia. For most people with dementia in the study, the home was found to be a peaceful, secure and settled space for people with dementia.

In contrast, the home spaces that were meant to be protecting people with dementia were given different interpretation by them. For some people with dementia, sharing living spaces endangered feelings of safety from others as some families were chaining or locking people with dementia up. Chaining and locking up restricted people with dementia's freedom to access social and physical spaces both within and outwith the home environment. In an anthropological study of people with mental illness in rural Ghana, Read *et al; (*2009) visited over 40 households with a family member with mental illness as well as churches and hospitals and found chaining and locking people up to be commonplace in homes and treatment centres. This current study is in line with Read *et al'*s (2009); where people with dementia were found to be locked up in their homes. Chaining and locking up people with dementia were seen as a social control or safety measure to prevent people with dementia from harming themselves and others or were used by families to avoid the shame and embarrassment associated with having a family member with dementia. Faced with the problem of looking after people with dementia with concerns about risk to self or others and lack of and ineffective psychiatric treatment services, many families with people with dementia appear to feel they had little or no option but to physically lock up or chain their relative with dementia (Puteh *et al*., 2011). Previous studies (Puteh *et al;* 2011; Hughes, 2018; Patel and Bhui, 2018) have reported that the practice of physical restraints in mental hospitals, religious shrines and healing sanctuaries and other settings remains common in many parts across the world. Multiple reasons have been assigned for restraining or chaining and confining people with dementia and severe mental illnesses and these have included violence, concern about the person wandering off or running away and coming to harm, concern about the possibility of suicide and unavailability of caregivers. These reasons reflected those raised by some participants during the interviews.

In summary, lived space was experienced differently by different people with dementia and their carers. Providing security and safety, connecting and reconnecting and socialising with families could be seen as a positive use of shared spaces by families. However, other people with dementia felt restricted and ‘imprisoned’ within their own home spaces, occasionally literally in the form of chaining people up or locking them in their rooms, which denied them opportunities to socialise with others or enjoy the physical spaces outwith the home environment. Thus, both people with dementia and family carers responded to and interpreted shared spaces differently.

10.3: Participants’ responses to dementia

Understanding people’s response to a chronic disease such as dementia is facilitated by examining it within its cultural contexts (Dilworth-Anderson and Gibson, 2002). Culture is a set of shared symbols, beliefs and customs that shape individual and group behaviour (LeVine, 1974). People’s responses to dementia in Ghana are being driven by different perceptions of the condition, interacting with cultural beliefs about its causes and social interaction problems associated with memory and cognitive impairment. Perceptions of dementia are heavily influenced by traditional and religious beliefs of the people of Ghana. It can be seen as the result of witchcraft, punishment from deities, or malevolent and ancestral spirits for the sins of the person who has the impairment or their families (Agbenyega, 2003). People with dementia experience rejection by family and wider society, neglect, inhuman treatment such as flogging and beating and in extreme cases can be murdered.

How we perceive, experience and cope with disease and ill health is based on our explanations of the condition; explanations are specific to the social positions that we occupy and the system of meaning we employ (Mapp, 2008; Miles *et al.*, 2013) and (Toombs, 1988a, 1995b) further assert that how we communicate about our health problems, the manner in which we present our symptoms, when and to whom we go for care and how we evaluate that care are all affected by our cultural beliefs. The social construction of dementia as an illness does not only affect the individual with the condition but also the whole social unit (family) and plays an important role in how people respond to dementia in Ghana.

The cultural values and beliefs shape the meaning that people assign to dementia for instance interpreting dementia symptoms as ‘madness’. From the findings people with dementia admitted to being old and forgetful but did not think they were ‘mad’.

Families' misunderstanding of dementia as normal part of the ageing process suggests that there is a wide belief that everyone would develop forgetfulness as a result of ageing. Families therefore did not respond to the behavioural symptoms of their relatives' dementia by seeking medical help, instead they ignored this as they felt it to be normal. In the literature Farina *et al*., (2021) explored the perception of Latinos in the USA and revealed people's belief in dementia as part of the normal ageing process. Symptoms of dementia were generally linked to the inexorable bodily decline understood to be characteristic of 'normal' ageing. The current study sheds light on the fact that both people with dementia and their family carers' knowledge and understanding of dementia as part of the normal ageing process caused a delayed response to seeking help.

Structural stigma involving societal conditions, cultural norms and institutional policies constrain opportunities, resources and well-being of the stigmatised individual or group of individuals and also played a role in making people with dementia feel different from others. One of the psychiatric hospitals' operation of a 'non-admission policy' for older people with dementia differentiated them from the other citizens thus limiting their access to state-owned services which should have been accessible to all. Several studies (Quinn, 2007; Barke *et al*., 2011; Jacobs *et al*., 2022; Ocran, 2022) have identified different forms of stigma which are commonly experienced by people with dementia, mental health issues and other psychiatric or neurological conditions.

Family carers' response to dementia was also manifested through care provision arrangements. The care of and for people with dementia was mainly delivered by and through families and this was often partly shaped by the family members' need to show gratitude for the care and support the cared for person may have provided to the carers earlier in their lives – thus providing care as a means of reciprocity. In Ghana, as in many other cultures, care provision to older people and people with dementia is often a collective responsibility with different family members divided on broadly traditional gender lines and expectations. In the literature, several studies (Dosu *et al*., 2014; Sanuade and Boatemaa, 2015; Coe, 2016, 2017, 2018; Agyeman *et al*., 2019) have found that caring for older people and people with dementia in Ghana continues to be mainly provided by family members, albeit the number of older people and people with dementia needing care has been found to be higher than the number of caregivers. This has, in more recent times, necessitated the use of private or agency carers to provide care to older people and people with dementia who are able to afford this although the cost of such care services has reportedly been high (Sanuade and Boatemaa, 2015; Coe, 2018b). As indicated earlier in the thesis, this has become necessary partly due to increased rural-urban and transnational migration taking place in the country.

Families' response to caring for their relative with dementia was dependent on their perception of the cause of dementia. If families perceived their relative's dementia to be associated with witchcraft or a punishment from sins they might have committed earlier in their life, that could negatively affect the care people with dementia would likely receive.

10.3.1 Religion and spiritual care

Religion has represented a channel for the transmission of the meaning around dementia (Jewell *et al.*, 2016b). Religions in Ghana, mainly Christianity and African Traditional Religion (ATR) hold unclear differing interpretations on whether dementia is a consequence of sinful acts practised by the individual before the diagnosis or a sin linked to insanity due to curses invoked on people with dementia by fellow human beings or God (Akotia *et al.*, 2014; Gyimah *et al.*, 2022b). This has led to associating dementia with a divine punishment with various underpinning beliefs of evil spirits', demon-possessed', divine 'punishment' or 'curses' from God or other fellow human beings (Spittel *et al.*, 2021).

Findings from this study showed that the behavioural and psychological symptoms of dementia were often considered to be signs of evil possession, 'madness' or witchcraft. Such a collective belief system and cultural construction of dementia in terms of sinful acts and divine punishment inevitably led to stigmatising views around the condition leading to social withdrawal or exclusion of people with dementia from community and family activities. This also brings stigmatising views and perceptions not just about people with dementia but also their families.

Participants' spirituality or religiosity also affected their perception of and attitudes towards preventing or seeking help for dementia. Study findings showed that for most participants, their spirituality involved family support, praying and attending church services as an expression of their faith. In the literature, many participants with faith held the most positive attitude of their religious groups and had thought that dementia can be cured through divine healing such as prayers and fasting.(Arias *et al.*, 2016; Hindley *et al.*, 2016; Lambert *et al.*, 2020; Gyimah *et al.*, 2022). As indicated in the thesis, religious healing centres in the form of prayer camps have become an alternative source of care provision for people with dementia in Ghana. Almost all prayer camps have residential facilities and on-site staff who care for people with dementia. Families with people with dementia often seek help, care and cure from prayer camps.

Summarily, religion and religious beliefs about the causality of dementia have shaped its meaning and interpretation. These have included perceiving dementia as a supernatural or spiritual illness relating to witchcraft, evil spirits, demon-possession, curses or divine punishment. For others dementia is considered part of the normal ageing process. People's response to dementia is more often than not, determined by their perceptions about the cause of the illness.

10.4. Contribution of study to knowledge

This section discusses the contributions this study makes to the field of dementia. Specifically, I focus on discussing the empirical, theoretical and methodological contributions.

Dementia in Ghana (as in other parts of the world) is a multi-dimensional phenomenon (Pai, 2008) and cannot be easily explained by a uni-dimensional theory such as the biomedical model. This study suggests that the biomedical model is not adequate in helping us understand the specific idea of the dementia experience in Ghana (Aminzadeh *et al.*, 2007). Unlike healthcare professionals who understood dementia from biomedical perspectives, both prayer camp staff and unpaid carers' perspectives reflected a spiritual understanding of dementia also expressed by people with dementia (Hindley *et al.*, 2016; Mkhonto and Hanssen, 2018b; Brooke and Ojo, 2020; Gyimah *et al.*, 2022). Older people and people with dementia experience multiple stigma – stigma associated with being old, having dementia and the possibility of being refused admission to psychiatric hospital. This may be due in part to the hospitals' non-admission policy for people with dementia and also the risk of families abandoning their relatives with dementia in hospital due to stigma of having someone with dementia in the family or lack of ability to care. One methodological contribution this study makes toward understanding dementia in Ghana is allowing different voices and views to be heard from people with dementia themselves and those caring for them. This area of study has been neglected within dementia research in Ghana and SSA.

10.5. Theoretical contribution

In this study hermeneutic phenomenology was recognised as a useful theoretical lens through which to understand the experience of living with dementia. For instance, the lived body (Toombs, 1988; Phinney and Chesla, 2003; Kontos, 2004; Kontos and Martin, 2013) and lived relations (Petherbridge, 2019) have previously been applied to dementia. This study is unusual in that it is the first of its kind to apply the theories of lifeworld existentials (Toombs, 1988; Phinney and Chesla, 2003) to explore the lived experiences of dementia in Ghana. I found van Manen's (1997) phenomenological lifeworld and its division into the four existential elements – lived body, lived relation, lived time and lived space and the guidelines for using the approach as a research methodology particularly useful. In hermeneutic phenomenological study, the language of the interview provides the means through with a person's lived experience becomes meaningful and being a native speaker of the language participants were interviewed in enriched the data and its interpretation.

I also found the aspects of people's lived experiences from listening to their stories through a phenomenological lens particularly useful in a number of ways. Firstly, it enhanced my understanding of what it means to live with dementia. Listening to participants shared stories and combining them with my subjectivity and pre-understanding was a particularly useful resource when interpreting the data. Secondly, listening to participants stories enhanced my understanding of how participants made sense of their experiences, the factors that influence their lived experience as well as the meanings that were attached to living with dementia within the Ghanaian context. As Heidegger emphasised, the usefulness of researcher's foreknowledge or pre-understanding aids the understanding of the phenomenon as well as providing the foundation upon which hermeneutic interpretation is based (van Manen, 2017).

10.6: My position on the biomedical model of dementia in Ghana

The biomedical model of dementia which focuses on pathology within the brain to understand dementia and its symptoms has dominated both the literature and practice since the 1980s (Doyle and Rubinstein, 2014). However the social constructionist approach to understanding dementia acknowledges that although the manifestation of the condition has a neurological basis, this medical view is tempered by an appreciation of how these changes in brain functioning are deeply affected by other factors including the relationship with others – carers, friends, professionals as well as the environmental settings of care (Behuniak, (2010). Thus, while many people take the initial understanding of dementia from this medicalised discourse (which views dementia in terms of pathological change) (Phinney 2002), in my view this pathological change in itself is not enough to understand dementia as it excludes consideration of how dementia is experienced and lived.

I suggest that alternative explanation model that is inclusive of people with dementia and their relationship with others may need to be considered in order to try and understand dementia within Ghanaian culture. Thus, understanding dementia in Ghana should focus on the biomedical model as well as a model that recognises and incorporates the fact that there is a lifeworld or a directly experienced world for people with dementia. For instance, within the Ghanaian context, being well and healing from illnesses including dementia extend beyond the treatment from healthcare professionals. Often healing requires that the ill person and their families have faith in the treatment method that is being applied (Lambert *et al.*, 2020; Ayinde *et al.*, 2021 ; Gyimah *et al.*, 2022d). Within the Ghanaian traditional worldview, ‘traditional and spiritual or faith-based treatments’ (*honhom mu ayaresa*) are a very important aspect of healing and all aspects of the life of the ordinary Ghanaian. These ‘spiritual or faith-based treatments’ often provided through different medium including shrines, Malams (Islamic type of treatment) or prayer camps are normally employed across all aspects of the treatment process - assessing the illness, providing ongoing care and support and sometimes towards end-of-life care. Traditional and spiritual or faith-based treatments have been found effective at calming and settling people with mental illnesses (Lambert *et al.*, 2020b; Ayinde *et* *al.*, 2021) including dementia. It is interesting to note that hallucinations that occur as symptoms of dementia may be understood from an alternative and positive perspective as the origins could be perceived as spiritual and therefore not problematic. A case in point was Gladys who owing to her experience of hallucinations as part of her dementia symptoms, was described as an evil-possessed, a witch or a mad person. Thus, if a person becomes distressed following their hallucinations, traditional and spiritual / faith-based type of healing may be more effective than medication to calm them down or give some meaning to their experience. In Gladys' case cited above, she would often run to the church for prayers instead of consulting biomedical or healthcare professionals for treatment. This was due in part to the socio-cultural understanding or perception of dementia in Ghana.

In my view there is therefore a need to integrate both the traditional / spiritual / faith-based and biomedical models of dementia, its care and treatment within the current practice of dementia care in Ghana. The care and treatment of people with dementia should be based on the cultural values and beliefs and the provision of biomedical treatment and other mainstream services as both systems of treatment complement each other. The Ghanaian culture appreciates health from a unique perspective of holistic interconnectedness – the body, mind and the soul; the Western definition of 'health being the absence of illness' ('The WHO Definition of "Health"', 2024) is not always adopted. It is imperative to note that within the Ghanaian culture, spirituality is an essential part of being well and traditionally, all aspects of ill-health have a spiritual component (Opare-Henaku and Utsey, 2017). People's cultural identity is an essential and integral part of the concept of being well and this is mostly viewed under the holistic umbrella where individuals are whole when connected with the cultural viewpoint of values and beliefs (Pokimica, Addai and Takyi, 2012). Therefore, to understand dementia and mental illnesses in Ghana, one's wellness should be acknowledged from a holistic perspective as one's wellness is inseparable from the language, spirituality, natural environment and the culture of Ghana.

In summary, it is imperative for all – readers, prayer camp staff and healthcare professionals to use the Ghanaian concept of well-being when attempting to understand dementia in Ghana. This is because the cultural viewpoint of dementia complements and should thus be incorporated into the biomedical model of the disease in order to fully understand and thus be able to adequately provide culturally sensitive care and treatment that could meet the needs of people with dementia and their family carers.

10.7: Conclusion of chapter

This chapter has revealed that the conceptualisation and meaning of dementia and dementia care were largely influenced by individual's and families' socio-cultural and religious beliefs, personal values, thoughts and attitudes rather than their knowledge and awareness of dementia per se. The discrepancy between awareness and lack of recognition that ageing as a major risk factor for dementia indicates that individuals might have become aware of dementia without necessarily understanding its causes.

Findings from this study suggest that participants' lack of awareness of dementia, insufficient human and financial resources, the low priority status accorded to dementia by the government of Ghana were among the factors impeding the development of dementia policies and interventions in the country.

To conclude, this thesis has described the lived experience of dementia within the Ghanaian context. An important aspect of this was how the local culture has shaped people's understanding of dementia and the care provided to people living with dementia. It is also important to note that people with dementia in Ghana are cared for in three key spaces, the home, prayer camps and psychiatric hospitals. In Ghana responses to dementia and care for people with dementia are mainly influenced by the people's beliefs about supernatural forces as one of the main causes of the illness.

It is important to emphasise three key findings from the study, lived experience of dementia, stigma and dementia care, and participants' response to dementia. Firstly, people with dementia viewed their impaired bodies as strange and unfamiliar which evoked uncanny feelings of not being the owner of their body parts (Phinney and Chesla, 2003). Forgetfulness and incontinence both contributed to the feelings of living in an unreliable body. Being unable to remember things, events, rituals, and places nor control bowels and urine contributes to insecurity of people with dementia in social settings. Living with impaired bodily functions linked to dementia involved facing a changed perception of oneself due to lost roles and preferred activities and appearance (Kitzmüller, Häggström and Asplund, 2013). Leder’s (1990) notion of bodily dys-appearance may illuminate the participants’ struggle to overcome the gap between their unfamiliar body and the perception of self. As Leder explains, under normal circumstances, the healthy and well-performing body disappears from our consciousness in a positive manner. The healthy body performs without any need to reflect or concentrate on actions to be performed. By contrast, the sick, painful or disabled body dys-appears in our consciousness, that is, it stands out as disturbing and interfering with our plans and actions. The dys-appearing body calls for an ongoing interpretive quest and the self can no longer act towards the world without hindrance but is forced to act towards the body in explicit awareness. The lived body experience of ‘‘I can’’ changes into ‘‘I cannot’’ and the body may even be perceived as separated from or opposed to the essential self (p. 70).

People with dementia also experienced stigma and discrimination within the lived space and lived relations. People with dementia were stigmatised through different responses by their families and others caring for them. Stigmatisation and discrimination against people with dementia took different forms including ignoring and confining them in rooms or homes or labelling them in different but negative ways. Consequently, people with dementia’s access to both physical and social spaces within and outwith the home were restricted either through withdrawing themselves socially or being locked up by their families or others including paid carers caring for them. People with dementia were made to feel imprisoned within their own homes and may have felt to be treated different from members of their own families and others as a result. In addition, people with dementia were stigmatised through labelling them as being ‘mad’, a witch or evil-possessed, attributes which are both derogatory and socially unacceptable within the Ghanaian (and many other places across the world). One other area of stigma and discrimination that people with dementia and older people experienced was lack of facilities and geriatric services for people with dementia.

Some people with dementia responded to stigma by keeping their dementia experience to themselves and not disclosing it to others. This is akin with the Ghanaian cultural belief and expectation of families to keep issues, especially of stigmatising nature including psychiatric issues to themselves for fear that they may be stigmatised. In summary, people with dementia may feel devalued, ignored or rejected by their families and the society because of dementia. People with dementia.

Chapter 11: Conclusion and recommendations

11.1: Introduction

This study has addressed a gap in the literature with an in-depth exploration of the lived experience of dementia in the Sub-Saharan African (SSA) country of Ghana. A hermeneutic phenomenological framework was used to explore what it is like to live with dementia from the perspectives of people with dementia, their family carers, prayer camp staff and healthcare professionals. This conceptual framework has involved illuminated the perspectives of the aforementioned participants about socio-cultural and biomedical models of understanding dementia relating to participants' everyday experiences. This chapter discusses the policy and practice implications and recommendations for future research.

11.1.1 Revisiting the research questions

The main aim of the study was to generate understanding of the lived experiences of dementia in Ghana, from the perspectives of people with dementia their family members and paid and unpaid carers. In this section I will return to the research questions and answer them by referring to study findings.

i) Question One

What is it like to live with dementia in Ghana?

For some people with dementia, living with the condition was associated with witchcraft, a stigmatising condition that could evoke fear in people – both family and non-family alike. Consequently, living with dementia had negative implications for families with people with dementia's health-seeking behaviours due to the stigmatising nature of the disease. Living with and displaying symptoms of dementia such as hallucinations led to self-stigmatisation of some people with dementia. This was because some symptoms of dementia are associated with witchcraft, evil-possession or madness, labels which people with dementia felt embarrassed and stigmatised about. People also fear those living with dementia based on their knowledge and perception of the disease due to the negative attributes of it highlighted above.

Living with dementia in the context of people's career as petty traders, businessmen/women or seamstresses, their marriages and personal confidence were profoundly affected by their diminishing cognitive abilities and skills. For some people with dementia, living with condition meant losing one's skills or remembering how to do some basic, everyday activities of daily living such as bathing, brushing teeth, going for shopping or preparing a meal that were once their taken for granted activities. Losing one's skills meant relying on others for help and support that one previously took for granted.

On the other hand, living with dementia offered them some solace as they searched for meaning in what had happened to them, their frustration about losing their skills or giving up their jobs as well as what they saw as their disappearing sense of self. Often families living with dementia would seek advice, care or support from traditional and spiritual / faith-healing sources including prayer camps because they believe in it.

ii) Question Two

What is it like to be an unpaid carer for a person with dementia in Ghana?

Unpaid carers are people (mostly relatives) who supported people with dementia often with activities of daily living. Providing care to people with dementia was multifaceted and crossed all aspects of unpaid carers' physical, psychological, social and economic life. Unpaid carers, who were predominantly women, undertook multiple and a diverse range of tasks of activities of daily living for their loved one(s). These included assistance with bathing, cooking, cleaning, assisting with toileting, laundry, arranging and supporting people with dementia to attend hospital appointments and providing financial and emotional support. Undertaking the unpaid caring role was commonly driven by people's deep sense of obligation to the person with dementia as well as being a cultural and gendered expectation. Thus, undertaking unpaid caring role was a familial obligation and cultural requirement often framed around reciprocity or marital responsibility.

Being an unpaid carer also meant an altered identity, social structure and in most cases reduced ability to participate in social or economic life as before. For some carers, being a carer meant taking on a new role and responsibility as they had to change or reconstruct their own identity within the family life, for instance, children or spouses becoming carers for their parents or spouse with dementia respectively. For most carers, being unpaid carer also meant reducing the amount of social time they could spend with friends and colleagues outwith the family home attending community events or economic activities. Being an unpaid carer therefore meant a loss of social life or relationship with others as the carers were no longer able to meet up with their friends or attend social and community events as before or as much as they would have liked. Similarly, some unpaid carers expressed feelings of sadness when talked about the notion of loss of relationship as they missed the role their relative with dementia previously played or held for their families. For some, being unpaid carer meant losing someone they loved while still looking after them which they described to be very emotional. Some unpaid carers also lost employment. Thus, giving up their full-time jobs or part of a job meant a loss of income for unpaid carers, most of whom reported living on low incomes owing to being carers for their relatives with dementia.

iii) Question Three

How do people with dementia and their carers understand dementia and what social and cultural resources do they use to do so? .

The expected significance of this research was its contribution to a more complete understanding of people's belief about and response to dementia. Dementia and its explanatory models differed across participant groups. People with dementia acknowledge being forgetful but mostly denied the cultural perception of them being a witch, evil-possessed or 'mad'. People with dementia themselves did not seem to know exactly what was wrong with them although some attributed the cause of their dementia to the result of a physical disease such as stroke or provided an account of their hallucinatory experience as a spiritual illness – hearing the voice of the devil. For the majority of family carers and prayer camp staff, dementia was perceived or understood to be a spiritual illness often resulting from supernatural or evil forces of witchcraft or a normal part of the ageing process, a belief that is if someone lives long enough, sooner or later they will probably become confused and experience some memory loss or decline. Most prayer camp staff believed dementia was the result of a retribution for the sins they or their family members may have committed. Other perceptions and understandings of dementia captured from families with people with dementia and prayer camp staff during interviews included psycho-social factors including excessive drinking of alcohol or thinking too much owing to, for instance, the death of a loved one, a job loss or a similar misfortune happening to them. These beliefs, initial understandings and perceptions of dementia suggest that dementia was not interpreted as a disease by these group of participants. However, some participants obtained different views, perceptions and understandings on dementia after watching or listening to health educational programmes on dementia presented by health professionals on the national media, mainly radio and television. These ‘new understandings’ of dementia were reflected in the interviews that sought to capture the views of people with dementia and their family carers. Having these different understandings of dementia meant that people had different options for support and care for dementia in Ghana.

iv) Question Four

What are the perspectives of paid staff and professionals caring for people with dementia in Ghana?

The biomedical or healthcare professionals viewed dementia as a disease with an emphasis on diagnosis of symptoms which are or can be treated primarily through medical interventions. Healthcare professionals recognised the effect of the change in people with dementia and managing their behavioural symptoms including incontinence to be stressful. They felt they had to remind people with dementia or attend to them by cleaning them up afterwards themselves. Healthcare professionals felt caring for people with dementia particularly with incontinence issues amidst the lack of appropriate tools and personal protective equipment such as aprons and masks could predispose them to health and safety hazards.

Healthcare professionals explained how they adapted and accepted their roles as healthcare professionals. They felt they had to take their roles as it they were and had to acclimatise to the situation. In healthcare professionals’ perspective, caring for people with dementia meant having essential attitudes that would enable them to better navigate their roles as healthcare professionals. They expressed learning and being compassionate through their care provision experiences.

While healthcare professionals viewed dementia as a disease their prayer camp counterparts did not, instead the latter held similar cultural beliefs as families with people with dementia, perceiving dementia as a spiritual illness requiring spiritual cure. The variety of the perceptions and views of dementia and its causality held by different participants had different implications on how people responded to the symptoms of dementia and consequently the care that they provided to people with dementia.

11.1.2: Implications for policy and practice

i) Collaborative working between biomedicine and traditional health care

Findings from this study have shown that unpaid care provision for people with dementia in Ghana is centred around a range of explanatory models for dementia including biomedical, social, religious or supernatural with carers holding different views, perceptions and experiences of dementia care provision. However, formal care provision appeared to be mainly focused on the biomedical model (see Chapter 2 and 3) which does not necessarily fit in well with dementia care provision within the Ghanaian context owing to the widely held cultural and religious beliefs about dementia. Collaborative working between the two systems of mental health care could help minimise tensions between them and thus improve the quality life and health outcomes of people with dementia and their families.

Currently the two systems of mental health care in Ghana, biomedicine and traditional or faith-healing seem to be in conflict with each other. However, working collaboratively together could help minimise the tensions between the two treatment systems. Gureje and colleagues describe collaboration as relationships in which 'traditional and conventional medicine practitioners remain autonomous and independent but co-operate fully; for example, by referring patients to each other or consulting on complex cases together' (Gureje *et al*. 2015).

It would be more beneficial to care for people with dementia in Ghana by integrating the biomedical approach with the traditional, cultural and religious-based models of health care. Collaborative working should require consultation with multiple different stakeholders of health and not only the biomedical health professionals. Traditional spiritual leaders should all play active roles in this action. Integrating the two systems of medicine would require introducing the benefits of each of them, providing opportunities for learning between practitioners and building trusting relationship. Doing so could help improve people with dementia's health, quality of life and their safety. As incompatible and conflicting integration may seem, providing opportunities for the two systems to learn from, understand and recognise each other's role could help each improve on and change aspects of their practices that impact negatively on people with dementia's care and support such as chaining people perceived to be aggressive or violent in their behaviours in prayer camps. Instead, such behaviours could be better managed through administration of appropriate medication or psychosocial interventions such as dementia training for carers.

Proper collaboration should also mean formalising the partnership between the two systems of health care. This could include providing technical support such as introducing medications and addressing the key shortcomings in the infrastructure and hygienic conditions of the prayer camps. As highlighted above, people with dementia and severe mental health issues are often chained in prayer camps. With proper collaboration healthcare professionals would be able to visit prayer camps to screen people with psychiatric conditions including dementia and offer biomedical medications and other interventions. This would provide healthcare professionals the opportunity to administer appropriate medication to people with psychiatric conditions whose behaviours prayer camp staff may find challenging, aggressive or violent to manage. This could prevent prayer camps from the use of chains to restrain people. For effective collaboration, healthcare professionals should be able to respond promptly when called by traditional healers and prayer camp staff. This will require training more mental health staff and placing them in the communities to enable them to respond promptly to calls by traditional and faith-healers whenever possible.

Additionally, focusing on studies that illustrate the complexities of dementia within the socio-cultural context of Ghana and the impact of traditional, faith-healing practices (Arias *et al.*, 2016) and biomedicine (Tabi *et al*., 2006) can help bridge the gap between the two healing worlds, religious-socio-cultural and biomedical worlds. These can lead to a better understanding of dementia and thus care and support that can be provided to and received by people with dementia in Ghana. If healthcare professionals want to help people with dementia they should, among other things, ask questions relating to how the illness has changed their life; what aspects of the illness affect them most, how can those effects of the illness be compensated for? These types of phenomenologically informed questions would elicit responses from people with dementia which can thus enable healthcare professionals to better understand dementia and its impacts on their lives.

ii) Training for both biomedicine and traditional practitioners

The findings also note a significant gap in the referral pathways in existing services provision for people with dementia and their family carers in Ghana. Currently, no clear pathways for dementia referral and support for people with dementia appear to exist in the psychiatric and mental health system. For some people, prayer camp and other traditional health-seeking behaviours remain the main pathways for support while for others, a biomedical model of care is the dominant dementia pathway. As highlighted in Chapter 3, the few psychiatric hospitals in Ghana are concentrated within two out of the sixteen regional capitals, all located in the south. This means people in the south and also urban areas have more access to psychiatric services and are thus more likely to take the biomedical route than their counterparts in the rural and other parts of the country (Ofori-Atta *et al.*, 2018).

Designing robust integrated pathways for dementia and other psychiatric services involving both biomedical practitioners and traditional healers could help in the early identification and diagnosis of dementia. The integrated pathway could involve developing community hubs as the first port of call where people with dementia-like or psychiatric symptoms could go for initial screening and assessment. Such hubs should be managed by trained psychiatric nurses and traditional healers who could offer advice, suggestions and signpost people with psychiatric issues to appropriate services for further assessment, diagnosis and support. Comprising staff from both biomedicine and traditional healers, patronage for such community-based services is likely to be high as people might see these as less-stigmatising than attending psychiatric hospitals which are perceived by the society as places for ‘mad people’ (Gyimah *et al.*, 2022).

There is also a general lack of knowledge and understanding of dementia and of the lived experience of dementia in particular (Spittel *et al.*, 2021). It is important that healthcare professionals listen to and accept carers’ subjective understanding of dementia rather than insisting that they accept the biomedical explanations as the only causation of dementia. Having said that, family carers may better cope with their relatives’ dementia and their caring duties if they are equipped with basic biomedical knowledge and psychosocial understanding of the disease. It is felt that the existing links between healthcare professionals and traditional practitioners including prayer camps could be used to educate people about signs and symptoms of dementia. Traditional faith-healers should be honest in advising families with dementia on what they could and could not treat and refer cases they are unable to treat to biomedical practitioners for diagnosis, treatment and support.

It is also recommended that widespread training be given to traditional, faith-healers and incorporate them into the health system to provide baseline services in dementia and other psychiatric illnesses. This can be piloted in some regional hospitals and supervised by medical practitioners. Once the training is completed, the traditional faith-healers can then return to work especially in the villages or areas where biomedical services are lacking. The wide disparity in the availability of psychiatric services and care provision between urban and rural areas due in part to lack of or inadequate attraction and infrastructural facilities in rural areas could be improved. Thus, with appropriate training, knowledge and skills to treat some basic psychiatric or mental health problems, traditional faith-healers could fill some of the gaps in mental health sector in the country.

iii) Awareness raising for communities

Another significant gap in dementia and dementia care provision relates to lack of awareness and disclosure of information by families of people with dementia. Lack of awareness, misunderstanding and misconception of dementia, its symptoms and the associated stigma often lead to families withholding instead of disclosing information about the illness. This often results in delayed help-seeking behaviours and subsequently diagnosis, treatment and support to people with dementia. The Ministry of Health together with other stakeholders in the health sector could raise more awareness of dementia as a disease to demystify the general perception and cultural and religious understanding of dementia as supernatural or spiritual illness. Dementia awareness creation could include raising awareness campaigns and observing such events as the World Alzheimer's Day and organising dementia-related programmes or health talks about dementia on national and local radio and TV stations. Additionally, organising workshops in schools, churches, mosques, marketplaces and other public places in the local languages so people can better understand the message that dementia is a natural but not supernatural disease. This could help increase the knowledge and understanding of dementia. Evidence suggests that dementia awareness creation through health promotion activities leads to early diagnosis and intervention and ultimately improves the quality of life of people with dementia and their families (Harrison-Dening, 2013). The reason being that as more people become aware and knowledgeable about dementia, public opinion on it could change. This can demystify any myths and superstitions around the beliefs about being caused by supernatural forces and curses. This can reduce stigma attached to dementia and increase people's confidence to disclose information on dementia and seek early support.

iv) Training for health care staff

Dementia and mental health issues are often felt to be too sensitive to discuss with families with people with dementia due to the shame and stigma associated with them. This appears to affect how health professionals deliver information about dementia to families after diagnosis and how families interpret this. Knowledge of such socio-cultural factors could influence health care practitioners' practices and thus improve the quality of care, health outcomes, and enhance the mental health literacy of the public (Koduah *et al.*, 2019). Health literacy is the degree to which people can obtain, process and understand basic health information and the services needed to make appropriate health decisions (Koduah *et al.*, 2019 p 2). Good health literacy practice should go beyond the individual. It should also incorporate the broader health system including frontline health professionals – doctors, nurses and administrators, the education system and how these systems would interact together. Ensuring that nurses and other healthcare professionals routinely receive health literacy education as part of their professional training could equip them to face and address the challenges of poor or low health literacy amongst Ghanaians. This will thus help improve the understanding of dementia, provision and delivery of appropriate and culturally-sensitive dementia services to people with dementia and their paid and unpaid carers.

v) Need for formal policy

Another area worth consideration is policymaking. Policymakers must have responsibility to enact relevant legislative framework that can be incorporated into practice. Such legislative framework should include developing and implementing national dementia care policies. The creating of dementia advocacy groups to represent people with dementia in the design, planning and implementation of any dementia-related policies is also vital. As the number of older people in Ghana continues to grow (Mba, 2010; Kwankye, 2013) such legislative framework would be helpful in designing and implementing culturally appropriate services for people with dementia to improve their quality of life and enable them to enjoy equal rights as their fellow citizens.

In addition to raising awareness of dementia, clarity on guidelines about dementia referral pathways would ensure that families of people with dementia and their carers receive the best possible care and support through their dementia journey. The Ghanaian dementia policy needs to focus on these two points.

11.2: Reflections on the research process

Undertaking this research including writing up the thesis, has indeed been a journey of learning and discovery for me. Ghana has wide linguistic and cultural diversities, and this can make it difficult for outsiders to value and understand its cultural practices. However, considering myself as an insider, my understanding, cultural awareness and the sensitivity of the local issues were impactful in enhancing my communication and interaction with the study participants.

As an insider doing research with a cultural group to whom I belong, I had the advantage of being able to use the knowledge of the participants' cultural context to gain more intimate insights into their opinions and views on living with dementia in Ghana. I understood participants' colloquialisms, idiomatic expressions and non-verbal communication cues, in particular, body language, gestures and some facial expressions. These understandings were due to my foreknowledge of the Ghanaian culture. Further, my status as an insider was helpful in overcoming some of the difficulties that can arise from both verbal and non-verbal communication practices. For instance, it was relatively easier to communicate effectively with the research participants in terms of interpreting their speech, tone, body language, facial expressions, gestures and assumptions shared by participants regarding the context and purpose of the study (Abugre, 2018). Some of the gestures would have been difficult for a non-native researcher to have comprehended.

In other respects, however, I considered myself an outsider as I did not feel a close sense of belonging to the participant groups, I interviewed neither did some of the participants perceive me as an insider. My position as a doctoral candidate and as such an outsider appeared somewhat suspicious to some especially, the prayer camp staff. In one instance a prophet denied me access to interview with him or members of his prayer camp as he suspected me to be an 'information-seeker' who may be working for the government. In another instance, a member of prayer camp staff held a similar view as the prophet's. Around the time of my fieldwork, the government of Ghana was investigating some of the prayer camps' activities in relation to human right abuses. Conscious of this, some of the prayer camps were not keen to entertain people like me whom they did not know well to undertake any research activities there for fear that they might get into trouble. However, other participants respected my status as an outsider and treated me as such.

11.3: Implications for future research

Findings from this study have illuminated a number of areas requiring further exploration. The number of men with dementia relative to women in this study is under-represented. Future research could focus on the lived experience of people with dementia of with more men relative to women with dementia in the wider population. Also, this study is broad in its scope as it covers four participant groups. This study provides foundational understandings of what is means to live with or care for dementia and further and separate studies exploring the lived experience of dementia in prayer camp and hospital settings may be needed to confirm or contrast these findings.

Future research could build upon findings from this study which currently offers a starting point of understanding the lived experiences of people with dementia in Ghana. Such studies could allow researchers to better understand the roles played by the different stakeholders in understanding dementia and thus provide lessons for care that is culturally appropriate to the needs of people with dementia while offering families the support they need to enable them to continue to care for people with dementia at home as long as they can.
A further recommendation is to conduct studies that focus on exploring views, perceptions and experiences of formal and professional caregivers. This will help in understanding of the issues, challenges and service gaps experienced by paid caregivers and enable comparisons with family caregivers' views and experiences. Findings indicate the need for and importance of raising dementia awareness (among people with dementia, family carers, prayer camp staff and members of the public) and professional support to improve quality of care and the lives of people with dementia and their unpaid carers. The information on support needs of family carers and suggestions to overcome their current issues and challenges are important.

11.4: Conclusion

In conclusion, this study has shown that receiving and providing care to people with dementia in Ghana had both positive and negative aspects for the people with dementia and family carers who took part in the study. Most people with dementia had positive experiences living with the condition and being cared for by their families. Some of the positive experiences included being together with families and being included in activities of daily living such as cooking and preparing meals, watching TV or attending church services together with their family carers. On the other hand, some people found the experience of dementia to be negative. People's relationships with their families and significant others broke down following dementia. This could result from the cultural belief that people with dementia are witches, evil-possessed or cursed and the stigma associated with these beliefs. Some people with dementia were also locked up in a room which made their experience of the home a 'prison-like' space. These resulted in some people with dementia becoming socially isolated and lonely.

In spite of the growing medicalisation of dementia in Ghana, the current study identifies that a more traditional, cultural understanding of dementia is still widespread and embedded in the minds of the people of Ghana. This suggests the importance of integrating the socio-cultural beliefs and healing practices traditional in Ghana with the biomedical model of care to help address the issues identified here with understanding dementia and dementia care in the country.

APPENDICES:

Appendix 1: General University Ethics Panel Approval Letter:

Stephen Antwi
Faculty of Social Sciences
University of Stirling
FK9 4LA

17 October 2017

Dear Stephen

Re: Exploring the experiences of living with dementia in Ghana (GUEP172)

I am pleased to confirm that Professor Helen Cheyne has approved the minor amendments you have made to your ethics proposal on behalf of GUEP.

Please revise your GUEP application form in line with the change to section B4 and submit this to the GUEP mailbox for saving to your file.

Please note that should any of your proposals change, a further submission (amendment) to GUEP will be necessary. Please ensure that your research complies with the University of Stirling policy on storage of research data http://www.stir.ac.uk/is/researchers/data/afteryourresearch/

If you have any further queries, please do not hesitate to contact the Committee by email to guep@stir.ac.uk.

Good luck with your research.

Yours sincerely,

p.p. On behalf of GUEP
Professor Helen Cheyne
Edna S Docherty
Deputy Chair of GUEP

Appendix 2: Letters to request permission to undertake research in PH1 & PH2.

Faculty of Social Sciences
University of Stirling
Stirling
FK9 4LA

27th September 2017

The Medical Director
[redacted]
Ghana.

Dear Sir / Madam,

Re Request for permission to undertake research at your institution:

I am a postgraduate research student from the University of Stirling, United Kingdom. I am interested in exploring how people with dementia and their carers experience living with the condition in Ghana.

I would like to talk to people with dementia and their families in order to find out more about what it is like to live with dementia. I will hold focus group discussions with healthcare professionals at your institution about their experiences of working with people with dementia.

I am writing to ask you to assist me in recruiting people with dementia and their carers to take part in the project.
Due to the stigmatising nature of dementia in Ghana, it may be difficult to recruit people with dementia into my study. However, people with dementia may be more likely to take part in the study if it was introduced to them by your staff, with whom they may be familiar.

I have prepared a brief description of the study including how participants will be involved. I have attached a copy for you to read. Ideally, I would like to begin the data collection by 25th October 2017, but I am happy to be guided by you on this.
I would therefore appreciate if you would inform your patients about the study. if they agree to take part, I would appreciate it if you would ask for their permission to share their contact details with me.

In addition, I would like to hold two focus groups with staff at your institution to discuss their experiences of working with people with dementia. Each focus group will last 1-2 hours, and it will be audio-recorded. I will endeavour to keep the disruption to your working day to an absolute minimum.

I hope my project is of interest to you and that you will be interested in working with me. Please feel free to contact me directly on (*insert Ghana mobile number*) or email me .s.f.antwi@stir.ac.uk if you have any queries. Alternatively, you may wish to contact my supervisor, Dr Louise McCabe on +44(0)1786466317 or email Louise.mccabe@stir.ac.uk.if you would like any further information about me or the project.

Many thanks for taking the time to read this and I hope to hear from you soon.

Yours faithfully,

Stephen Antwi

Appendix 3: Letters to request permission to undertake research in MPC & ƆPC

Faculty of Social Sciences
University of Stirling
Stirling
FK9 4LA

27th September 2017

The Prophet & Prophetess
[redacted]
Ghana.

Dear Sir / Madam,

Re: Request for permission to undertake research at your institution

I am a postgraduate research student from the University of Stirling, United Kingdom. I am interested in exploring how people with dementia and their carers experience living with the condition in Ghana.

I would like to talk to people with dementia and their families in order to find out more about what it is like to live with dementia. I will hold focus group discussions with healthcare professionals at your institution about their experiences of working with people with dementia.

I am writing to ask you to assist me in recruiting people with dementia and their carers to take part in the project. Due to the stigmatising nature of dementia in Ghana, it may be difficult to recruit people with dementia into my study. However, people with dementia may be more likely to take part in the study if it was introduced to them by your staff, with whom they may be familiar.

I have prepared a brief description of the study including how participants will be involved. I have attached a copy for you to read. Ideally, I would like to begin the data collection by 25th October 2017 but I am happy to be guided by you on this.
I would therefore appreciate if you would inform your patients about the study. if they agree to take part, I would appreciate it if you would ask for their permission to share their contact details with me.

In addition, I would like to hold two focus groups with staff at your institution to discuss their experiences of working with people with dementia. Each focus group will last 1-2 hours, and it will be audio-recorded. I will endeavour to keep the disruption to your working day to an absolute minimum.

I hope my project is of interest to you and that you will be interested in working with me. Please feel free to contact me directly on (*insert Ghana mobile number*) or email me .s.f.antwi@stir.ac.uk if you have any queries. Alternatively, you may wish to contact my supervisor, Dr Louise McCabe on +44(0)[redacted] or email Louise.mccabe@stir.ac.uk.if you would like any further information about me or the project.

Many thanks for taking the time to read this and I hope to hear from you soon.

Yours faithfully,

Stephen Antwi.

Appendix 4: Letter to PH2 agreeing to share research findings upon completion.

Faculty of Social Sciences
University of Stirling
Stirling
FK9 4LA
United Kingdom

27th September 2017

The Medical Director
[redacted]
Ghana

Dear Medical Director,

Re: Letter of undertaking to PH2 Ghana

I, Stephen Antwi, a Research Postgraduate Student of the University of Stirling, United Kingdom, write to assure that, I would make my thesis available to the Pantang Psychiatric Hospital after its completion. I can confirm that the final thesis will be available online and that the Hospital will be provided with a link to enable them to access this document.

Your request has been discussed with my supervisor, Dr Louise McCabe and can now confirm that there is no reason(s) that your institution should not be given access to my write up.

I would be happy to provide you with a short report outlining the key findings of my project once it complete.

Yours sincerely,
Stephen Antwi.

Appendix 5 Approval letter from PH2 confirming agreement to undertake study

[redacted] HOSPITAL

OUR CONE` VALUES'-
Recognition of diversity
' Equal treatment *.
Confidentiality
Prof I
1:s.1 Compassion
* Teamwork

[redacted]
[redacted] 7 mail:
[redacted]

28th September, 2017

PHZ reply

My Ref. No: .... 11'
Your Ref. No' .... , ... „.,

THE HEAD
FACULTY OF SOCIAL SCIENCES
UNIVERSITY OF STERLING
STERLING
UNITED KINGDOM
FK9 4LA

Dear Stephen Antwi,

PERMISSION TO CONDUCT RESEARCH BY MR. STEPHEN ANTWI

Your letter dated 4th August, 2017 refers.

We are pleased to inform you that **MR. STEPHEN ANTWI** has the permission of our institution to collect data for his research titled: **"Exploring the experiences of living with dementia in Ghana".**

We hope he will fulfil the ethical measures outlined in his proposal, as well as his undertaking to share key findings of the project with our institution upon completion.

Thank you.

Yours faithfully,

....

[redacted] CLINICAL! COORDINAT

Appendix 6: Approval letter from PH1 to undertake research

In case of reply the number
and the date of this letter

18th October, 2017

Stephen Antwi

Faculty of Social Science
University of Stirling
Stirling
United Kingdom
FK9 4LA

RE: REQUEST FOR PERMISSION TO UNDERTAKE RESEARCH AT YOUR INSTITUTION

Your letter dated 4th August 2017 on the above subject has reference, please.

This is to inform you that approval has been granted you to undertake research on "Exploring The Experiences Of Living with Dementia In Ghana" at this Hospital.

The Hospital is, however not in a position to recruit patients for 'you for the study. You are therefore required to organize that using other means. The staff of the Hospital are available to assist you in any way possible with your study.

I wish you success in your endeavour.

Thank you.

[redacted]

Appendix 7 A letter to the recruitment gatekeepers (PH1 & PH2)

Faculty of Social Sciences
University of Stirling
Stirling
FK9 4LA
United Kingdom

4th August 2017

The Training and Development Officer
[redacted]
Ghana

Dear Sir / Madam,

I am a postgraduate research student from the University of Stirling, United Kingdom. I am interested in exploring people with dementia and their carers' experiences of living with the condition in Ghana.

I would like to talk to people with dementia and their families in order to find out more about what it is like to live with dementia. I will also hold focus group discussions with staff at prayer camps and health professionals at your institution about their experiences of working with patients with dementia.

I am writing to request you to act as a recruitment gatekeepers in order to access people with dementia and their carers to interview for my project. It is anticipated that due to the stigmatising nature of dementia in Ghana, it may be hard to access people with dementia. It is however felt that as your institutions are two of the three public psychiatric hospitals for diagnosis and treatment of mental illness including dementia, people with dementia are more likely to agree to taking part in the study if

it was introduced to them by their staff whom they may be familiar with rather than a stranger.
I have prepared a brief description of the study including what it will mean for potential participants to be involved in it. I have attached a copy for you to read. Ideally, I would like to begin the data collection by mid-October 2017, but I am happy to be guided by you on this.

I would appreciate if you would contact potential participants, inform them about the study and ask if they wish to take part. If they agree to take part, I would appreciate if you would ask for their permission to share their contact details with me so I could follow up the contact to discuss the study in a bit more detail. In addition, I would like to hold two focus groups with staff of your institution to discuss their experience of working with people with dementia in the country. Each focus group will last 1-2 hours, and it will be audio-recorded. I would need a quiet place on your premises to conduct the study. I will endeavour to keep the disruption to your working day to an absolute minimum.

I hope you find my project is of interest to you and that you will be interested in working with me on it. Please feel free to contact me directly on xxxx or e-mail me on my e-mail address below if you have any queries. Alternatively, you may wish to contact my supervisor, Dr Louise McCabe on xxxx if you would like a reference or other information.

Many thanks for taking the time to read this and I hope to hear from you soon.
Yours faithfully,

Stephen Antwi
s.f.antwi@stir.ac.uk.

Appendix 8: Invitation to participate in a focus group discussion (MPC & ƆPC)

Faculty of Social Sciences
University of Stirling
Stirling
FK9 4LA
United Kingdom

4th August 2017

The Prophet / Prophetess
[redacted]
Ghana

Dear Sir / Madam,

I am a postgraduate research student from the University of Stirling, United Kingdom. I am interested in exploring people with dementia and their carers' experiences of living with the condition in Ghana. I would like to talk to you in order to find out more about what it is like to live with dementia. I have enclosed an Information Sheet to help you make an informed decision about whether you would like to take part in this project or not. Should you wish to discuss further or if you have any questions about this project, please contact me on [redacted] or my supervisor Dr Louise McCabe on [redacted] or e-mail [redacted]

If you are happy to take part in the study, I would be grateful if you could complete the enclosed consent form to confirm your agreement to participate in the project. Once you consent to take part, I will be contacting you with details of the date, venue and time of the focus group.

Thank you very much for taking time to read this.

Yours sincerely,
Stephen Antwi.

Appendix 9: Invitation to participate in a focus group discussion (PH1 & PH2)

Faculty of Social Sciences
University of Stirling
Stirling
FK9 4LA
United Kingdom

4th August 2017

PH1 & PH2
[redacted]
Ghana

Dear Healthcare professional,

I am a postgraduate research student from the University of Stirling, United Kingdom. I am interested in exploring people with dementia and their carers' experiences of living with the condition in Ghana. I would like to talk to you in order to find out more about what it is like to live with dementia. I have enclosed an Information Sheet to help you make an informed decision about whether you would like to take part in this project or not. Should you wish to discuss further or if you have any questions about this project, please contact me on xxxx or my supervisor Dr Louise McCabe on [redacted] or e-mail xxxx.

If you are happy to take part in the study, I would be grateful if you could complete the enclosed consent form to confirm your agreement to participate in the project. Once you consent to take part, I will be contacting you with details of the date, venue and time of the focus group.

Thank you very much for taking time to read this.
Yours sincerely,
Stephen Antwi.

Appendix 10: Information Sheet for people with dementia and their carers. (include photos here).

About the project

I am Stephen Antwi, a research postgraduate student from the University of Stirling, United Kingdom. I am interested in learning about the experiences of people with memory problems and their family members in Ghana. This research will help improve the understanding of memory problems, help to write future policies and find out better ways to support people with memory problems and their family members in the country.

Why I have been contacted?

I am contacting you because I would like to talk to you about what is it like to live with memory problems. I am contacting people with memory problems and their carers who might be interested in taking part in my study about their experiences of living with the condition. You will be asked questions about your experience of living with memory problems looking back to when the problems started and how they impact on you on a day-to-day basis.

What does the research involve?

The interview session will last between 1-2 hours. During the session, I will ask you some simple questions and we will discuss your experiences. You can be interviewed alone or jointly with the person who looks after you, whatever you prefer. If you do agree take part, I will be contacting you to arrange the date, venue and suitable time for the interview.

Do I need to take part in the study?

No. You don’t have to participate in it if you don’t wish to. Your participation is completely voluntary and if you agree to proceed, you may choose to withdraw at any time without giving reason(s) for this.

What will happen to the information I give?

Everything that you discuss will be kept confidential and no details of you including your name, hometown, details about your family or any information of yours will be disclosed or used to identify you. Responses about your experiences will be used to help other people with similar conditions and experiences and health care needs. The information you give during the discussion will be audio-recorded and your consent will be sought prior to recording it. I will analyse the information you provide, and I might quote some of your responses in my reports. The quotations will be used to illustrate points made in the analysis. Where quotes from in the transcripts are used pseudonyms or initials of participants' names will be used. Transcripts will be kept for a maximum of 10 years as per the University of Stirling's data protection policies.

Are there any benefits for taking part?

There are no direct personal benefits for you from taking part in the study. However, it is anticipated that the findings from the study will help improve understanding of memory problems, inform future policies and improve care practices in Ghana. It will also provide an opportunity for you to meet people and share experiences about living with or caring for someone with memory problems.

Further information

Should you wish to take part or like to discuss this project further, you can contact me directly on xxxx or my supervisor Dr Louise McCabe on (Louise's or myself) e-mail xxxx and telephone xxxx. You may also contact Dr McCabe if you have any concerns.

Thank you so much for taking time to read this information sheet

Stephen Antwi

s.f.antwi@stir.ac.uk.

Appendix 11: Information sheet for focus groups

(include photo here)

About the project:

I am Stephen Antwi, a research postgraduate student from the University of Stirling, United Kingdom. I am interested in learning about the experiences of people with dementia and their carers in Ghana. It is expected that this will help improve the understanding of dementia, help to inform future policies and identify better ways to support people with dementia and their carers in the country.

Why I have been contacted?

I am contacting you because I would like to talk to you about what is it like to live with dementia. I am contacting health care professionals and staff at prayer camps who might be interested in taking part in a group discussion regarding their experiences of caring for someone who has dementia. You will be asked questions about your experience of caring for or working with the person with dementia from the moment they were diagnosed, or you recognised the presence of the illness and to talk about the impacts you see among families with dementia and how you support them.

What does the research involve?

About 4-8 people are expected to take part in the discussion. The session will last about between 1-2 hours. During the session, the group will be asked to share their experiences and respond to comments from others in the group. Everyone within the group will be a member of staff within your organisation or church. If you do agree take part, I will be contacting you to confirm the date, venue and time of the group discussion.

Do I need to take part in the study?

No. You don't have to participate in it if you don't wish to. Your participation is completely voluntary and if you agree to proceed, you may choose to withdraw at any time without giving reason(s) for this.

What will happen to the information I give?

Everything that you discuss be kept confidential and no details of you including your name, hometown, details about your family or any information of yours will be disclosed or used to identify you.

The information you give during the discussion will be audio-recorded and your consent will be sought prior to recording it. I will analyse the information from the focus group, and I might quote some of you during the write-up. The quotations will be used to illustrate points made in the analysis. Where quotes from in the transcripts are used for the purposes of this research, pseudonyms or initials of participants' names will be used. Transcripts will be kept for a maximum of 10 years as per the University of Stirling's data protection policies.

Are there any benefits for taking part?

There are no direct personal benefits for you from taking part in the study. However, it is anticipated that the findings from the study will help improve understanding of dementia, inform future policies and improve dementia care practices in Ghana. It will also provide an opportunity for you to meet people and share experiences about caring for and supporting people with dementia.

Further information

Should you wish to take part or like to discuss this project further, you can contact me directly on xxxx or my supervisor Dr Louise McCabe on (Louise's or myself) e-mail [redacted] and telephone [redacted]. You may also contact Dr McCabe if you have any concerns.

Thank you so much for taking time to read this information sheet.

Stephen Antwi
s.f.antwi@stir.ac.uk

Appendix 12: Consent form for people with dementia and their carers

Please initial boxes

1. I confirm that I have read and understood the information sheet. I have had the opportunity to ask questions, and I feel happy with the answers provided to me.	
2. I understand that my participation is voluntary and that I am free to leave at any time without giving a reason.	
3. I know that taking part or not taking part will have no effect on any services I receive from the ministry of health or any other organisation.	
4. I understand that all information will be kept confidential.	
5. I agree that the information can be used on condition that it is anonymised.	
6. I understand that all information will be accessed only by the researcher and his supervisor and that the audio-recordings will be deleted upon completion of the study. Anonymised transcripts from the interviews will be kept for ten years in line with data protection requirements.	
7. I give my permission for the interview to be audio-recorded.	
8. I agree to take part in the above research.	

Participant's name: Signature: Date:

Researcher's name: Stephen Antwi Signature: SFAntwi Date:

Appendix 13: Consent form for focus groups

Please initial boxes

1. I confirm that I have read and understood the information sheet. I have had the opportunity to ask questions, and I feel happy with the answers provided to me.	
2. I understand that my participation is voluntary and that I am free to leave at any time without giving a reason.	
3. I know that taking part or not taking part will have no effect on any services I receive from the ministry of health or any other organisation.	
4. I understand that all information will be kept confidential.	
5. I agree that the information can be used on condition that it is anonymised.	
6. I understand that all information will be accessed only by the researcher and his supervisors and that the audio-recordings will be deleted upon completion of the study. Anonymised transcripts from the interviews will be kept for ten years in line with data protection requirements.	
7. I give my permission for the group discussion to be audio-recorded.	
8. I agree to take part in the above research.	

Participant's name: Signature: Date:

Researcher's name: Stephen Antwi Signature: SFAntwi Date:

Appendix 14: Topic guides for in-depth interviews

* Can you tell me what were the first signs that something was wrong with your memory
* Who did you tell and why?
* What is life like for you now?
* What challenges do you face?

Probes or follow-up questions will be used to add more depth and richness into the data. For instance, please

i) can you tell me a bit more about
ii) could you tell me more about that
iii) how was that for you?
iv) what do you think this means for you?

What are your experiences of the following and why?

* friends, family and relationship
* housing
* stigma / discrimination
* leisure
* income / money / wealth

Appendix 15: Topic guides for focus groups

What challenges are you facing in caring for or supporting the person with dementia? And why? Think about the following:

* physical and mental health
* relatives / friends, family and relationship
* recreation / leisure
* work / job
* feeling useful / having purpose
* housing / living arrangement

Are these more important for some people than they are for others in supporting the person with dementia? Think about:

* Gender differences
* Generation/age differences
* Social class / background differences
* People providing care or support for relatives

What factors are needed to ensure that these aspects feature in people’s lives? Think about:

* Individual resources
*Family resources
*Neighbourhood / community and environmental features
*Local services and organisations
* National policies

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