



## **AN ETHNOGRAPHIC STUDY OF PALLIATIVE CARE IN A NIGERIAN HOSPITAL**

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## **Acronyms**

This list is confined to acronyms used more than once, and in more than one places, within the thesis.

<i><b>Acronyms</b></i>	<i><b>Full meaning</b></i>
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APCA	Africa Palliative Care Association
MEDCs	More Economically Developed Countries
WHO	World Health Organisation
SI	Symbolic Interactionism
PC	Palliative care
PCU	Palliative care unit
WHCA	Worldwide Hospice Care Alliance
OE	Organisational ethnography
QOD	Quality of death
PCIN	Palliative Care Initiative, Nigeria
HCPs	Health care providers
TMT	Terror Management Theory



## **Abstract**

Palliative care has become an important public health issue in recent years and has been declared a universal human right. A wealth of literature can be found describing its effectiveness and numerous benefits, yet significant disparities exist in worldwide palliative care development between, and within, countries. To date, previous studies indicate that it has steadily improved in the more economically developed countries, although its utilisation remained uneven in western societies between the blacks compared with the white people. In low- and middle-income countries, palliative care has continued to be less available, underutilised and not integrated in many of the healthcare systems, especially in the African countries such as Nigeria. This qualitative study using an ethnographical approach to understand the cultural, socio-political, environmental, and organisational dynamics which influenced the provision of palliative care, and the patients' and relatives' behaviour towards its utilisation in a Nigerian hospital. Data was collected using participant observation, ethnographic interview and review of documentary sources, involving 43 participants, comprising healthcare professionals, members of the hospital management, patients and their families.

The findings show a dominant discourse of culturally-based perceptions rooted in belief systems and inadequate knowledge of palliative care associated with insufficient education and training which manifested in several ways, such as conceptualisation of palliative care as a '*dead end*'. The service-users predominantly used their belief systems in decision-making, whereas dichotomy existed amongst the professionals about using either ethno-religious knowledge or biomedical knowledge to inform practice. These culturally-based perceptions were found to be contributory to, and a result of, a political and organisational culture that did not value palliation. Thus, the insensitivity of the bureaucrats was displayed in numerous ways, such as lack of funding for palliative care. Consequently, the environment for care represented space rather than a place that could promote the wellbeing of the service-users, which thereby contributed to various organisational cultures, such as weak interdepartmental collaboration and work-stoppage, with negative impacts for the

service-users. The findings also suggest that the customary code of behaviour used by the service users was conditioned mainly by complex interactions of economic conditions, social relationships and lack of a governmental social support system. The professionals, therefore, used their personal resources as well as provided physical cash to the patients to cushion the effect of government inadequacies and to improve their wellbeing. These findings indicate the need for a cultural shift towards a mind-set that values palliative care in Nigeria in order to enhance its development. This study adds to the knowledge of this field and provides clinicians around the world with further understanding of meaning making in illness from the perspective of the Nigerian culture, which may be applicable to other people of African ancestry and could be used to boost cultural competence in palliative care.

## CHAPTER ONE

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### INTRODUCTION AND BACKGROUND TO THE THESIS

#### 1.0 Identification of the broad area of investigation

Palliative care (PC) is fundamental to health and has been endorsed as a human right by international organisations such as the United Nations, World Health Organisation, and National Hospice Palliative Care Association because of its effectiveness and numerous benefits (Connor and Sepulveda, 2014; WHO, 2013; Radbruch *et al.*, 2013; Brennan, 2007; UN, 1996). The need for PC is rapidly increasing due to rising ageing populations across the world, the success of new technology at prolonging the lives of individuals with serious illnesses, the globalisation of unhealthy life styles, rapid unplanned urbanisation, and increases in cancer and other non-communicable diseases (Connor and Sepulveda, 2014; WHO, 2014; Economist Intelligence Unit, 2015). Yet there is significant disparity and inequality in the world provision of PC for individuals with serious and/or life-limiting illnesses (Connor and Gwyther, 2018).

The global atlas of PC at end-of-life by the Worldwide Hospice Care Alliance (WHCA) and WHO estimated that in 2011, less than 10% of 40 million individuals that required PC around the world received it (Connor and Sepulveda, 2014). Currently, the WHO project that of the 40 million people in need of PC worldwide, only 14% receive it (WHO, 2018a), implying that the vast majority of people lack access to the PC services which could improve the quality of their lives. More specifically, the research by the Economist Intelligence Unit (EIU) found that only 34 out of 80 countries had an above average score in the 2015 Quality of Death (QOD) index (EIU, 2015). Although this study included slightly below one-third of all countries, they warned that this score does not necessarily indicate that these countries provide satisfactory PC across all the factors considered in the index; rather, the scores relate to the mathematical average of the scores in the index. Interestingly, the UK ranked first in the overall index, with other countries such as Australia, New Zealand, Ireland, Belgium, Taiwan, Germany, Netherlands, US and France forming the first ten countries that performed well in the index (EIU, 2015). However, many low- and middle-income countries, particularly

countries within the African region, were clustered down the index, suggesting that provision of high-quality PC had not gained momentum mostly in low and middle-income countries (EIU, 2015). This finding reflects the WHO statement, highlighting that 78% of individuals in need of PC live in low- and middle-income countries (WHO, 2018a). Thus, it could be suggested that the hope of a good death for many people with serious and/or terminal illnesses appears unlikely, especially in many African countries.

Africa is the second largest continent in the world, currently experiencing epidemiological transition, such that the burden of cancer and other non-communicable diseases has continuously risen over the past decade (Jedy-Agba *et al.*, 2015). For instance, out of 14 million new cancer cases which occurred globally in 2012 (WHO, 2015), developing countries were assumed to be experiencing about 56% of cancer incidence (Ferlay *et al.*, 2010; Jedy-Agba *et al.*, 2015). Of the 8.8 million deaths from cancer recorded globally in 2015 (WHO, 2018b), 70% of these deaths were assumed to have occurred in low- and middle-income countries (WHO, 2018b). Indeed, cancer requires palliation but more striking is that 80% of the cancers in Africa are incurable at the time of detection and diagnosis due to late presentation and lack of human and material resources (Kanavos, 2006; Parkin *et al.*, 2008; Jedy-Agba *et al.*, 2015) with palliation being the only option. Cancer patients account for one third of people in need of PC, while the rest include individuals suffering from varieties of chronic progressive diseases, such as HIV/AIDS, chronic obstructive pulmonary disease, cardiovascular diseases, renal failure, mental illnesses, dementias, drug-resistant TB, diabetes, multiple sclerosis, Parkinson's disease and rheumatoid arthritis (Connor and Sepulveda, 2014). At the end of 2017, 36.9 million people were living with HIV virus globally, with 940,000 deaths recorded (WHO, 2018c). But the African region remains the most severely affected, accounting for two-third of the people living with HIV worldwide (WHO, 2018c).

In Nigeria, there is a lack of national statistics about cancer prevalence and the death rate, though Akinde *et al.* (2015) predicted that as many as quarter of a million new

cancer cases occur in all regions of Nigeria annually. The cancer registries across ten teaching hospitals and one Federal Medical Centre in Nigeria recorded a total of 6,484 cancer cases between 2009 and 2010 (Jedy-Agba *et al.*, 2012). Whereas, the population-based cancer review from the Abuja and Calabar cancer registries recorded a total of just below half a million (4,077) cancer cases from 2009 to 2013, while 1,738 cancer cases were recorded in the Enugu cancer registry between 2012 and 2013 (Jedy-Agba *et al.*, 2015). However, the authors stated that only malignant cases were included in the analysis (Jedy-Agba *et al.*, 2015), implying that these figures do not represent the overall total number of cancer cases in Enugu, Calabar and Abuja for the periods under review. In 2016, 18,599 cancer cases were recorded from 16 out of 36 states in Nigeria (Morounke *et al.*, 2017), though Akinnwande *et al.* (2009) argued that only 7.2% of the Nigerian population are covered by the cancer registries. Similar to cancer, there are high number of individuals with HIV/AIDS in Nigeria.

There were 220,000 new HIV infections and a total of 3.2 million people living with AIDS, with about 230,000 AIDS-related deaths in Nigeria in 2016 (UNAIDS, 2018). Overall, the WHO has predicted a 20% chance of death from cancer, chronic respiratory diseases, cardiovascular diseases and diabetes by Nigerians between the ages of 30 to 70 (WHO, 2014), suggesting that about 37,000 Nigerians would have died from these illnesses in 2017. Irrespective of the evidence about the high number of individuals that would benefit from PC, provision of PC remains limited and inconsistent, and continues to be unavailable to the majority of people in Nigeria (Lynch *et al.*, 2013). The 2015 QOD index further showed that Nigeria ranked lowest among other African countries (EIU, 2015), suggesting that unmet PC needs may be higher in Nigeria compared to other African countries; thus, there is a critical need to scale up PC in Nigeria. This study adds to the understanding of why PC is poorly developed in Nigeria. The knowledge gained from this study will provide evidence that will help to improve service provision and utilisation.

## **1.1 Palliative care**

### **1.1.1 What is palliative care?**

Dame Cicely Saunders is recognised as the founder of the modern hospice movement (Fallon and Smyth, 2008; Clark, 1999; Richmond, 2005). She founded St. Christopher's Hospice, London in 1967, based on her desire to improve the standard of care being rendered to dying patients (Richmond, 2005). Dame Saunders developed the principle of 'total pain' and the concept of a holistic approach to care which incorporated the assessment and management of the physical, social, emotional and spiritual needs of patients (Twycross, 1980; Clark, 1999). The term PC emerged from the hospice movement, but was strictly understood to mean end-of-life care or terminal care (Fallon and Smyth 2008). The first PC team was, therefore, formed in the 20<sup>th</sup> century between 1974 and 1975 with the introduction of the use of morphine for pain management (Fallon and Smyth 2008). PC continued to develop and was formally recognised as a specialty in 1987 when the WHO formulated its first definition (Hiller, 1988; Fallon and Smyth 2008).

The most commonly used and accepted definition of PC is provided by WHO, in which PC is defined as *'an approach that improves the quality of life of patients and their families faced with the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'* (WHO, 2018d). This definition further highlights that PC alleviates patients' pain and any other troubling symptoms, affirms life and considers the process of dying as normal, with the intention of neither to quicken nor delay death. It offers a support system to help the family cope during the patient's illness and their own bereavement, whilst adopting a team approach to enhance the quality of life for patients and their families. PC is also applicable early in the course of illness, in conjunction with other therapies (WHO, 2018d).

### **1.1.2 Why palliative care?**

There is an extensive body of evidence about the numerous benefits of PC and why it should be a quality standard for the care of individuals with advanced and/or life-limiting illnesses. PC reduces suffering and improves patients' ability to cope with illness (Bakitas *et al.*, 2009; Temel *et al.*, 2016) and also helps families (Brumley *et al.*, 2007; Gelfman *et al.*, 2008). In addition, PC consultations have lowered the amount of acute care hospitalisation, as well as the frequency of emergency admissions (Dunn *et al.*, 2018; Wright *et al.*, 2018), and also improved survival (Temel *et al.*, 2010). This shows that the burdens derived from symptoms associated with serious and/or life-threatening illnesses can be improved with the use of PC, which, in turn, enhances the quality of life for patients and their families. However, these studies have consistently showed that these benefits are likely to be achieved with early integration of PC with other therapies such as standard oncology care.

Lastly, PC is not only relevant in symptom management, but it also reduces the cost of care for the hospital and the patients (Brumley *et al.*, 2007; Kim *et al.*, 2018; Hung *et al.*, 2018; May *et al.*, 2018; Wright *et al.*, 2018;). This implies that a healthcare system with well-developed PC will have lower healthcare expenditure and less wasteful resource utilisation, thereby saving money for both service-users and the government by avoiding futile life-sustaining treatments while providing adequate PC that will avoid unplanned hospital admissions (Obermeyer *et al.*, 2014; DiMartino *et al.*, 2014). The current research is significant because the findings will provide insights that could be used to enhance culturally accepted PC in order to improve the service-users' quality of life. It could also save costs for the service-users, the hospitals and the government.

### **1.1.3 Palliative care in Nigeria**

Palliative care was first introduced in Ibadan and Lagos Nigeria by Olusola Fatunmbi and Olaitan Soyannwo through their non-governmental organisations, named Hospice Nigeria and Palliative Care Initiative, Nigeria (Wright *et al.*, 2006). Olusola Fatunmbi, a founder of Hospice Nigeria, is a nurse who developed an interest in hospice-palliative care services as a result of knowledge she acquired during her training at St Christopher's Hospice in the UK (Wright *et al.*, 2006). In a 40-minute interview with

David Clark in 2004, she gave an account of how she came back to Nigeria to establish a non-governmental organisation (Wright *et al.*, 2006). She initiated provision of hospice-palliative care in 1991 after she returned from the UK, and continued to advocate for the establishment of Palliative Care Unit (PCU) in government hospitals. Unfortunately, the government lacked political interest to embrace the introduction of PC to Nigerian healthcare system. However, Olusola did not give up her aspirations and, instead, established home care for terminally ill patients with her husband. Her networking with oncologists within her environment attracted some patients to her, but the majority of her patients were being referred from St Christopher's Hospice. She continued with her inspiration and other PC activists and professionals joined in her vision for the provision of PC in Nigeria.

Secondly, Olaitan Soyannwo, a Professor of Anaesthesia and Dean of Clinical Science at the College of Medicine, University of Ibadan, Nigeria founded Palliative Care Initiative, Nigeria (PCIN). In a 40-minute interview with David Clark on June 2004, she also gave an account of how PC was developed through her non-governmental organisation (Wright *et al.*, 2006). Olaitan explained that her interest in pain management evolved from seeing patients suffering from pain. In 1996, she attended the World Pain Congress of the International Association for the Study of Pain. Following this conference, she established a pain and PC team at the University of Ibadan Teaching Hospital in 2003 with responsibility for provision of PC in that hospital. In addition, this team formed an organisation known as PCIN, which was formally commissioned in 2005 for the provision of PC services. She also advocated the availability and accessibility of oral morphine for pain management.

Thus, the establishment of Hospice Nigeria in 1991 and PCIN in 2003 was how PC services began in Nigeria. The provision of PC slowly advanced to a few other healthcare organisations in Nigeria as the first hospice and PCU was established in 2007 at the University College Hospital Ibadan, headed by Professor Olaitan Soyannwo (Soyannwo, 2012). Still in 2007, Clark and colleague identified only five organisations providing hospice and PC in Nigeria, argued that Nigeria belonged to countries *with*



'localised provision of hospice care services' (Clark *et al.*, 2007:702). The number increased in 2011 to seven organisations, but still Nigeria belonged to countries with limited availability and poorly developed PC (Lynch *et al.*, 2013). Some of Nigerian PC advocates in their opinion papers confirmed that PC is limited in coverage, for instance, Oliver *et al.* (2011) reported that only eight hospitals in Nigeria were providing these services and this was supported by Oyebola (2013). Whilst Onyeka *et al.* (2013) stated the existence of six PCUs in Nigeria, the Africa Palliative Care Association atlas of PC in Africa showed that seventeen PC services were available in Nigeria (Rhee *et al.*, 2017a). The study conducted at University College Hospital, Ibadan-Nigeria reported that many of the terminally ill patients regretted non-availability of PC service in their locality (Elumelu *et al.*, 2013). More than two decades after PC commenced in Nigeria, it continued to remain patchy and is poorly developed in relation to symptom burden and control (Otegbayo *et al.*, 2010; Kolawole *et al.*, 2013; Omoyeni *et al.*, 2014; Olaital *et al.*, 2016). The current research will contribute towards understanding the complexities underlying PC development in Nigeria with intention to provide evidence that may be relevant to change practice and minimise the existing inequalities in the access and provision of care.

## **1.2 Research questions**

The decision about the specific focus of the research was made following a scoping literature review, as presented in chapter two. The research gaps identified from this review informed the broad aim: To understand the cultural, socio-political, environmental and organisational dynamics which influence the provision of palliative care, and the patients' and their relatives' behaviour towards the use of palliative care in a Nigerian hospital. To achieve this aim, the following research questions will be addressed:

- What are cultural and socio-political factors that influence the provision and utilisation of palliative care in Nigeria?
- How do cultural, and socio-political complexities influence behaviours towards provision and uptake of palliative care in Nigeria?

- In what ways do environmental and organisational dynamics shape the professionals' and service-users' provision and use of palliative care in Nigeria?

### **1.3 Choice of research design**

Choice of the research design or approach arose from the nature of the research questions of the current study. These research questions required a methodological approach that facilitated an in-depth exploration to capture the experiences, interpretations and perceptions of the participants about the culture of provision and use of PC. It may be important to note that the focus of this current research has not been previously studied; therefore, the research questions were exploratory. Because the research was exploratory, a methodology that allows for the pursuit of meaning, rather than quantification, was desirable. Qualitative research methodology was chosen because one of the criteria for its use is when the phenomenon under investigation is not understood, because little or no research work has been conducted in the area (Creswell, 2018). Qualitative research is a form of social enquiry that focuses on investigating the way people make sense of their experiences and interpret or perceive the world in which they live. I followed the advice of Gray (2014), that when researching a complex and sensitive area (as was the case in this current research), interpretations and experiences are best captured through a qualitative approach employing multi-methods, such as observations, in-depth interview, focus group discussion, and review of documentary sources, to gather data from the participants with the most knowledge of the research topic.

Finally, I argue that qualitative methods were most appropriate for the current research because they provided the participants with freedom to express their ideas and views and facilitated understanding of the complex social interactions that existed among the participants involved with the provision and use of PC, as well as the context of care. Ethnography was the specific qualitative approach chosen because it is recommended when access to beliefs, social, environmental and cultural process is required (Savage, 2000). Such an approach was valuable and fitted well into this current study, which sought cultural understanding about provision and use of PC.

## **1.4 Thesis structure**

This thesis consists of nine chapters. Chapter one sets the background of the study by presenting the global picture of the state of PC in relation to the burden of illnesses that require palliation and, more specifically, in Nigeria, identifying the broad area of investigation and providing justification why it was necessary to conduct the current research. It also provides background to contextualise PC, both historically and within the present day.

Chapter two presents the scoping literature review, exploring what is known about PC and how it has been studied in Africa. The gaps identified from the literature review formed the focus for the current study.

Chapter three describes the methodology of ethnography chosen for this study, which was influenced by social constructionist philosophy and the theory of symbolic interactionism. In this chapter, there is a discussion of how the methods of ethnography were applied in the conduct of the research, with a concluding section on reflexivity. This is followed by chapter four which presents contextual information about the organisation of PC in the studied hospital, because it was relevant to understanding the ethnography.

Three findings chapters are then presented. The first findings chapter presents analysis of the perceptions of terminal illness and palliation. This chapter covers issues concerning the belief systems and education about PC, which are the two domains upon which the individual perceptions that inform the behaviour regarding the provision and use of PC were based. The socio-political and economic influences on PC are addressed in chapter six, while environmental influences on PC are addressed in chapter seven.

Chapter eight presents a discussion of the key findings by drawing all the cultural themes together and presenting them as a holistic organisational ethnographic story within a cultural scene. This was followed by a section on the contributions and implications of the ethnography. Finally, chapter nine presents the conclusions, direction for future research, final reflections and Knowledge mobilisation and strategy in plan.

## CHAPTER TWO

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### PROVISION AND UTILISATION OF PALLIATIVE CARE IN AFRICA: A SCOPING REVIEW

#### 2.0 Introduction

The previous chapter presented the global picture of PC, primarily highlighting that rising number of individuals with illnesses that could benefit from palliation is not proportionate with the availability and development of this specialised services in many countries of the world. This chapter presents the scoping literature review of PC, focusing on the continent of Africa because it appears that countries within this region are mostly slow with PC development (Lynch et al., 2013; EIU, 2015; Rhee et al., 2017).

Scoping reviews assess the breadth and depth of literature in a particular field, such as nursing (Brien *et al.*, 2010; Pham *et al.*, 2014), and this was deemed appropriate, given the paucity of literature about PC in Africa. In addition, a scoping review can be particularly useful when the topic is complex, abstract and heterogeneous in nature (Arksey and O'Malley, 2005; Davis *et al.*, 2009). It may be important to highlight that scoping reviews have been criticised due to variation in methodological rigour (Davis *et al.*, 2009), however, it is considered to be an appropriate method for refining or providing a foundation for future research (Rumrill *et al.*, 2010; Levac, *et al.*, 2010). In line with the aim of a scoping review, this chapter will identify, report and critique the existing evidence about PC in Africa, in order to identify any research gaps and establish a foundation for advancing knowledge.

#### 2.1 Methodology of the scoping review

The Arksey and O'Malley (2005) methodological framework for conducting a scoping review consists of a six steps process (identifying the research question, identifying the relevant studies, study selection, charting the data, collating, summarising and reporting the data and consultation which is an optional step). This process was adopted to assess what is known about PC in Africa. However, some of the recommendations for enhancing scoping study methodology proposed by Levac *et al.* (2010) was utilised in this current study. For instance, combining the broad research question with a clearly articulated scope of inquiry by defining the target population,

the concept, health outcomes of interest in order to establish effective search strategy. I therefore adopted the definition of PC presented in chapter one and has defined the target population of interest. As also recommended by Levac and colleague, I have used specific questions to guide my decision-making around the scope of the review. These questions are outlined next.

### **2.1.1 Step one: Identifying the research question**

Arksey and O'Malley (2005) stated that the research question in scoping literature review should be broad in nature as they seek to provide breadth of coverage and also highlighted that its identification is the step that provides roadmap for the subsequent stages. This implies that research questions must be clearly defined as they have consequence for search strategy (Arksey and O'Malley, 2005) and will facilitate decision making about study selection and data extraction later in the methodological process (Levac *et al.*,2010). Therefore, the specific questions guiding this review are:

- What is known about the provision and use of palliative care in Africa?
- How have the questions relating to the provision and uptake of palliative care been studied in Africa?

### **2.1.2 Step two: identifying the relevant studies**

This step includes identifying the relevant studies as well as making decisions about where to search for literature, the search terms to use, time span and the language (Arksey and O'Malley, 2005).

#### **Where to search**

To identify relevant studies, the sources searched include electronic databases, reference lists, hand searching of key journals, and google scholar as shown in Box 2.1 below.

Allied and Alternative Medicine (AMED), MEDLINE, PubMed Central (PMC), Internurse, Science direct, PsychINFO, Webs of science and Cumulative Index to Nursing and Allied Health Literature (CINAL), Global Health, African Journals online, Journal of West African College of Nursing, Reference lists and Google scholar

Box 2.1: Databases and other sources searched

## **Search term and search strategy**

The key words and the search strategy are shown in Box 2.2 below.

<b>Key words used for search</b>	<b>Search strategy</b>
Palliative care, terminal care, hospice care, end-of-life care, supportive care, chronic disease (s), terminal disease, terminally ill, terminal illness, progressive disease, palliation, death and dying, pain, nursing, hospice, critical care, end of life, Sub-Sahara Africa, Africa, critically ill patients, social support, cancer, non-cancer. The name of individual countries within WHO classification of African region was also used.	<ul style="list-style-type: none"><li>▪ The electronic search across different databases used the key terms as a single search and combination of the key terms with Boolean operators and truncation ('OR' 'AND' 'NEXT'). The results were combined with each other as a single search in order to yield a broader result.</li><li>▪ Citation tracking and hand searching of the articles identified on the reference lists.</li><li>▪ African Journal online and Journal of West African College of Nursing were searched</li><li>▪ Google Scholar was also searched to ensure that articles not indexed in the databases searched were retrieved and included</li></ul>

### **Box 2.2 Key words used for search and search strategy**

## **Time span and language**

It has been recognised that balancing breadth and comprehensiveness of the scoping study with feasibility of resources and practicalities of the search could be challenging (Arksey and O'Malley, 2005; Levac *et al.*, 2010). There is no generally accepted timeframe for scoping review, it could be from ten years or more (Fang *et al.*, 2018;

Merisier *et al.*, 2018) but depends on (though not limited to) availability of resources, quantity of the literature, key historical dates of interest to the phenomenon and the expertise of the reviewers. The literature published in English between January 2005 and June 2018 was searched and included. I have provided a rigorous and transparent method used for mapping this area of research.

### **2.1.3 Step three: selection of studies**

As recommended by Arksey and O'Malley (2005), the selection of studies was based on the inclusion and exclusion criteria, as shown below;

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
Written in English language	Not published in English
Empirical studies published between January 2005 to June 2018	Focused on PC for children
Retrospective case file reviews	
Scoping, systematic, integrated reviewed articles	
Focused on the provision and use of PC/end-of-life care for adults in Africa	

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### **2.1.4 Step four: charting the data**

Data from the included articles was charted in relation to the author(s), publication year, country, title, methodology, aim/objectives and relevant key findings. See Appendix A.

### **2.1.5 Step five: collating, summarizing, and reporting results**

As shown in the PRISMA diagram in figure 2.1, 5,238 articles were originally identified and after duplicates and articles that did not meet the inclusion criteria were removed, forty-one eligible papers were identified as eligible to be included in the review. Guided by the inclusion and exclusion criteria stated above, the selection process involved the initial assessment of the title and abstract of all the articles to evaluate for its relevance. The number of the articles considered to have met the inclusion criteria at this stage were further assessed by reading the full text, leading to the selection of the included papers. There were two types of eligible studies; one was empirical studies (n=34) originated from 9 African countries (Nigeria, Uganda, Ghana, Kenya, South

Africa, Malawi, Congo, Ethiopia and Rwanda), while the others were reviews (n=7). Quality assessment for these studies were not conducted because it is not required element of scoping review, rather I focused on the comprehensiveness and breadth which are the important element is scoping literature review (Arksey and O'Malley, 2005; Brien *et al.*, 2010).

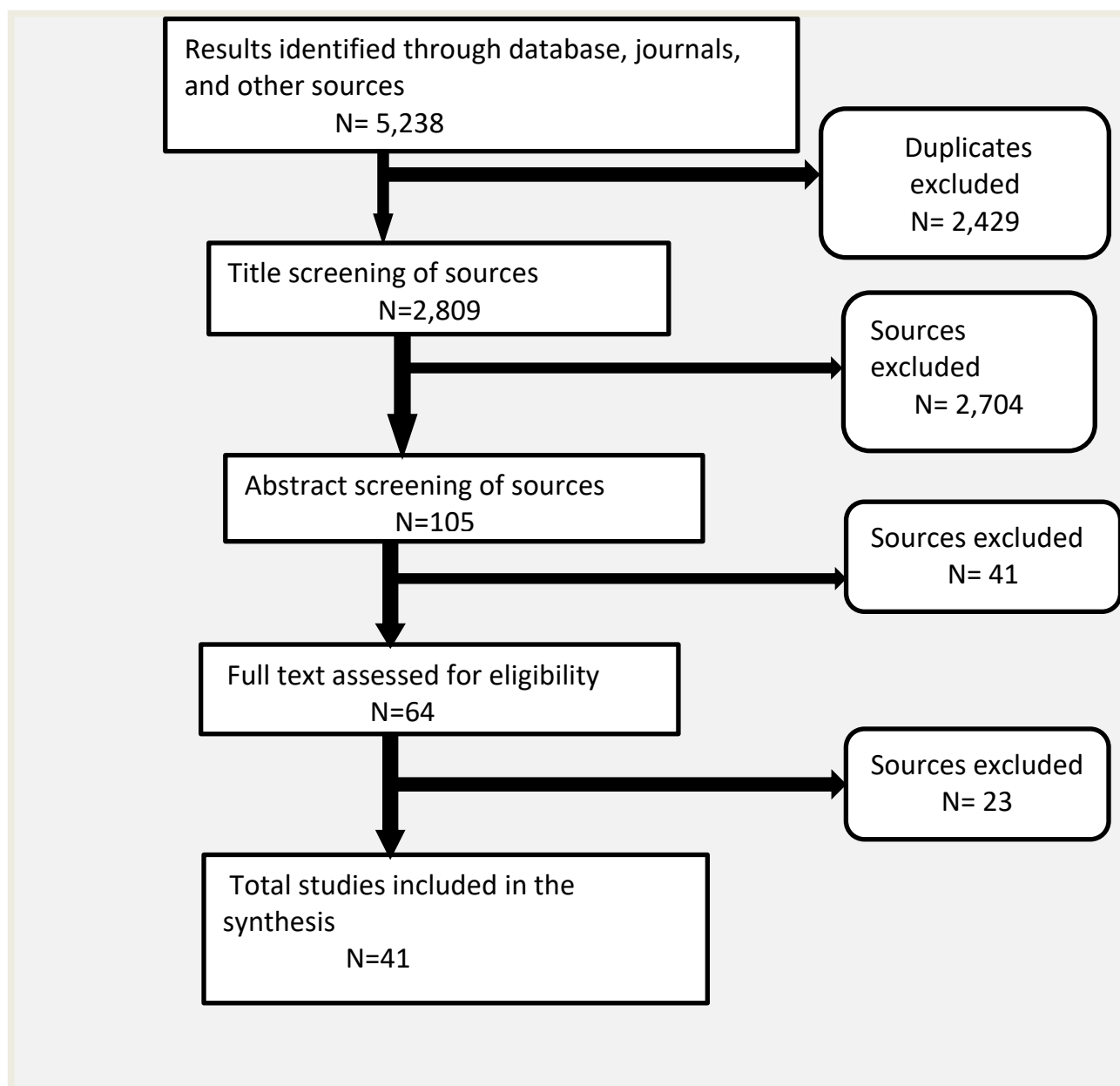


Figure 2.1 Literature identification and selection process

## 2.2 Findings

Descriptive thematic analysis of the various sources was undertaken to provide an overview of the breadth of the literature as recommended by Arksey and O'Malley (2005). Specifically, a data extraction sheet was created which comprised of codes



generated inductively while reading details of the selected papers. The Braun and Clarke's (2006) six steps framework of thematic analysis were conducted. Three themes emerged as shown below. The relevant findings of the included studies were used to inform the narratives within the identified themes.

Themes	Subthemes
Individual-level factors influencing palliative care	Knowledge and attitude of healthcare Providers  <b>Patients' and relatives' factors</b> Awareness/knowledge attitude Poverty Late presentation Religion
Systemic-level barriers impacting on palliative care	Availability and accessibility of palliative care Symptoms control and burden Education and training Resources (Staffing, Availability of the opioids) Funding Policy
Relational barriers to palliative care	Referral practices among healthcare professionals Communication with healthcare professionals

### 2.2.1 INDIVIDUAL-LEVEL FACTORS INFLUENCING PALLIATIVE CARE

The individual-level factors consist of the issues which were peculiar to the healthcare professionals, patients and their relatives, which influenced the provision and use of PC. This theme will be presented in two subthemes: firstly, factors specific to healthcare professionals and secondly, factors related to patients and their families.

### **2.2.1.1 Knowledge and attitude of the healthcare Providers about palliative care**

The knowledge and attitude of the healthcare providers (physicians, nurses, pharmacists, social workers, medical interns, medical students and the clergymen), was one of the dominant issues featuring in nine empirical studies and four reviews. The majority of the nurses, doctors and other medical staff were reported to be aware of PC (Akinyemiju *et al.*, 2015; Eke *et al.*, 2016; Nnadi and Singh, 2016), contrary to 61.8% religious leaders and seminarians who had not heard of it (Badru and Kanmodi, 2017). Two studies (Fadare *et al.*, 2014a; Fadare *et al.*, 2014b), both conducted in Nigeria and used questionnaires for data collection, concluded that healthcare professionals had good knowledge about PC because most the nurses and doctors understood PC to be active care for the dying, thought PC was about pain or geriatric medicine, and felt that PC recognises death as a normal process and affirms life. However, a similar study conducted in Nigeria by Eke *et al.* (2016) and Nnadi and Singh, (2016) reported that healthcare professionals had insufficient knowledge on the interdisciplinary nature of PC, service-users who could benefit from palliation, and components of PC. The findings of these two later studies corroborates with that of Kass *et al.* (2014) and Mukemo *et al.* (2017) who reported that only a few nurses selected from some hospitals in Congo and Ethiopia had good knowledge of PC.

Only the article by Kass *et al.* (2014) acknowledged that nurses who had formal training in PC had greater knowledge than others who had no such training, while other socio-demographic variables had no association with level of knowledge. Nnadi *and* Singh, (2016) reported positive relationship between the number of sources of information and knowledge level about PC. In addition, they also stated that medical interns' PC knowledge level improved following analysis of postintervention questionnaires from post-educational intervention lectures (Nnadi *and* Singh, 2016). However, some of the critical elements of the lecture package such as length and duration of the lectures as well as condition of the learning environment were not provided, they highlighted that their findings underscore the need for inclusion of PC into the school curriculum at both undergraduate and post-graduate medical and nursing education (Nnadi *and* Singh, 2016).

In the three studies mapping the level of PC development across several countries of the world; Kenya, Uganda and South Africa were the three out of 47 African countries that were consistently placed in the group of countries with a broad awareness of PC by healthcare professionals and local communities (Clark *et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013). In contrast, 12 African countries (Botswana, Congo, Egypt, Malawi, Zambia, Zimbabwe, Nigeria, Morocco, Gambia, Tanzania, Sierra Leone and Swaziland) were grouped among countries that had partial/local awareness of PC (Clark *et al.*, 2007; Lynch *et al.*, 2013). The 2015 Quality of Death (QOD) Index conducted by the Economist Intelligence Unit (EIU) reported that Uganda and Zimbabwe were the only two countries in the African region that ranked topmost in the category of community engagement, meaning that they were African countries where the healthcare providers including other members of the society had an awareness and understanding of PC (EIU, 2015). The countries that the public including the healthcare professionals were reported to have only a limited understanding and awareness of PC included Malawi, Morocco, Nigeria, Egypt, Ethiopia, Ghana, Kenya, South Africa and Zambia, whilst Botswana was the only country which was reported that healthcare professionals and other members of the public had no awareness and understanding of PC (EIU, 2015). Interestingly, irrespective of the level of knowledge about PC, four studies conveyed that all the healthcare professionals had favourable/positive attitudes about PC, revealed by their strong desire to support issues pertaining to the provision of optimum care for terminally ill and dying patients (Kass *et al.*, 2014; Fadare *et al.*, 2014a; Opoku, 2014; Mukemo *et al.*, 2017). The positive attitude towards PC by nurses was found to be associated with higher levels of education, working in medical wards, and PC training, but age, gender and work experience had no significant association with attitude towards PC (Kass *et al.*, 2014).

#### **2.2.1.2 Patients' and relatives' factors impacting on palliative care**

Nineteen of the included papers explicitly discussed the awareness of PC, knowledge and attitude, poverty, late presentation and religion as factors peculiar to the patients and their families which impacted on the use of PC. Substantial differences in the awareness of PC existed among patients and their families in 47 African countries (Clark

*et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013; EIU, 2015; Hannon *et al.*, 2016). Uganda, Kenya and South Africa were the three countries where local communities and society in general had a broad awareness of PC, whereas local communities in other African countries had only partial awareness of PC (Clark *et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013). These findings correspond with those of Opoku (2014), whose 79 out of 115 respondents in Ghana indicated their awareness and knowledge about PC, although the majority of these participants were neither aware of the healthcare settings that provided PC services, nor were they aware of persons who had received PC in Ghana. Conversely, three articles (Adenipekun *et al.*, 2005; Kolawole *et al.*, 2013; Lakew *et al.*, 2015) found that the majority of the patients and their family members had no knowledge of, and were inadequately aware of, palliative and hospice care services, while the most recent QOD Index reported no public awareness or understanding of PC among the public in Botswana (EIU, 2015). The two studies by Adenipekun *et al.* (2005) and Lakew *et al.* (2015) provided insights that the level of education impacted both on whether respondents had, or had no, knowledge of PC, indicating that higher educational level was associated with higher level of awareness/knowledge. Remarkably, there was consensus in the literature that patients desired knowledge about PC, particularly in respect to the causes of cancer, treatment options (Otegbayo *et al.*, 2010) and aspects of PC which would require decision-making (Mkwinda and Lekalakala-Mokgele, 2016). Although, agreement existed in the literature about poor public knowledge of PC in the majority of the African countries, most of the patients from Nigeria, Ghana, Uganda and Zimbabwe demonstrated a positive attitude towards PC through their expression of acceptance and willingness to receive PC (Adenipekun *et al.*, 2005; Opoku, 2014; Hannon *et al.*, 2016).

Overall, the review evidence indicated that the public (patients and their families) were unlikely to seek PC because of their inadequate knowledge of it. It could also be for the reason that pertained cultural acceptance of spiritual and traditional care practices since they were keen to seek care from churches, mosques, spiritual homes and traditional medicine men (Opoku, 2014; Hannon *et al.*, 2016). The few patients and

their families who were aware and knowledgeable about PC, as well as those without knowledge of PC, often presented themselves for PC in the healthcare setting at the advanced stage of their illness and this accounted for complications and poor quality of life (Hannon *et al.*, 2016; Agodirin *et al.*, 2017; Nwabuko *et al.*, 2017). Late presentation of illness was further complicated by poverty and the religious beliefs of the patients and their families. Specifically, the majority of the patients perceived that PC was expensive and, therefore, they were reportedly unable to pay due to poverty and lack of health insurance coverage, leading to a high rate of patient drop-out, stoppage or restricted access to PC (Rhee *et al.*, 2018; Opuku, 2014; Kolawole *et al.*, 2013; Lewington *et al.*, 2012).

Notably, Lewington *et al.* (2012) reported that the majority of the patients and their families had faith, while other articles also showed that patients and their families had inclinations to religious faith. The study by Opoku (2014) mentioned that religious belief system, socio-cultural background was cited in the minority among other listed factors that Ghanaians (though not explicit as to whether from public or healthcare professions) marked as obstacles which affect the provision of PC in Ghana. whilst, the findings by Otegbayo *et al.* (2010) on the aspect of spiritual assessment, utilised modified needs questionnaires and identified some spirituality concerns, for instance, they reported that 86% of the cancer patients felt that God is a doer, with few patients of the opinion that God was a supporter and could heal them. Also, an impression about religious belief as a barrier to PC was made in the study van Gurp *et al.* (2015) who used unstructured interview to elicit information from the perspectives of three key managers of University College Hospital (UCH), Ibadan and other representatives from UCH telemedicine unit, zonal office Nigerian communications and Glo mobile telecom provider. Most of the patients and their families were suggested to have resorted to an attempt to reconcile hope with religion (van Gurp *et al.*, 2015), leading to hopes for miraculous cures, healing and recovery (van Gurp *et al.*, 2015; Otegbayo *et al.*, 2010). Although religious belief system was among the factors identified in three articles as obstacles to patients seeking PC, the methodological approach used in these studies mean that there is limited understanding, for instance none of these studies

had explored in greater detail the various beliefs held by the patients and their families and how these beliefs may, or may not, have impacted on the utilisation of PC, suggesting that that a nuanced account is required. The following section will present findings about the second theme.

### **2.2.2 SYSTEM-LEVEL BARRIERS IMPACTING ON PALLIATIVE CARE**

Thirty papers reported a range of systemic structures at both hospital and national level hindering the provision and use of PC. These factors (availability and accessibility of PC services, symptoms prevalence, burden and control, education and training for healthcare professional in PC, and political factors impacting on PC) are reported as follows:

#### **2.2.2.1 Availability and accessibility of palliative care services**

Thirteen primary studies reported limited availability of PC, with poor access for the service-users in various countries, such as Nigeria, Ghana, Kenya, Malawi, and Ethiopia (Adenipekun *et al.*, 2005; Otegbayo *et al.*, 2010; Kolawole *et al.*, 2011; Elumelu *et al.*, 2013; Opoku 2014; Omoyeni *et al.*, 2014; Downing *et al.*, 2015; Lakew *et al.*, 2015; van Gorp *et al.*, 2015; Olaitan *et al.*, 2016; Agodirin *et al.*, 2017; Ndiok and Ncama, 2018; Sharkey *et al.*, 2018). Of these countries, Malawi and Kenya seemed to have the most comprehensive PC services, delivered across specialist, district hospital and community levels (Downing *et al.*, 2015). One of the recent surveys about national PC capacities around the world found that only 20% of the African countries had PC available in primary healthcare for patients with non-communicable diseases (Sharkey *et al.*, 2018).

In addition, and in support of the above findings, the review mapping the level of PC development in Africa reported that PC services were unavailable in 21 out of the 47 countries included in this study, as of 2005 (Clark *et al.*, 2007), with no progress made as of the 2006 global mapping of PC development (Wright *et al.*, 2008). However, progress was made in 2011, as six countries (Libya, Ethiopia, Namibia, Sudan, Cote d'Ivoire and Rwanda) had established PC services, although there was still absence of this specialised service in 28 of the 54 countries in the African region (Lynch *et al.*,

2013). Still, in 2011, additional progress had been made whereby fourteen countries increased the number of PC services they provided, of which there were the greatest increases in South Africa, from 120 to 210, Kenya, from 8 to 44, Uganda, from 8 to 34, Tanzania from 4 to 20, and Nigeria, from 5 to 7 (Wright *et al.*, 2008; Lynch *et al.*, 2013). This was also reported in the scoping review by Rhee *et al.*, (2017) and narrative review by Hannon *et al.* (2016). Other countries that had also made this progress included Mali, Botswana, and Egypt (Hannon *et al.*, 2016; Rhee *et al.*, 2017; Lynch *et al.*, 2013; Wright *et al.*, 2008). These studies provided useful insights into the extent of the availability of PC services in African countries, showing its lack in some African countries consistent with the findings in the review by Hardings and Higginson (2005), conducted over a decade ago. This indicates lack of development over 12-year period. Similarly, the most current QOD Index which assessed the quality and availability of PC services for adults in 80 countries around the world showed that the majority of the African countries were clustered at the lowest part of the index, with Nigeria at the bottom of the index (EIU, 2015).

Generally, evidence from the literature showed that the availability and provision of PC across African countries is patchy and its access is limited for seriously and/or terminally ill and dying patients, because it has not been integrated into the mainstream of healthcare systems in almost all the African countries, except for a few countries, such Uganda, Kenya, Malawi, Zambia, Tanzania and Zimbabwe (Lynch *et al.*, 2013; Hannon *et al.*, 2016). Other potential key factors accounting for the limited access include late presentation, inadequate referral systems, client previous knowledge of PC and service-users' incomes (Kolawole *et al.*, 2013; Lakew *et al.*, 2015; Agodirin *et al.*, 2017). However, efforts are being made to improve access through the use of mobile phones to deliver PC and home visits by professionals (Omoyeni *et al.*, 2014; Grant *et al.*, 2011; Agodirin *et al.*, 2017). Barriers (patients not having access to phones, limited mobile networks and access to expertise and hardware) required for mHealth (use of mobile phone) for PC delivery (Allsop *et al.*, 2018) and lack of vehicles for home visits (Kolawole *et al.*, 2013) has made access to PC ineffective.

### **2.2.2.2 Symptoms prevalence, burden and control**

Twelve articles examined symptom prevalence for patients and families who had received PC and their experiences in relation to symptom burden and control. The most prevalent symptoms and needs reported by the patients and their families who had been under PC included worrying, feeling sad, lack of energy, pain, sexual problems, weight loss, financial assistance, nutritional support, home-based care, counselling, inability to share feelings, spiritual support, nausea, coughing, constipation, information, family burden, unable to walk, shortness of breath, anxiety, depression, spiritual issues (Uwimana and Struthers, 2007; Otegbayo *et al.*, 2010; Harding *et al.*, 2011; Selman *et al.*, 2011; Tapsfiedl and Bates, 2011; Lewington *et al.*, 2012; Kolawole *et al.*, 2013; Omoyeni *et al.*, 2014; Hardings *et al.*, 2014; Downing *et al.*, 2014; Olaitan *et al.*, 2016; Ndiok and Ncama, 2018). The general public, particularly those with chronic and/or terminal illness, were motivated to seek PC so that these symptoms and needs (physical, social, emotional, spiritual, information) could be addressed (Opoku, 2014). Unfortunately, the patients and their families across all these studies were dissatisfied with symptom control, demonstrated by poor scores in all the questions contained in the African Palliative Care Association (APCA) Palliative Outcome Scale (POS) (Lewington *et al.*, 2012; Hardings *et al.*, 2014) and the Memorial Symptom Assessment Schedule Short Form (MSAS-SF) (Hardings *et al.*, 2011).

Overall, in the literature, pain was the most reported complaint and the lowest ranked item in POS and MSAS-SF in terms of satisfaction with care, reflecting high levels of dissatisfaction with PC. Other highly prioritised needs of the patients and their families were information need, family burden, dying at home, and home-based care. These needs were unmet, resulting in poor quality of life (Uwimana and Struthers, 2007; Selman *et al.*, 2011), which had contributed to the request for euthanasia made by some patients, for the fear of being a burden to their families or relatives (Omipidam, 2013).

### **2.2.2.3 Education and training for healthcare professional in palliative care**

Three primary research papers found that healthcare professionals from Rwanda and Nigeria complained that they lacked formal training in PC, although they had learnt



about some aspects of PC while providing care to service-users (Uwimana and Struther, 2007; Akinyemiju *et al.*, 2015; van Gurp *et al.*, 2015), confirming what has been reported in the literature about the development of PC around the world (Clark *et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013). Findings across the previous review papers about PC consistently reported that countries such as South Africa, Uganda, Botswana, Kenya, Zambia, Swaziland, Malawi, Rwanda, Namibia, Nigeria, Ethiopia, Egypt, Cote d'Ivoire and Tanzania had developed national PC programme which were either being implemented in collaboration with local universities or were planned to be implemented (Clark *et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013; Hannon *et al.*, 2016; Rhee *et al.*, 2017). Uganda and South Africa were the two countries in the African continent recognised to have developed educational centres and academic links forged within universities (Lynch *et al.*, 2013; Hannon *et al.*, 2016). This finding revealed that there is a complete lack of education or training institutions for healthcare professionals in most African countries, despite the desire among healthcare professionals across many countries, such as Nigeria, to be trained in PC (Akinyemiju *et al.*, 2015).

The lack of education or training institutions for healthcare professionals in most African countries was recognised as a possible factor explaining the lack of knowledge of PC among the professionals, which leads to misunderstanding of what PC is, impacting on care provision (Rhee *et al.*, 2018). In addition, this shortfall may possibly have contributed to the shortage of staffing for the provision of PC. The finding from the 2015 QOD Index showed that many African countries belonged to the category of countries that had a shortage of specialised PC professionals, with the exception of countries such as Uganda, Morocco and Egypt, which had specialised PC professionals, although Specialist PC training is generally not accredited by national professional boards in these countries (EIU, 2015).

#### **2.2.2.4 Political factors impacting on palliative care**

The political factors that were described in the sixteen included articles as hindering the adequate provision of PC include limited availability/accessibility to opioids, funding and policy for PC. Whilst three empirical research studies reported on the

unavailability of and/or limited accessibility to opioids in countries such as Malawi, Nigeria, Kenya, Namibia, Cote d' Ivoire (Tapsfiedl and Bates, 2011; van Gorp *et al.*, 2014; Rhee *et al.*, 2018), the survey, which involved 75% of countries in the African region, found that 14% of them had oral morphine available in most of their pharmacies (Sharkey *et al.*, 2018). The likely factors explaining the limited availability/accessibility to opioids included opiophobia, lack of knowledge, inadequate trained manpower for opioid prescription, lack of nurse-prescribing laws/policy and lack of infrastructure to store and distribute them (Clark *et al.*, 2007; Hannon *et al.*, 2016; Rhee *et al.*, 2018; Fraser *et al.*, 2017). This limited availability/accessibility to opioids contributed to unmet pain needs for the terminally ill and dying patients (Uwimana and Struthers, 2007; Tapsfiedl and Bates, 2011; Kolawole *et al.*, 2013; Harding *et al.*, 2011; Harding *et al.*, 2014; Downing *et al.*, 2014; Olaitan *et al.*, 2016). Although, there is limited availability/accessibility of opioids in most of the African countries, countries such as Uganda, Kenya, Malawi, Zambia, Tanzania, Mongolia, Ethiopia, and Zimbabwe were reportedly making great progress to improve their availability and accessibility (Lynch *et al.*, 2013; Hannon *et al.*, 2016; Fraser *et al.*, 2017). Only South Africa belonged to the countries in which opioids analgesic were available but access was restricted by bureaucratic forces (EIU, 2015).

Another political factor hindering PC related to funding and policies. The multi-method review that mapped the level of PC development in 2007 showed that 26 out of 47 African countries with a known PC activity hugely depend on external funding for PC (Clark *et al.*, 2007; Wright *et al.*, 2008). The similar review conducted four years later showed there was no significant improvement in the commitment by the government for funding PC because majority of African countries were still reliant on the external financial aid to fund PC except Cote D' Ivoire that has established multiple source of funding for PC (Lynch *et al.*, 2013). Poor funding of PC has continued to exist in most of the African countries as shown in the 2015 quality of death index and other reviews (EIU, 2015) and as also acknowledged in the scoping and narrative reviews by Rhee *et al.*, (2017) and Hannon *et al.*, (2016). The availability of public funding for PC which is one of the three indicators assessed on the category of affordability of care among

other five categories in the QOD index showed that few African countries such as Uganda, Ghana and Kenya had government funding for PC though funds were difficult to access (EIU, 2015). Nigeria ranked last in this category among other 80 countries assessed in this index, though with countries such Malawi, Tanzania and Egypt also had total absence of government subsidies for individuals accessing PC, unlike other countries (Botswana, Ethiopia, Morocco, South Africa, Zambia, Zimbabwe) that had a limited number of government subsidies (EIU, 2015). This could indicate that Nigeria was one of the African countries where the government seemed to be generally reluctant in the internal funding of PC.

Furthermore, the healthcare professionals that participated in the empirical study conducted in Nigeria reiterated lack of government funding for PC (van Gurp *et al.*, 2015). Likewise, the in-country experts in PC from Ghana, Kenya, Mozambique, Namibia and South Africa was said to have unanimously reported that their countries have continued to depend largely on external funding for PC (Rhee *et al.*, 2018). For instance, they reported that withdrawal of external funding for HIV/AIDS in South Africa caused closure of many hospices (Rhee *et al.*, 2018). Concordant with previous findings, the survey about the countries' capacities for the prevention and control of noncommunicable diseases that included questions on a number of PC development metrics among the WHO member states reported that a small proportion of countries in Africa region had funding available for PC (Sharkey *et al.*, 2018). This could imply that funding of PC could still be one of the barriers impacting on PC development in African countries, however these studies did not capture the underlying reasons for this, suggesting a need for a more comprehensive and in-depth study.

Lack and/or inadequate policy implementation for PC was revealed as a barrier to provision of optimal PC in the empirical research conducted in Rwanda and Nigeria (Uwimana and Struthers, 2007; van Gurp *et al.*, 2015). These two studies did not provide explanations as to why there was lack/inadequate policy for PC. The use of survey by Uwimana and Struthers, (2007) may have accounted for this, though the latter study used qualitative approach, yet the complexities underlying PC policy was

uncovered. This suggests limited knowledge about PC policy in these two countries. However, other African countries appear to be in a similar situation because only 54% among 35 countries in African region that participated in the survey conducted by Sharkey *et al.* (2018) reported having a National policy for non-communicable diseases including an operational policy for PC. Other previous reviews also showed that most of the African countries lacked policies for PC (Clark *et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013; Hannon *et al.*, 2016). However, countries such as Uganda, Kenya, Zimbabwe; South Africa (Clark *et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013) Cote D'Ivoire, Rwanda, Tanzania (Hannon *et al.*, 2016; Rhee *et al.*, 2017) were reported to either have integrated PC into healthcare policy or are gaining wider PC policy recognition.

### **2.2.3 RELATIONAL BARRIERS TO PALLIATIVE CARE**

Relational barriers in the context of this section is pertained to the interactional intricacies which impacted on the provision and use of PC. Two relational barriers were identified from nine included studies. They are healthcare professional communication with the terminally ill patients/families and the referral relationships that existed among the providers. In countries such as Malawi, Kenya and Uganda, some studies reported that terminally ill patients and their families desired advice, information, guidance and support through regular communication with PC nurses and other healthcare professionals when in the hospital or at home (Harding *et al.*, 2014; Mkwinda and Lekalakala-Mokgele, 2016), but there was limited access to counselling, information and support (Lekew *et al.*, 2015). Similarly, the population-based survey of public preferences and priority in end-of-life care conducted in Kenya found that the public prioritised having information higher than choosing who makes decisions about care at the end-of-life (Downing *et al.*, 2014).

However, despite the importance placed on the need for communication/information, the majority (83.6%) of the nurses preferred to hide the truth from the patients, with few nurses providing counselling to the service-users in Ethiopia (Kassa *et al.*, 2014). Most of the nurses felt uncomfortable holding end-of-life discussions with dying patients (Kassa *et al.*, 2014), because such a discussion was said to be complicated by

taboos about dying of a life-threatening illness in Nigeria (van Gorp *et al.*, 2015). The review by Hannon *et al.* (2016) also reported that talking about possibility of death in the presence of an ill person is considered taboo in some African cultures whilst Hardings *et al.*, (2005) highlighted that bearing bad news is sometimes believed to have caused terminal illness. Thus, in Nigeria, some cancer patients were reportedly unaware of what they are being treated for (Otegbayo *et al.*, 2010).

Reporting on the second relational barrier concerning referral relationships that existed among the providers, Tapsfiedl and Bates (2011) found that average length of involvement by the PC team was about six days, suggesting that PC was not integrated early into the care of cancer and HIV/AIDS patients in Malawi, possibly due to lack of referral. More clearly, the case notes review of the patients referred to the Pain and Palliative Care Unit (PPCU) of the University of Ilorin Teaching Hospital, Nigeria from May 2009 to June 2014 found a steady decline between 2010 and 2013 in the number of patients referred to PPCU (Agodirin *et al.*, 2017). This study revealed a lack of commitment to referral of patients for PC by non-palliative care clinicians. However, this study did not identify reasons for the lack of commitment or any underlying referral complexities, possibly due to limitations peculiar to retrospective studies. Thus, a prospective study is required for a more in-depth understanding of the referral practices to PC among clinicians in Africa.

### **2.3 Discussion and summary of findings**

This scoping review provides evidence regarding the multi-level factors influencing the provision and use of PC in Africa and has uncovered the research designs used in these studies. Spirituality, awareness, knowledge and attitude were the factors at an individual-level which impacted on the provision and use of PC. Three articles reported spirituality and existential problems as barriers to PC in Nigeria and Ghana, though detailed explanation was not provided possibly due to methodological limitations. Still on individual-level factors, there was broad awareness of PC among healthcare professionals across many African countries, unlike the members of the public that had partial awareness of PC. Although many had heard of PC, their knowledge regarding

the meaning and philosophy of PC, team composition, beneficiaries of PC, communication issues and opioids analgesic were found to be inadequate among both the healthcare professionals and the public. Despite the poor knowledge of PC, both the professionals and the public largely showed acceptance of, and a positive attitude towards, PC. The use of questionnaires in all these studies was one of the identified design issues in accessing the knowledge and attitudes towards PC. The closed questions elicited information on aspects of knowledge and attitudes that the researcher considered to be a priority, rather than providing an opportunity for the participants to explain and demonstrate their knowledge of PC. Thus, these findings suggest a limited understanding of the overall knowledge and attitude of PC amongst both professionals and the public.

The inadequate knowledge of PC seemed to impact on both the system-level factors and relational barriers, thereby influencing the provision and utilisation of PC. In this scoping review, it was found that formal education in PC or training institutions for healthcare professionals was lacking in most African countries, thus explaining the inadequate knowledge of PC held by healthcare professionals. Most of the professionals across many African countries (such as Nigeria, Congo, Egypt, South Africa, Ethiopia) were found to lack competence, and skills, in engaging in end-of-life discussions (Mukemo *et al.*, 2017; van Gorp *et al.*, 2015; Kassa *et al.*, 2014), which can be seen as evidence of the lack of aspects of PC knowledge. However, several African countries were shown to be making efforts to develop national PC programmes to bridge the gap in knowledge and skills required for the practice of PC (Clark *et al.*, 2007; Wright *et al.*, 2008; Lynch *et al.*, 2013; Connor and Sepulveda, 2014; Rawlinson *et al.*, 2014; Hannon *et al.*, 2016). Further to the professional lack of adequate knowledge and skills, it appeared that the dissatisfaction in symptom management, especially pain control, experienced by the patients was attributed to inadequate knowledge and skill about PC (Clark *et al.*, 2007; Fraser *et al.*, 2017; Rhee *et al.*, 2018), although other bureaucratic challenges, such as policy and funding, complicated the patients' satisfaction with PC.

Furthermore, this scoping review showed that PC services were either unavailable or patchy in many of the African countries because of issues possibly related poor funding, inadequate knowledge and lack or inadequate policy. This suggests that many patients in need of PC in Africa may not be accessing this service when needed. Nevertheless, there had been an increase in the number of PC services available in the continent of Africa, with countries such as Uganda, Kenya, Malawi, Zambia, Tanzania and Zimbabwe having integrated PC into the mainstream of their healthcare systems (Lynch *et al.*, 2013; Connor and Sepulveda, 2014; Rhee *et al.*, 2017). Therefore, it could be deduced that PC was most developed in these countries, although there was still room for advancement. It is surprising that there was a slight increase in the number of organisations providing PC from five to seven and to 17 in 2003, 2011 and 2016 respectively in Nigeria (Clark *et al.*, 2007; Lynch *et al.*, 2013, Rhee *et al.*, 2017a), because one would assume there should be higher increase considering that people needing PC may be more due to the large size of this country. Instead, other countries with lower population such as South Africa, Kenya, Uganda, Zambia, Zimbabwe, Tanzania, Malawi and Cote d' Ivoire, had much higher numbers of PC services (Lynch *et al.*, 2013, Rhee *et al.*, 2017a). More precisely, it could be expected that Nigeria, being the most populous and one of the resource rich countries in Africa, with a population of over 180 million people, unlike Kenya, with a population of slightly above 45 million, Uganda, with population of nearly 36 million and South Africa, with a population of just over 48 million people (Central Intelligence Agency, 2014), should have the highest number of PC services. All the existing primary research included in this review and opinion papers (Soyannwo, 2007; Oliver *et al.*, 2011; Onyeka *et al.*, 2011; Onyeka *et al.*, 2013) pertaining to PC in Nigeria further confirmed that there is still very low coverage, and low demand, as well as poor quality PC (defined in terms of opioid availability and accessibility, use of opioids in pain management, inadequate psychological and spiritual support), consistent with the findings about Nigeria in the 2015 QOD index.

Notably from this review, previous research on PC in Nigeria centred around the knowledge of, and attitudes towards, PC among healthcare workers, religious leaders



and the public (Adenipekun *et al.*, 2005; Fadare *et al.*, 2014a&b, Akinyemiju *et al.*, 2015; Eke *et al.*, 2016; Nnadi and Singh, 2016; Badru and Kanmodi 2017), retrospective study of patients' experiences of palliative care (Elumelu *et al.*, 2013; Kolawole *et al.*, 2013; Otegbayo *et al.*, 2010; Omoyeni *et al.*, 2014), telemedicine's potential to support good dying in Nigeria (van Gurp *et al.*, 2015), and PC needs (Omipidam *et al.*, 2013; Olaitan *et al.*, 2016; Agodirin *et al.*, 2017; Nwabuko *et al.*, 2017; Ndiok and Ncama, 2018). No research has focused on investigating the organisational dynamics, and how culture and religion may be influencing the provision and use of PC in Nigeria, or any other African country. This claim was reiterated by Powell *et al.* (2014) and was also highlighted in the integrative review by Cain *et al.* (2018) that ways in which people make meaning in their illness and end of life care was particularly lacking in Africa. Finally, this review has identified other potential key factors contributing to the limited access and use of PC by service-users, such as late presentation of the patients with cancer or other serious illness to the hospital, the high cost of care, poverty and inadequate referral system. However, almost all articles that reported these barriers used either retrospective reviews of the patients' case notes or a descriptive study design using questionnaires for data collection (Uwimana and Struthers, 2007; Tapsfiedl and Bates 2011; Agodirin *et al.*, 2017; Opuku, 2014; Kolawole *et al.*, 2013; Lewington *et al.*, 2012; Otegbayo *et al.*, 2010). None of these studies provided an opportunity for their participants to give their views of what they considered to be impacting on the use of PC. However, van Gurp *et al.* (2015) unstructured interview to collect data from their participants about issues that affect PC. Therefore, in-depth examination of factors influencing PC using rigorous methods that would include evidence from observed realities is needed.

## **2.4 Gaps in literature that inform the research focus on Nigeria**

Following a comprehensive search of existing literature on what is known about the provision and use of PC in Nigeria and other African countries, three themes with several subthemes emerged about multi-level factors influencing the provision and use of PC. Studies originating from Nigeria centred around the knowledge of, and attitudes



towards, PC among healthcare workers, religious leaders and the public; retrospective study of patients' experiences of palliative care; telemedicine's potential to support good dying in Nigeria and PC needs. Two key gaps were identified from these literature; firstly, several authors reported that healthcare professionals in Nigeria have heard of PC, though contradictions existed about findings on the level of knowledge. For instance, Fadare *et al.*, (2014a) and Fadare *et al.*, (2014b) concluded that healthcare professionals had good knowledge about PC. A similar study conducted by Eke *et al.* (2016) and Nnadi and Singh, (2016) reported that healthcare professionals had insufficient knowledge on the interdisciplinary nature of PC, service-users who could benefit from palliation, and components of PC. The use of questionnaires for data collection in these studies suggest limited understanding about aspects of PC knowledge. Therefore, a study using exploratory design is required to explore knowledge and attitude about PC in Nigeria, in order to make more authentic conclusions.

Secondly, only two studies in Nigeria (Otegbayo *et al.*, 2010; van Gorp *et al.*, 2014,) mentioned that religious belief was an obstacle to PC with no information on how this impacted on the provision and utilisation of PC. No research has focused on investigating the organisational dynamics, and how culture and religion may be influencing the provision and use of PC in Nigeria, or any other African country. Thus, this shows a clear gap in evidence which have been used to form the focus for the current study.

## **2.5 Conclusions**

This scoping review revealed that PC is underdeveloped in the African continent; specifically, that millions of people lack access to PC due to issues such as its unavailability, isolated services, poor funding, lack or inadequate policy, and inadequate referral practice. However, some African countries have made good progress, but more effort is required to improve the coverage of, and quality services available to service-users. Whilst the first scoping review of PC in Africa by Rhee *et al.* (2017), which included 49 publications and aimed to improve the understanding of the progress of PC between 2005 and 2016, provided findings on medication availability,

education, policies, vitality, service provision and implementation, this current scoping review has provided additional findings on relational barriers, and knowledge of, and attitude to, PC, which have advanced the understanding of what is known about PC in Africa. This current scoping review revealed that knowledge and attitude about PC is a critical indicator for PC development in Africa, but the study design used in the articles means that there is limited understanding about aspects of knowledge of, and attitude to, PC that are deficit among the professionals and the public. Thus, research using qualitative design is required to explore the knowledge and attitude about PC in various African countries.

Secondly, this review showed, from the demographic information, that the majority of the professionals and the public were religious, but more important was that some participants indicated that religious beliefs (Opoku, 2014) and that Rwandan culture (Uwimana and Struthers, 2007) were obstacles to PC. However, two other studies showed that some terminally ill patients and their families reported that they believed in God and had made attempts to reconcile hope based on religion (van Gurp *et al.*, 2014, Otegbayo *et al.*, 2010) whereas the study by (Uwimana and Struthers, 2007) provided no account of Rwandan culture or how it impact on PC. There may be a myriad of religious and cultural influence that account for the poor development of PC in Africa; thus, further research is required to explore both professionals and service-users' view about religion and culture in relation to how it influences the provision and use of PC in an Africa context. Indeed, research in PC has neglected exploration of the religious and cultural dynamics within the African context that influence PC; thus, further studies could focus on this area because without knowledge and understanding of such, evidence that would guide improvement of PC in Africa would be incomplete. Generally, more research is need in Africa to understand underlying factors that impede PC development, but there is a critical need to understand why PC is particularly poorly developed in Nigeria

Lastly, this scoping review is not without limitations; the papers included in this review may have not represented the true picture of the countries included in this review

about the status of PC because of the none representative sample used in these studies as well as small sample size in most of the papers; thus, the themes generated should be interpreted with caution. I should also stress that, due to the broad scope of the inclusion criteria and the confusion related the interchangeable use of PC with concepts such supportive care, terminal care, end of life care, hospice care, best supportive care and comfort care (Hui *et al.*, 2013), it is possible that some of articles may have been missed. Despite, these limitations, the scoping review has provided useful insights and extended on what is known about PC in Africa.

## CHAPTER THREE

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### METHODOLOGY AND METHODS

#### 3.0 Introduction

The previous chapter on the scoping review about provision and utilisation of PC in Africa showed that PC is underdeveloped in the African continent but especially in a country such as Nigeria. It specifically found that several issues such as inadequate knowledge of, poor funding, lack or inadequate policy, and inadequate referral and communication practices were key issues contributory to why millions of people lacked access to, as well as inadequate provision of, PC. Several gaps in knowledge were uncovered from this review, such as limited understanding of the overall knowledge and attitude of PC amongst both professionals and the public as well as unknown intricacies underlying inadequate policy and funding of PC. The most compelling was that few of the studies mentioned that religion and culture were obstacles to PC without providing explanation to these factors. Therefore, this current research has focused on understanding the organisational dynamics, and how culture, environmental and socio-political issues may be influencing the provision and use of PC in Nigeria.

This chapter explains the methodology chosen to achieve the aims of the research, and discusses the methods used to collect and analyse data. Firstly, the chapter begins with a discussion of the philosophical assumptions and theoretical framework underpinning the research (Guba and Lincoln, 1994), because it provides framework upon which to investigate or make sense of the social world (Crotty, 1998; Gray, 2014). It is, therefore, crucial to make my epistemological and ontological assumptions explicit as they constitute the context/lens in which this study must be understood. This chapter concludes with a section on reflexivity.

### **3.1 Philosophical perspectives of the research**

Philosophical perspectives are assumptions about the world that represent a system of values which form the beliefs that guide actions (Spirikin, 1983; Guba, 1990; Evely *et al.*, 2008). We often bring certain philosophical assumptions to our research, either consciously or unconsciously. In qualitative research, it is commonly accepted that these assumptions guide a researcher to ask certain questions and lead to the choice of a certain approach to systematically study an aspect of the world, in an attempt to construct knowledge (Crotty, 1998; Denzin and Lincoln 2011; Kawulich, 2012). Philosophical perspectives also influence how researchers create knowledge and derive meaning from their data (Moon and Blackman, 2014). These assumptions have been called worldviews, which refers to how we view the social world and guides how problems are framed and addressed (Schwandt 2001; Guba and Lincoln, 1994; Creswell, 2009). Worldviews consist of the underlying ontology, epistemology and methodology that underpin research (Crotty, 1998; Guba and Lincoln, 1994; Creswell, 2018; Moon and Blackman, 2014), and are discussed in relation to the position I adopted for this current study.

Ontology relates to questions regarding the nature of existence, whether we believe that there is one verifiable reality or that reality is multiple and socially constructed (Patton, 2002). This means that researchers are required to make a decision about whether reality is a product of individual cognition/mind or is of an objective nature. For Braun and Clark (2013) the ontological position lies on a continuum, from relativism to realism, while critical realism lies in-between them. Relativism constitutes an ontological notion which holds that multiple realities exist. Multiple realities can be examined in relation to an individual's experiences or perceptions, or they can be seen as co-constructed with others (Denzin and Lincoln, 2011). Relativists argue that no one reality exists; instead, reality exists in the mind and is relative to an individual's point of view at a given time and place (Guba and Lincoln, 1994; Crotty, 1998; Braun and Clark, 2013; Moon and Blackman, 2014). Conversely, realist ontology holds that reality is entirely independent of human ways of knowing about it (Guba and Lincoln, 1994; Braun and Clark, 2013). Realists hold that reality can be objectively measured because

the natural or social world exists independently from human actions and observations (Moses and Knutsen, 2012). Braun and Clark (2013:6) state that critical realism is the ontological idea that 'reality exists but we can only partially know it'. My ontological position is relativism, a perspective that opposes the existence of a single reality; rather, I concur that individuals will offer multiple social constructions in relation to the context and culture. Reality has a plurality; thus, I sought to learn constructions of reality about the provision and use of PC among healthcare professionals and the service-users in a Nigerian hospital.

Secondly, the epistemological issue questions the nature of knowledge, and the relationship between the inquirer and what can be known (Denzin and Lincoln 1994; Cohen *et al.*, 2007), and whether knowledge is something that has to be experienced, acquired or attained (Crewell, 2013). Whilst there are many epistemological positions, social constructionism was chosen to underpin this study. This epistemological stance is mainly concerned with social and relational processes in knowledge construction, with less emphasis on cognitive or biological processes (Young and Collins, 2004; Burr, 2015; Gergen 2015). This means that reality or truth about knowledge is attained when we explore the ways in which people interact together and engage in their social activities (Young and Collins, 2004; Galbin, 2014; Gergen, 2015). Thus, I agree with Gergen (1985) and other proponents of social constructionism that a great deal of human life exist as it does due to social and interpersonal influences.

In addition, and in support of this, Young and Collins (2004) highlight that social constructionism focuses on how behaviours, ideas and attitudes have developed over time, and emphasises the importance of culture and historical context in understanding what occurs in society and constructing knowledge based on this understanding. In this current research, my aim was to gain an in-depth understanding within a social and cultural context. Therefore, there was the need to understand the role of social interaction, processes, social practices and the everyday patterns of communication which informed the social rules and symbolic meaning that shaped the attitudes and behaviour regarding the provision and use of PC. Thus, this research is

firmly placed within the epistemological stance of social constructionism, because I believe that knowledge and understanding are situated in performance and not in persons or cognitive processes.

Lastly, knowledge was constructed through interpretation of data about participants' experiences, perceptions and the interactions amongst them. I focused on what people did together (provision and use of PC) in an attempt to construct knowledge, as opposed to the individual and cognitive processes about the provision and use of PC. I believe that relational configurations, such as the cultural, historical and contextual understanding gave rise to individual actions about provision and use of PC. My view is consistent with an argument that meaning-making is a relational process through which we accomplish the creation of a sense of individuality (Gergen, 2001). Interestingly, Burr (2015), Gergen (2015) and other social constructionists are in favour of relativism which is the ontological position that underpins the current research. They contend that there are many realities within the boundaries of cultures, contexts, and language. Accordingly, both the ontology and epistemological stance of this current research fit together.

### **3.2 Theoretical perspective of the study: Symbolic Interactionism**

Consistent with the epistemological stance of social constructionism, Blumer (1969) emphasises the nature of meaning-making, stating that we know things by their meaning and that these meanings are created through social interaction. Remarkably, Blumer emphasised that the meaning individual places on an object emerges from an interactive process of joint action. Thus, Blumer's theory of Symbolic Interactionism (SI) (Blumer, 1969) was further used as a lens to underpin knowledge construction and meaning-making in this current research. The tenets and root images of SI were a useful guide that, when employed, facilitated an in-depth understanding of cultural, socio-political, environmental and organisational dynamics that influenced the provision and utilisation of PC in a Nigerian hospital.

SI historically emerged from American Pragmatism; this sociological theory was elaborated by Charles Peirece, William James and John Dewey in the late nineteenth century (Sandstrom *et al.*, 2001). These theorists referred to perceived meaning as being connected to social actions and perspectives, reality as being dynamic, individuals as active knowers, and knowledge as an instrumental force that enables people to solve problems and reorganise the social world (Thayer, 1981; Joas, 1996). Pragmatist philosophy is thought to be introduced into sociology by Mead through the inspiration he got from Dewey (Sandstrom *et al.*, 2001). This led to Mead developing a sociological account of human consciousness, selfhood and behaviour which was printed in a book 'Mind, Self and Society (1934). Furthermore, Mead's idea was propagated by Blumer in his book, Symbolic Interactionism (Blumer, 1969).

Symbolic interactionism is a theoretical perspective that underpins the study of human group life, human conduct and the wider context that informs human conduct (Blumer, 1969; Davetian, 2012). It has been described by Clamp and Gough (1999:136) as '*the study of how the self and the social environment mutually define and shape each other through symbolic communication*'. Blumer's theoretical orientation toward symbolic interactionism can be summarised through three premises: human action is always based on the interpretation he/she gives to a particular phenomenon or objects in the world, the meaning ascribed to things arises as a result of the social interactions, and that meaning ascribed to a phenomenon is modified based on the interpretation people give to the phenomenon that is encountered (Blumer, 1969). These premises could imply that symbolic interactionists are concerned about how repeated interactions among individuals come to define the makeup of society (Carter and Fuller, 2015). Drawing from these premises, this study sought the construction of meaning about cultural and social processes related to PC among the healthcare professionals and the services-users based on social interaction between and among them as well as the researcher, which inform the social action or behaviours about provision and use of PC.



Consequently, human action about the practice of PC was a product of symbolic meanings or interpretations given to words, events, symbols or circumstances that arose from relational processes (Blumer 1969;1986). Blumer added that the understanding of these social and relational processes that influence action/ behaviour is based on the understanding of intentions and motives that interplay between individual actions and society (Blumer, 1969). Thus, human behaviour is viewed as a result of the response to one's intention and the perceived intention of others formed within social interaction (Blumer 1969; Meltzer, 1975). Symbolic interactionists contend that researchers can understand the manner in which individuals and groups construct their social realities when they engage in focused participant observation in order to understand social interactions and other relational processes (Davetian, 2012). This has been supported by ethnographers, for instance, Atkinson *et al.* (2001), who highlighted that the social world is seen as a place where an object, individuals and their activities have evolving and different identities that may not be revealed objectively or to outsiders.

Furthermore, SI is grounded on some basic ideas, or what Blumer refers to as 'root images' (Blumer, 1969:6). They include the nature of human groups' life or societies; Blumer argued that human society or human groups exist in actions (Blumer, 1969). This implies that people in any society are agents in an interactive world whereby there is a continuous adjustment to accommodate changing levels of awareness and socio-cultural situations (Davetian, 2012). The nature of objects is another root image of SI, which Blumer applies to anything that can be indicated to, referred to or pointed to (Blumer, 1969). The world is made up of objects (physical, social and abstract objects) and that these objects are the product of symbolic interaction (Blumer, 1969). I was committed to understanding how the materials and equipment used for the provision of palliative care (physical objects), service-users, the hospital managers, the PC team and other healthcare providers (social objects) and the philosophy of PC (abstract object) interacted to shape the construction of knowledge about the culture of PC. The other 'root images' of symbolic interactionism are humans as actors, the interlinkage

of actions, and human action (Blumer, 1969). These root images depict how SI views human societies and human conduct in an attempt to understand human behaviour.

SI has been criticised for being a micro-sociological theory focusing only on self- and group- interaction in understanding human behaviour in a particular social context, and not addressing the macro-sociological issues/large-scale social processes (Sandstrom *et al.*, 2001; Brittan, 1973). Meltzer (1975) criticised SI for not being relevant in cross-cultural studies because the meaning of symbols, roles or behaviour may differ between cultural groups and their social contexts. However, Meltzer appeared to have neglected the main focus of symbolic interactionism, which is to understand the behaviour of individuals or groups with the same or a similar culture (Denzin, 1992). Other criticisms of SI include negligence of the emotional and unconscious elements of human conduct, and overemphasis of self-consciousness, thereby placing little emphasis on the unconscious and emotive factors that influence the interactive process (Brittan, 1973; Huber, 1973). From my viewpoint, some of these criticisms, for instance, neglect of the emotional and unconscious elements of human conduct, appeared to be important. However, I was more interested in the social and relational processes that shape behaviour in line with my epistemological stance of subjectivity within social constructionism, though did not ignore the cognitive and psychological processes that inform behaviour. The development and refinement of this perspective has enabled SI to survive criticism and to be used as a theoretical framework for interpretive research (Oliver, 2012). Symbolic interactionism is a theory that has potential to increase the understanding of human health behaviour (Benzies and Allen, 2001). As such, it was relevant in this present study because it enhanced the understanding of relational processes upon which the culture of PC is rooted.

Finally, considering the philosophical position of symbolic interactionism, as presented above, Prus (1996) suggested that any research grounded in this theoretical perspective should adopt a research methodology that is sensitive to the human capacity for symbolic interaction. The methodology of ethnography fits well and grounded into SI because ethnography is based on the premise that people, actions

and objects have evolving identities, the meaning of which can only be revealed to an insider (Rock, 2001; Tan *et al.*, 2003). It unravels the complexities of human interaction or relations (Rock, 2001), suggesting that it is congruent with SI. The decision-making processes to arrive at the chosen methodology for the current study from the philosophical assumptions is presented next.

### **3.3 Choice of methodology**

The choice of an appropriate research methodology is a difficult step in the research process (Walker, 1997) and was particularly problematic for me as I needed to make a choice from a range of qualitative approaches to explore my research questions. Phenomenology, grounded theory, case study and ethnography were considered because they are the predominant qualitative approaches that could be used in the study of social world. Phenomenology is an approach that explores human lived experiences, through a detailed description of the people being studied (Creswell, 2018). The goal of phenomenological research is to seek understanding of meaning through accurate description of a person's lived experience in relation to what is being studied (Crotty, 1996; Ball, 2009). Although this approach would have set out rich description and gained insight into the 'lived experience' of the professionals and the service-users regarding PC, it would not have provided a focus on the socio-cultural context, environmental and organisational dynamics, which was the aim of this research. Thus, phenomenology was not adopted for this study.

Grounded theory was also considered; it is the discovery of theory from data systematically obtained from social research (Glaser and Strauss, 1967). This approach seeks to identify basic social processes and develop explanatory models of human behaviour grounded in the context in which they occur (Glaser and Strauss, 1967; Charmaz, 2006). Although Crooks (2001) highlighted that this methodology is ideal for exploring integral social relationships and the behaviour of groups, especially where there has been paucity of research that has explored the contextual factors that affect individual's lives, it is not centred towards cultural understanding of human behaviour,

which was one of the key issues set to be addressed in this research. In addition, this research did not aim to develop a theory, which is the explicit goal of grounded theory.

Case studies have been largely used in the social sciences and have been found to be especially valuable in practice-oriented fields such as nursing and was considered for the current study. Case studies as a qualitative research type has been argued to appear unclear due to disagreement among its definitions, focus, contention of what count as 'case' in a case study, types or classification (Verschuren, 2003; Gerring, 2004; Starman, 2013). Various inconsistent definitions of case study have been provided by many authors such as Sturman, (1997), Stake, (2005) and Yin, (2009). Nevertheless, following a critical review that sought commonalities in definition of case study, Simons (2009:21) defined it as *'an in-depth exploration from multiple perspectives of the complexities and uniqueness of a particular project, policy, institution, program or system in a 'real life''*. Case study is useful when researchers aim to identify variables, structures, forms, orders of interaction between participants in the social situation or when researchers require to assess the performance of work or progress in development (Stake, 2005). Whilst, Sturman (1997) added that case study is required when we seek to analyse and describe each person individually, or group of people, individual institutions, processes, phenomenon or event in a particular organisation (s) whilst focusing on the context. In addition, Yin (2009) maintained that case study is helpful when we seek to answer 'how' and 'why' questions but when we cannot influence the behaviour of the participants and when we are eager to uncover contextual conditions underlying the phenomenon under study.

The focus of the current study appears to align broadly with the focus of case study because it would have been relevant to assess the practice of PC and could have revealed progress in its development and provided understanding of the context about provision and use of PC in the studied hospital. However, it would not have provided cultural understanding upon which the current study centres. Besides, its methodological 'looseness' (Starman, 2013) and disagreements such as preference for selection of a representative or typical case (Yin, 2009), atypical case (Thomas, 2011)

and contentions of what comprises a unit of research (Starman, 2013) contributed for its rejection as the methodology for the current study. Therefore, the methodology considered appropriate to address the research question was the approach that would allow participation with the activities of the people, as well as prolonged engagement with the participants in order to observe, question and listen to them, to uncover or understand the taken for granted meaning about a culture of interest. Therefore, ethnography was the methodology chosen for this research after consideration of the alternative research approaches.

### **3.3.1 Ethnography**

Ethnography is both a process (research methodology) and a product (a written account of the culture being studied) (Savage, 2000; Germain, 2001; Reeves *et al.*, 2008). As a process, its focus is to understand the cultural perspectives of the group in their natural setting (Atkinson *et al.*, 2001; Reeves *et al.*, 2008). It has its roots in the early 20<sup>th</sup> century of anthropological studies of scholars such as Malinowski (1922), Mead (1935) and Boas (1966), who focused on the description of 'primitive' or colonised tribes/culture outside Europe whereby the researchers travelled far from their home environments and embedded themselves within a culture for several years in order to grasp what Malinowski termed as the 'native's point of view' (Malinowski 1922:25). However, since the Chicago school of urban sociologists, researchers have often focused their studies on sites close to their homes (Hammersley and Atkinson, 2007).

Understanding the definitions of ethnography was necessary because it helped me to place my study in context, particularly with regard to the conduct of the research. Several scholars have provided various constructions of the definition of ethnography, with description and explanation of a culture central to these definitions. For instance, it has been defined as:

*'Study of social interactions, behaviours, and perceptions that occur within groups, teams, organisations and communities'* (Reeves *et al.*, 2008:1)

*'Systematic process of observing, detailing, describing, documenting and analysing the lifeways or patterns of the people in their familiar environment' (Leininger, 1985:35)*

*'The first-hand experience and exploration of a particular social or cultural setting on the basis of (though not exclusively by) participant observation' (Atkinson et al., 2001:4).*

*The study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researchers participating directly in the setting, if not also the activities, in order to collect data in a systematic manner without meaning being imposed on them externally (Brewer, 2000:10).*

Ethnography's strength lies within its tenet to provide researchers the opportunity to identify the cultural and social behaviour through participant observation and then questioning the meaning of behaviour through informal chat and formal interview (Spradley, 1979). This approach is recommended when access to beliefs, social, environmental and cultural process is required (Savage, 2000). Such an approach was, therefore, valuable in this current study, which sought a cultural understanding about provision and use of PC. Ethnography, as a process, provided an opportunity that allowed for a holistic understanding of the culture of PC that facilitated the construction of knowledge or meaning-making about the socio-political, cultural, environmental and organisational dynamics that shaped the provision and use of PC, from the perspective of those studied (Hammersley and Atkinson, 1995; Brewer, 2000).

It may be important to mention that various classifications of ethnography exist, for instance, reception ethnography, feminist ethnography, performance ethnography, constitutive ethnography, and global ethnography, institutional ethnography, focussed ethnography, and descriptive and critical ethnography (Smith, 1987; Schwartzman, 1993; Sarantakos 1993; Thomas 1993; Muecke 1994; Gobo 2008). My study was in the form of organisational ethnography (OE). OE is defined as *'doing ethnography in and of organisations'* (Silverman, 2011:53), while Ybema *et al.*, (2009:4) defined it as *'ethnographic study, and its dissemination, of organisations and their organising*

*processes*'. I chose this form of ethnography because one of the central focus of my research was to understand the environmental and organisational dynamics that influenced the provision and use of PC in a Nigerian healthcare organisation. Neyland (2008) states that the primary aim in OE is to understand how the actors work, act and interact in their organisation as they perform their duties or carry out their daily activities. I was, therefore, interested in how meanings were constructed within organisational context in line with focus of OE. Lastly, this genre of ethnography was relevant and facilitated an understanding of the processes and practices (provision and use of PC) that affected people's life (Nader, 1972; Smith, 1987).

As stated earlier, ethnography is a process which involves sampling, recruitment, and procedures for data collection and analysis. These processes or the conduct of the research will be discussed next.

### **3.4 Sampling**

#### **3.4.1 The setting**

The choice for the research setting is one of the decisions a researcher must make in formulating a research design (Denzin and Lincoln, 2000). This decision is guided by the suitability of the research setting and the participants in generating valuable research data which is relevant to answering the research questions (Gray, 2014), and in accordance with the ethnographic tradition of purposive sampling (Savage, 2006; Guetterman, 2015). The aim of this research was to understand the cultural, socio-political, environmental and organisational dynamics which influenced the provision of PC, and the patients' and their relatives' behaviour towards its use in a Nigerian hospital. Thus, it was considered appropriate to choose a hospital that provided PC services in Nigeria as the research setting for this study. However, evidence from the literature review (see 2.2.2.1) showed that Nigeria has eight organisations that provide PC across the six geopolitical zones.

This study was conducted in the south east geopolitical zone of Nigeria because findings from the literature review showed that this was one of the zones in Nigeria mostly affected by poor development of PC. Also, Nigeria is a culturally diverse country

with over 250 ethnic groups (Gandonu, 1978; Edewor *et al.*, 2014). Each cultural and geopolitical region have their own unique cultural beliefs, behaviour and attitudes that guide their practices, daily routines and activities (Gandonu, 1978; Edewor *et al.*, 2014). My choice of the south-east zone for this research was also guided by its geographical proximity, familiarity and accessibility. I am familiar with many of the cultural traditions and practices of the people in this part of Nigeria and this had a positive impact during the fieldwork. Specifically, I engaged with the local language used in daily communication within this society and grasped the tacit meanings of daily conversation and rituals while observing the daily activities in this hospital. Hammersley and Atkinson (2007) argued that accessibility and availability influence the choice and selection of the research site. Furthermore, Yebema (2009) agreed that convenience and accessibility promote prolonged engagement and immersion during fieldwork. However, the more justifiable choice of the research site should be based on its suitability and potential to yield research data relevant to answering the research questions under investigation.

There are many hospitals in the south east geopolitical zone in Nigeria. However, only one hospital was known to be providing organised PC services in this region, based on evidence from the scoping literature review. Therefore, this study was conducted in that particular hospital. It was necessary to conduct the study in such a hospital because the professionals and service-users had experience of the provision and use of PC and would be most appropriate for eliciting information that would provide a rich description of the culture under investigation. It is not uncommon to conduct ethnographic research in one site, because Hammersley and Atkinson (1995) highlighted that ethnographers study only one or a small number of settings, and usually ones that are geographically close to them, to gain understanding and draw conclusions about a specific group or event studied in the social and cultural context. Notwithstanding, I acknowledge that there may be difficulties associated with generalisation of the findings as this study was conducted in one hospital, but I would pursue analytical generalisation which focuses on generalising from a particular to broad constructs that will be generated in this study (Firestone, 1993; Polit and Beck,



2010). This is possible because the hospital used in this study was representative of other healthcare organisations within Nigeria and some other African countries.

#### **3.4.2 The participants (sample designation and size)**

The members of the PC team, consisting of three doctors, four nurses, a physiotherapist, two medical social workers and a pharmacist, in the chosen study setting were initially included as participants for this study. It is perhaps important at this stage to state that data analysis in ethnography commences immediately an ethnographer gets into the field for data collection (Hammersley and Atkinson, 2007; LeCompte and Schensul, 2013), and this occurred in this current research. Following domain analysis in the field (Spradley, 2016), there was insufficient understanding of some of the cultural domains as the members of the PC team were unable to provide underlying reasons for some behaviour regarding the provision and use of PC. It was, therefore, necessary to identify and include other participants who would provide additional information to clarify, enhance, and provide a deeper explanation of the emerging cultural patterns, as would be expected in ethnographic research (Fetterman, 2010; Spradley, 2016).

Other participants identified during the observation, that constituted what Creswell (2018) regarded as culture-sharing group, included the service-users, professionals in other units and members of the management. These participants constituted the sample size for this research, as shown below.

**Members who made up palliative care team**

Three doctors

- A volunteer doctor to PCU
- A doctor from PCU
- A doctor from anaesthesia department

Four nurses

One physiotherapist

Two medical social workers

One pharmacist

**Other key medical professionals involved with care of terminally ill patients**

Head of HIV/AIDS unit

Head of haematology and Immunology

Head of surgery

Two doctors from oncology unit

Three nurses from oncology unit

**Service-users**

10 patients with progressive life limiting illnesses

10 patient relatives

**Members of the management**

Chief Medical Director

Head of Finance

Chairman Medical Advisory committee

Head of administration

**Total = 43 participants**

There is disagreement about what constitutes sufficient sample size in an ethnographic study. Some recommendations include 30 to 40 (Morse 1994), 30 to 60 (Benard, 2000) and 40 participants (Liamputtong and Ezzy, 2005). In addition, Moser and Korstjens, (2018) suggested 25 to 50 interviews and observations, including about four-to-six focus group discussions. However, Creswell (2013) was of the view that sample size should comprise a single culture-sharing group, implying that sample size will be determined by the number of persons in a specific cultural group. Sample size for this study as shown above fits within these recommendations but the more practical issues which informed that sample size for the current study include the number of individuals connected with provision of PC, data saturation and availability of resources.

Lastly, purposive sampling technique was adopted for this current research and is widely used in organisational ethnographies (Sinclair, 2011; Andersen and Vedsted, 2015; Chan *et al.*, 2018). Patton (2015) states that purposive sampling involves selecting information-rich cases; as such, the participants for this study were selected purposely based on: their experience of providing, receiving and/or requiring PC; that they were living with serious or progressive life-limiting illnesses; that they were connected to those who received and/or required PC; or that they were involved with the hospital management in connection with the provision of PC.

### **3.5 Methods of data collection**

One of the key characteristics of organisational ethnography is a combined fieldwork method, which is referred to as the set of methods undertaken to grasp complex organisational processes (Ybema *et al.*, 2009). The ethnographers use a combined field research method of observing, conversing, and reading documentary sources, and taking photographs to explore what people do, what they know, and the things they make and use (Ybema *et al.*, 2009; Spradly, 2016). By using these different methods, ethnographers are able to provide a thick description of organisational life (Ybema *et al.*, 2009); thus, these methods were used to access or generate data for this research. In addition, the decision about the choice of participant observation, ethnographic interview and review of documentary evidence as methods for data generation in this study was also based on contemplation about where, and from whom, to get the data including what sort of data will help to answer the research question, as recommended by Newell and Burnard, (2011). These methods and how they were used are discussed next.

#### **3.5.1 Participant observation**

Participant observation is defined as a *'method in which a researcher takes part in the daily activities, rituals, interactions, and events of a group of people as one means of learning the explicit and tacit aspects of their life routines and culture'* (DeWalt and DeWalt, 2011:2). To participate involves getting involved, joining in, being subjective and immersing yourself, while to observe involves being clear-eyed, objective, critical,

and unbiased (O'Reilly, 2012). Participant observation is widely recognised as the central method for data generation in ethnographic research because it improves researchers' understanding of the situation, adding strengths to the truthfulness of the data as ethnographers get involved and participate in the activities of their participants in order to learn, see and understand what they do and what they say they do (Fetterman, 2010; O'Reilly, 2012; Patton, 2015; Spradley, 2016; Creswell, 2018;). As such, I relied on this method to develop an understanding of the culture under study.

Guided by Spradley (2016), descriptive, focused and selective participant observations were conducted. I commenced by undertaking broad descriptive observation about care of the terminally ill and dying patients in the study site, recorded in the field notes with concentration on Spradley's nine dimensions of social situations: space, actor, activity, object, act, event, time, goal and feeling (Spradley, 2016). In the conduct of ethnography, understanding the meaning that participants attach to their behaviour and the world of their objects can be uncovered as a process of 'a stratified hierarchy of meaningful structure...of inference and implication through which an ethnographer is continually trying to pick his way' (Geertz 1973:7). Thus, as the fieldwork progressed, daily reflection and various layers of analysis of the data were done in keeping with the ethnographic tradition of domain analysis of the descriptive observation (Spradley, 2016). At this stage, the broad overview of the cultural scene relating to PC was grasped, with descriptive units identified, but further exploration was required in a more focused observation. The related cultural domains, which were useful in answering the research questions, provided focus for the next level of observation (focused observation). Finally, I conducted selected observations of issues that emerged from the cumulated reflection and analysis of repeated previous observations. It is important to state that general descriptive observation about the provision and use of PC continued throughout the fieldwork, to note fresh domains or issues as they occurred, while maintaining focused attention on the selected issues that required further observation to grasp different dimensions that would provide insight into the holistic understanding of the culture under study.

Conducting participant observation was initially found to be a difficult task, as it required thoughtful consideration and negotiation of roles to be assumed among the group being studied. There are different terminologies used to describe roles or degree of involvement during participant observation. Gold's (1958) view of the roles that a researcher can adopt during data collection using observation to includes complete participant, observe-as-participant, participant-as-observer and complete observer. On the other hand, Adler and Adler's (1987) categorisation include peripheral, active and full membership while DeWalt and DeWalt (2011) suggested different types of participation, which included passive, moderate, active and complete participation during observation. Spradley (1979; 2016) concurred with the classification of DeWalt and DeWalt (2011) but added non-participation as an additional type of participation during observation. The choice of the role and degree of participation undertaken by ethnographers during participant observation, according to Hammersley and Altkinson (1995), should be based on the purpose of the research and the setting. Kawulich (2005) suggests that the researcher's age, gender and ethnicity should also be considered as a factor for making decisions on the choice of degree of participation during observation.

Considering these factors and guided by DeWalt and DeWalt (2011) and Spradley (2016), I adopted the role of complete participation both with people and in their activities during observation and this approach aligned with what Gold (1958) regarded as participant-as-observer or full membership in line with Adler and Adler 's categorisation. In complete participation, the *'ethnographer is or becomes a member of the group that is being studied'* (DeWalt and DeWalt, 2011:24) and share with their roles within the context of the study. This was an effective way to work as a nurse researcher in a hospital setting. I completely or holistically participated in all the activities of the professionals (members of palliative and oncology team) to fully learn about the cultural rules for actions/behaviour and context of the provision and use of PC. My professional training as a nurse made it possible to achieve complete participation in the activities of the professionals. However, I was cautious about the potential limitations associated with this type of participation, which can be drawing

too close to the participants and the events, and developing blind spots that could only see issues in the same way as ordinary members of the group.

Lastly, I participated in and observed the daily activities and interactions of the members of PC and oncology team in the wards, the PC outpatient clinic, the PC nurses' station, the oncology outpatient's clinic, chemotherapy room and observed family meetings between the patients' relatives and the members of PC team as shown in participant observation schema in Table 3.1 below. The period of participant observation lasted for nine months; firstly, from September 2015 to March 2016 and then from March 2017 to May 2017. There is a disagreement about length of field immersion in ethnographic study. Smith (2001) suggested an average of ten years, seven months for anthropological ethnography and nine years, two months for academic ethnography (Smith (2001b)). A one-year field immersion was recommended by Jeffrey and Troman (2004) while Gray (2014) stated that conventional ethnography could involve from six months up to two or more years. Nyland (2008) conveyed difficulty in finding evidence that could be used to support or refute the suggestions of Smith, Jeffrey and Troman, indicating lack of a generally acceptable period of immersion in the ethnographic field site.

<b>First episode of Participant observation (September 2015 to March 2016)</b>			
Participant observation in PC unit	Where?	Number of observations	Duration
	Wards	30	Three days in each week (Monday, Tuesday and Friday) for eight hours in each day
	PC clinics	20	
	PC nurses' station	35	
	Family meetings	10	
<b>Second episode of Participant observation (March 2017 to May 2017)</b>			
Participant observation with oncology unit	Where?	Number of observations	Duration
	Oncology ward/ nurses station	18	Three days in each week (Monday, Tuesday, and Thursday) for average of eight hours in each day
	Chemotherapy room	10	
	Oncology clinic	8	
First episode of observation = 576 hours			
Second episode of observation = 111 hours			
Total hours of participant observation = 687 hours			

**Table 3.1 Participant observation schema**

Long period of immersion could possibly provide more opportunity for an ethnographer to understand the patterns of cultural behaviour and relationships while putting them in context, reflecting what Geertz (1973) regarded as 'thick description'. In contrast, Hammersley and Atkinson (1995) warned against what they regarded as 'quick description', which is regarded as ethnography without a rich detailed and contextual description of the group or activity under study, due to short field immersion or a flying visit to several study sites (Bate, 1997; Nyland, 2008). The current research adopted a reasonable length of field immersion in order to gain an in-depth understanding of the culture under study and, thus, to produce a thick description of the ethnography. The length of immersion for this current research was dependent on factors such as the activities incorporated into the research, the demands of the organisation, the appropriate time to develop field relations, and the period to achieve data saturation.

Overall, six hundred and eighty-seven hours of participant observation were achieved as shown in Table 3.1. Different hours of observation, such as 250 hours, 200 hours, 130 hours, 360 hours respectively, have been achieved by previous ethnographers (Costello, 2001; Kinsman Dean and Gregory, 2004; Stajduhar and Davies, 2005; van Keer *et al.*, 2015), suggesting that the number of hours for participant observation can vary in different studies. Following the advice about the variability of time for observation (DeWalt and DeWalt, 2011), participation and observation were conducted for over eight hours in each observation period, on different days, and during the morning and evening shifts in both the PC and the oncology unit, but during the night shift only in the oncology unit, in line with the shift pattern of the PC and oncology units. This provided me with an opportunity to observe various routines about the care of terminally ill patients at various periods of the day and night, which added to the depth of unravelling the intricacies about the culture under study. It is important to mention that the Hawthorne effect (Chiese and Hobbs, 2008) was minimised during participant observation, through developing good field relations, and



prolonged and persistent observation. Also, the possibilities of the researchers' bias and interference with interpretation of what is observed (DeWalt and DeWalt, 2011) was acknowledged, although this was minimised through informal chats, the use of additional methods for data collection to enable data triangulation, which added strength to the truthfulness of the data, and engaging in reflexivity, as discussed in later section of this chapter. Embedded in the conduct of participant observation is opportunistic or causal chat (Fetterman, 2010), to clarify what is being observed during participation. How data was documented in the field notes will be discussed next.

### **3.5.1.1 Field notes**

Field notes are the written recordings upon which ethnographies are constructed (Walford, 2009). Three kinds of field notes were kept, namely, condensed notes, expanded notes and a fieldwork journal, as recommended by Spradley (2016). A sample of each of these types of notes is attached in Appendix F. Condensed notes were initially written because it was practically impossible to write extensively about what was observed and said during participation. This kind of note enabled me to document quickly as far as possible all of the issues observed or said on the spot during participation by using phrases, single words and disjointed sentences. This was followed by the second type of field note, known as expanded accounts. I did as suggested by Chiseri-Strater and Sunstein, (1997) and Emerson *et al.* (2001), that field notes should be written immediately if possible, and then the condensed notes expanded at the end of the daily observations. As recommended by Chiseri-Strater and Sunstein, (1997) and Spradley (2016), my expanded field notes contained the following, which I regarded as my checklists for every observation.

- Date, time and place of observation
- Description of the physical place and space, objects
- Specific facts, numbers, details of what happens at the site
- Sensory impressions, emotions felt and expressed
- The people involved, sets of acts people do and personal responses
- Specific words, phrases, cultural jargon

- Questioning about people and behaviour
- Sequences that take place over time
- The goals people are trying to achieve

Lastly, a fieldwork journal was kept. This is because field notes do not focus only on recording the observations, but also include the researchers' experiences while participating in the daily routine and rituals of the group (Emerson *et al.*, 2001; Spradley, 2016). These notes were kept separate from the expanded notes, in line with the idea of Hammersley and Atkinson (1995) that researchers' personal experiences and reflections should be recorded in field notes but should be separated from the narrative description of the events during observation. The fieldwork journal contained my feelings, experiences, ideas, mistakes, thoughts, breakthroughs, questions and concerns that arose during the fieldwork. This journal was reviewed constantly to see how the subjective traits or internal processes may or may not be influencing the research process, in keeping with the theoretical concept and methodological tool of reflexivity. Although writing the field notes was time-consuming, it was necessary to write about the details of the culture observed during participation, so I could analyse this data to produce a written account of the culture studied.

### **3.5.2 Ethnographic interview**

An ethnographic interview is a one-on-one interview conducted in conjunction with immersive observation, when the researcher has developed good field relations with interviewees, to enable genuine exchange of views about the culture under study (Spradley, 1979; Heyl, 2001). This was the second method for data collection in this research. Nyland (2008) states that the choice of methods used to supplement observation data should be grounded on what they add to the study, and whether they are acceptable to the organisation and its members. An ethnographic interview was particularly useful because it provided me with an opportunity for more relaxed and in-depth conversations in order to learn about and clarify issues about the behaviour and activities observed around the culture of PC, enhancing the understanding of the context and intentions behind the observed behaviour and practices and giving voice to the participants to tell about their past experiences, which may have not be

captured during observation. This is what Ong (1993) referred to as getting under the skin of the participants.

Guided by Spradley (1979) and Heyl (2001), ethnographic interviewing began when I had gained general knowledge about the provision and use of PC and developed trusting relationships with the healthcare professionals and the service-users to facilitate honest discussion around the sensitive issues about death and dying in order to gain greater understanding of the culture under study. Initially, all the members of the PC team were interviewed. This was followed by an interview with other key professionals involved with the care of terminally ill patients, the service-users and members of the management team as enumerated above (see 3.4.2). The two episodes of ethnographic interview are shown in Table 3.2 below.

<b>First episode of ethnographic interview</b>	<b>Who was interviewed</b>	<b>Period</b>
	All members of palliative care team (see 3.4.2) n= 11	September 2015 to March 2016
<b>Second episode of ethnographic interview</b>	Other key medical professionals involved with care of terminally ill patients (see 3.4.2) n= 32	March 2017 to May 2017

**Table 3.2 Ethnographic interview schema**

The interviews were loosely semi-structured, in line with ethnographic tradition (Spradley 1979), because this provides freedom for the interviewees to express or/and elaborate their experiences, values, beliefs and views regarding the culture under investigation. I followed the advice by Spradley (1979), that ethnographic interviews should begin by asking descriptive questions (see Box 3.1, below), which allowed the participants to describe their experiences, their daily rituals, objects and people. This was followed by asking structural questions (See Box 3.1, below), which were more specific questions to explore responses offered to the descriptive questions. These

questions enabled a more in-depth exploration of the domain and descriptive units that emerged following analysis of data gathered through participant observation. Whilst asking structural questions, prompts, a form of encouragement (Fielding and Thomas, 2001), were used to probe further into the developing issues, to gain a more in-depth understanding and to encourage the interviewee to speak further. For example: do you think...?, do you mean...?, really?, how does that make you feel?, why is that...?, And then?, how?, tell me a little more about that, why did that happen?, what happened next?, and how did that made you feel?.

Finally, contrast questions (See Box, 3.1 below) were asked, to elicit information about meanings of the various native languages or terms used in order to grasp the dimensions of the meanings the participants used to distinguish the world of their objects and events. All through the period of fieldwork and particularly during the ethnographic interview, I remained open and flexible to the discovery of the participant's worldviews about their cultural rules and knowledge that guided behaviour and the practices of provision and use of PC. The subordinate role of learner as an ethnographer during the ethnographic interview encouraged the participants to provide dense and in-depth information about the culture. Although a learner, I maintained self-awareness of the impact of the relationship positionality during the interviews and remained conscious that I was a co-constructor of the knowledge, consistent with my epistemological standpoint.

### **Descriptive questions for the healthcare providers and the service users**

- Can you tell me about issues that influence the care of terminally ill and dying patients in this hospital?
- Can you tell me about your illness?
- Can you tell me about the illness of your family member?
- Can you tell me about the care you (or your family) are receiving in this hospital?
- What has not been easy for you here so far?

### **Structural questions**

- ❖ Please can you tell me more about:
  - Funding of palliative care
  - Facilities and equipment for palliative care
  - Kinds of support available for these patients or their families
  - How you care for terminally ill and dying patients in your own department/ unit
  
- ❖ Please, can you tell me more about:
  - Staffing for the provision of palliative care
  - Guidelines for the care of terminal illnesses in this hospital
  - Training/education for the staff involved with the care of terminally ill patients
  - About the services you provide and how you provide care for your patients and family members
  
- ❖ Please, can you tell me more about:
  - What you believe regarding this illness?
  - Kind of issues that you consider problematic while you are in this hospital and before you sought for care in this hospital?

### **Contrast questions**

- ❖ Can you tell me the difference between care you received in other places and now you are in the hospital?
  
- ❖ Can you tell me what you think are the difference between care provided by members of the palliative care team and members of your unit to these patients?

### **BOX 3.1: Sample of ethnographic questions asked**

The procedure adopted during the interviews with the healthcare providers and the service-users is discussed next.

### **3.5.2.1 Interview procedures**

#### **Interviewing the healthcare providers (professionals and members of the management)**

As mentioned earlier, interviewing commenced when I had developed a good rapport with the participants, particularly the professionals and the service-users. The interviews with the healthcare providers were conducted in a venue chosen by each of them, mainly in their offices or in the meeting room within the hospital. Where possible, the room was accessed prior to the interview day, to ensure that the venue had minimal distraction during the interview. Each interview was conducted based on the availability of each participant and lasted between 45 minutes to 90 minutes, while empowering the interviewee to talk about their beliefs, experiences and all the issues about the culture of PC according to their worldviews. A digital audio recorder was used to record the conversations during each session of in-depth interview with the permission of the interviewee. This provided the opportunity to focus on listening, probing and to follow up interesting developments while maintaining eye contact with the informants, in line with the recommendation by Edward and Holland (2013). During each interview session, I paid attention to the specific language used to communicate cultural meanings, but also noted the nonverbal expressions. This was done in a manner to avoid distracting the interviewee and to allow a free flow of information. Finally, reflection about each interview session was done to identify areas for improvement and further follow-up in the subsequent interviews.

#### **Interviewing the service-users (terminally ill patients and their relatives)**

Interviewing terminally ill patients requires eliciting sensitive information which may encroach into their private sphere or delve into their deep personal experience with the potential to re-awaken feelings of emotional distress (Elmir *et al.*, 2011). In this research, risk assessment (see Appendix B) was conducted and measures to prevent, reduce or address the potential risks were put in place before the actual interviewing. It is important to state that terminally ill patients who were unstable, unconscious and/or dying, and patients' families who were not the key informal carer of the members of the family who was ill were excluded from interview. Prior to the interview

and guided by the recommendation by Elmir *et al.* (2011), I was mindful of issues such as the timing of the interview, the suitability of the venue, and sensitive and open questions. I went further to re-affirm the steps to ensure confidentiality and anonymity prior to the start of each interview session. The interviews with the in-patients and their relatives were conducted in the evening, when the ward routines were minimal, in order to minimise disruption of the ward routines and to secure full attention of the interviewees. In addition, a screen was used to demarcate the patient bedside from other beds in order to maintain privacy and to encourage the interviewee to discuss sensitive issues, as the ward had no curtains to demarcate between the beds. For the terminally ill patients and their relatives that were not under admission, interviews were conducted in the meeting room near the PC nurses' station. All the interviews were digitally audio recorded with the permission of the interviewees.

It may be important to highlight that interviews with some of the service-users were conducted in Igbo language, requiring translation into English. An interpreter was not used during the conduct of interviews because Igbo, used by some of the terminally ill patients and the patients' relatives during conversation, is my first language and a general language used by the people of south eastern Nigeria, where this study was conducted. I am fluent in speaking this language and able to translate it into English, although I acknowledged the possibility of mistakes during translation. However, the issue of mis-translation was unlikely because translation was done by me. I had no conflict of interest; therefore, there was no case of partiality in the translated documents. I also acknowledged the complex power dynamics between myself and the interviewees, especially service-users, which may have influenced the ethnography. How I minimised power inequalities during fieldwork was based on the strategies as recommended by Karnieli-Miller *et al.* (2009) and Cannella (2015) such as creating and maintaining good field relationship, creating non-threatening environment, avoidance of any form of dominance or authority with the participants and maintaining participant's right to autonomy. These strategies are further discussed in the reflectivity section.

### **3.5.3 Documentary evidence**

Material artefacts, autobiographies, memos, records, biographies, organisational charts, diaries are all sources of documentary evidence which can be valuable ethnographic data when reviewed (Brewer, 2000; Reeves *et al.*, 2008). Documentary evidence, when reviewed, can add further depth towards understanding social and cultural processes (Fetterman, 2010). Four documents (admission register, daily report register, home visit register and follow-up register) from the PC and oncology units were collected and reviewed. These were the only identified documents in the study site which were useful to supplement, enrich, validate or provide new insights into the culture of PC. Prior to the fieldwork, I proposed to review a document on the protocol and guidelines about PC in the study site but, unfortunately, such a document did not exist. Finally, methodological triangulation, in line with ethnographic tradition, was utilised to compare and contrast information collected from documents, participant observation and ethnographic interviewing (Reeves *et al.*, 2008). By doing so, it was intended that comprehensive insights and a greater understanding into the culture under study would be gained.

### **3.6 Gaining ethical approval (negotiating for access)**

Ethnographic fieldwork does not begin when the researcher gains entry into the study site for data collection; rather, it commences with negotiation for access to the site, event or the participants (Hammersley and Atkinson, 2007). This process began informally several months prior to the fieldwork by contacting the head of PCU and formally by seeking ethical approval, for the purpose of safeguarding the participants' dignity, rights, safety and wellbeing in line with UK Policy Framework for Health and Social Care (UK PFHS, 2018). I obtained ethical approval from the University of Northampton Research Degree Board and the Research Ethics Committee; following the submission of the research proposal and ethical considerations. Also, a letter of research approval was also given by the Hospital Research and Ethics Committee following their review of the research proposal (see Appendix C). It may be relevant to point out that gaining formal ethical approval was less problematic than negotiating access to the hospital, event and the participants through the gatekeepers. These



problems were reflected upon and are presented in the section about reflexivity in the latter part of this chapter. Some of the ethical issues considered and how they were addressed are presented next.

### **3.6.1 Ethical considerations**

#### **Informed consent**

Informed consent was gained from all the participants as an aspect of maintaining their autonomy. Following the recommendations by Antoniou *et al.* (2011), the participants were provided with adequate information about the research (see Appendix D), presented in a plain English, so that they were capable of comprehending the information in order to make the decision about whether or not to participate in the study. However, it was necessary to translate the participant information sheet into the Igbo language for a few patients and their relatives, who were unable to understand English. Translation into Igbo was done by me as previously explained above in section 3.5.2.1.

The participants were provided an opportunity to ask any further questions about the research if they wished. This was followed by handing them a copy of the consent forms (see Appendix E). The participants were given up to two weeks and a minimum of 24 hours to sign the consent form to say that they were happy to take part in the study. The participants were informed that they could withdraw from the research at any time without reason and their data destroyed if it has not been anonymised. Extra care was taken to ensure that patients and their relatives did not feel that they were coerced to participate in the research, by making them to understand that any decision made regarding participation in the study would not affect their care. Specifically, I sought consent from only terminally ill patients who had the capacity to provide their consent after reading through the participant information sheet.

Ethnography also requires process informed consent, which entails continuous negotiation and renegotiation of the access to various people and activities. This requires the ethnographer either to seek to maintain the initial informed consent or to gain fresh consent to observe new interesting routines (Plankey-Videla, 2012).

Following the initial consent, I sought verbal consent from the participants at the start of each daily observation, due to the long immersive nature of the study. I also renegotiated consent to observe additional activities from new participants to gain a comprehensive understanding of the emerging cultural domains.

### **Confidentiality**

Confidentiality can be referred to as safeguarding information obtained during and after field work (Toffoli and Rudge 2006), in keeping with principle of non-maleficence and respect for autonomy (Jahn, 2011). Several measures were taken, which included but not limited to, anonymised personal details of the participants, headphone usage during transcription to ensure no one listened to the interview audio, and data being kept in password protected computer files. All the information in the field notes and the interview transcripts which could lead to identification of participants were removed and pseudonyms used during reporting of the findings, as will be applied in all future publications. The consent forms were stored under lock and key. Generally, the university guidelines regarding data storage were followed.

### **3.6.2 Potential risks and ethical issues specific to the study**

#### **Boundaries of observation**

There were so many activities that went on in the studied organisation that, as acknowledged by DeWalt and DeWalt (2011), it was practically impossible to observe all the activities in this social situation. I was particularly conscious to conduct observation within the scope of my ethical approval but encountered challenges about deciding what was and was not data in my efforts to uphold the privacy, respect and autonomy of the participants. The nature of the care environment and activities of the PC team exposed me to activities of other professionals within the studied hospital. It was an ethical dilemma to restrict my observation to the activities of the PC, especially when the roles of other professionals were connected to the care of terminally ill patients. However, I resolved to remain guided by the objectives and focus of the study, but renegotiated additional ethical approval to observe some of the interesting activities of other professionals involved with care of the terminally ill patients because it was necessary to the understanding of the emerging cultural patterns. O' Brien

(2006) noted that everyday realities are unpredictable and are largely shaped by context and unforeseen circumstance; thus, being prepared to adjust to different ethical dilemmas and field circumstances was necessary for the success recorded in my field work, as also highlighted by Li (2008) in her reflection on ethnographic field work.

### **Re-awakening negative feelings and emotional suffering/distress**

Observing the care of terminal and dying patients has the potential to reawaken negative feelings and emotional suffering on the part of the researcher. Also, listening to the interview audios during transcription is another typical activity that may arouse strong negative feelings. If not managed, this could lead to emotional distress or even depression. In addition, negative feelings and emotional distress could be awakened for terminally ill patients, patients' relatives, and other participants during the interviews. Although I have some necessary clinical expertise to care for this group of patients, plan for psychological support was made in the studied hospital should I, the patients, patients' relatives or other participants, become distressed. In addition, an assessment of the potential risks to myself and the participants was carried out throughout the research process to maintain maximum safety, with some corresponding strategies to reduce the chance of emotional distress and other risks (see Appendix B).

### **Nurse-Researcher dilemma**

The nurse-researcher dilemma is one of the inherent problems in ethnographic research that has been encountered by some previous doctoral researchers (Seymour, 2001; Costello, 2001). A situation arose during the fieldwork in which I encountered a dilemma about either to act in full capacity for patient advocacy, in line with my professional responsibility, or to act within the ethical clearance, as an honorary nurse in the studied hospital. This ethical dilemma and how I resolved it, is presented in the reflexivity section of this chapter.

Another ethical issue that might have occurred in this study would have been if any inappropriate or harmful practices were observed during participant observation that could have caused harm to the patients, and also if anything was disclosed by the

nursing staff or any other member of the PC team during informal conversations or formal interviews that could have been of importance to the care of the patients. Although I did not experience such a scenario, I had planned to follow the organisational procedures to handle such issues if such a situation had occurred.

### **3.7 Ethnographic data analysis**

Ethnographic analysis is an iterative and inductive process for searching for the parts of a culture, the relationships amongst the parts and their relationships to the whole (Spradley, 2016). It is important to state that ethnographic data analysis and data collection overlapped with each other, as would be expected in ethnographic study (Hammersley and Atkinson, 2007; LeCompte and Schensul, 2013; Spradley, 2016), although, for the purpose of clarity, they have been presented in a linear order, as is widely done in a research report. The task of ethnographers, according to Spradley (2016), is to describe cultural symbols and to identify their coding rules. Thus, I systematically examined and searched the field notes and interview transcripts for the discovery of cultural patterns which is a task expected of an ethnographer (LeCompte and Schensul, 2013; Spradley, 2016). However, Patton (2015) and Hammersley and Atkinson, (2007) argue that there is no formula or recipe to guarantee the success of this task. This implies that a researcher has to make decisions about the analytical strategies/framework to be used to analyse data. I considered strategies/frameworks that have been used by previous ethnographers to analyse the data. For instance, a modified grounded theory approach was used in the ethnographic study by Costello, (2001), while content analysis has been used by some ethnographers (Wilkinson and Callister 2010). In addition, thematic analysis has been used by previous ethnographers to analyse their data (Allen *et al.*, 2015; Schober *et al.*, 2016; Guelia *et al.*, 2016), whilst Altkinson *et al.* (2001) highlighted that narrative analysis is gradually gaining relevance and recognition for analysing ethnographic data, but no article was found that had adopted this method. Notably, these methods of analysis are not peculiar to ethnographic research, but can also be used for other qualitative approaches.

I therefore considered it necessary to search for an analytical framework that is specific for analysing ethnographic data. One of the frameworks that has been widely used by

previous ethnographers is known as Ropers and Shapira's (2000) framework for ethnographic data analysis. These authors suggested five steps for ethnographic analysis, namely, coding for descriptive labels, sorting for patterns, identifying the outliers, generalising constructs and theories and, finally, memoing with reflective remarks. The ethnographic work of Allen *et al.*, (2015) adopted Ropers and Shapira's (2000) framework for ethnographic data analysis. Similarly, this framework was used in the studies by Higginbottom (2008), and Wilkinson and Callister (2010) for their ethnographic data analysis. Another framework for ethnographic data analysis was developed by Spradley in 1979 and was supported by LaCompte and Schensul (2013). Some ethnographers, for instance, Fraser *et al.* (2009), used Spradley's framework for ethnographic data analysis. This framework has been recently reviewed (Spradley, 2016) and its evaluation seems to imply that it is more comprehensive than Ropers and Shapira's (2000) framework. Spradley (2016) presented explicit steps for analysis of ethnographic field notes and interview transcripts for the discovery of cultural themes that uncover cultural meaning. As such, I adopted this framework for the analysis of data in this research. Spradley's framework for ethnographic data analysis comprises domain, taxonomic, componential analysis and the discovery of cultural themes. These steps are briefly discussed in relation to how they have been used to analyse data in this current research to yield the cultural themes.

### **Domain analysis**

Domain analysis is searching for cover terms, included terms and semantic relationships within the ethnographic field notes and interview transcripts. Cover term is the name for a cultural domain, while the included term is the name for all smaller categories inside the domain. The linking together of two categories is known as a semantic relationship. Table 3.2, below, shows an example of domain analysis, although the list is incomplete as it is a sample used to demonstrate how the domain analysis was conducted.

Included terms	Semantic relationship	Cover term
God is the healer Pray it out Devil causes sickness God cures all diseases God does not allow people to be sick God is the holder of life Satan causes cancer Pastors have spiritual eyes God can change all situations God is the giver of all good things	Is a form of	Religiosity

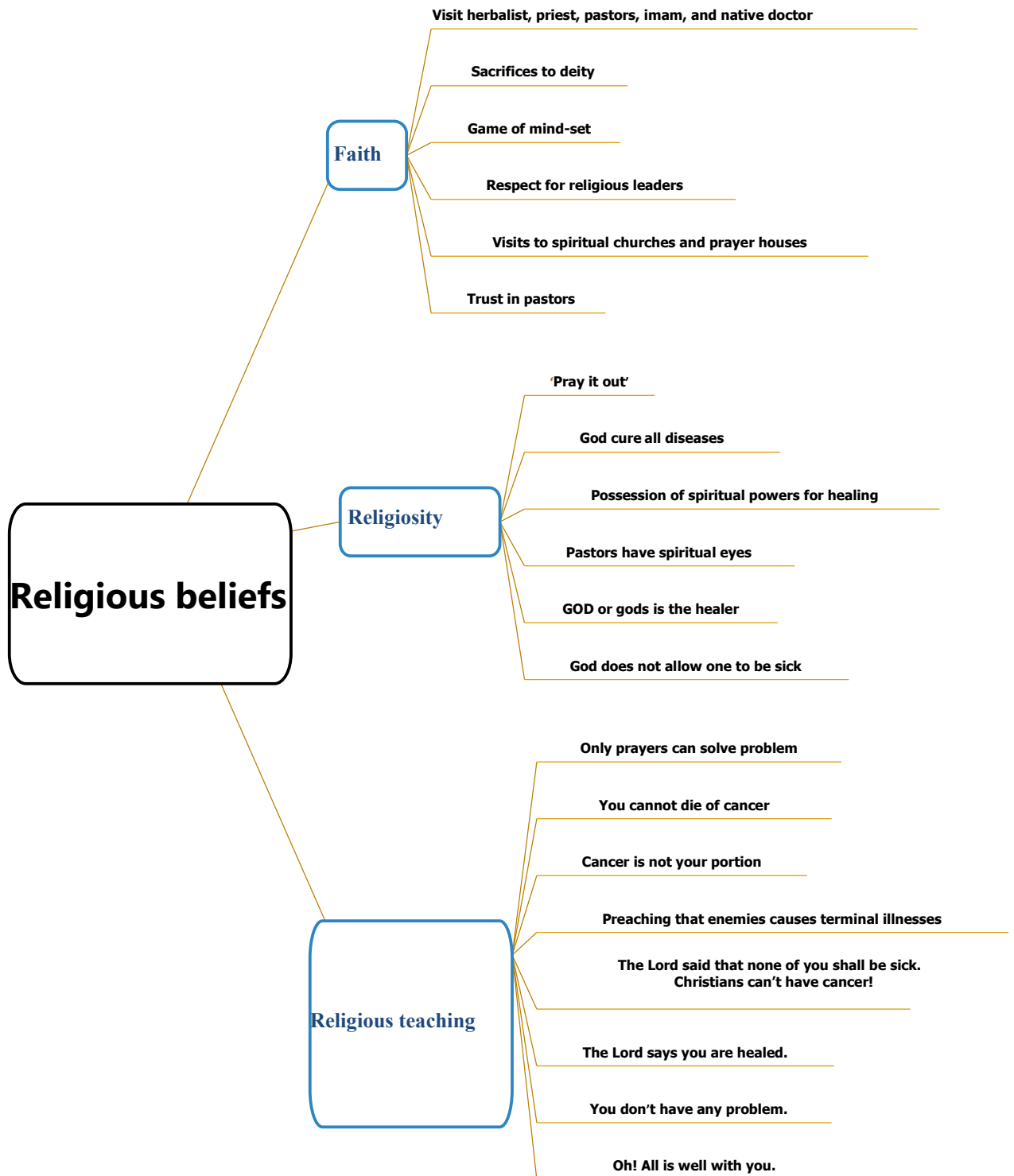
**Table 3.3: sample of domain analysis worksheet**

There were enormous amounts of various clusters of included terms, cover terms and semantic relations identified from repeated reading of the field notes and interview transcripts. A computer software programme, Nvivo 10, was used to aid storage and organisation/management of the voluminous amount of data gathered from the field notes, interview transcripts, analytical memos, reflexive and reflective notes at this stage of analysis. Nvivo 10 is one of the most up-to-date computer software programmes that aids qualitative data analysis (Bazely and Jakson, 2013) and facilitates the storage and handling of large data sets (Bazely and Jakson, 2013). It facilitates easy, effective and efficient coding, searching, data retrieval and enables exploration of relationships between concepts (Zamawe, 2015). Folk terms and analytic terms were used in the construction of the included terms, cover terms and taxonomy through all the stages of analysis. Finally, several cultural categories were identified as well as gaining the overview of the cultural scene, as consistent with the goal of domain analysis (Spradley, 2016).

### **Taxonomic analysis**

Taxonomy 'is a set of categories organised on the basis of a single semantic relationship' (Spradley 2016:112). Having discovered and identified several cultural domains (an important unit that exists in every culture) and the smaller units that

constituted these domains, the next step was a search for the relationships that existed within and among the cultural domains. Cultural meaning arises from the organisation of cultural domains and this is represented by means of taxonomy. Figure 3.1, below, shows a sample of the taxonomic analysis.



**Figure 3.1 sample of taxonomic analysis**

As shown in Figure 3.1, above, and as highlighted by Spradley (2016), taxonomy reveals subsets and the way they are related to the whole, and it can be constructed from folk terms, analytic terms or both. Nvivo 10 was used to aid this stage of analysis whereby the relationships between parent nodes were examined, which gave rise to a category or larger cultural domain. These relationships are the taxonomies which represent the cultural patterns under study. The five steps for taxonomic analysis (Spradley, 2016), namely, selection of a domain for taxonomic analysis, looking for similarities based on the same semantic relationship, looking for additional included terms, searching for larger, more inclusive domains that might include as a subset of the domain you are analysing, construction of tentative taxonomy, making focused observation to check out the analysis and construction of a complete taxonomy, were undertaken. At this stage, the cultural patterns people were using to organise their behaviour and make decisions that guide their practices became more explicit.

### Componential analysis

Cultural meanings are not only driven by the relationship and similarities that exist within the cultural domains but are also based on the differences and contrast that are found among the cultural domains. During componential analysis, ethnographers focus on searching, discovering, organising and representing all the contrasts/attributes/components of meanings associated with several cultural categories identified during taxonomic analysis. Following the steps recommended for componential analysis, an illustration of how the researcher organised and represented the contrasts/units of meaning from a cultural category into what Spradley referred to as ‘paradigm worksheet’ (Spradley 2016:135) is shown below.

Domain (cultural category)		Dimensions of contrast	
		Evil others	Mystical/ supernatural beings
Religious belief	Terminally ill patients	Yes	Yes
	Patients families	Yes	Yes
	Healthcare providers	No	Yes

**Table 3.4: Paradigm worksheet using cultural categories of religious beliefs**



In this stage of analysis, various units of meaning were identified and will be clearly shown when presenting the ethnography in all the findings chapters. At this stage of analysis, the information was verified during further interviews and selective observations, as recommended by Spradley (2016).

Prior to the last stage of the analysis, data triangulation was done during the taxonomic analysis, whereby different sources of data were examined for similarities. At the stage of componential analysis, data triangulation focused on examining the contrasting or cultural contradictions in the participants' opinions and perceptions in different data sources, as well as contradictions between what was observed and what was said. Fetterman (2010) stated that ethnographic analysis involves data triangulation, whereby the ethnographer compares the different sources of information with a single focus to identify areas of similarities and differences in order to understand alternative explanations of the issues under investigation. As done in this current research, previous ethnographers have reportedly undertaken data triangulation (Stajduhar and Davies, 2005; Baggs *et al.*, 2007; Sinclair 2011; Dembinsky 2014) because it enhances the credibility of a study. On completion of this layer of analysis, the next stage, based on the Spradley framework, is to search for cultural themes which will lead to writing up the ethnography.

### **Discovery of cultural themes**

The idea of cultural themes is based on the premise that a culture is more than units of domains and pieces of customs. It is, rather, composed of a system of meaning that is integrated into some kind of a more complex and larger pattern that conveys a sense of the whole. A cultural theme is defined as *'any principle recurrent in a number of domains, tacit or explicit, and serving a relationship among subsystems of cultural meaning'* (Spradley 2016:141). They connect subsystems or elements in the patterns that make up a culture. Having done various layers of analysis, at this stage I shifted attention towards examining the relationships that existed amongst the larger set of cultural categories, grouping the categories that fitted together as subsets of single

ideas to arrive at three cultural themes that fitted together into one cultural scene, as shown below.

cultural theme one	cultural theme two	cultural theme three
<b>Perception of terminal illness and palliation</b>	<b>Socio-political and economic influence on palliative care</b>	<b>Environmental Influence on Palliative Care</b>

These themes have subthemes, which will be discussed in the various findings chapters.

Finally, as mentioned earlier, data analysis commenced immediately when/after I got into the field. I began to make sense of the daily field notes and writing reflective notes following the first day of participant observation, before the next visit to the field, even prior to commencing domain analysis and other layers of analysis. All through the period of fieldwork, I had several supervision meetings where I discussed the progress of the data collection and sections of the field notes with my supervisors. During these meetings, I shared my impressions and discussed issues which I believed were emerging from the data. These meetings were particularly important during all phases of data analysis because the supervisors shared new ideas about the data, which left me with extensive thoughts around the emerging patterns of cultural behaviour that informed the cultural practice for the provision and use of PC. These thoughts led to a more critical reflection and identification of questions that may need further investigation for better understanding of the emerging cultural issues. I constantly reflected on how I may or may not be influencing the data collection process and analysis; this is presented in a section containing my reflexive account.

### **3.8 Evaluating ethnographic research**

The trustworthiness or 'goodness of fit' criteria for ethnography is under contention. Whilst some ethnographers have argued that general standards for assessing qualitative research are appropriate for ethnographic research, others have argued that there are assessment criteria distinctive to ethnography (Hammersley, 1998). Although qualitative traditions have some common quality criteria, I concurred with

ethnographers who believed that there should be some distinct criteria for assessing ethnography. The argument in support of the unique criteria for judging ethnographic research usually draws on one or more of the methodological features, such as naturalism, understanding and discovery (Hammersley, 1998).

The feature of ethnography pertaining to naturalism is aimed at capturing the character of naturally occurring human behaviour in its natural setting. Thus, the commitment to naturalism while assessing ethnography should be whether the account accurately captures the phenomenon being described (Hammersley, 1998). In this context, the ethnography could be assessed in relation to whether it captured the perceptions and interpretation of the participants, as well as whether the phenomenon being studied goes beyond the participants' understanding to include the understanding of the participants' behaviour and its wider context. The criterion in relation to naturalism considers the extent to which the people's perspective and/or behaviour and context are accurately captured, while the criteria related to understanding, pertains to the fluidity of human action, which involves the capacity of an ethnographer to appropriately interpret and construct human actions and behaviour. From this perspective, ethnographers are expected to gain cultural perspectives and the etic view, if valid explanation of human action or behaviour is to be produced.

The features of ethnography were the basis for the identified criteria for assessing ethnographic research drawn from published work of several ethnographers (Frake, 1962, Lofland, 1974, Wolcott, 1975, Owens, 1982, Lincoln and Guba, 1985) as printed by Hammersley (1998) in his book titled Reading Ethnographic Research. These criteria are presented in Box 3.2, below.

1. *The extent to which substantive and formal theory are produced and the degree of development of the theory.*
2. *The novelty of the claims made.*
3. *The consistency of the claims with empirical observations.*
4. *The credibility of the account to readers and/or to those studied.*
5. *The degree to which the culture description produced provides a basis for competent performance in the culture studied.*
6. *The extent to which the findings are transferable to other settings.*
7. *The reflexivity of the account*

Box 3.2: Quality criteria for ethnography (Hammersley, 1998:60)

Whilst these criteria appeared useful, Hammersley (1998) argued that the first criterion is not appropriate for ethnographic research because ethnography is not primarily concerned with producing theory. His argument appeared convincing because the idea of substantive theory and formal theory originated from Glaser and Strauss (1976), grounded theorists. In addition, Hammersley (1998) pointed out that the third, fourth, fifth and seventh criteria, as shown in Box. 3.2, above, were rather the means for assessing, rather than being, standards for judging the quality of ethnography. In addition, these criteria appear not to be unique to ethnography, as they appear to fall within the general criteria for evaluating qualitative research (Leininger, 1994, Denzin, 1994). So far, it appears that no general acceptable criteria can be used to distinctly assess ethnography but, based on the available evidence and personal views from various ethnographic texts and previous research, the following appeared to be criteria upon which the assessment of ethnography may be relied upon.

### **Thick description**

The phrase 'thick description' was coined by Ryle (1949) and was later used by Geertz (1973) who applied it in ethnography to mean the kind of description that provides sufficient cultural context and meaning that people assigned to the 'world of objects', and outsiders to the culture can make meaning of the behaviour. The level of

'thickness' required in ethnography was not highlighted by Geertz, although the strategies for achieving this comprehensive and contextualised description of the social action within the setting was stated to be through prolonged field engagement and persistent observation. Some authors have stated that prolonged field engagement and persistent observation are used to demonstrate the quality of a study involving participant observation (Borg and Gall, 1989; Mertens, 2005; Boellstorff *et al*, 2012; Anne, 2014). Prolonged immersion in the field advanced a positive field relation between me and the participants, which enhanced free flow of what seems to be honest and sensitive information, which, in turn, facilitated insight into the context of the culture under study, leading to thick description, as has also been acknowledged by other researchers (Krefting, 1991; Hammersley and Atkinson, 2007; Onwuegbuzie and Leech, 2007). These strategies (prolonged engagement and persistent observation) conform to Lincoln and Guba's (1985) approaches to demonstrating the credibility of research. In addition, thick description is consistent with what Richardson (2000:254) termed '*substantive contribution*', a criterion to assess whether the product (ethnography) contributed to an understanding of social life and was deep-rooted in human-world understanding and perspectives.

Furthermore, thick description portrays an insider's (emic) perspective, in which the meaning of the social action for the actors is paramount and takes precedence over, yet does not ignore, that of the researcher or outsiders (Hammersley and Atkinson, 2007). Again, persistent observation and prolonged engagement provide opportunities for an ethnographer to understand participants' qualities and the hidden dimensions (Nyland, 2008), in order to produce tacit, as well as explicit, knowledge of the culture.

### **Relevance**

The relevance of ethnography is a quality criterion suggested by Hammersley (1990), who argued that in addition to 'thick description', ethnography must also be relevant to the issue of actual, or potential, public concerns. Research can be relevant if it either adds to the body of knowledge or increases the confidence on which the existing knowledge was based (May and Pope, 2000). Relevance is consistent with what

Richardson (2000:254) termed as *'impact'*, a criterion to assess ethnography as to whether the product would impact on organisational development or if it emotionally and intellectually affects the readers and if it generates new questions that move other researchers to write or engage in other actions. Congruently, Nyland (2008) highlighted that utility of organisational ethnography is based on its relevance, on the basis of whether it produces a detailed, in-depth picture of a group, organisation and its members, as well as uncovers the social, cultural and political issues which other methodologies find intangible (Nyland, 2008). The relevance of this current ethnography will be discussed in a section of the discussion chapter.

### **3.9 Reflexivity**

Reflexivity in ethnography is the demonstration, recognition and placement of the self within the ethnographic inquiry (Reeves *et al.*, 2013). This concept is ambiguous because it is associated with various meanings (Doyle, 2013; Darawsheh, 2014). In this study, reflexivity is a technique which involved the consideration of the researcher's background, values, knowledge, beliefs, actions, perceptions, position, behaviour, feelings, thoughts and emotions in relation to their influence on planning, conducting and analysing ethnographic research (Reeves *et al.*, 2013). Consideration of the effects of these subjective traits and internal processes through critical self-evaluation is crucial, because it enhances the accuracy of the research process and the credibility of the findings (D'cruz *et al.*, 2007), thus providing readers of research reasons to trust the researchers and the knowledge generated as the final products of their research. The evaluation of the researcher's background and experiences, and how these may or may not have affected the research outcomes, is presented first.

#### **3.9.1 Researcher's background and experience**

It is recommended that qualitative researchers should acknowledge their background, experience, values, bias and beliefs (Bott, 2010). Guided by this recommendation, my personal experiences, cultural and educational background are described and evaluated in this section. This concurs with Holloway and Biley (2011), that it is a way to reveal self which will help to sustain thoughtful self-awareness throughout the research process. In conducting this research, I negotiated to work with the members

of palliative/oncology team as a nurse because of my previous training and experiences working as a nurse. I became a nurse-ethnographer conducting research within a study site similar to other tertiary healthcare hospitals where I had worked in Nigeria. My clinical nursing background was sufficiently similar to provide me with some implicit assumptions and knowledge regarding the daily activities of healthcare professionals within the studied hospital. In addition, the theoretical knowledge about PC I acquired during a Master's degree, the review of literature for this project and also being a nurse lecturer in a Nigerian University, and having maintained links with the Nigerian healthcare organisations, I inevitably came to the study with knowledge about death and dying. As a nurse who had worked in medical wards and other wards where patients with chronic and terminal illness are being managed, I had always felt that the healthcare system in Nigeria is insensitive to meeting the needs of these patients. There was a case where a friend who had a terminal illness was forcibly discharged from the hospital where I worked because services to improve his quality of life were unavailable. There was no follow-up care while he was at home, leaving him dying an agonising death. I felt terrible and was disappointed with the healthcare system and never forgot this experience, which is still embedded in my consciousness. It was one of the motivations behind this study.

Furthermore, I come from the geopolitical and cultural region of Nigeria where the study site is located. This placed me with the advantage of knowing the wider sociocultural context that can influence the health and wellbeing of people in this region of Nigeria. However, I was unfamiliar with the research setting or the staff and lacked knowledge about the culture of providing PC in Nigeria. This unfamiliarity helped me to maintain detachment and the critical eye required for ethnographers while immersed in the culture under study. Based on my experience, educational and professional background as a nurse, I therefore acknowledged that these would have influence throughout the fieldwork, interpretation and knowledge construction. This is not unusual because it was recognised many years ago that researchers' social identity and background, including their experiences, have impacts on the research process (Lincoln and Guba, 1985). Patton (2015) acknowledged that researchers'

personal and professional background may have an impact on the data collection, interpretation and analysis. I continued practicing reflection and reflexivity at all stages of this research to remain conscious about my personal traits and the internal process in the ongoing relationship between me and the participants at the study site. This was an easy task as a nurse-ethnographer, because reflexivity is inherent and fundamental to nursing practice (Borbasi *et al.*, 2005). The reflexive account during data collection and analysis is presented next.

### **3.9.2 During data collection and analysis**

The dynamics involved in knowledge production were constantly reflected upon and continually modified these dynamic during field work to enhance the trustworthiness of the research (Bover, 2013). I maintained consciousness of my roles as a nurse as well as a researcher during the field work. Also, I recorded my thoughts, emotions, feelings, fears, hunches, mistakes, reactions, decisions and emotion in the research journal and it was constantly reviewed, which helped me to turn back or modify some of the initial reactions. Previous researchers have engaged in a similar process during data collection, to develop self-awareness during this phase of data collection (Probst and Berenson 2013). In addition, I engaged in daily reflection of the field notes and also kept analytical memos as the research progressed.

On the third day of participant observation, I spontaneously expressed cultural shock/disappointment when I observed that some terminally ill patients had waited for a very long time to be seen by a doctor, but eventually no doctor was available to provide PC and these patients had to leave without receiving care. However, following the daily reflections, I realised my mistakes and reminded myself of my position as an ethnographer. The importance of remaining open-minded and objective during field work was clearer. Reflexive practice helped me to ponder how I may have hindered or facilitated the process of co-construction of meaning. I became more conscious of my emotions, beliefs, views, actions and personal feelings. Subsequently, I was able to maintain calmness, learn to cope with cultural shocks and did not express any form of emotion when I observed things which I considered to be strange, for instance, when a terminally ill patient, under the care of PC team, died because there was no water for



dialysis, and when some terminally ill patients were referred to the PCU but no PC doctor was available to consult these patients for more than three days.

It was relevant to consider the impact of a power relationship, especially with regard to my involvement with the service-users during data collection. This has been discussed in relation to the researchers' positionality, because Bourke (2014) highlighted that the act of examining the research process in the context of positionality is an aspect of reflexivity.

### **3.9.2.1 Researcher's positionality: the insider-outsider perspectives**

The concept of positionality is described as how people are defined, based on their changing position and identity within a network of relationships (McGarry 2016). For Merriam *et al.*, (2001), it is where one stands in relation to others. In the context of this research, it is the reflection of who I am as a researcher, and as a member of the group within the culture under investigation and how my shifting positions affected the knowledge under construction. It was relevant to analyse the researcher-researched positionality because Archer (2007) highlighted that it can give rise to a diverse and complex form of socially and culturally situated knowledge. Thus, ethnographers are committed to acknowledging and documenting their position within the social world being investigated and its effect on the research outcome (Bourke, 2014; Milligan, 2016).

The identity and position of the researcher in relations to the participants can be situated as insider, or outsider, or both (Milligan, 2016). An insider is a person who possesses knowledge and has some shared features with the group and phenomenon under study, while an outsider is a stranger with no shared features with the participants or the phenomenon under investigation (Milligan, 2016). I assumed the position of insider-outsider. Other researchers have been positioned similarly in their respective research (Thomson and Gunter, 2011; Katyal and King, 2014). The theoretical development of insider-outsider positioning is based on the premise that some researchers are neither entirely insider nor outsider in the conduct of their research (Milligan, 2016). I shared professional, geographical, religious and ethnic

identity with the participants, thus was an insider, but also an outsider by the way of being a researcher, who lacked the cultural knowledge of providing PC services, who has neither sought for care nor previously worked as a nurse at the study site. My shifting positionality (insider-outsider) in this research had positive impacts during the fieldwork; however, there were methodological and ethical challenges experienced as I iteratively shifted between the insider and outsider positions.

The position as an insider earned me a degree of acceptance which facilitated field relations or trusting relationship with members of the PC team. This offered me an easy access, without any restrictions, to their daily routines within the organisation and easy interaction, which would have been more difficult to gain as an outsider (researcher). In addition, my insider position eliminated communication barriers and facilitated the understanding and interpretation of tacit cultural behaviour and symbolic language, which could have been difficult to gain if I had conducted this study in an ethnic and geopolitical zone of Nigeria not similar to mine. Therefore, my cultural identities facilitated more accurate description and interpretation of the cultural codes and symbols shared and used by all groups of participants, resulting in an understanding of the tacit and explicit cultural intentions that informed the cultural practices.

However, the 'insiderness' position was not without challenges, as Lincoln and Guba (1985) stated that the researcher's 'nativeness' will likely make him/her go native, thereby overlooking important issues during fieldwork. This was not experienced during the fieldwork because I only engaged in fieldwork for three days every week, in order to sustain my detachment as an outsider. Remarkably, my role as a nurse amongst the members of PC team, thus an insider, conflicted with my role as a researcher. Despite a pocket tag notifying the service-users and other healthcare providers within the hospital of my role as a nurse researcher, one of the patient's relatives privately approached me after one of the PC ward rounds and narrated her worries about the oncology care being provided to her mother. She wanted me to advocate for them by meeting the consultant oncologist. This was an ethical dilemma

because, as a nurse, I have a professional duty to advocate for the patients and their relatives (Agom *et al.*, 2015), but, as a researcher, the ethical clearance and honorary contract as a nurse-researcher does not permit me to intervene with the care of patients. I, therefore, directed the patient's relative to another member of the PC team who could assist in addressing her complaint.

From the perspective of an outsider, the members of the PC team continually shared their experiences with me because of their awareness and construction of my role as a researcher. Similar to the ethnographic study conducted by McGarry (2015), most of the participants were more comfortable sharing sensitive information with the researcher because of his outsider position. One of the participants said to me, 'I am sharing this information with you in confidence and for research purpose'. Ryan (2015) stated that the outsider position often dispels concerns about gossip, the leaking of research data and shapes the boundaries of data; therefore, participants have confidence that information they provide will remain confidential. However, this was not the case at the earlier stage of the fieldwork, where the outsider position had the Hawthorne effect, as would be expected in ethnographic research, but this became phased out as the trusting relationship improved.

Furthermore, the theory of positionality also proposes that the research relationship is characterised by complex power dynamics which can influence the research outcomes (McNess *et al.*, 2015). Power relationships between the researcher and the participants could influence the ethnographic knowledge under construction (McNess *et al.*, 2015). Therefore, its impact was analysed in this research. Karnieli-Miller *et al.* (2009) and Holland *et al.* (2010) made it clear that the task of researchers is not to overcome the power inequalities during fieldwork, but to understand and acknowledge how power dynamics may have shaped the research outcome. One of the participants told me during a causal chat that 'I should rather be the person to educate her about PC because I had more educational qualifications than her and I came from a University in the UK'. This expression is suggestive of a power imbalance, because this participant considered herself as being educationally disadvantaged and,

therefore, less powerful than the researcher. However, this was managed through further explanation about the aim of the research.

Power dynamics were often located within my shifting positionality. For instance, my age and lower professional rank as a nurse were constantly at work shaping the power discourse in my relationship with the nurses and other professionals. Most of nurses considered me as a junior colleague and, thus, less powerful. However, being perceived as a researcher, particularly from a University in the UK, facilitated open communication by the participants because of a general perception in Nigeria that persons that live abroad have more privileged circumstances, which could benefit others living in Nigeria. Most of the healthcare staff narrated their experiences of providing PC and, in turn, wanted to learn from me by asking how the services were being provided in the UK and the possibility for me to help them to come to the UK to work.

Finally, service-users had continuously seen me with members of the PC team during ward rounds. Perhaps, some of them may have assumed that their refusal to participate in the study may influence their care due to their low literacy level, suggesting that power dynamics may have interplayed during the fieldwork. However, it was made clear to them that they could either accept or reject participation without any consequences. Power was like a fluid, neither seized by me nor the participants. Overall, I declared that my cultural identities may have tacitly influenced the data interpretation and knowledge generation, but that this had been minimised through reflexive practice.

### **3.10 Summary of the chapter**

This chapter began with a discussion of the philosophical and theoretical framework taken to research the cultural, socio-political, environmental and organisational dynamics which influenced the provision of PC, and the patients' and their relatives' behaviour for its use in a Nigerian hospital. I have discussed the rationale for the methodological approach and methods used to undertake the study. It was acknowledged that data collection and analysis were interlinked with each other, but

they have been presented in separate sections for enhanced clarity. I then discussed the ethical processes undertaken and drew from the existing evidence to present the overarching principles upon which the assessment of ethnography may be relied upon. This chapter concluded with a reflexive/reflective account of the different stages of the research process.

An overview about PC in the study setting is provided in the following chapter, in order to set the scene and provide the context in which to understand the findings.

## CHAPTER FOUR

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### **The ORGANISATION OF PALLIATIVE CARE IN THE STUDY SETTING**

#### **4.0 Introduction**

This chapter sets the scene for the organisational ethnography of palliative care (PC) in the studied setting. Specifically, it provides baseline information about PC in the study setting, which is of relevance to understanding the finding chapters. The historical account and organisation of service provision will be discussed, with the intention of gaining insight into the available services and the level of PC development in the studied hospital. Firstly, a historical account of PC, which consists of the inception of palliative care unit (PCU) and the physical layout, is presented.

Lastly, in this chapter, and the following three finding chapters, extracts from the field notes taken during participant observation and document analysis are represented by the letter 'F', followed by the number of the note. For instance, 'F10' indicates field note number 10. In addition, data from ethnographic interview is used to illustrate how the cultural domain emerged. Each interview excerpt is presented to show the reader whether it originated from a nurse, doctor, social worker, physiotherapist, hospital manager, patient, patient's relative or the head of the department. Fictitious names have been assigned specifically to a Pharmacist and the Physiotherapist that participated in this study in order to maintain anonymity. The phrase 'studied hospital' has been consistently used throughout the thesis to maintain anonymity of the study site. The findings are presented in relation to the relevant literature and theories where appropriate, in order to show how the finding fits within the existing knowledge.

#### **4. 1 An historical account of palliative care in the study site**

##### **4.1.1 The inception of the palliative care unit in the study setting**

The PCU in the studied hospital was not originally established at the point when this hospital was built. Therefore, this section presents a brief account of how the PCU was established in this setting; this will provide the basis for understanding the characteristics and organisation of the service provision. Betancourt (2012) highlighted that an understanding of the past is crucial to grasping the meaning of the present

social world. Thus, a historical insight may facilitate cultural awareness and understanding of the intricacies underlying the present culture of PC in the studied hospital. The account of PCU, recorded during interviews with the leaders of this unit, which comprised a doctor and a nurse, is presented below as there was no other documentary evidence found about its origin in the studied hospital.

*I am a doctor employed in this hospital to work in a 'Fetha' unit. While working as a consultant in that unit, the head of another unit approached me, told me about palliative care. He said that there was need to establish palliative care unit, and then asked if I was interested to head the unit. I accepted and the palliative care unit was established in September 2008 as part of the Multidisciplinary Oncology Centre of the hospital. I am faced with the challenge of doing my primary duty which the hospital recognised and rendering palliative care services, which is a responsibility I voluntarily accepted. I enjoyed rendering palliative care services because of the passion for the care of people with life limiting illnesses. The big 'ogas' (managers) of this hospital do not provide support for this unit. This is why this unit looks a bit malnourished. It is not like a unit that is over 8 years old. (Interview excerpt, Doctor 1)*

*In 2008, when the palliative care unit commenced in this hospital, me and one other nurse were privileged because the management sent us to Uganda for a five weeks training in palliative care, though all the money we spent have not been reimbursed to us as they promised (Interview except, Nurse 3)*

The idea to establish the PCU seemed to have originated from personal insight and request from an employee of this hospital. Key decision makers of the studied hospital (such as the Chief Medical Director, the Head of Clinical Services, the Head of Administration nor the clinical panel) seemed not to have assessed the proposal to establish this specialised service. This could imply that PCU was launched without undergoing processes of impact analysis, service specifications, and other stages of new service development. Furthermore, the PCU leaders perceived that the services they provided were not well-developed because the managers of the studied hospital did not offer the necessary support to this unit. It is therefore plausible to postulate that foundation of PCU constitute constraint to service delivery; further analysis of this claim will be expounded in the subsequent chapters.



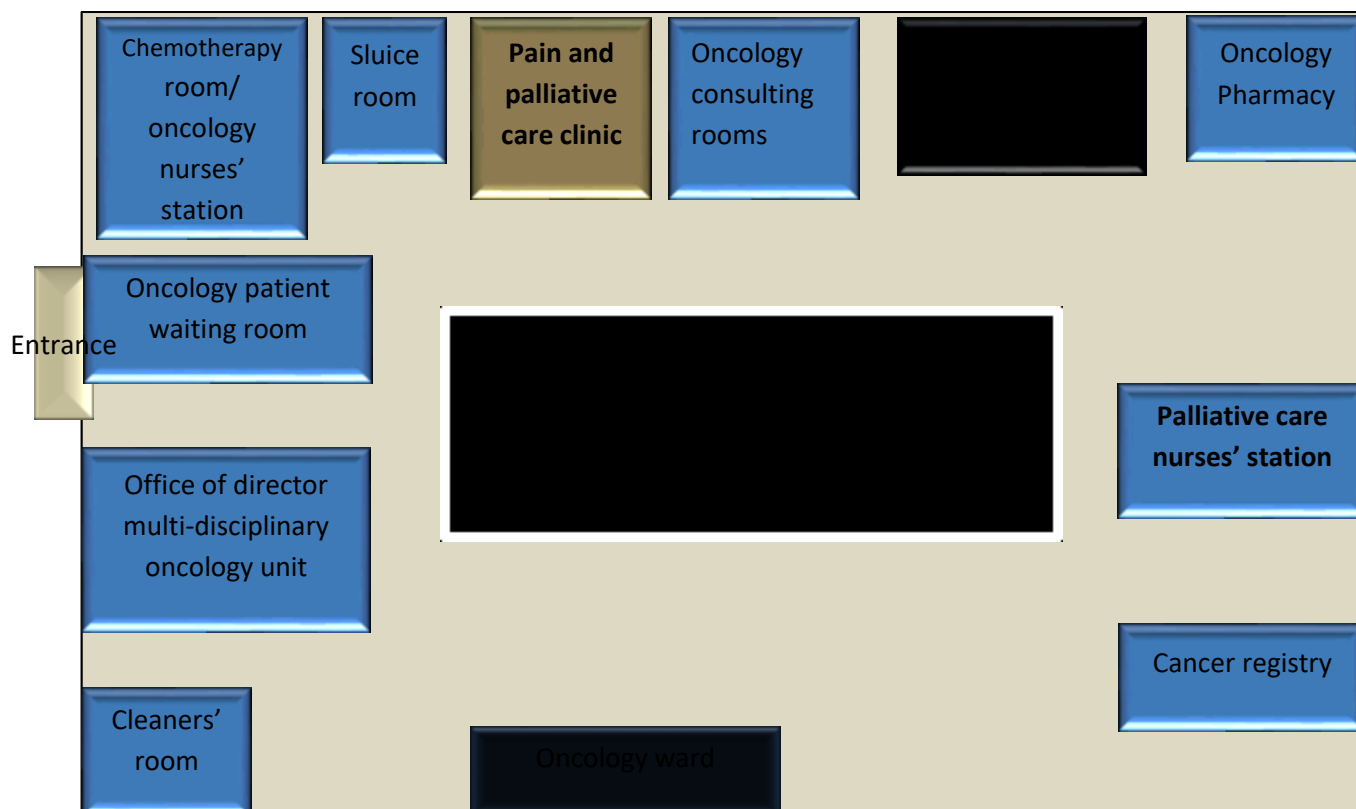
#### **4.1.2 The physical layout of the palliative care unit**

The PCU was situated at the back of the hospital within the oncology complex where only two rooms were allocated to it. One of the rooms was used for a PC out-patient clinic, while the other was used as a PC nurses' station. Image 4.1 and Figure 4.1 below show the PCU within the oncology complex.



**Image 4.1: Palliative care unit within the oncology complex**





**Figure 4.1: Oncology complex showing the palliative care unit**

The oncology complex, as shown in Image 4.1 and Figure 4.1, above, had a pharmacy for easy access to drugs by out-patients requiring PC, but there was no side laboratory to minimise the travel distance of this frequently used space by terminally ill patient. It was also observed that there were no cues for the patients and visitors to know where they are, or how to locate and/or get to their destination:

*The oncology complex is a rectangular shaped building comprising oncology unit, palliative care unit with two rooms for nurses' station and palliative outpatient clinic, cancer registry unit and colposcopy unit (Field note, F2)*

*It was not easy for us the first day we came to this hospital because we had to move around, asking questions on the right place to go. At a time, we got so exhausted and had to sit to rest with my daughter that is unwell. I was so frustrated that I held a female doctor that I saw, told her that I will not leave her until she takes us to a place we will receive care (Interview excerpt, Patient relative 1)*

The physical location of the oncology centre, particularly the PCU, seemed to make it difficult for patients and visitors attending the hospital to locate this unit and was further worsened by a problem of poor signage. The image showing the exterior view

of the physical layout showed that the environment looked untidy and even the grass was not maintained; this gives the impression of lack of place-making about the environment for the care (Feld and Basso, 1996) and limited understanding of the restorative properties of the natural environment and its relation to care provision (Nordin *et al.*, 2017). Also, Figure 4.1, above, showed that the PCU lacked the essential space required for the provision of care to terminally ill patients and their families. An in-depth analysis of the physical layout and how it influenced the provision and use of PC in this hospital is presented in the chapter 'Environmental influence on palliative care.'

## **4. 2 Organisation of service provision**

The members of the PC team reported how PC was organised in their hospital. During my time working with the PC and oncology teams, I also observed how PC was organised. Firstly, the model of PC is presented.

### **4.2.1 Models of palliative care delivery**

The models of care available in the studied hospital were explored with the intention of revealing the range of services available for service-users with life-limiting illnesses or/and serious illnesses. Knowledge of how the PC was organised, in terms of its models, will provide insight into the hospital's level of preparedness to accomplishing the goal of PC, which is to achieve the best quality of life for patients and their families. It could also provide insight into whether PC provision in the studied hospital aligns with the recognised African Palliative Care Association (APCA) standards for providing quality PC across Africa (APCA, 2010). During the ethnographic interviews, members of the PCU explained that they undertook various services, such as home visitations, family meetings (meetings between the patients' relatives and members of the PC team), ward-rounds, enrolment and consultations:

*We conduct palliative care ward rounds every Monday and Friday. During these ward rounds; we go from one ward to another, providing care to our patients in various wards (Interview excerpt, Doctor 1)*

*We do enrolment on Tuesdays and Thursdays. We also conduct family meetings on Tuesdays and in this meeting, we provide psychological support to the*

*patient's family. We also counsel them and inform them of what they should expect as the outcome of the patients' condition (Interview excerpt, Nurse 2)*

*On Wednesdays, we visit our patients that live within the city. We are not able to visit those living in rural areas... when we visit them, we provide services like wound dressing, bathing, treat their pressure areas, and assist in their medication, provide counselling on drugs, personal and environmental hygiene (Interview excerpt, Nurse 1)*

Two models of PC delivery seemed to be available in this hospital. They are hospital-based care delivery, in the forms of family meetings, in-and out-patients' consultation services and secondly, the home-based delivery model conducted once in a week, particularly on a specified day. The organisation of home-based care implies that service-users may not have access to the services when required and this may lead to poor quality of life. Overall, there seems to be absence of other models of care delivery such as hospice, ambulatory PC clinic, specialist, regional and district facilities (APCA, 2010; Morrison, 2013; Wiencek and Coyne, 2014).

Remarkably, I observed that patients were not involved in the '*family meetings*' and it was conducted only when the patient was nearing the end of life. Some of the healthcare providers (HCPs) during interview reinforced this observation:

*In palliative care, we invite the patients' relatives for family meetings especially when the patient is nearing his or her last days of life. We provide explanation to the family members of the patients about the prognosis and the goal of care (Interview excerpt, Nurse 4)*

*Family meeting is to counsel, explain the diagnosis and the prognosis to the family members often conducted in the last days of patient life (Interview excerpt, Social worker 2)*

The system for discussing disease progression and PC exist in the studied hospital consistent with one of the APCA criteria for achieving standard 2.3 (communication in PC), though discussions were conducted late as well as patients excluded from it contrary to the APCA standard (APCA, 2010). The practice of not including patients in the family meeting appears to be an organisational cultural norm rooted in the principle of non-maleficence; this is explored in greater detail in the next chapter, 'perception of terminal illness and palliation'. It could also be that HCPs lacked

knowledge of the importance of early patient-family education and continual communication with the service-users. Early education and communication would perhaps provide an opportunity to identify the needs of the service-users and facilitate a plan to meet the identified needs. In addition, it may be important to mention that these services were available only for adults; even the available services were sometime inaccessible to service-users:

*If you look at our enrolment record, you rarely see paediatrics receiving palliative care but there are many children in the wards with malignancies that require palliation but they don't refer to us (Interview excerpt, Doctor 1)*

*We don't provide care for children that are supposed to benefit from palliative care services (Interview excerpt, Nurse 2)*

The data shows that PC services were not available for children in this hospital contrary to the call by APCA for the availability of PC for adults and children (APCA, 2010), indicating that this hospital may be failing in its responsibility to recognise and provide specialised PC to improve the quality of life for children with life-limiting illnesses. In addition, while working with the palliative and oncology teams, I observed that ward-rounds and PC consultation were strictly doctor-led. Although, physician-led PC is widely recognised, several countries, such as the UK, Switzerland, and Canada, have introduced nurse-led PC clinics, which have been shown to broaden access, improve quality of care and facilitate an interdisciplinary network of care (Imhof *et al.*, 2016; Pesut *et al.*, 2017). The strictly doctor-led PC in the study setting indicates that if a doctor was not available to lead the service provision, the patients may not have access to care. Several participants repeatedly mentioned that service-users do not receive care when a doctor is not available. I also observed that there were several missed PC ward-rounds and consultations:

*... Last week, we had many consults but no doctor to see these patients (Interview excerpt, Nurse 1)*

*Most of the time, patients come here without receiving care. Myself and one of my colleagues received training in palliative care but when we came back, we attempted to implement what we learnt but were prevented by the hospital management. For instance, I am not allowed in this hospital to prescribe*

*morphine but this is part of what nurses do in Uganda where I was trained (Interview excerpt, Nurse 4)*

*Sometimes, there is no doctor at the palliative care clinic to see a patient referred by other unit. In such situation, the patient will wait until a palliative care doctor comes (Interview excerpt, Doctor 2)*

These comments show that the participants acknowledged that the available PC services in this hospital were not consistently accessible to the service-users, indicating that the aims of PC may not have been adequately met.

Furthermore, the comment by 'Nurse 4', above, suggests that nurses and other members of the PC team were not empowered to independently provide care to the service-users in the study setting. A physician, who was one of the participants, re-affirmed that nurses were prohibited from prescribing morphine and to independently lead PC ward rounds:

*...if I create a job description, who will perform the duties of the doctors? This is why I have decided to leave it for now. If I develop a protocol, all the duties will be performed by the nurses, as I am the only doctor that works in the palliative care unit. When I eventually have doctors, it will be a conflict to relinquish some of the jobs to them. I give you example, some nurses went for training in Uganda, when they came back they started agitating that they want to prescribe morphine because their colleagues over there prescribe drugs to their patients. We told them that it cannot work in Nigeria... (Interview excerpt, Doctor 1)*

There may be hidden power rivalries between doctors and the nurses in the study setting, which seemed to have an influence on the provision of PC. This supposition was reiterated by some of the participants, who acknowledged the existence of a power struggle between doctors and other health care professionals:

*There is inter-professional rivalry due to power tussle. Doctors feel they are more superior to others (Interview excerpt, Oncology Nurse 3)*

*In this hospital, doctors tried to hold power on all aspects of clinical services. They try to use their power to suppress other members of the healthcare team. This has caused some conflicts which negatively affected the care of our patients (Interview excerpt, Pharmacist Lily)*

The 'latent war' in the healthcare system in Nigeria between doctors and other healthcare professionals is recognised to have existed for a long time, due to a struggle

for power and leadership dominance (Alubo and Hunduh, 2017). In this current research, there was a display of power imbalance, where the doctor appeared to possess an absolute power which was exercised in decision making that seemed to have affected other members of the healthcare team. Instead of empowering the nurses and other healthcare members of the PC team to compensate for the low number of doctors, the physician appeared to place more priority on retaining medical dominance for the doctors. Having presented the models of PC delivery, the next section will present the shift patterns undertaken by the members of the PC team.

#### **4.2.2 Shift patterns of the palliative care unit**

The shift patterns for nurses have traditionally been based on eight-hour shifts per day (Estabrooks *et al.*, 2009; Ferguson and Dawson 2011) and this continues to be the predominant practice for nurses in the Nigerian healthcare system. However, many hospitals in different countries, such as the UK, have moved away from this pattern of working in preference to a twelve-hour shift (McGettrick and O'Neill 2006) because many nurses preferred to condense their weekly working hours to save on travel costs. Hospital managers also think that it is more cost effective and that fewer shifts also prevent mistakes that may occur with more frequent handovers (Josten *et al.*, 2003; Estabrooks *et al.* 2009). In this current research, nurses from PCU had only two shift patterns, which were an early shift from 7:00 am to 2.00 pm and a late shift from 2: 00 pm to 7:00 pm.

It was surprising to find that nurses and other members of the PCU did not work weekend shifts (Saturday and Sunday) and night shifts:

*We do two shifts in this unit. The morning and evening shifts. Our patients are provided care by other nurses in the night and weekend (Interview excerpt, Nurse 1)*

*We do not have specific ward for palliative care. We only do ward round and sometimes, we go back to the ward to provide support to our patients (Interview excerpt, Nurse 4)*

The PCU in this hospital arguably operated as a PC day centre, although they had many patients admitted to various wards. Most likely, the PC needs of the in-patients may

not be adequately met, especially during weekends and overnight because the nurses and other team members do not operate 24-hour shift pattern. During the periods when members of the PC team were not available to provide specialised care to service-users with progressive life-limiting illnesses, they assumed that nurses and doctors from other units would take over the care of their patients. However, nurses from other units professed that they were unable to provide all the dimensions of care, due to their workloads. In addition, the in-patients and their relatives who were enrolled for PC repeatedly mentioned that clinicians from other units did not provide them with social and psychological support:

*We do not provide emotional, spiritual and psychological care to these patients because of the workloads. Some patients already have mindset that nurses are very wicked and even when a nurse want to come close to the patient, the person will not give her attention (Interview excerpt, Oncology Nurse 3)*

*I have spent three weeks in this ward; the nurses and doctors do not spend their time to discuss with me about my children and other family members which I left at home. This illness gives me worry but no one to discuss about it. The nurses only come to give me tablets, then move to another bed (Interview excerpt, Patient 1)*

This contradicts the assumptions made by the members of PC team that their patients received PC from others during the periods they were not on shift. Some of the nurses and other members of the PC team highlighted that the lack of a specific ward for PC was a hindrance for 24-hour PC in this hospital. Whilst this made sense, it would be possible to organise members of their team into groups that would supervise and monitor the implementation of individualised care plans for every patient requiring PC in the various wards at all times, without necessarily having a specific ward for PC. The impact of the lack of a 24-hour shift pattern on the quality of life of the service-users who sought PC in this hospital will be explored in the subsequent findings chapters.

### **4.3 Summary of the chapter**

Palliative care in the studied hospital could be said to be adult patient-centred, with minimal attention to service provision for children and this is contrary to the philosophy of PC that seek to improve quality of life for patients irrespective of their

age. This chapter further revealed that the physical layout for PC, the team composition and models of the care were not well developed. In addition, although this chapter provided baseline information about PC in the study setting, it has also provided insight into some underlying complexities which may be useful to explain some cultural elements about the provision and utilisation of PC; the finding chapters are presented next.



## CHAPTER FIVE

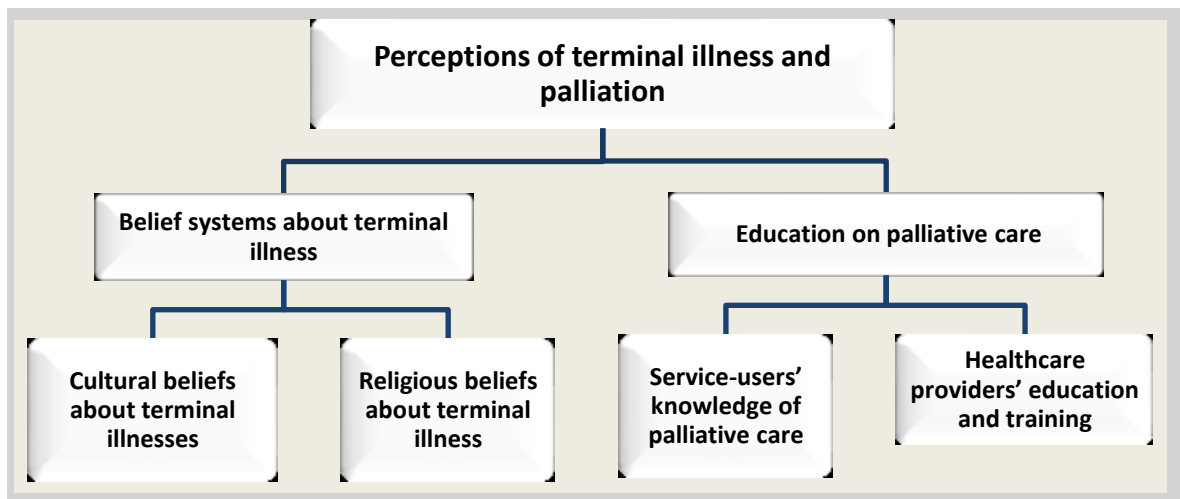
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### PERCEPTIONS OF TERMINAL ILLNESS AND PALLIATION

#### 5.0 Introduction

The three findings chapters present the organisational ethnography in relation to the research aim: to understand the cultural, socio-political, environmental and organisational dynamics which influence the provision of palliative care (PC), and the patients' and their relatives' behaviour regarding the use of PC in a Nigerian hospital. The first finding chapter presents the perception of terminal illness and palliation which focuses on how healthcare providers (HCPs), patients, and their families make sense of life-limiting illnesses and how this impacts on the provision and use of PC. The second finding chapter explores how socio-political and economic factors influence the provision and utilisation of PC, and the third chapter presents the impact of the environment on PC. Notably, cultural complexities on the provision and use of PC threaded through all the finding chapters.

Perceptions of terminal illness and palliation is a core cultural theme which centres on how the participants constructed meaning in relation to their perceptions about their illnesses. The participants' belief systems and education informed their perceptions and understandings, and these appeared to have impacted on both the attitude of HCPs as well as the behaviours of service-users towards the provision and use of PC. Theoretical insights have been drawn from symbolic interactionism (Blumer, 1969), terror management theory (Greenberg *et al.*, 1986) and other relevant theories to aid an in-depth understanding of this cultural theme. This chapter explores how the HCPs and the service-users understood terminal illness and how decisions were made based on their understanding and assessment of this condition. In addition, this chapter explores the underlying intricacies which influenced the service-users use of PC. Finally, the interlinkage between care providers' knowledge, education and training are explored in relation to their perceptions of terminal illness and how PC is rendered to the terminally ill patients. This theme is represented in the Figure 5.1 below.



**Figure 5.1: Thematic framework of chapter five**

## **5.1 BELIEF SYSTEMS ABOUT TERMINAL ILLNESS**

Belief systems was a cultural domain that emerged following analysis of the data and it connotes the set of beliefs the service-users and the HCPs constructed and used to make sense of the terminal illness and care of the terminally ill. These sets of identified beliefs are rooted in the societal-cultural and religious beliefs which provide rules and guidelines for individual social construction of meaning and a personal sense of reality about terminal illness and palliation. An understanding of these beliefs and how they influence the delivery and utilisation of PC is vital, because it may stimulate an awareness of the need for more culturally sensitive PC and as well as revealing changes needed to enhance the development of PC in culturally diverse societies, such as Nigeria. This cultural domain named ‘belief systems about terminal illnesses’, will be presented in two subdomains, namely cultural beliefs and religious beliefs.

### **5.1.1 Cultural beliefs about terminal illnesses**

Cultural beliefs are the socio-culturally accepted traditions and norms that shape how people interact with, and respond to, situations in their world (LeVine, 2017). Similarly, Thompson *et al.* (1990) highlighted that each culture holds a unique set of beliefs, biases, and habits that inform people’s preferences and choices in a social situation. In this current research, the majority of the patients and their families, as well as some of the HCPs, held cultural beliefs about terminal illness and palliation; thus, this section will explore how these belief sets influence the provision and use of PC.

There were widespread beliefs held by most of the terminally ill patients and their families (service-users) and some HCPs that terminal illness was either caused by 'evil others' or mystical/supernatural beings. Specifically, the service-users expressed their belief that terminal illness was caused by the activities of evil or wicked people in society. These wicked or evil persons were reportedly to be mothers-in-laws, grandmothers, grandfathers, neighbours, brothers, sisters and other family members or friends:

*This illness did not just come on its own. I quarrelled with someone in my neighbourhood and the person said that 'I will see'. After some weeks, I noticed a lump in my breast. I have a feeling that this illness is inflicted on me by that woman (Interview excerpt, Patient 4)*

*During family meeting, some patients and their relatives often told us that evil person from family of their husband and people that do not want their success caused their diseases (Interview excerpt, Doctor 1)*

*I have been facing so many challenges in my family because of my wife sickness. After I married my wife, she got pregnant and was delivered through caesarean section, and then she stopped breastfeeding because of the pain in her breast. After some month, she had something like a lump in one of her breast. It has been from one problem to another one. Her family, specifically her grandfather, is a known evil man; he is the person that caused these sicknesses to her (Interview excerpt, Patient relative 5)*

It appears that some of the service-users perceived that evil persons within their society had the power to use witchcraft to inflict terminal illness on someone. In addition, other participants believed that 'evil others' could use poison, place a curse, or act as witches or wizards to cause terminal illnesses:

*I was walking and then stepped on poison. My enemies are responsible for this thing happening in my leg (Interview excerpt, Patient 1)*

*Our landlord is a witch. She sends different kind of illness to people. She even killed her own sisters with cancer and she caused this sickness to my sister (Interview excerpt, Patient relative 7)*

*I have been thinking what could be the cause of this illness to my daughter; sometimes I think it may be a curse from my grandfather (Interview excerpt, Patient relative 1)*

The narratives about terminal illnesses may have emerged from cultural philosophy that informs the worldview held by the participants about perceived meaning of illness.

Although, the various set of beliefs associated with 'evil others' revealed the uniqueness of the subjective positions, it also portrays shared understanding in constructing meaning about terminal illness. This finding is consistent with the theory of symbolic interactionism (SI), which states that meaning ascribed to an object is relative to individuals or groups of persons within the same social space (Blumer, 1969). This theory provided understanding that juxtapositions of interpretations attributed to illness may have been negotiated over time by community. Thus, it can be deduced that people in this cultural environment have defined, interpreted and managed risks (terminal illness) based on the principles and value system inherent within their culture. Furthermore, an alternative explanation to the narratives about terminal illness could be that the participants seemed to have constructed meaning about their illness in line with disease-theory system (Foster, 1976), specifically, the personalistic paradigm which attributes the cause of illness to the intervention by agents such as a supernatural force (deity) and another human (evil persons) or non-human (evil spirit) forces.

In addition to perceived activities of the 'evil others' in the causes of terminal illness, other participants also considered the causes of terminal illness to be mystical or spiritual. The participants held common beliefs that terminal illness was caused by a spiritual attack, punishment from gods and witchcraft:

*My wife had attacked four years ago, she nearly died but through prayer, the enemies were defeated. I think this illness is a spiritual attack (Interview excerpt, Patient relative 9)*

*I lived a bad life and I think god is angry with me. This illness is a punishment from god for my offence (Interview excerpt Patient 10)*

These excerpts further showed that interpretations of terminal illnesses by the patients and their relatives were filtered through cultural lens to create meaning. However, some of the healthcare providers made statements suggesting that they shared a similar set of beliefs about the causes of terminal illness. For instance:

*As an African man, I believe there are forces. In our environment, we believe that there are unseen forces everywhere pursuing people (Interview excerpt, Doctor 3)*

*Yes, I believe that people do have spiritual attack but I am against people believing that the entire sicknesses or bad things that happened to them is a spiritual attack (Interview excerpt, Nurse 3)*

The beliefs about mystical causes of terminal illness suggest that it was an issue of superstitions or cultural myths shared by HCPs and service-users in this society. This belief aligns with the personalistic paradigm, which is one of the perspectives of disease-theory system (Foster, 1976). However, the service-users appeared to have nurtured and developed these two core beliefs about the activities of 'evil others' and spiritual causes of terminal illness when their expectations of a cure failed after attempting several treatments:

*In my own opinion, I would say that this sickness is a kind of spiritual problem. I called a friend of mine who is a prophet, told him how this sickness started and its progression. This prophet 'sees clearly', he told me that it is spiritual problem. Considering the places my sister has gone for treatment but her case was not healed whereas other people with similar cases were healed, I, therefore, believed it is a spiritual problem (Interview excerpt, Patient relative 7)*

*I do attribute illness to spiritual attack but when all the medical interventions have been provided, yet the cause of the illness was unknown (Interview excerpt, Doctor 3)*

Beliefs about the mystical causes of illness in this society may have been reinforced when the medical or traditional intervention expected to achieve a cure for the illness was unsuccessful. This interpretation was reflected in the excerpt of Patient relative 7 who stated that her sister's illness was a spiritual attack because all the treatment she had received had not cured her. Alternative interpretation could be that people created and maintained faith in absolute validity of their cultural worldviews and the standards upon which their self-esteem depended when they became aware of the inevitability of death in line with terror management theory (TMT) (Pyszczynski *et al.*, 2015). Therefore, the consciousness of the potential death by the service-users and some professionals in the current study appeared to have unconsciously exerted diverse thoughts in favour of personalistic disease aetiology.

Although the concept of patients having expectations of a cure is perhaps not surprising, what could be surprising is for a service-user to hold what could be termed

as 'false expectations for a cure', even after being told about the incurable nature of the illness. Notwithstanding, some previous research similarly found that most terminally ill patients held false expectations of a cure instead of accepting PC and the reality about their illness (Robinson *et al.*, 2008; Temel *et al.*, 2011; Weeks *et al.*, 2012; Chen *et al.*, 2013). It can be reasoned that service-users' perceptions of the causes of terminal illness may be suggestive of the gap in scientific knowledge and understanding about the terminal illness and palliation, when viewed with western cultural lens and this could be associated with lack of adequate information. However, some doctors involved with the care of terminally ill patients clarified that some service-users were provided with an explanation about their illness but were not convinced; instead they continued to hold their unscientific beliefs about their illnesses:

*...even when we had educated the terminally ill patients and their family members about their diagnosis, some of them continue to believe it is a spiritual attack (Interview excerpt, Doctor 2)*

The extract from Doctor 2 could signify miscommunication between the doctor and the patient, but an important factor rests in the willingness of the patient and their relatives to accept the information provided by the HCPs. Week *et al.* (2012) found that terminally ill patients accept physicians' information when they convey more optimistic views. In other words, terminally ill patients and their families are more likely to accept information that provides psychological security or protect their sense of self-esteem consistent with their cultural values. The culturally located beliefs about the causes of terminal illness held by service-users may reveal a cultural strategy for maintaining hope for a cure. As a result of the quest for a cure, some terminally ill patients and their relatives rejected medical advice for palliation:

*When we explain the diagnosis to our patients and their families, tell them that the goal of care is not curative, most of these patients and their family members often request for discharge. They always told us that they believe that the illness will be cured, therefore, they will seek traditional care because they think the illness is spiritual (Interview excerpt, Doctor 2)*

Furthermore, during PC ward rounds, I repeatedly observed that some patients and their relatives refused medical advice and insisted that the doctor should discharge

them because they did not see any sign of cure from their illness. For instance, one of the patients' relatives approached the doctor during the ward round:

*She frowns her face and said 'Doctor I want you to discharge us. I want to take him somewhere for traditional care. Since my brother was admitted in this hospital, his abdomen is still enlarged; he can neither stand up nor carry out any activity to help himself, I believe that his condition is spiritual, he will be cured with spiritualists' interventions (Field note, F28)*

Curative care unlike PC seemed to be more culturally valued and accepted in this society, perhaps due to acceptance of Western-based medical ethos that focused on prevention, cure and longevity of life inline with Hippocratic Oath (Edelsten 1943). Thus, the patients and their families anticipated gaining a cure from their illnesses which may provide insight into their unwingness to use PC. The hopeful but unrealistic beliefs and expectations about the prognosis for terminal illness held by service-users may have driven their desire for the continual search for a cure rather than accepting PC. Consequently, many of these service-users requested discharge against medical advice, because of their perception of the ineffectiveness of PC to meet their perceived expectation. Some of the service-users considered traditional medical care, prayer houses, and spiritual care as alternatives to PC in achieving their expected goal. For instance:

*I want to go home because I want to visit the kingdom house for prayer to Jehova. I have faith in God because he can heal me from my sickness. Jehova said that I should not be afraid that he will heal me (Interview excerpt, Patient 2)*

*I have asked the doctors to discharge me because I want to try spiritual care. I have not seen improvement in this medical care (Interview excerpt, Patient relative, 9)*

*...yes, I asked him to discharge me because there is need to go make a sacrifice to appease the gods. We have tried medical but 'it is not working', we need to go back to the tradition of our land (Interview excerpt, Patient relative 3)*

The dominant discourse about requests for discharge and preference for spiritual/traditional care could be explained based on the theoretical idea of TMT. For instance, the services users' thought or awareness of potential death seemed to have increased their likelihood to embrace the providers who provided them with hope for

psychological security, life sustainability and self-preservation by promises for cure as against palliation. Again, the perception of care 'not working' could be an expression of hopelessness, which possibly may be due to lack of understanding about the goal or purpose of the PC. These extracts support the views of the HCPs that many terminally ill patients and their families prefer to seek care from native doctors, herbalists, spiritualists, and pastors, due to the perceived worthlessness of the PC in meeting the expectation for a cure:

*...based on my experiences, many of our people with terminal illness do not attend hospital for care but preferred to visit prayer houses, traditional medicine and make spiritual sacrifices because of their beliefs as I have told you earlier (Interview excerpt, Doctor 1)*

*Some of the patients and their relatives prefer to seek for traditional medicine locally called 'ogwu Igbo' while others visit native doctor and pastors (Interview excerpt, Doctor 2)*

The service users' decisions about the choice of care outside the hospital could be attributed to beliefs in the supernatural being able to provide a cure for terminal illness, and also on the cultural context centred on the belief that spiritualists, pastors, and native doctors are endowed with supernatural abilities to confront the activities of wicked persons, and that they possess metaphysical eyes which are able to understand spiritual mysteries and to provide solutions to terminal illness. The excerpt by patient relative 7, above, depicted this view was echoed by some of the healthcare providers. For instance:

*...'O nafu uzo', interpreted as 'he sees', they have spiritual eyes to see the causes and solution to such problems (Interview excerpt, Pharmacist Lily)*

The service-users' perception that they would be cured when they sought care outside the hospital could be a tactic used to sustain faith in their cultural worldview. Therefore, cultural beliefs provided protection to the service-users against their death-related cognition arising from the perceived threat of their life by their illnesses. Terror Management Theory (Greenberg *et al.*, 1986) provides a useful insight to understand why the service-users adopted behaviour of denial and were focused on the alternative hope for a cure. The TMT postulates that anxieties arise when people become aware



of their imminent death and there is an instinct for self-preservation. TMT highlights that individuals defend their death anxieties in different ways, such as believing that valued aspects of self will continue either literally or symbolically after death (Greenberg and Arndt, 2012). The proponents of TMT further state that individuals believe in the validity of their cultural world views or the values associated with their world views in defence of their death anxieties (Solomon *et al.*, 1991). According to this theory, death anxieties are unconsciously formed, and their existence therefore triggers death defences to maintain the worldview and self-esteem (Pyszczynski *et al.*, 2015).

In this current research, most of the service-users consistently denied the reality of their illness, instead choosing to believe in the rationality of their cultural worldview, which led to formation of an intention or expectation which did not favour positive behaviour towards the use of PC. However, despite some service-users defence of the legitimacy of their worldview, a few service-users appeared to accept the reality that their illness required PC, but only when they had exhausted all the perceived options for a cure without success:

*I went to Port Harcourt where I drank herbal concoction for seven months but the illness was getting worse. I left to another place in Kogi state to visit a native doctor for treatment. He uses water filled with many worm-like creatures for the mixture of the herbs. I received his treatment but the illness was not any better. At that point, I decided to come back to my village and my father carried some sacrifices but the illness was still getting worse. Finally, I returned to this hospital as my last hope (Interview excerpt, Patient 9)*

The terminally ill patients' and their families' search for a place for a cure outside the hospital appears to provide an explanation why not many patients were seen to be receiving PC throughout the nine months of fieldwork in this hospital. The evidence from the reviewed enrolment register further shows that many terminally ill patients did not seek PC in this organisation:

*In 2014, total 80 patients from Enugu, Imo, Akwa-Ibom, Anambra, Cross River, Abia and Ebonyi state were enrolled for palliative care and 37 terminally ill patients across five states in south-eastern Nigeria were recorded to have received palliative care in 2015 (Field note, F2)*

The number of terminally ill patients that received palliative care between 2014 and 2015 in this organisation was low in comparison to the number of people that may have required PC services in this cultural environment. For instance, the population-based cancer review recorded in the Enugu cancer registry for the two-year period between 2012 and 2013 was 1,738 cancer cases (Jedy-Agba *et al.*, 2015), while 447 cancer deaths were recorded as having occurred in a medical ward at the University of Nigeria Teaching, Hospital, Enugu, for the period between 1996 and 2010 (Arodiwe *et al.*, 2013). No evidence was found about the magnitude of illnesses which need palliation in any of the cultural environment of the current study, but the increase in the trend of new cancer cases and other illnesses requiring PC in Nigeria (Jedy-Agba *et al.*, 2015; Morounke *et al.*, 2017) suggests that many of the terminally ill patients may not receive PC until death in the south east and other parts of Nigeria. Other sets of beliefs rooted in religion were also identified during data analysis, which is explored next.

### **5.1.2 Religious beliefs about terminal illness**

Religious beliefs, as used in the context of this research, are defined as a particular set of beliefs and tenets held by those who serve and worship God or other deities. The sense-making or reality about terminal illness, as constructed by the service-users and some HCPs was also rooted in religious beliefs. Most of the terminally ill patients and their relatives (service-users) expressed a shared belief that God controlled their life and, therefore, had the ultimate power to heal their terminal illness:

*The important thing for me is according to Philippians 6:4, Jehova said in all things we should not worry but trust in him. God created human and own our lives. The most important thing for me is that I have trust in God because he is the holder of my life. I have faith that God will heal me from my sickness (Interview excerpt, Patient 2)*

*The doctor told me that my daughter is cancerous. I started praying to God because God can change any situation. God can cure my daughter because he has control over life and everything that happen in this world. I know that God can do my heart desire because God always listens to the desires of his own children and is a giver of all good things (Interview excerpt, Patient relative1)*

Most of the service-users used their religious faith/beliefs to construe the meaning of an acceptable way of life at that point of their illness. Life was perceived as originating

from God, whereas illness was perceived as a threat to life. Since the service-users perceived that God was in control of things that happened in this world, they chose to persevere with their belief, and hoped-for healing and cure of their cancers by God. This finding is consistent with that of Bullock (2011) who found that Black Americans tended to talk more about belief in higher power and miracles unlike their white counterparts that expressed confidence in PC team and health care system in addressing their needs. Other studies documented similar findings about strong spiritual/religious beliefs among African Americans (Rhodes *et al.*, 2012; Breland-Noble *et al.*, 2015), suggesting that this way of thinking may likely be inherent in most of the black race irrespective of the country they live. Perhaps, the difference in meaning-making among people from African descent could be based on the degree of how westernisation or modernisation has affected the beliefs of the people.

It is argued that people react to threats that they are unable to eliminate by adhering to their worldviews, ideas and meaning (Kay *et al.*, 2008). Using TMT (Greenberg and Arndt, 2012) as a lens to explain why some of the participants chose to rely on supernatural being for cure, it is possible, therefore, that the service-users' decisions were driven by a desire to affirm the symbolic value of self and pursuance of the standard upon which self-esteem is based. The belief that God controls one's life and is capable of providing healing or cure appears comforting and seems to be a psychological strategy used by service-users to foster hope and trigger mortality silence. The expression above from 'patient relative 1' that God is the giver of all good things could denote a belief that terminal illness is not of God. Other participants supported this view and expressed their belief that terminal illness was caused by Satan or the devil:

*I have been praying to Almighty God for mercy and healing. Honestly, Satan causes this kind of terrible illness (Interview excerpt, Patient relative 9)*

*This sickness is caused by the devil. Satan is responsible for the cause of this sickness and other bad thing that happens to human being (Interview excerpt, Patient 2)*

*My wife and I have strong faith that God will cure the breast cancer. My spirit keeps telling me that devil cannot win over this battle. God expectation for my wife is to live long (Interview excerpt, Patient relative 5)*

The presupposition that Satan or the devil causes terminal illness is an expression which suggests the use of religious knowledge in the construction of meaning, indicating seeking solace in supernatural being but could also suggest a lack of scientific understanding of terminal illness. Thus, the service-users perceived that God had the ultimate power to decide the outcome of life-limiting illnesses. It was perhaps surprising to find that some of the healthcare professionals shared similar beliefs as the service-users, that if medicine fails, a miracle is possible:

*Although the illness has advanced, I believe that Almighty God is still on the throne, he can cure me because doctors do not cure. Whoever God wants to live and survive will do (Interview excerpt, Patient 10)*

*Christ raised a dead person to life after four days. Because Christ has the ability to do that, I believed that He will do a miracle for me and cure my daughter. God has started healing my daughter; I believed that God will not stop the good work that he has started (Interview excerpt, Patient relative 1)*

*I don't consider my patients with cancer as terminally ill patients. Truly, I don't see them as terminally ill patients, but like every other patient. That is my own belief because I believe in God very much and I believe in miracles. I believe that God can heal and God uses us to achieve his miracles (Interview excerpt, Head of Department 1)*

Some services-users seemed to possess some level of understanding about the severity of their illness but chose to maintain their sense of life worthiness and sustainability by a belief in divine miraculous healing. This seemed to be an act of repression, a coping mechanism to overcome the fear of death and dying, suggesting that death from cancer and other terminal illnesses seemed to be a taboo in this culture. In southwestern culture of Nigeria, van Gurp *et al.* (2015), reported that dying of a life-threatening illness was regarded as a taboo. The service-users in this current study consistently expressed statements indicative of dispelling any thoughts about death and dying, while increasing their commitment to a comforting belief in divine miraculous healing for life preservation. In addition, another possible explanation of the excerpts quoted above, particularly the statement from 'Head of Department 1', is that some of the HCPs saw themselves as a tool used by God to offer miraculous

healing to their patients. This clearly signposts that few healthcare professionals and the majority of the service-users subscribed to religiosity as a standpoint for making sense of a terminal illness and palliation.

Furthermore, some of the healthcare providers alleged that the perception of terminal illness held by service-users, including some healthcare providers, was based on the teachings of the religious preachers. For instance, some participants mentioned various phrases/sentences used by religious preachers during preaching:

*The Lord said that none of you shall be sick  
Healing is your birthright  
Cancer is not your portion  
God is in the business of performing miracle today  
(Interview excerpt, Doctor 2)*

*You cannot die of cancer  
Back to sender (a phrase which culturally symbolise a command for the illness to return to the evil person perceived to have sent it)  
God is a healer  
(Interview excerpt, Nurse 3)*

This gives impression that religious preachers propagated religious values that consider dying of cancer as a taboo and fostered hope in people about divine miracles and healing. It can be construed that religious teachings inspired unrealistic hopes for healing and encouraged the pursuance of any means to stay alive. Presumably, any patient and/or a family member that believed in these religious teachings would likely to be in conflict with the decision for acceptance of PC. This claim seems accurate because some of the patients and their relatives rejected medical advice for PC and preferred to engage solely in the religious rituals, such as prayer, whilst others sought care in religious places, such as churches and prayer houses:

*In a situation that people are told about their illness, they will refuse medical advice and rather prefer to visit the church to pray it out. This is not bad. Laugh! I am an African person too (Interview excerpt, physiotherapist Zoe)*

*After counselling her and concluded discussion to commence drugs for her, she told me that her case was different, that she will go to prayer house where HIV/AIDS is cured (Interview excerpt, Head of Department 2)*

*When I was told that it is cancer, I went to the church, cried to God and told God that he created all parts of my body, that am relying on him to cure me. I went*

*home after crying to God. I trusted God and believed that God will cure me (Interview excerpt, Patient 4)*

Decision making about the choice of PC appeared to be influenced by the service-users religious beliefs, which were founded on religious teachings. Based on these extracts, it can be surmised that faith in God about miraculous healing deterred some service-users from seeking or accepting PC. This was contrary to other previous research, where religious beliefs facilitated patients' acceptance of their illness and PC based on their belief that illness is God's will and death is a passage to another life (Branch *et al.*, 2006, Bouso *et al.*, 2011). Some of the service-users and the healthcare providers further added that religious preachers verbally discouraged their congregants with life-limiting illnesses from accepting PC, but encouraged them to have faith in God for a cure:

*I told my pastor about what the doctors said about the breast cancer. He (pastor) rebuked me for not telling him about my illness before going to the hospital. The pastor told me that I will not go for breast surgery or any care in the hospital because he will pray-it-out. I started praying and fasting based on the instruction of my man of God (Interview excerpt, Patient 5)*

*There was a patient with breast cancer who is a close friend of mine. She came to this hospital and was advised for immediate surgical intervention because the cancer was still in early stage. This, my friend, went for prayer in the church; during the prayer session, the pastor said, 'there is a woman with breast cancer here; this woman should not go for breast surgery because God has healed her'. My friend refused to return for a hospital appointment. I followed her up but it wanted to cause a quarrel between two of us. At that moment, I left her with her decision. Three years later, she visited my house with her husband, pleaded that I should take her back to the doctor. I took her back to the doctor but was told that cancer has spread to internal organs. After few weeks, she died...tears (Interview excerpt, Pharmacist Lily)*

Religious beliefs introduced into the minds of some service-users by the religious preachers may have contributed to either non-acceptance of, or late presentation for, PC. The service-users in this cultural environment seemed to have more trust in their pastors than in their doctors, leading to accepting the advice and instructions from pastors relating to praying and fasting for their illness, rather than advice about treatment or PC. The stronger trusting relationship between service-users and the

pastors could be rooted in the premise that pastors are believed to possess spiritual powers for healing of terminal illnesses, unlike doctors:

*Many of the pastors claim they have spiritual and supernatural power for healing. They tell people of their superpower and ability to cure diseases (Interview excerpt, Doctor 2)*

*In our environment, pastors tell people with life-threatening illness and other sicknesses what they want to hear (Interview excerpt, Doctor 1)*

The researcher, being a member of this ethnic group, has also witnessed several religious teachings, radio messages by pastors and traditional herbalists about their ability to cure diseases, including cancers. However, it could be argued that religious preachers unintentionally mislead the service-users through transmitting a message of false hope, resulting in some people upholding optimistic views about the possibility of a cure. It may also be possible that some preachers engaged in these practices as means for livelihood.

Lastly, the service-users appeared to be deeply committed to their religious beliefs and engaged in their religious practices, even in their hospital beds. For example, I observed some patients and their relatives wearing a religious bangle and a string of beads for counting prayers on their wrists and necks. There were also stickers of an image of a pastor on some of the patients' beds. When asked, one of the patients said:

*This picture on my bed is my daddy in the lord. I go for prayer there and I believe God can do all things. God raised the dead person to life. I believe that God will cure me. This cancer will go because God will heal me (Interview excerpt, Patient 10)*

Patient 10 was bed-bound, with assisted ventilation and appeared to be approaching the end of her life. This patient seemed not to have accepted the reality about her imminent death despite being in the advanced stage of her illness. Denial, or what could be termed as disbelief in experienced reality, appeared to be culturally permissible in this society and was transferred through religious teaching; therefore, it could be presumed that the Nigerian south-eastern society is a 'death-denying culture' because most of the participants' consistently rejected their terminal diagnosis instead expected a cure, through a widely held religious belief in miraculous healing. [However,](#)



it may not be strange that terminally ill patients and their families did not accept the finality of the terminal diagnosis because this reaction is one of the stages of grief (Kubler-Ross and Kessler, 2014). Notably, most of the service-users persisted on denial stage and did not seem to progress to other stages of their grieving process, which supports the idea of Kubler-Ross and Kessler (2014) that not everyone goes through all the stages or goes through them in a prescribed order. Although, denial may be labelled to those patients and their families who resisted the dominant discourse on the perceived right way to die, it may not be denial per se, but a unique way of dying process. Knowledge, education, and training of both the service-users and the healthcare providers seemed to impact on their cultural and religious beliefs, and together this shaped their perception of terminal illness and palliation, which, in turn, influenced their behaviour and attitudes towards provision and use of PC. The subdomain named 'educational factors' is explored in the following section.

## **5.2 THE INFLUENCE OF EDUCATION ON PALLIATIVE CARE**

Some educational scholars have stated that one way to acquire knowledge is through education by the transmission of certain information (Daniel *et al.*, 2012), whereby information not only has a fundamental worth of providing knowledge but also is a medium for learning (Foyle and Hosted, 2007). It is this learning acquired through education which informs people's understanding and interpretation of their situation and guides their decision-making. PC is also concerned with helping the terminally ill patient and their families, through education, to understand their changed and changing health situation and the consequences thereof. This section will focus on how patients make sense of their illness and care, particularly in relation to whether the information they obtain from PC team and other clinicians involved in their care informs their understanding and decisions regarding the use of PC. This domain will also present the healthcare providers' perspectives of the knowledge about PC, and how their education and training influenced their roles in the provision of PC. Therefore, the domain named 'the influence of education on palliative care' will be presented as two subdomains, namely, service-users' knowledge of palliative care, and healthcare providers' education and training.



### 5.2.1 Service-users' knowledge of palliative care

The terminally ill patients' and their families' choice to use PC appeared to centre on the issue of their knowledge of the illness and their understanding of the goal of the care. The data analysis is suggestive that most of the terminally ill patients and their families may not have an adequate level of understanding of their illness and palliation because information about their diagnosis, prognosis, and management was not provided to them:

*The nurses administer medication to me while the group of doctors that come to see me only talk to themselves. These doctors do not explain what they are doing to me but only ask me how am feeling or if have a new complaint. After explaining to them, they will speak grammar among themselves and write something on the folder. Honestly, I do not know the name of my illness; nobody has told me the name (Interview excerpt, Patient 1)*

*...I do not know the truth, whether this illness is caused by an evil person as I was told in the prayer house or if it natural. The doctors and the nurses did not explain anything to me. The doctor tells me to buy these medications, go for chemotherapy and radiotherapy (Interview excerpt, Patient 8)*

*The doctor told us that surgery will be done to remove the lump and nothing else was explained to us. We do not know the name of this illness and what to expect after the surgery (Interview excerpt, Patient relative 3)*

These terminally ill patients and their families reported that clinicians did not provide health education about their condition and therefore lacked understanding about their illness including the goal of their own care. However, some of the service-users disclosed that they had been told about their diagnosis and the management of their illness but purported that the information provided to them was not comprehensive.

For instance:

*The doctors do explain the management to me but you know that doctors do not provide all the information to patients about their illness, especially the possible outcome. For instance, the doctor refused to provide an answer to my question of whether chemotherapy will cure the illness. I was expecting the doctor to tell me about the chemotherapy and what to expect but they did not explain these to me (Interview excerpt, Patient 10)*

*I was told by the doctor that I have cancer but I did not understand what that means (Interview excerpt, Patient 3)*

*I approached one of the doctors that usually come to see my daughter, asked him to tell me the name of the illness but this doctor told me that he will tell me later. I continued to remind this doctor every day to tell me about the diagnosis. After few days, the doctor told me that my daughter is cancerous but warn me not to inform my daughter about it (Interview excerpt, Patient relative 1)*

Withholding information from the service-users appeared to be an organisational cultural practice embedded in the provision of PC because some HCPs involved with the care of terminal illness concealed information from patients and their relatives about the diagnosis. However, some service-users admitted that a few of the clinicians had informed them about their diagnosis but alleged that they were reluctant to provide information about the prognosis and the goal of the care. This could imply that most of the service-users may have had an unmet educational need that appeared to influence their understanding of the illness. Perhaps, lack of knowledge and understanding could be why most the service-users did not participate in decision-making about their care, as revealed in the excerpts from patients 1 and 8 and patient relative 3, above. Therefore, the treatment and care decisions appeared to be made solely by the clinicians without the full involvement of the service-users. A practice suggestive of medical paternalism; which is a therapeutic relationship that recognises doctors as the only decision-makers who can act on their own, withholding information from patients at their own discretion (Steinbock, 2007).

Medical paternalism is argued to be justifiable, based on the reasons that it prevents patients' irrational decisions, while empowering the physicians and other health care professionals who possess knowledge and experience to make decisions and act for the patients' own good (Conly, 2014; Ayodele, 2015). Conversely, the more compelling argument against medical paternalism is that it denies patients' right of informed consent, violates the right of patients to make decisions about their own healthcare, is against modern medical practice of person-centred care, and promotes power abuse (Hayry, 2002; Beauchamp and Childress, 2013; Ayodele, 2016). It can be deduced that paternalistic practice was still embedded in the day-to-day rituals of PC delivery in the studied Nigerian hospital, indicating that decision-making had not evolved from a paternalistic approach to a modern medical tradition of patient-centeredness or an

autonomy-based approach as practiced in most of the western countries, such as the United Kingdom. The principle of patients' autonomy emphasised the need for adequate information to be provided to the patients in order for them to participate in the decision-making (Beauchamp and Childress, 2013).

The controlled provision of information, leading to partial-/non-disclosure of diagnosis and prognosis as purported by the service-users was confirmed by most of the HCPs:

*We, the doctors do not tell the patients and their families the truth about their prognosis. We do not want to be the bad news bearers and many of these patients and their family members are not informed about their diagnosis and prognosis (Interview excerpt, oncology Doctor 1)*

*A patient will be instructed to go for chemotherapy, radiotherapy or surgery without explanation of the goal for these therapies. Sometimes, a patient is booked for surgery but it will be cancelled without explaining the reason for the cancellation. Patients are not involved in the decision making for their care (Interview excerpt, oncology Nurse 3)*

The HCPs in this hospital seemed to possess a fear of being labeled a bad news conveyor and this deterred them from providing information about the disease prognosis to the service-users. It may be that some HCPs preferred to uphold their personal values/principles rather than ethical principle of veracity. Remarkably, one of the reasons for withholding information from the service-users was to stop them from asking for a discharge against medical advice:

*If you tell the patient, the truth about their illness, they will run away and will assume that you have pronounced death upon them, they will disappear (Interview excerpt, Doctor 1)*

*When the patient is informed about the incurable state of her illness, many will request to be discharged because they believe it is no more important to provide hospital care (Interview excerpt, Oncology Nurse 3)*

The clinicians perceived that providing adequate information to the service-users would discourage them from utilising PC. Instead, they preferred not to tell the truth as a strategy for retaining patients for care. This could be regarded as a deceptive practice which perhaps, was aimed at a financial gain for the organisation because

when patients are retained for care, they continue to pay for the services they are receiving.

Another perceived justification for non- or partial disclosure of diagnosis and prognosis to the service-users was to reduce the psychological and emotional distress that such information would cause to service-users:

*We do not educate the patient about their diagnosis and do not inform them of the prognosis but sometimes we communicate this information to their relatives because informing patients will worsen their emotional and psychological distress (Interview excerpt, Head of Department, 4)*

*The doctor told that my sister has enlarged liver and cancer but we do not let her know about it because we feel that informing her will make her to be depressed and worsen the condition (Interview excerpt, Patient relative 5)*

Concealing information from the service-users appeared to be a culturally acceptable strategy used by the clinicians to foster hope and to reduce the perceived psychological distress that 'bad news' would cause to the patients, while some family members also adopted this strategy to protect their ill family member from a feeling of hopelessness. Not taking away hope and protecting the patients from the perceived negative emotional reactions suggest the use of the principle of beneficence to rationalise the non/partial disclosure of information. However, previous research evidence does not support the idea that disclosing prognostic information or providing enough information to patients and their relatives to enable them to understand their illness will destroy patients' hope, or increase anxiety and depression (Smith *et al.*, 2010; Enzinger *et al.*, 2015). Despite the established evidence that shows no association between information disclosure to terminally ill patients and increases in the levels of anxiety and depression, some of the HCPs in this organisation maintained that they had had an experience where a patient developed anxiety and depression following disclosure and education about their diagnosis and prognosis:

*I have experienced some cases where a patient was depressed when he was told that his condition is incurable. For instance, a woman that has offensive protruding cancer of the vulva was sedated for excision of the mass for histological study. When this patient recovered from the effect of anaesthesia, she felt the mass and then called the house officer to ask why the mass was not*

*removed. The doctor told the woman that nothing can be done about the mass, that it is not curable. From that moment, the woman stopped talking. During my ward round the next day, the sister said she has not eaten and refused to talk to anyone. Two days later, the woman died of depression (Interview excerpt, Doctor 1)*

*A doctor informed her about the diagnosis and the possible diagnosis, the woman immediately started screaming and crying very loud for more than two hours in the clinic, telling her relatives to take care of her children because she was on her way to the grave. She drew the attention of other patients and their relatives (Interview excerpt, Social worker 1)*

Yoshida *et al.* (2012) found that prognostic information may generate some psychological distress; supportively, the extracts from 'Doctor 1' and 'Social worker 1' show that patients presented some difficult emotional reactions which lead to depression as a result of the information provided to them about their diagnosis and prognosis. However, it could be that the patient may not have been educated about the diagnosis, management and the prognosis even before carrying out the procedure on her, or may not have received enough information to understand her illness and the goal of the care. Misunderstanding of the information by the patients could be the fault of the doctor by not providing information in a way that would promote understanding. It can be construed that most of the HCPs in this hospital seemed to prefer withholding information from the patients and their families to dealing with any difficult and unpleasant reactions that may precede telling or educating them about their illness. Perhaps the doctors and other healthcare providers in this organisation either lacked emotional resilience or lacked the knowledge, competence and effective communication skills for patients' education. An alternative explanation when viewed through the lens of TMT, could be that the conscious or unconscious awareness of potential death may have contributed to some HCPs either intentional or unintentional avoidance of communicating 'dead-associated information' to the service-users. The next cultural domain, 'Healthcare providers' education and training' will explore the healthcare providers' knowledge of PC.

### **6.2.2 Healthcare providers' education and training**

The Department of Health in the UK and several professional bodies recommend that clinicians who care for patients with life-limiting illnesses should have the knowledge,

skills, behaviour, experiences, and attributes required to perform the job effectively (RCN, 2002, NCPC, 2006, NMC, 2008, DH, 2009). Competency is attained through formal theoretical teaching and mentored clinical exposure, but almost all of the HCPs involved in the care of terminally ill patients in this organisation acknowledged that they had not participated in any formal training and education in PC:

*I have no certificate in palliative care because I have not undertaken any formal education or training, though I have MSc in pain management. I have interest to undertake formal education in this specialty to broaden my skill and knowledge of pain and palliative care... (Interview excerpt, Doctor 1)*

*Only two nurses had training in palliative care for six weeks in Uganda among the members of palliative care team. I have no formal training in this area... (Interview excerpt, Nurse 4)*

*Another issue is lack of training or formal education. I have no training in palliative care. Training will assist us to improve the services we render to terminally ill and their families (Interview excerpt, Social worker 1)*

It is plausible to assume that PC in this cultural environment was delivered by a team who appeared not to be competent on the basis that they lacked specialist knowledge; rather, their involvement with the care of terminally ill patients was based on what some participants regarded as ‘*mind qualification*’ and personal interest:

*I do not consider any paper qualifications before I post a nurse to palliative care or oncology unit but I consider their mind and heart qualifications. I post them based on the staff I consider having the ability to work and have heart to care for this group of patients (Interview excerpt, Head of Department 3)*

*I work in this unit because of my interest in palliative care. I am a consultant employed to work in another department; I do not receive additional money for working in palliative care unit (Interview excerpt, Doctor 1)*

The absence of formal training/education in PC for the HCPs was not peculiar to this organisation located in the southeast part of the Nigerian ethnic environment. Previous research conducted in the Lagos state in the south-west of Nigeria found that HCPs involved with the care of cancer and HIV patients learned some aspects of PC on the job without any formal training (Akinyemiju *et al.*, 2015). The HCPs attributed their lack of formal training/education to the absence of training institutions that provide such education, and lack of PC residency programmes in Nigeria:

*There is no residency program in palliative care in this country. Any doctor in Nigeria with Bachelor of Science degree or Master of Science degree in palliative care obtained the certificate abroad. We are waiting for our 'big ogas' to start residency training in palliative care in Nigeria (Interview excerpt, Doctor 1)*

*There is no institution in Nigeria for training healthcare workers in palliative care. Palliative care is not among the post basic training programme offered by Nursing and Midwifery Council of Nigeria (Interview excerpt, Nurse 2)*

Palliative care training/education seems not yet integrated into the undergraduate and postgraduate educational curriculum in Nigeria and this may signify a lack of commitment by political actors regarding the development of PC, which will be examined in a greater detail in chapter six. The symbolic language 'big ogas' which could be interpreted as 'the health and education policymakers' in Nigeria appeared not to have the drive or will to commence residency programmes and other training in PC and this could be associated with widespread culturally based perception about terminal illness, leading to what could be argued as societal culture that does not value care of terminally ill and dying patients. Interestingly, most of the healthcare providers expressed their desire for education in PC but they were limited by their inability to afford the cost of such education abroad:

*I am looking forward to doing MSc or Ph.D. in palliative care but I can only do that abroad, this requires that I leave my job, travel abroad for study. I can't leave my job and you know education in abroad is very expensive (Interview excerpt, Doctor 1)*

*For me, my plan is to enroll for a master degree in palliative care in any of the universities abroad after my residency programme in anaesthesia. I need to acquire specialist knowledge in palliative care to broaden my skill but cost of education will be my challenge (Interview excerpt, Doctor 2)*

*If there are training institutions in Nigeria, it will encourage most of us that are willing to gain formal education in palliative care. I will go for training if I receive financial support (Interview excerpt, Nurse 3)*

Possibly, the clinicians may have lacked the skill and competence required to deliver quality care to terminally ill patients and their relatives. It could also mean that most of the HCPs may not have been knowledgeable about the unique physical, spiritual and psychosocial needs of the service-users throughout their disease trajectory, thereby making it difficult to meet the challenging needs of the patients and their families. The



extract from Doctor 1 below and the researcher's observations confirmed that most of the HCPs involved in the care of terminally ill patients were ill-prepared and lacked knowledge of the provision of PC:

*There was a referral sent to us last week but a resident doctor in anaesthesia after reading through this referral letter ask me 'chief, why are there sending this patient to us? I told him that the patient has malignancy, so they want us to collaborate in the care of the patient. What this doctor was expecting to see in the referral letter is that the patient was having breathlessness, confusion, agitation, in severe pain and other symptoms that tilt towards end of life (Interview excerpt, Doctor 1)*

*...the team immediately moved to another patients' bedside but the doctor said there was no need to provide palliative care to the patient because he was still stable and relatively active (Field note, F26)*

My observations and the extract of Doctor 1 could be interpreted as an understanding by some of the HCPs that PC is prognosis-dependent. This provides insight that some terminally ill patients in the early stage of their illness who sought for care in this hospital may have experienced unmet PC needs because of the perception that PC was end-of-life care. This may be one of the reasons family meetings (see chapter 4, 4.2.1), were repeatedly conducted when the patient was approaching the end of their life.

As a result of poor knowledge and expertise in the area of PC, some of the HCPs were observed to appear confused regarding what to do for the patients during the ward rounds, while some were observed to be in a rush, and did not engage patients or their families in discussion about the illness and the care:

*The palliative care team arrived at ward 10 and went to one of the patients' bedside, the doctor only asked the patient how she is feeling and documented in her folder. The doctor with other team members moved to other patients and did not carry out examination or communication with three out of five patients in the ward. The team did not hold a conversation with patient relatives. The team left ward 10 to oncology ward (Field note, F9)*

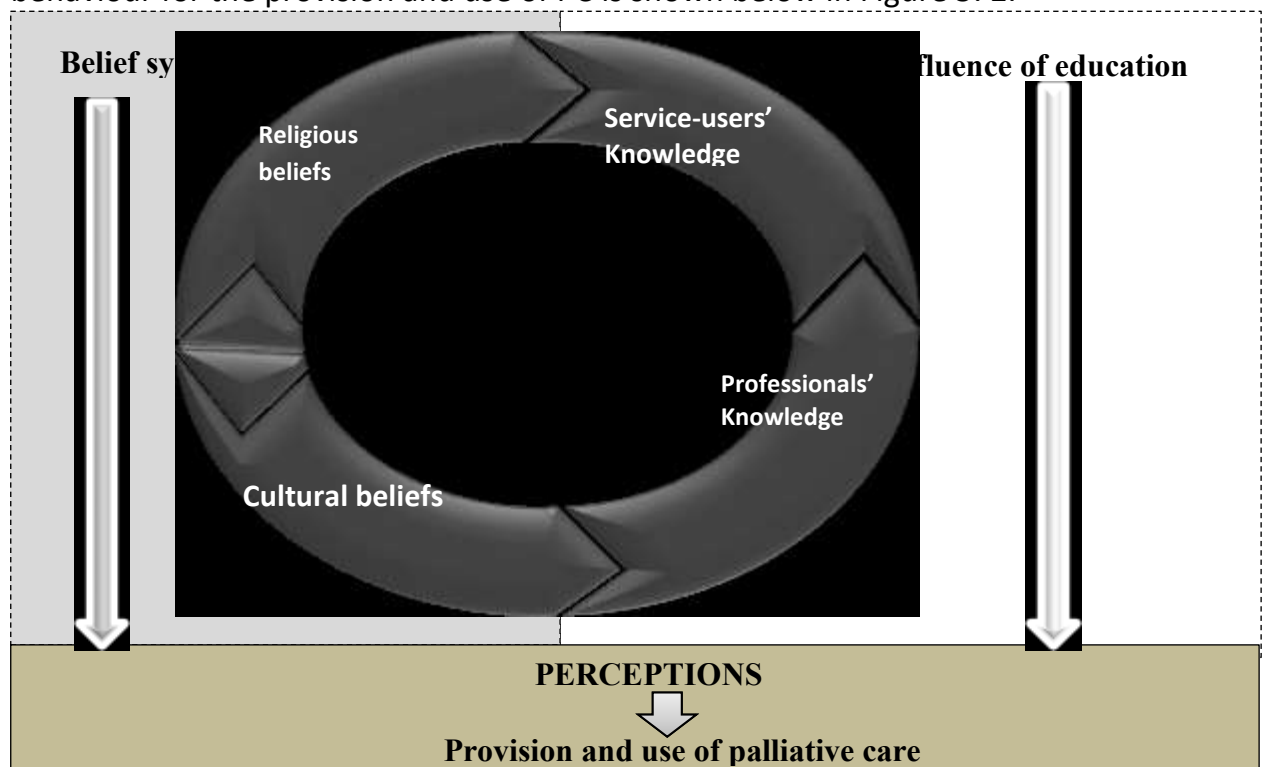
*The palliative care team arrived in the oncology ward, moved to one of the patients receiving palliative care. The doctor stood by the patients' bedside, flipped through the patient folder. He said, 'I do not even know what to do for this patient'... (Field note, F32)*



Acknowledgment of not knowing what to do could signify either expressing fact or regret which seems to be the outcome of ill preparation for the provision of PC. Perhaps this clarifies one of the perspectives why most of the healthcare providers did not initiate conversations with the terminally ill patients and their families, during or after ward rounds, about their diagnosis, prognosis, and care. It is therefore possible that terminally ill patients and their families may have not gained an improved quality of care because the clinicians did not possess adequate knowledge and skills in PC to deliver quality care.

### 5.3 Chapter summary

The perception of terminal illness and palliation by most of the service-users and some of the HCPs was grounded in belief systems, particularly, religious and cultural beliefs. These cultural-based perceptions held by the patients and their families were further reinforced by professionals' lack of education and training in PC, which, in turn, resulted to professionals' lack of knowledge and skills to effectively communicate and educate the service-users about their terminal illness and palliation. This complex interlinkage between belief systems and education in shaping perceptions and behaviour for the provision and use of PC is shown below in Figure 5. 2.



**Figure 5.2: Cultural schema informing perceptions of palliative care**

The differences in the cultural and religious beliefs among the HCPs and the service-users could most likely be based on the degree of level of how westernisation or modernisation has affected their beliefs about terminal illness and approach to care. Symbolic interactionism theorised that the world is made up of objects and that these objects are the product of symbolic interaction (Blumer, 1969). Using this theory as a lens, it was found that the participants constructed meaning about terminal illness and palliation based on their interaction with others in the same social space and in line with their culture and disease-theory system. Drawing from Blumers' classification of objects, the meaning ascribed to the abstract object (Blumer, 1986), which in the context of this research is the terminal illness and PC, informed the service-users' and the healthcare professionals' perceptions, which, in turn, influenced the behaviour about the provision and use of PC. The majority of the service-users were found to have non-biomedical knowledge about terminal illness and relied on their cultural worldview to make decisions about their care, which resulted in pursuance of the standard upon which their self-esteem was based, such as faith in God for supernatural and miraculous healing. Consequently, the service-users tried to protect their hope for cure by engaging in psychological defense mechanisms, such as projection and denial, consistent with TMT, and this led to non-acceptance of PC.

Nearly all the professionals were found to have lacked specialist education and training in PC, which resulted in their lack of competence to deliver quality care that would encourage acceptance, use of PC and promote the service-users' wellbeing. As a result of lack of knowledge and skills in PC, the culture of PC was embedded in non-or partial disclosure and medical paternalism whilst using the principle of non-maleficence as against veracity in the defence for their practices. Finally, the paternalistic approach to PC thrives in this cultural environment because of the poor public knowledge about terminal illness and palliation.

## CHAPTER SIX

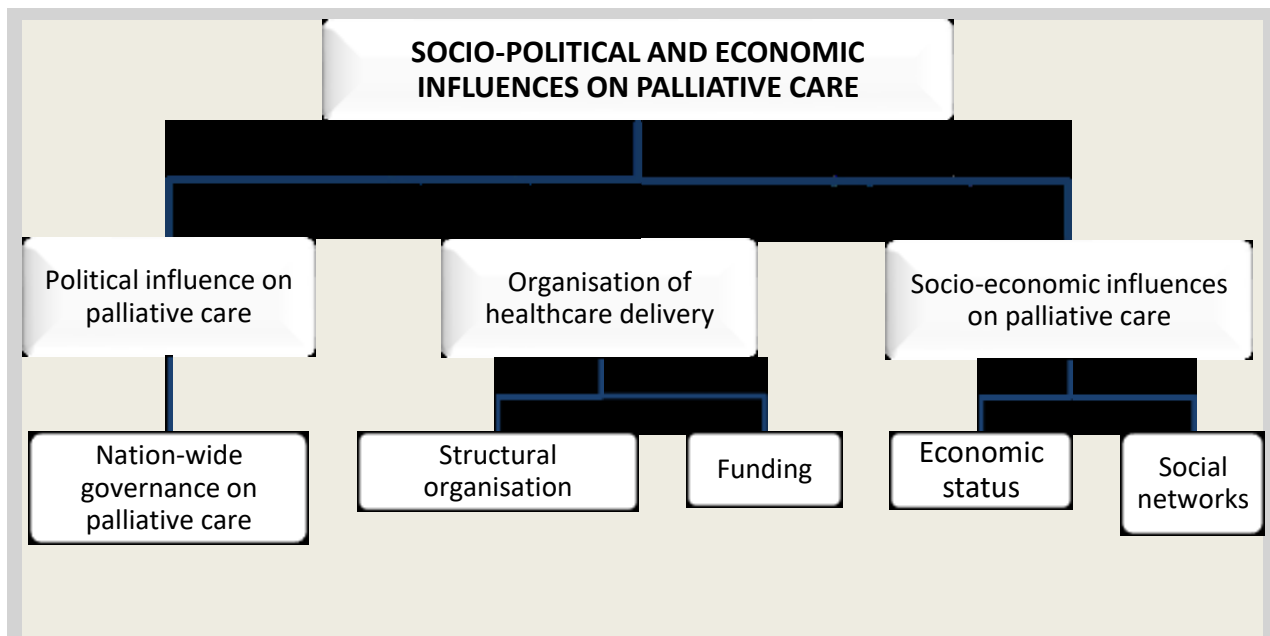
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### **SOCIO-POLITICAL AND ECONOMIC INFLUENCES ON PALLIATIVE CARE**

#### **6.0 Introduction**

The previous chapter suggests that perceptions of terminal illness and care of terminally ill patients by healthcare providers (HCPs) and service-users is rooted in their cultural and religious beliefs. The various sets of identified beliefs mainly informed how the terminally ill patients and their families perceived their terminal illness, and this influenced their utilisation of PC. In addition, the previous chapter revealed that HCPs lacked formal education and training in PC, resulting in 'erroneous' perceptions about, and inadequate provision of, PC. This chapter will explore how the cultural-based perceptions of PC impacted on the national socio-political and economic factors which influenced the provision of PC.

The healthcare providers and the service-users perceived that persons in governance (bureaucrats) had failed to provide resources and support for the care of terminally ill patients, which, in turn, influenced the provision and utilisation of PC. It appeared that the countrywide political culture did not value PC because there was no provision made for it in the national and organisational budget for healthcare delivery. This theme named 'Socio-political and economic influences on palliative care' is grouped into three subthemes, which are: political influence on PC, the influence of the healthcare delivery system on PC and socio-economic influences on PC. It is presented under subdomains, as shown in Figure 6. 1, below. The influence of national governance on PC will first be explored in this chapter, because of its impact on the healthcare system and the socio-economic factors that influenced the provision and utilisation of PC.



**Figure: 6. 1: Thematic framework of chapter six**

## **6.1 POLITICAL INFLUENCE ON PALLIATIVE CARE**

### **6.1.1 The Influence of national governance on palliative care**

Governance, as used in this context, is defined by the Organisation for Economic Co-operation and Development Governance (OEDG) as the exercise of political, economic and administrative authority necessary to manage a nation’s affairs (OECD, 2007). This section explores how the process of governance influenced the delivery and utilisation of PC. It is important to highlight that the Government of Nigeria, through its public sectors, plays an important role in the provision of public services, and the formulation and implementation of policies to promote the welfare of her citizens. The President of Nigeria uses his constitutional authority and power to appoint other political office holders, such as the ministers who coordinate the federal ministries, such as the Federal Ministry of Health. The healthcare providers, comprising the hospital managers and the healthcare professionals (doctors, nurses, a physiotherapist, a pharmacist and social workers), mentioned that healthcare delivery in Nigeria is politicised and that the political ideology empowers a certain group of people to hold the positions of leadership/authority:

*The healthcare system is politicised, you know that most of the political appointments from this government are not based on competency, but on sentiments and ethnicity (Interview excerpt, Head of Department 1)*

*In this country, only the 'thieves' can win the election. Political positions are not for decent people, but for thieves. These thieves manipulate the political system to attain authority; they are the ones that pilot the affairs of this country (Interview excerpt, Manager 2)*

These participants believed that people with particular ethnic identities and/or political connections were considered for political appointment without consideration of their competency for the position of leadership in the political culture of Nigeria. This aligned with what a famous Nigerian writer, Chinua Achebe, stated long ago in his book titled 'The Trouble with Nigeria', is that '*it would be difficult to point to one important job held by the most competent person we have*' (Achebe, 1984:19). In general, therefore, it seems that politicians in Nigeria for a long time have functioned in a political culture which divides the country's multi-ethnicity in their favour by promoting ethnic interests. This act may symbolise an abuse of public power for private benefit by individuals who find themselves in positions of trust and authority. Almost certainly, it points to nepotism and cronyism, an act of corruption.

The World Bank defined corruption as the abuse of power or public office to promote personal interest (World Bank, 1997). In the 2017 survey of perceived level of corruption, Nigeria scored 27 on a scale of 0 to 100, where 0 is highly corrupt and 100 is very clean (Transparency International, 2018). This survey was based on assessment of bribery of the public servants, embezzlement of public funds, cuts in public procurement and the effectiveness of the public sector's anti-corruption efforts. Nigeria had failed to improve its score on the index since 2012 to 2017, indicating mismanagement, lack of transparency and accountability by political leaders in Nigeria, thus demonstrating poor quality of governance. In line with the findings of Transparency International, some participants highlighted that the government lacked the capacity to effectively formulate and implement sound policies that would enhance healthcare delivery, including PC, because they perceived that competent individuals

had not been appointed and/or elected to occupy the positions of leadership due to personal sentiments, and regional and/or ethnic interests:

*...there is nothing of such in this country; the government has no policy to render financial or material support for the care of cancer and other life-limiting illness except HIV/AIDS care (Interview excerpt, Manager 1)*

*You know that the Federal government delayed national budget for this year because ministers of finance and others responsible to prepare this document are not expert; this affected the healthcare services we render to people (Interview excerpt, Manager 3)*

*... even some of the polices about the controlled drugs do not favour the quality care for these patients because many of the hospitals have no access to morphine and other strong painkillers (Interview excerpt, Pharmacist, Lily)*

*There is no policy that mandate government to provide support for the care of cancer patients and other terminally ill patients (Interview excerpt, Social worker 1)*

As stated earlier, the Federal Government is responsible for making health policies, and providing planning and coordination, but the authorities appear unresponsive to the needs of the populace, especially terminally ill and dying patients, because no policy exists to provide aid to them. For instance, Taylor *et al.* (2014) found that the Government failed through their policies to make opioids available and accessible for treating pain for patients with terminal illness in Nigeria. These researchers interviewed the medical regulatory authority and reviewed the relevant laws, policies, regulatory control practices, procurement, and supply management relating to narcotics and controlled medicines, and found that there was no specific national policy on controlled medicines to promote equitable access and rational use. Instead, laws and policies focused on the control of opioids without a corresponding strategy/policy for their availability for medical use. They also found that controlled medicines were limited to hospital pharmacies in the public hospitals because their distribution from the Federal Medical Stores in Lagos required approval from several officers situated in different locations in Nigeria. It can thus be suggested that policy did not promote care of terminally ill patients and their families, implying a failure in governance related to lack of political commitment. This was also the situation at the time of the current research.

Furthermore, some of the managers in the studied hospital described political leaders as 'thieves' and this was echoed by other participants, who stated that political leaders misappropriated public funds for their personal interests:

*Most of the people who are leaders in Nigeria are interested in themselves and pocket, not the masses (Interview excerpt, Manager 2)*

*...these politicians are the people stealing money and diverting public funds... (Interview excerpt, Manager 4)*

*...the politicians are corrupt, not sincere and have no passion to alleviate the suffering of the people. When you have corrupt leaders, people will suffer (Interview excerpt, Head of Department 4)*

Achieving a political position has seemingly become the primary avenue and the fastest route for political leaders to achieve wealth and affluence and this idea is in line with that of the 'CLEEN Foundation', a non-governmental organisation in Nigeria, who highlighted that many citizens of Nigeria have the mentality that being in a political position is a quick means to wealth (CLEEN Foundation, 2010). The politicians and public servants were believed to take advantage of their offices to embezzle public funds for their personal interests. This could be regarded as an act of exploitation of taxpayers and mismanagement of national funds; thus, arguably, these practices could reduce the funds available for the delivery of appropriate services, such as PC. The misappropriation of public funds is an act of corruption, and it indicates the power dynamics that interplayed between the small group of the political class, public officials and the mass of ordinary Nigerians, such as terminally ill patients and their relatives. These individuals in the position of authority appeared to use their political power to steal entrusted funds from powerless and vulnerable citizens, due to what Odeah (2015) perceived to be lack of a strict regulatory system as a result of poor governance. The web of corrupt practices reveals the level of non-accountability in the authorities who have the responsibility to allocate funds to meet the PC needs of the people.

As a result of the Government failure related to embezzlement, political leaders were reported to travel abroad for their medical care when they were sick, rather than

formulating policies and providing support to strengthen the country's healthcare system:

*Most of the government officials including the President travel abroad for medical care because they know that they have left nothing in the Nigeria healthcare system. Some of us here do our best to help the poorest of the poor, but if there is any slightest mistake they treat you like a thief but these are the ones stealing money...sigh...My brother, I cannot wait to finish my tenure, so I can go my way (Interview excerpt, Manager 2)*

*...they use people's money to travel for their own medical care, while millions of people are dying here with no care (Interview excerpt, Manager 4)*

*The politicians seek care outside the country, while some and other wealthy individual meet consultants in their private hospital for care (Interview excerpt, Oncology Doctor 1)*

The Government may possibly have had the resources that could fund healthcare services, including PC, but may have lacked the political will and commitment to adequately fund the healthcare system; instead, they diverted the funds for personal gain. The high-pitched vocal tone and grimaced face of most of the managers while expressing their views regarding how government officials and public servants mismanaged the national funds could imply a demonstration of anger and dissatisfaction. However, these participants (managers) appeared to lack insights on how they have contributed to inadequate PC delivery in the studied hospital, instead they were engrossed in blaming politicians and government officials. This study appeared to have provided an opportunity for the managers and other participants to voice their grievances and express their feelings about the government inadequacy in resource management. This finding is allusive of the need for a more transparent system, where the public could contribute to policy formation and have a say in how the nations' resources should be utilised. The lack of such a system indicated leadership failure, which has an impact on the healthcare delivery. The next domain, the influence of Healthcare delivery system on PC, is detailed in the following section.

## **6.2 ORGANISATION OF HEALTHCARE DELIVERY**

The healthcare providers, together with the terminally ill patients and their relatives in the studied hospital felt that the organisation of healthcare delivery in Nigeria is an



important issue that influenced the provision and utilisation of care. Two key perspectives expressed by the participants were structural organisation and funding of healthcare delivery.

### **6.2.1 Structural organisation of the healthcare delivery on palliative care**

The structural composition of the Nigerian healthcare system was perceived to be an issue that influenced the provision of PC by HCPs and the utilisation of care by service-users. As discussed in Appendix G (overview of Nigerian healthcare system), the structure of the Nigerian healthcare system is organised into primary, secondary and tertiary healthcare levels, whereby the Local Government areas, through their Local Health Authorities, are responsible for the operation of primary healthcare centres, while the State Government, through its State Ministry of Health, is charged with the responsibility for managing/operating general hospitals and, in some cases, teaching hospitals, as well as providing regulation and technical support for primary healthcare centres. The Federal Government, through the Federal Ministry of Health (FMoH), is responsible for providing policy guidance, planning, and coordination of the state-level implementation of the National Health Policy. It is also responsible for managing federal teaching hospitals, orthopaedic and psychiatric hospitals (FMoH, 1999). The government recognises and regulates these three tiers, but there are also private sectors that provide private healthcare services in their private clinics and hospitals.

The participants mentioned that the structural organisation of the Nigerian healthcare delivery was malfunctioning, and pointed out that the primary health care level was ineffective, while the secondary and tertiary levels were muddled and politicised:

*The problem is that primary healthcare system is not functional, secondary health care is disarrayed because sometimes the simple cases that would have been managed in the primary centres or secondary centres come here to increase our workload. The tertiary hospitals are politicised (Interview excerpt, Head of Department 1)*

*...Our healthcare system in this country is not well organised. The three tiers system for providing healthcare services is in a state of pity. Imagine most of the primary centres have collapsed, while the general hospital and even the teaching hospitals are not well equipped to deliver quality care to the people. Most of the conditions to be managed in the lower levels come here (Interview excerpt, Manager 2)*

These participants highlighted that though primary care centres (which should be the first point of access to healthcare) existed, they were perceived to have ‘collapsed’ and ‘not functional’, due to lack of maintenance. The tertiary hospitals were perceived to be affected by the inefficiency of the political actors. Overall, it appeared there is a breakdown of the structural pathway for the delivery and utilisation of healthcare services in Nigeria. This ineffective structural organisation could be linked to leadership failure by the political leaders and/or public office holders from both the Federal and State Ministry of Health, including local government authorities, with the joint responsibility of managing the healthcare system. This claim was based on the view of the participants, who emphasised that the supposed regulatory body and the government failed to make provision for the effective functioning of the structural pathway of the healthcare delivery in Nigeria:

*...most of these primary health centres have no equipment and manpower; the buildings are not maintained because the leaders divert funds for projects into their pockets (Interview excerpt, Manager 2)*

*The first point of entry for the healthcare service in this country is the primary health care centre where the primary healthcare physicians evaluate the case and probably make referral either to the secondary or tertiary health care levels for expert care but government do not implement this policy (Interview excerpt, Head of Department 1)*

*The structure of the healthcare delivery in this country is poorly managed by our leaders who mismanage the resources for healthcare development (Interview excerpt, Doctor 1)*

The defective structure of the system for healthcare delivery, especially the primary care centres, was perceived by participants to be related to misappropriation of resources by those entrusted with the responsibility for managing the healthcare system. This could be a reason why patients sought care at the tertiary healthcare level without first passing through the primary or secondary levels. These excerpts also depict defective control of the healthcare system as a result of poor policy implementation, which supports the impression of leadership failure. The inadequacy of the political actors to effectively manage the three tiers of the healthcare delivery has given rise to a heterogeneous structural system of healthcare delivery, which has

impacted negatively on the utilisation of PC. These multiple or heterogeneous structural system of healthcare delivery as cited by the participants include spiritual healing services, traditional healing services, patent medicine dealers, church-based healers, prayer houses. Remarkably, these non-orthodox centres were said to operate alongside the three-tier government recognised structure of healthcare delivery:

*There are heterogeneous healthcare systems and services in this country. For instance, there are standard orthodox centres and there are so many non-orthodox centres, which include spiritual healers, traditional healers, prayer houses and church-based healers (Interview excerpt, Head of Department 1)*

These non-orthodox centres were perceived to have gained increased prominence because the supposed regulatory agencies of the government had failed in their responsibility for policy implementation and the monitoring of 'quack' practices in the Nigerian healthcare system:

*...those that are supposed to check and monitor what these people do are bribed. They leave these non-orthodox centres to provide care without measures to monitor their activities (Interview excerpt, Manager 3)*

*This morning, I went to represent the Minister for Health in a gathering of the patent medicine dealers and proprietary association. They invited the minister but he sent me to represent him. These are the quacks that sell medicine and provide healthcare service in different parts of this state without any form of regulation. Over five thousand people attended this meeting and all that they do is to contribute money and give to those that are supposed to regulate them and they will look away (Interview excerpt, Manager 2)*

A possible explanation for these extracts may be that those in positions of authority benefitted from the Government's collapsed structure for the delivery of healthcare services through receiving bribes from the non-orthodox practitioners to promote their healthcare businesses for personal gain. This further supports that corrupt practices are widespread in the Nigerian healthcare sector, a confirmation of a failure in governance.

As a result of the plurality in healthcare delivery, most of the service-users had experienced difficulties in making decisions regarding a place for their care. Almost all the terminally ill patients and their relatives expressed that they had patronised

various non-orthodox centres before they sought care in this hospital, indicating that medical pluralism had put the service-users at risk of making wrong choices, therefore receiving wrong care for their illnesses:

*I have suffered since January when this illness started. I have gone to different places where I was told that my wife has a fibroid. People keep referring us to different places and I became confused about the right place to go. I decided to come to this hospital (Interview excerpt, Patient relative 9)*

*I received herbal medication that I rubbed at the affected part of the breast. I also visited prayer house where I was told that a woman caused the illness. You know different places claim they can cure all the diseases. I have tried many places but no improvement before I come to this hospital (Interview excerpt, Patient 3)*

*...it is difficult to know the right place to go when someone is sick. I took the herbal mixture and went for prayers but the illness persisted. In November 2015, the illness became very severe. I started going for a scan, I went for a scan for more than four times but I was told nothing was wrong with my breast. In March 2016, I noticed heaviness of the breast, I went to another place for scan and they told me I had early-stage cancer, was advised to start chemotherapy (Interview excerpt, Patient 10)*

The decision-making process for the use of PC by the service-users might have been influenced by the heterogenous structure of the healthcare delivery. Some of the patients patronised different non-orthodox centres probably because there was no organised and functional structural pathway for seeking healthcare services in the Nigerian system of healthcare delivery. This contributed to the late presentation of the terminally ill patients and their relatives in seeking PC in orthodox healthcare centres:

*The non-orthodox centres are unchecked. Some patients who ended up in these centres believe what they are told by those providers. They incline the causes of terminal illnesses as spiritual; make people believe that if they exorcise them of these causes, they will be cured. Such people keep hoping and waiting for the cure but most times, they realised that they have wasted their time and money but the disease is not cured. At that point, some of them present in the orthodox centre when their illness has advanced (Interview excerpt, Head of Department 1)*

In summary, the defective structural system of healthcare delivery in Nigeria was seen to be due to mismanagement and poor governance. As a result of corruption, several non-orthodox centres were thriving, with no quality control measures from those in

authority. Due to the high level of poor public knowledge of terminal illness and palliation, which led to the widespread erroneous perception of PC as discussed in chapter five and the dysfunctional structure of the healthcare delivery, terminally ill patients and their relatives were faced with difficulties in decision making about an appropriate choice of a place of care. The majority of the service-users reportedly sought care from the non-orthodox centres, leading to late presentation for PC in the hospitals. Although lack of political will appeared to be the reason for the failure of the structure of the healthcare delivery system, some participants mentioned that government officials usually attributed the failure to lack of funding. This will be explored in the following subdomain, named funding.

### **6.2.2 Funding of palliative care**

The Federal Government of Nigeria, through its national budget office, allocates funds from the Federation account to the health sector (Budget Office of the Federation, 2018a). Because the healthcare sector is one of the items in the concurrent list, as stipulated by the 1999 Constitution of the Federal Republic of Nigeria, it implies that funding the Nigerian public healthcare system is the exclusive responsibility of the Federal and the State Government. The participant managers highlighted that they received funds yearly for personnel, capital costs, and the overhead costs from the Federal Government:

*The government fund this hospital through budgetary allocation. The budget for each year consists of personnel cost used for the payment of staff salary, capital cost used for capital projects such as building and overhead cost utilised for maintenance, managing daily activities of the hospital such as supply of equipment, provision of consumables, payment of bills and others (Interview excerpt, Manager 4)*

*...financing the activities of this hospital is the responsibility of the Federal Government and we do receive fund that is allocated to this hospital every year... (Interview excerpt, Manager 1)*

Although all the key managers interviewed in this organisation stated that they received funds from Federal Government for the provision of healthcare services and the management of other activities, they expressed the common view that their organisation was under-funded by the government:

*The truth is that this hospital is poorly funded by the Government. The money we receive from the Federal Government is not enough to pay electricity bill... (Interview excerpt, Manager 1)*

*The Government does not near the minimum budgetary guideline as stated by World Health Organisation. WHO proposes that about 10% of the annual budget for each country should be allocated to health, but it is less than 5% here. The fund given to institutions is very small... (Interview excerpt, Manager 2)*

*The fund for overhead cost is too little, it is not enough to pay half of the electricity bill (Interview excerpt, Manager 4)*

The managers revealed that funds, especially the overhead costs, were insufficient to pay hospital utility bills. This provides impression that fund for the maintenance of the activities of the studied hospital including PC might not be available. The purportedly less than 5% budgetary allocation for the health sector, less than the perceived World Health Organisation recommended benchmark for budgetary allocation to the health sector, portrayed that the Government appeared to give less priority to healthcare delivery. In addition, and in support of this, Nigeria has consistently failed to implement 'The Abuja Declaration 2001' signed by Heads of State of the African Union, including Nigeria, to allocate at least 15% of their annual budget to improve the health sector (Federal Republic of Nigeria, 2001; WHO, 2018e). In fact, Nigeria budgeted 4.13% and 4.17% of the national budget to the health sector in 2016 and 2017, respectively (FMoH, 2017, Budget Office of the Federation, 2018b). Further analysis of the budget from 2015 to date for different sectors in Nigeria showed that funding budgeted to the health sector was far less than that allocated to other sectors, such as transportation, water resources, interior, defence, the Nigeria Delta Development Commission, power, works, housing and others (Budget Office of the Federation, 2018c). This confirms the earlier impression that the Government gave the health sector a low priority when allocating their budget and this may lead to financial insecurity or lack of financial protection for a household who may not be able to afford the high costs of healthcare services in Nigeria.

It can be assumed that provision and utilisation of healthcare services such as PC may not be affordable, accessible and effective due to inadequate and unsustainable funding. The participants (managers), when probed further concerning the low

budgetary allocation for the health sector, acknowledged that it was due to poor national governance. Some participants maintained that government leaders were corrupt, egocentric and not concerned about the health of the masses. For instance:

*...the government play politics in allocating funds to different sectors and ministries. For instance, the ministry of power may receive high allocation because the minister is close to the presidency. The presidency will demand some percentage of the approved fund from such minister. What goes on in government is terrible! (Interview excerpt, Manager 4)*

*The government loot the public fund and use it for their personal needs (Interview excerpt, Head of Department 4)*

*Poor funding of health sector is a leadership issue. When you do not have the right leadership, people will suffer. The leaders in government have no moral discipline, not patriotic and have no passion for the people they serve. These leaders are not sincere and are not concerned about people's health needs. The government officials travel abroad for medical care because they understood that Nigeria healthcare system is poorly funded (Interview excerpt, Manager 2)*

The allocation of funds to different sectors, including the health sector, appeared to be based on political sentiments, which suggests that funds were inequitably distributed and, therefore, indicative of poor governance in relation to corruption. Transparency International (2018) estimated that Nigeria has lost more than £225 billion to corruption over the past decade. Currently, the Economic and Financial Crime Commission (EFCC), a body that fights against corruption in Nigeria, has identified many of the past and present public servants, government officials and individuals allegedly involved in corruption, with court cases in progress. Some of them have been convicted, including one of the past Minister of Health and was removed from office for diverting funds for personal interest (EFCC, 2017). There is a possibility that much-needed funds, which could have been used to promote the delivery and utilisation of healthcare services, such as PC, have been lost to corruption.

In addition to poor governance, some participants thought that poor funding of the healthcare sector was due to the national economic recession:

*The Federal Government do not have the money because of recession. This recession is because the Niger Delta boys are vandalising the pipeline and this affects oil production. The Federal Government relies heavily on the oil for*



*revenue. The production and sales are low, it affected the income. It is not as if the Federal Government is not interested or callous, but it is because there is a recession (Interview excerpt, Manager 1)*

*When I go for budget defense, the Government usually tell us that the Government financial sources are dwindling. They say a barrel of oil was sold at a high price but the price is very low now. They encourage institutions to generate ideas to raise fund to manage their organisation (Interview excerpt, Manager 4)*

*The whole nation is in recession, it is affecting every areas and system in this country (Interview excerpt, Manager 5)*

The economic recession was perceived to have resulted from low production of crude oil due to destruction of pipelines, an indication of political instability possibly exacerbated by poor governance. It appeared reasonable that the low price of crude oil and reduced production led to decreased Government revenue, which affected the amount of funding allocated to the different sectors, including healthcare. However, economic recession may not be the fundamental issue for the low budgetary allocation for Nigerian healthcare organisations because there was no economic recession during the first six months period of data collection, yet all the participants emphasised the issue of poor funding by the Federal government. It can be deduced that poor funding of healthcare organisations seemed to be as a result of a complex web of interwoven issues related to misappropriation, non-accountability, self-centredness and economic recession.

Furthermore, the insufficient budgetary allocation to the health sector influenced the performance of different healthcare organisations in Nigeria. Specifically, its impacts on the studied hospital as mentioned by the participants (managers) included non-payment of salary, poor maintenance of facilities, and inadequate human and material resources:

*As we talk now, we owe security outfit several months of their salary. Our staff paid via GFMIS platform such as the honorary consultants, resident doctors, interns received 68% of their salary in the last two months because the budgetary allocation was not enough. There is a need for nurses, resident doctors, but we cannot employ because there is no money to pay their salary. We are struggling to meet up with the payment of the existing staff of the hospital because of poor funding (Interview excerpt, Manager 1)*



*Facilities are poorly maintained because of poor funding. The fund given to us is very small. We do not have enough fund to maintain the hospital equipment or to buy new ones that are needed for the care of patients... You have seen some uncompleted building in this hospital; it is because the Federal Government has not provided a fund for these projects in the recent years. That is why those projects are uncompleted and nearly abandoned (Interview excerpt, Manager 2)*

*It is a matter of funding. I have sat with the Chief Medical Director face to face, and he told me that he couldn't employ doctors because there is no money (Interview excerpt, Doctor 1)*

The studied hospital could be said to be poorly developed, as evidenced by the shortage of human and material resources, due to inadequate financial support from the Government. The impact of the poor funding in relation to the provision of PC will be explored in more detail in the next chapter. Some participants revealed that the provision of healthcare services, including PC, in this hospital was 'commercialised', which resulted in an increment of hospital bills to generate income that will supplement the poor funding by the Government:

*The management has converted all the units and departments to a business centre; we are encouraged to generate our own income and use the profit to manage the unit. For instance, if I put a request for 5 million naira for things needed for the provision of care in my unit, the management will check the income my unit has generated, if I have generated more than the fund I requested, my request will be approved but if not, it will not be approved (Interview excerpt, Head of Department 1)*

*What we do is to commercialise our service by increasing our fees to be able to generate money to manage the activities of this hospital (Interview excerpt, Manager 4)*

*We rely on internally generated fund to manage this hospital. Patients pay out of their pockets, the fee they pay will ever continue to increase because we are trying to make the ends meet. Most people do not come to the hospital because they do not have the money and cannot afford the cost of their treatment. Some of these patients later present late when their illness is complicated. As a result, the mortality is increased. It is a vicious circle due to poor funding (Interview excerpt, Manager 2)*

Managerialism, a concept that could be suggestive of an ideology that adopt business-like approach and centres on profit making achieved through incessant organisational restructuring (Lynch, 2014; Klikaue, 2015), seemed to be operational in the studied

hospital, because of the commercialisation of its services due to poor funding from the Government. This ideology in use could imply that vulnerable populations, such as terminally ill patients and other patients of low economic status may have limited utilisation of PC and other services. Although poor funding affected the entire services of this hospital, surprisingly no fund was allocated by the managers of this hospital to the PCU:

*The hospital management did not provide financial support to palliative care unit. There is no funding of palliative care unit (Interview excerpt, Doctor1)*

*In this hospital, there is a mindset of not investing in the group of patients that will die soon. The managers feel that palliative care services do not yield income to the hospital. Therefore, the management is reluctant to invest money in the unit that does not generate revenue to the hospital (Interview excerpt, Social worker 2)*

*We do not have the budget for palliative care unit... (Interview excerpt, Manager 1)*

The lack of budgetary allocation for PCU as purported by members of PC team was acknowledged by the Manager '1'. This provides insight that Managers might have allocated funds based on their perceived relevance of different units in contributing revenue to the hospital as alleged by some member of the PC team. Probing of the members of the management team further supported that funds were allocated to units that could generate a profit for the hospital:

*What we do here is to push fund to areas where we can deliver critical care and area we can recover fund. We do not spend fund on dead-ends, we try to spend it on area we can recover cost so that we can continue to render services without experiencing failures (Interview excerpt, Manager 4)*

*For me, I spent the impress in the area of priority. The areas of priority are patient comfort and things that will cause service failure (Interview excerpt, Manager1)*

Profit making being a criterion that shaped the funding of different units and departments in the studied hospital connotes that healthcare organisation owned by the Nigerian Government may be shifting into a state whereby healthcare services were perceived as 'economically good' rather than 'socially good'. This could have an

adverse effect on vulnerable groups, such as terminally ill patients, because of the failures of public policy, particularly regarding insurance coverage. The National Health Insurance Scheme (NHIS) in Nigeria so far has provided coverage for only 6% of the Nigeria population (Onwujekwu *et al.*, 2009; Odeyemi and Nixon, 2013;), indicating that out-of-pocket expenditure predominantly operates in Nigeria's healthcare system (Onoka *et al.*, 2013; Adewole *et al.*, 2015). Lastly, the conceptualisation that PC was a 'dead-ends' care could be one of the fundamental reasons for why the managers of this hospitals did not allocate fund for this service. It could be an indication of a culture and mindset that did not understand the value of the care of terminally ill and dying patients. The impact of this mind-set on the care delivery will be discussed in the next chapter. Poor funding for PC had impacts on the patients' and their relatives' socio-economic status and this will be explored in the next section.

### **6. 3 SOCIO-ECONOMIC INFLUENCES ON PALLIATIVE CARE**

It is known that patients and their families that seek healthcare services in Nigerian healthcare organisations pay an amount of money in exchange for the services provided to them by the members of healthcare teams (see Appendix G). As discussed above, the fees paid by these service-users have continually increased, because the hospital managers have been reliant on the internally generated funds to finance the activities of the hospital, due to poor funding from the Government. The service-users appeared to have suffered financial pressure associated with the increased cost of their care, which affected the use of PC. This section will explore how the socio-economic status of terminally ill patients and their relatives rendered them more vulnerable in relation to the utilisation of PC, which was reliant on the out-of-pocket payment for the service that operated in this hospital. This domain is discussed as two subdomains, namely, economic status, and the impact of social networks.

#### **6.3.1 Economic status**

Most of the people who had a terminal illness and were provided with PC in this hospital appeared to belong to a lower socioeconomic group:

*...95% of them are poor; they do not afford the cost of their management  
(Interview excerpt, Oncology Nurse1)*

*Many of the terminally ill patients are poor; some are not able to pay for oral morphine sold at the reduced price between 800naira and 1,600 naira (Interview excerpt, Social worker 2)*

*I went home to look for money to commence chemotherapy, but my husband and I could not be able to raise money ... (Interview excerpt, Patient 10)*

*My husband has no money to pay for the care (Interview excerpt, Patient 9)*

*The doctor told me that it is necessary for my sister to receive another medication before chemotherapy, but I have no money to pay for it (Interview excerpt, Patient relative 8)*

The above quotations indicate ways in which the context of care in this organisation was overwhelmingly determined by the capacity of service-users to pay for their care. Unfortunately, most of the service-users were less likely to pay due to poverty. The out-of-pocket payment appeared to render terminally ill patients and their families with a lower economic status more vulnerable to poorer access to services and consequently to poorer health and wellbeing. Although, poverty is a socio-economic issue that is widespread among the population of terminally ill patients and their relatives, it was not restricted to this population group. In 2017, World Bank estimated that 49.1% of Nigeria's population lived below the international poverty line of \$1.90 per person per day (World Bank, 2018b). Although, the majority of Nigerians are poor with associated difficulties but what appeared different for the population of terminally ill patients was that the cost of care seemed to worsen their economic status. The HCPs and the service-users highlighted that the huge financial requirements for the management of terminal illness contributed to their poor economic status:

*Cancer care consumes so much money, it renders people poor even when they were rich (Interview excerpt, Oncology Nurse 4)*

*Cancer treatment and management are very expensive; no single person can afford the cost of the treatment, even the rich ones. When someone continues to pay for chemotherapy, radiotherapy, surgery, buy medication and pay for the services, before you knew it, such person may not have money to pay for his care (Interview excerpt, Head of Department 1)*

*I have spent much money; it is more than 600,000 naira for the management of this illness. This illness has made me poor that am not able to pay for the care and feed my children (Interview excerpt, Patient 5)*

*...we spent so much money in that hospital and now we had no money to pay for our care here... (Interview excerpt, Patient relative 8)*

The service-users emphasised that they have spent a great deal of money due to the high financial cost of cancer and other terminal illnesses; this underpins why some service-users appeared to have suffered what could be termed as 'situational or circumstantial poverty' which has made them to suffer high degree of vulnerability. Some participants supported the impression about circumstantial poverty, highlighting that the majority of the service-users were unable to pay for the services that could improve their quality of life because they had spent all their money with non-orthodox providers:

*Based on my experience, most of the terminally ill patients and their relatives seek for herbal treatment and visit traditional healers. These people drain their pocket; some of these patients come to the hospital at either stage 3 or 4 of their illness. When they are asked to pay money for their care, they will say that they have no money because they have spent all their money in other centres (Interview excerpt, Oncology Nurse 1)*

*Most of these faith-based and traditional centres usually start by telling these patients to bring yams and fowls. They start with what these patients can easily afford but progress to ask them to bring money to buy things for sacrifice to appease gods. The patient ends up spending all their money in these centres before they come to the hospital (Interview excerpt, Head of Department 4)*

*...I spent 7 months at the native medicine man in Port Harcourt, he charged me three hundred thousand naira but I gave him all the money I had for the treatment. I noticed there was no improvement, and then I went to other places... it was one of my friend that gave me transport fare to come to this hospital, I do not have any money to pay for treatment here...tears (Interview excerpt, Patient 9)*

These quotes give the impression that most terminally ill patients and their relatives had exhausted their monetary resources with non-orthodox providers before they sought PC. It also raises the possibility that providers in the non-orthodox centres may have financially exploited these vulnerable people for their own personal benefit, which is an act of corruption, which thrived in this cultural environment because of

lack of policies to regulate the activities of various groups of providers that operated in the Nigerian healthcare system, as discussed in the section above.

Furthermore, some participants added that most of the terminally ill patients were poor because they were either unemployed or in poorly paid jobs and, therefore, unable to pay for their PC due to low or no income:

*Most of these patients are poor because they are not employed. Most of them are farmers and traders (Interview excerpt, Oncology Nurse 2)*

*Some people's salary is thirty thousand naira per month. For instance, many of the staff employed under this unit does not receive a salary of up to fifty thousand naira. If any of these people fall sick and require the kind of care we provide to our patients, where can they get such money? (Interview excerpt, Head of Department 4)*

*I spend more than 40,000 naira every three weeks, to buy a cup of medications containing thirty tablets. Yet my salary is not up to 100,000 naira. It has not been easy for me (Interview excerpt, Patient 5)*

Unemployment may also contribute to inability to afford the cost of care. The National Bureau of Statistics (NBS) shows a continuous rising rate of unemployment in Nigeria from 2015 to date. For instance, unemployment increased from 13.9% in the last quarter of 2016 to 18.8% in the last quarter of 2017 (NBS, 2017). This illustrates that high unemployment is a nation-wide menace in Nigeria, but could have more impact on the terminally ill patients and their relatives because of additional costs of living with these illnesses. For instance, some of the service-users and a doctor said:

*It's been long when I first notice this illness but due to my condition of no money, I did not go to the hospital (Interview excerpt, Patient 9)*

*I did not come back for the treatment as advised by the doctor because I have no money (Interview excerpt, Patient 10)*

*Many people with cancer are dying because they lack money to visit the hospital for their care. Most of the people that do not have the money stay at home to die without care. Someone here told me that she will discontinue chemotherapy because she can no longer afford the cost and also told me that she will not go for radiotherapy because she has no money (Interview excerpt, Patient 8)*

*...she came back in respiratory distress, told me that she stopped attending her clinical appointment because she has no money to pay for her care (Interview excerpt, Oncology Doctor 1)*

Some patients and their relatives could be said to have presented late to the hospital and/or missed their clinical appointment, while others did not seek/attend hospital for PC due to their poor economic status. This suggests that the financial ability to pay for care was a criterion considered by some of the service users in their decision to seek PC, and this illustrates how the financial mechanism that operated in the studied hospital and the entire Nigerian healthcare system discouraged or caused the patients to have limited access and use of PC. Previous studies similarly found that poverty is one of the barriers to healthcare access and utilisation in Nigeria (Adedini *et al.*, 2014; David-Wayas *et al.*, 2017). The poor economic status of some service-users led them to patronise less expensive care as an alternative to PC:

*I went to herbalist that gave me herbal mixture and I also went to prayer houses, but that wasn't the reason why I delayed medical care as the doctor advised when I first came to the hospital. If I had money, I would have commenced care in the hospital while I back-up myself with prayer (Interview excerpt, Patient 10)*

*...because of poverty, many people cannot afford the orthodox care. People that cannot come to the hospital patronises something else (Interview excerpt, Manager 2)*

*When people consider the cost of their care, they will resort to herbal mixture and other native treatment because it is cheaper (Interview excerpt, Doctor 3)*

The healthcare choice and behaviour for the use of PC by the service-users might have based on the economic constraints, rather than their preferences. This discourse may not be surprising in the context of the Nigerian healthcare delivery because the healthcare providers professed that provision of PC services was based on the financial ability of the service-users to pay for it:

*You witnessed what happened in the clinic this afternoon. This woman started crying because I told her that I would not administer the chemotherapy until she pays for it (Interview excerpt, Oncology Doctor 1)*

*We manage our patients based on their available financial resources (Interview excerpt, Head of Department 4)*

*...it is not easy in this environment because we have to consider the pocket of the patients in providing care to them (Interview excerpt, Head of Department 1)*



The fee-for-service could be presumed to be the healthcare payment model that shaped the provision and use of PC in this hospital, an indication that beneficial care which could improve the quality of life may not be provided to the service-users due to their poor economic status. In addition, behaviour towards, and use of, the PC was not only influenced by the economic status of the service-users, but also the social context of the decision, which will be explored in the following section.

### **6.3.2 Impact of social networks on palliative care**

Social networks, as defined in this section, constitute social structures comprised of social actors (service-users, friends, neighbours and family members) who are closely tied and socially engage in a relationship with each other (LeGrand *et al.*, 2016). The data analysis indicates that information in terms of advice and recommendations was received by the terminally ill patients from friends, neighbours and family members who genuinely wanted to help and this influenced their decision concerning whether or not to seek/use PC:

*When I noticed the lump in my breast, some of my friends and family members recommended that I should go for herbal treatment, while some said that I should visit people that use supplements for treatment of illnesses. I chose to go for herbal treatment because I want something more natural. I drank the herbal concoction for six months but there was no improvement. The herbal medicine man told me to continue with his treatment, but after one year, I noticed there was still no improvement and I stopped (Interview excerpt, Patient 7)*

*I showed the affected breast to my friends and neighbours. They advised me to go somewhere in Port Harcourt because someone who had similar problem went there for treatment. I spent seven months there but there was no improvement. I also went somewhere else as recommended by people (Interview excerpt, Patient 9)*

The network members were reported as supportive in providing information about where to access health care, but their 'culturally-based perception' about terminal illness and palliation, as explored in the previous chapter, appeared to have defeated their good intentions. Hyde *et al.* (2011) found that service users who received palliative daycare in the UK felt that being socially supported through their social relationships and having an extended family, including their informal caregivers and even the members of staff, was beneficial. Similarly, the excerpts above may also portray



how terminally ill patients may have felt supported by members of their social networks, especially through the provision of information that played a role in their health-seeking behaviour. Probably, the service-users might have acted on the basis of defining, interpreting and ascribing meaning to the situation that confronts them in relation to the advice received from the members of their social circles, which is consistent with one of the premise of symbolic interactionism, that human action is a product of the shared-meaning or interpretation given to an object, events, symbols or circumstances (Blumer, 1969).

However, this social network was detrimental, because it encouraged non-use of PC. For instance, the patient relatives 1 and 7 as shown in the extract below rejected the advice for PC from medical professionals when they initially visited the hospital but, instead, accepted lay advice from members of social networks to seek non-orthodox care.

*I informed my mother and elder brother about my daughter's illness when I was in the hospital and they said that I should bring her back home for traditional care. I brought her back home and we took her for herbal treatment. My daughter condition got worse while taking herbal medicine and someone told us about another traditional place. We took her there for treatment, after several weeks, the condition became worse and my husband said that we should go back to the hospital. We are here now (Interview excerpt, Patient relative 1)*

*We came to the hospital, the doctor advised that surgery will be done on the breast, but my sister refused because our parents said the illness would be treated in a native way. She has been receiving the traditional medicine but the lump has not melted as my parents said, so we came back to the hospital. I even advised my sister that we should visit a man of God in Port Harcourt ... (Interview excerpt, Patient relative 7)*

The non-acceptance of professional advice by the service-users could have been because information may not have been provided in a manner that would encourage acceptance, due to lack of cultural competence complicated by professionals' lack of training in providing end-of-life communication or that information re-awakened their death consciousness instead of providing them with psychological security and protecting their sense of self-esteem as found in the previous chapter. Non-acceptance of the professionals' advice may also be viewed from the perspective that service-users

lacked trust in medical professionals and the healthcare care system; instead, they held more trust for individuals in their social circles, which appeared to have resulted in wider acceptance of their advice and recommendations. It can be assumed that the information support that was available to the service-users contributed to their health care-seeking behaviour and where they decided to seek for care.

Although service-users' negative attitude towards the use of PC was influenced by others with whom they had close and direct interpersonal ties, some individuals provided positive advice that encouraged the use of PC:

*...all my family members supported that I should seek for care in the hospital (Interview excerpt, Patient 3)*

*...while I was in the village, I met one woman that was my classmate, I explained the situation to her, but she advised me to seek care in the hospital, promised to provide financial help for my care (Interview excerpt, Patient 9)*

*When I noticed the lump in my breast, I showed it to my husband and he told me that we should go to the hospital immediately. When I told my friends about it, some of them suggested that I should visit prophet and prayers house, but I insisted for care in the hospital (Interview excerpt, Patient 4)*

*As I am in this hospital taking care of my mother, I received some phone calls from friends that I should take her for herbal treatment but I refused...It is because of ignorance that some people patronise traditional treatment and other things...(Interview excerpt, Patient relative 4)*

These excerpts indicate advice in favour of the use of hospital care (PC) from individuals who had social ties with the service-users but, remarkably, some of the terminally ill patients upheld their decision to use PC despite the conflicting advice from other individuals from the same social connections. It can therefore be deduced that service-users' levels of knowledge and understanding about terminal illness influenced their acceptance of advice to either use or not to use PC. Some previous research found that greater knowledge of hospices was associated with a more favourable attitude towards hospice philosophies and a greater preference for its use (Cagle, *et al.*, 2014). Although ignorance or lack of knowledge was perceived as a contributing factor underlying non-use of PC, in addition, lack of other social support, in terms of lack of financial support, divorce, and abandonment by friends, neighbours and family

members, were identified as issues embedded in the structure of social networks that compelled some service-users not to utilise PC:

*...most of the women diagnosed of breast cancer lose their marriages. A lady currently receiving care here was abandoned by her suitor even when their traditional marriage had been scheduled. It affected her and she stopped coming for her clinical appointment though later continued with her care (Interview excerpt, Oncology Nurse 1)*

*When this illness started, my family members refused to provide financial assistance to me. I spent two years at home managing the condition but was brought to the hospital unconscious ... (Interview excerpt, Patient 10)*

*Most of these patients come to the clinic without being accompanied by any of their family members. Sometimes, a patient may be required to go to the town centre to buy medication or to go for laboratory investigation, but some of them are very weak and have nobody to assist them. One of our patients reacted to her medication on her way home; she was semi-conscious when the passers-by brought her back to the hospital (Interview excerpt, Oncology Doctor 1)*

Some of the friends and family members that were socially connected to the service-users seemed not to have provided practical assistance, such as financial aid and other tangible support, which would encourage the utilisation of PC. LeGrand *et al.* (2016) referred to this as instrumental support, an aspect of a functional component of social support. Lack of financial support from members of social networks might have compelled some terminally ill patients not to seek PC against their wish. However, the preceding section (economic status) showed that the majority of people in this cultural environment were economically disadvantaged and this highlights that terminally ill patients that depended on the members of their social network for financial aid may suffer the risk of a poor end-of-life outcome unless additional networks of support were identified and used. Although, the majority of the network members did not provide instrumental social support, a few family members, however, were committed to providing instrumental support to their ill family member:

*...but some patients' relatives are supportive to their ill members though they are few, for instance, that man you saw in the ward has been here with her sick wife for several months, providing financial support and helping her ... (Interview excerpt, Oncology Nurse 1)*

*I offered to dress the wound of my brother who has a chronic leg ulcer and even take him to the hospital but he refused. Instead he visits traditional herbalist to dress the wound because he believed that someone poisoned him... (Interview excerpt, Oncology Nurse 4)*

*My family members are very helpful to me.... (Interview excerpt, Patient 4)*

*We will continue to care for her and provide money for her treatment. I am ready to bring her for clinical appointments (Interview excerpt, Patient relative 6)*

It is surprising to note that despite it being socially acceptable to receive social support (such as money, advice and other instrumental support) from members of the social network, some patients not only rejected positive advice to seek PC, but also turned down offered financial assistance and other social support. This could be interpreted that the kind of social support some terminally ill patients would embrace depends on whether the person providing the support share with their cultural worldviews or whether the support itself conforms to their cultural values and would facilitate behaviour which serves to minimise terror associated with death and dying in line with TMT's fundamental propositions. This signifies the powerful influence of beliefs or cultural worldviews in shaping the social rule for behaviour. In addition, human action is a process of 'indications and interpretation' in line with theory of symbolic interactionism (Blumer, 1969); thus, rejecting the social support in favour of PC seemed to be as a result of indications (various things that individuals consider when forming a line of action based on how they interpret them) ingrained in actors' beliefs which formed their defining process. In summary, this section showed that the use of PC by terminally ill patients and their relatives was embedded into a complex structure of social networks that exist among people in this cultural environment.

#### **6.4 Chapter summary**

The national political structure and governance were found to be characterised by a social system ruled by a limited number of people who used the power of their political offices to appoint individuals into Government positions on the basis of ethnic background or friendship over individual competency. This practice appeared to be one of the factors that may have been responsible for the governmental inefficiency that contributed to the endemic corruption in various aspects of governance. As

further revealed in this chapter, the culture of leadership practiced by the politicians and other public office holders was characterised by enormous mismanagement of funds, insufficient accountability, inadequate checks and balances, and lack of responsiveness and transparency. This indicates poor governance in accordance with criteria used by the World Bank (2018) and the Organisation for Economic and Cooperation and Development (2007). Poor governance quality appeared to reduce social gains, such as improved health, because the organisation of healthcare delivery was dysfunctional and poorly funded due to corruption related to embezzlement and inadequate policies to promote PC and other healthcare services. There seemed to be a political culture that did not specifically value care of terminally ill patients because the leaders in both the national government and the hospital did not budget for PC services, partly due to what could be regarded as 'erroneous perceptions' about terminal illness as well as corruption.

Furthermore, poor governance and corruption lay behind the continued socio-economic hardships and income inequalities experienced by terminally ill patients and their relatives, which negatively influenced the use of PC. Drawing from terror management theory and symbolic interactionism (Blumer 1969), service-user choices surrounding PC were affected by lack of understanding, cultural worldviews, poverty, the financial mechanism that operated in the hospital and the impact of individuals in their social network. These findings provide a new understanding that choices made primarily driven by poverty and ignorance by cancer patients and their families in this cultural environment increases terminal illness, as patients who could have been treated become terminally ill. In addition, the findings could help to awaken the consciousness of the political class and the public to understand the impact of existing governance crises on the care of dying people and could help the policymakers to increase the formulation of public policies that aim to raise the quality of, and increase the utilisation of, palliative care.

## CHAPTER SEVEN

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### ENVIRONMENTAL INFLUENCE ON PALLIATIVE CARE

#### 7.0 Introduction

The findings presented in the two previous chapters revealed that service-users' and some healthcare providers' perceptions about terminal illness and palliation were rooted in religious and cultural beliefs. The 'cultural-based' perceptions and poor knowledge about PC were both contributing factors to, and a result of, political and socio-economic influences on PC, as explored in chapter six. This chapter brings together the findings presented in the preceding two chapters through a discussion of issues that internally affected this hospital, such as resources and rituals, which are believed to be the outcome of the interplay between people's perceptions of terminal illness and the socio-political and economic factors that existed in this cultural environment.

The healthcare providers (HCPs) shared their experiences about the traditions and rituals of the hospital which they believed impacted on the provision and utilisation of PC. During my time working with the PC and oncology teams, I also observed issues within the hospital, such as resources and practice norms which impacted on the provision and utilisation of PC, and these will be discussed in this chapter. Photographs of both the physical structure and material resources were taken during the fieldwork and have been included in this chapter; as a result, knowledge from the field of semiotics was applied to make sense of these images, since it is consistent with the interpretive philosophy that underpins this research (Chandler, 2017). Although photographs portray exact likenesses which will enable someone to gain a literal meaning, Barthes (1988) argued that photographs also have connotative meaning open to diverse interpretation. In this section, both the literal meaning and the underlying interpretation of the images in relation to PC will be explored. It should be noted that I did not photograph the entire material resources of the palliative and oncology unit, but chose to photograph and include objects which provide cues that may lead to an understanding of the issues that influence provision and utilisation of PC, particularly when triangulated with other sources of data.

The two subdomains under the broad theme named ‘Environmental influence on palliative care’ are, therefore: the physical environment and organisational healthcare norms (See Figure 7.1, below). Firstly, the physical environment, which consists of resources (human resources and material resources,) is considered.

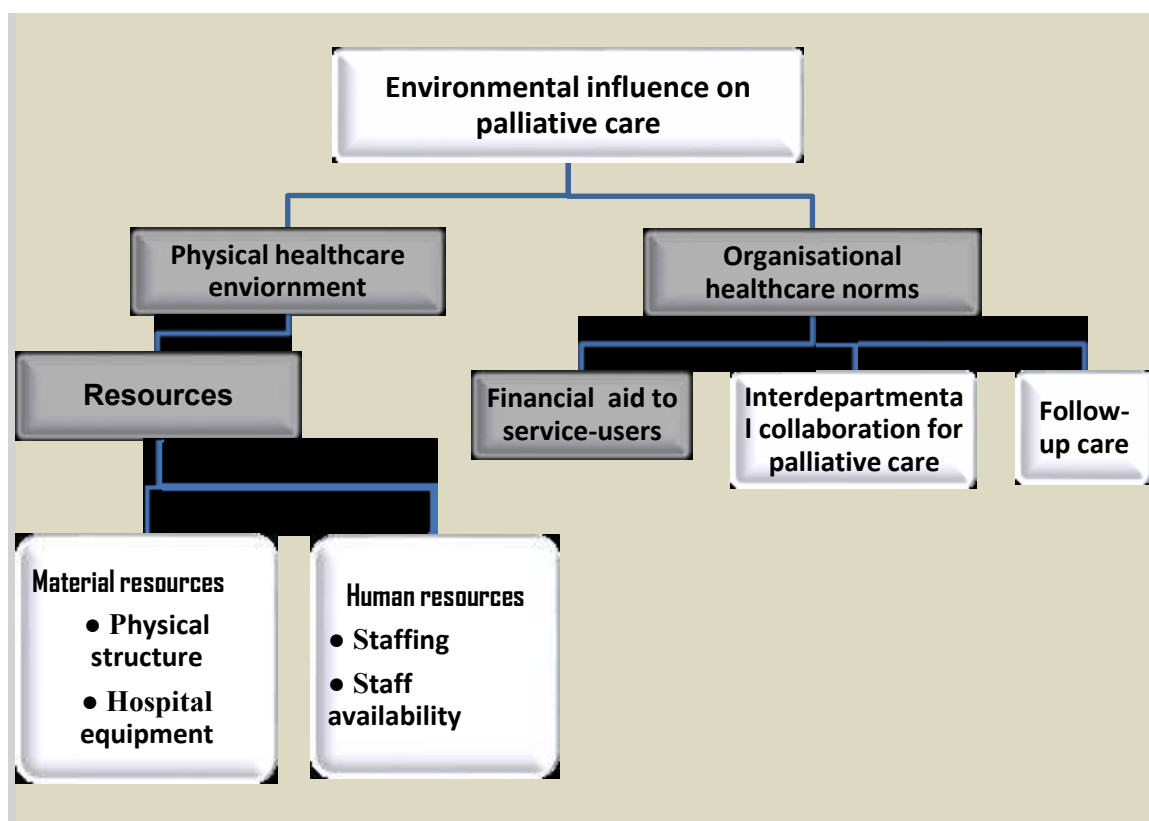


Figure 7.1: Thematic framework of chapter seven

### 7.1 The physical healthcare environment for palliative care

Analysis of the physical healthcare environment in the context of this chapter centres on the impacts of material and human resources on the provision and utilisation of PC. Previous studies have shown that the physical environment in a variety of healthcare settings is an important determinant of how people feel, think and act (Garre-Olmo *et al.*, 2012; Potter *et al.*, 2017; Nordin *et al.*, 2017). Historically, Florence Nightingale, in her writings on environmental theory, believed that providing a suitable environment (ventilation, clean water, cleanliness, lighting, prevention of noise, heat, and odour) will enhance the well-being of patients (Nightingale, 1946). In the current research, the terminally ill patients and their relatives seemed to have suffered greater impacts of distressing environmental stimuli that arose from the architectural layout, interior

designs and ambient features of the studied hospital, including the impact of human resources. This is in agreement with environmental docility hypothesis, which assumes that less competent individuals, in relation to their physical, social and psychological situations (deprived status), have a narrower range of adaptability to increasing environmental stressors and are therefore more susceptible to the influence of factors in their physical environment (Lawton and Simon, 1968). In addition, the data analysis provided understanding that healthcare providers seemed to be working under extremely stressful physical healthcare environmental conditions, which impacted on care outcome, indicating that both the service-users and the HCPs suffered an impact from the physical healthcare environment. Understanding the difficulties that service-users and the healthcare providers experience in relation to the hospital environment is essential if we are to identify the strategies that could be used to plan for the improvement of provision and use of PC in a hospital setting. Therefore, the impacts of physical healthcare environment in relation to material and human resources are discussed next.

## **7.2 Resources**

### **7.2.1 Material resources**

The material resources in relation to the physical environment comprise the physical structure, such as architectural layout, interior design, ambient features and, then, the hospital medical equipment. The architectural layout in the context of this chapter refers to spatial layout (single room design and/or multiple bed spaces), size, and shapes of space/room used to provide care to terminally ill patients and their relatives. The interior features were the furnishings of the space/room, while the ambient features included the lighting, temperature of the space/room and the noise level. This section is, therefore, categorised into two subdomains: the physical structure and the hospital medical equipment. The impact of them on the provision and utilisation of PC will be explored next.



### **7.2.1.1 The physical structure used for palliative care**

Description of the physical structure used for PC was presented in chapter four; this section will provide a more in-depth analysis of the interior and ambient features, and architectural layout because there were the issues that had the greater impacts on the care of terminally ill patients. Only two rooms (a nurses' station and the PC outpatient clinic) were allocated to the PCU in the oncology complex of this hospital. Other essential spaces, such as a treatment room, a lounge for patients' relatives, and a patients' waiting room were identified to be lacking; even the allocated space for PC was sometimes being used by some physicians from the oncology unit:

*...and there are only two rooms in this complex for palliative care unit. We do not have treatment room, counselling room, and even patient waiting room and this affects the care we provide to these patients... (Interview excerpt, Nurse 3)*

*We struggle for space here, can you imagine that other doctors are trying to take the only space we have here (Interview excerpt, Doctor 1)*

*On arrival at the oncology complex from palliative care ward round, there was a doctor using palliative care outpatient clinic. The doctor and nurses from the palliative care unit had to wait in front of the clinic... (Field note, F5)*

The absence of space (rooms) for terminally ill patients and their relatives to stay while waiting for a doctor or to receive other PC, such as counselling, wound dressing, and injections from the nurses and/or other members of PC team, illustrates that service-users may have suffered preventable distress related to lack of space and, as a result, may not have received some services, such as counselling, due to lack of dedicated space. Lack of essential space for PC could be an indication that this service was not valued in this hospital, although the managers in this hospital stated that poor funding from the government was the reason for the inadequate supply of the resources needed for PC, as explored earlier in chapter six. The insufficient physical space was not peculiar to the PCU, because I observed some doctors from the oncology unit searching for a space where they could sit to consult patients, and also most of the patients had to arrive very early to secure a bed for their chemotherapy, while others had to sit on the chair to receive chemotherapy due to the small size of the room that accommodated only a few beds. The lack of space was a general issue in the oncology complex, and this proposes that cancer care (oncology and palliative care) may not to

be one of the priorities of this hospital. It can, therefore, be assumed that insufficient physical space in this hospital appeared not to promote patients' and staff comfort and, therefore, detracted from the quality of care.

In addition, while I participated with the daily activities of the PC team, I observed that terminally ill patients and their relatives were admitted and cared for in an open ward arranged with numerous beds without curtains to demarcate spaces between one patient and another, as shown in Image 7.1 below. Visibly from this image, there was a close distance between one bed and another, suggesting that an appropriate level of privacy would be difficult to maintain and this could make it more difficult for patients to engage in difficult conversations with HCPs and/or their families.



**Image 7.1: Interior view of the ward**

Furthermore, this image also shows the poor state of furnishing of the space, the dangerous state of plugs, poor condition of the side cupboard and metal projection of the beds, suggesting lack of place-making, which is consistent with the third triadic element of Lefebvre's theory of space (Lefebvre, 1979; 1991). The Lefebvrian analysis considers space to be fundamental to our lived experience of the world, which he termed as 'space of representation' or space of 'inhabitants or users' (Lefebvre, 1991:

39). In this current research, all the spaces used for the care of terminally ill patients appeared uninhabitable and did not serve the purpose they were supposed to play in enhancing the quality of life. For instance, all the spaces looked dirty, lacked appropriate furniture, lacked features to demarcate a space between one bed and another and did not have air-conditioners to maintain appropriate ventilation, although there were a few functional ceiling fans in some of the wards. This provides evidence that service-users would have poor life experience because the space for PC could have constrained their quality of life. The managers of this hospital appeared to have not taken responsibility for making the space for PC conducive and inhabitable, perhaps because the idea to establish PCU did not originate from them, as previously discussed in chapter four.

Consensus exists in previous research that the physical environment should support service-user needs for privacy at the end of life, but there is contention about the use of a single versus a shared room for PC (Spichiger 2008; Rowland and Noble, 2008; Williams and Gardiner 2015). Whilst some patients and their relatives at the end of life prefer to be cared for in a single room because it promotes their dignity, greater privacy, better sleep, improved comfort, better interaction with healthcare providers and relatives, greater control of the environment and reduced worry about disturbing other patients (Mooney, 2008; Mckeown *et al.*, 2010; Williams and Gardiner 2015), others choose a shared room because they feel that it improves their social support, in terms of company from other patients, and reduces patients' loneliness and isolation (Rowland and Noble, 2008; Williams and Gardiner 2015).

Presumably and as obtainable in the UK hospitals, varieties of room-types such as a one bed room (side room), bays, and a room with more than one bed (main ward) with curtains that can be pulled round to provide privacy with 'do not disturb signs' hung on these curtains to ensure patients are not disrupted unnecessarily would be appropriate for PC because that would contribute towards meeting the individualised PC needs of the patients. Unfortunately, there was an absence of this kind of room-types in the studied hospital; rather, there was the old Nightingale ward design (open-

spaced ward design with several beds and without demarcation between beds). Surprisingly, none of the service-users in the wards verbally expressed their dissatisfaction about being cared for in a Nightingale style ward that was unclean and without air-conditioning. This could be due to existing culture in Nigerian hospitals where clean and air-conditioned single rooms (private wards) are used for the care of service-users who are affluent and/or belong to the political class. The service-users in this current study might have no prior experience of being cared for in a private ward, which seemed to be why none of them indicated their preferences for such types of rooms. This is consistent with other research, which has suggested that prior experience of room type may predispose patients to a future preference for that type of room (Lucas *et al.*, 2004).

It is perhaps remarkable to note that all the service-users in the oncology ward were observed to move away from the surrounding area of bed of a patient who had passed away, which was covered with a drape, as there were no curtains to demarcate one patient's bed from another. Service users were observed to be panting and groaning to each other about the delay in the removal of the corpse from the ward, suggesting distress and dissatisfaction with the open plan ward design. Socioeconomic conditions, such as poverty, as explored in chapter six, could be a limiting factor for service-users' lack of demand for a more conducive physical environment that would enhance their comfort and wellbeing, indicating that inequality in distribution of social capital in a Nigerian society negatively influenced the quality of life of people with terminal illness.

Furthermore, it may be important to note that terminally ill patients and their relatives shared a particular space (ward) with other patients that had either acute or non-life-limiting illnesses, because there was no designated ward for PC:

*... You are aware that there is no specific place or ward where terminally ill patients are admitted and cared for. Its lack affects the services we render (Interview excerpt, Doctor 3)*

*We don't have a ward for palliative care. We can't be in all the wards at the same time to care for our patients (Interview excerpt, Nurse 2)*

*We have structural problems. The setting is not ideal for the services we render; it is noisy... (Interview excerpt, Nurse 3)*

The lack of a specific ward for PC implies that terminally ill patients were cared for in the same ward as acutely ill patients, even though these two groups of patients have different health care needs and that it may have been inappropriate to share the same room because of some practical difficulties. For instance, noise from television, bells, and shouting, moaning or groaning were identified by families of patients with life-limiting illness as environmental deficiencies that do not support person-centered care for those who are in the process of dying (Hawker *et al.*, 2006). Supportively, all the healthcare providers (members of PC team) in this current research criticised the hospital wards as being noisy and inappropriate place for PC. Noises can create additional discomfort and stress for terminally ill patients and their families, thereby worsening their physical and psychological well-being (Hsu *et al.*, 2012). Lack of a designated ward for PC not only impacted on service-users, but it also influenced the working conditions of HCPs. For instance, some HCPs highlighted that their job was made tedious and more tiring because of the inappropriate plan of the physical structure:

*When the patients are scattered in all the wards, it makes the work tedious and cumbersome (Interview excerpt, Doctor 3)*

*We the nurses do not stay with our patient in the wards because we cannot be resident in all the wards due to our limited number (Interview excerpt, Nurse 4)*

*As we left ward 10 to ward 2, one of the team members complained that she was already tired of moving from one ward to another. Said that their patients were scattered in different wards not close to each other (Field note, F34)*

The absence of a particular ward for the PC may have significantly increased the time taken to walk from one ward to another, while reducing the amount of time the PC team could spend delivering care. In the addition, the HCPs were working in the extremely hot weather of Nigeria, without air conditioning in the wards, which could possibly lead to discomfort and exhaustion; consequently, the quality of care may be compromised. Although, the architectural layout, interior and ambient features was

found not to promote effective provision and utilisation of PC, but clinical equipment appeared to also contribute to the environmental impact on the PC; this will be explored next.

### **7.2.1.2 The hospital infrastructure and equipment for palliative care**

The members of the PC team highlighted that basic clinical equipment and infrastructure, such as drapes, examination couches, wheelchairs, thermometers, stethoscopes, and sphygmomanometers, were lacking in the PCU (nurses' station and outpatient clinic):

*Another issue is inadequate facilities for the care of terminally ill patients. You have worked with us for some months; you would have observed we have no core equipment like a stethoscope, sphygmomanometer and ordinary thermometer (Interview excerpt, Nurse, 3)*

*As you can see, there is no examination couch in this clinic. Most of the time I had to check if the examination couch in one of the doctors' consulting rooms in oncology unit is free to be used and sometimes, I examine my patient while sitting on the chair. This standing fan was not provided by the hospital, it was donated to the unit by one of these drug companies that wants to market their products (Interview excerpt, Doctor 1)*

The lack of equipment as professed by the members of PC was consistent with observations during my time researching in the PCU. Specifically, I observed that most of the clinical equipment was unavailable for the care of terminally ill patients, and even most of the furniture in the nurses' station of the PCU (see image 7.2) and doctors' room used as PC out-patient clinic (see image 7.3) was labelled 'Oncology clinic':

There was no wheelchair to move the patient from palliative care clinic to chemotherapy room.... (Field note, F4)

*Some of the chairs and tables at the palliative care nurses station and the outpatient clinic had an inscription of oncology clinic though few of them were labelled palliative care unit (Field note, F6)*





**Image 7.2: interior view of palliative care nurse's station**



**Image 7.3: interior view of palliative care outpatient clinic (doctors' consulting room)**

My observations of the material resources indicate a shortage of equipment but what appears more shocking was that most of available equipment looked unusable and badly maintained, as was the case of the wheelchair shown in Image 7.4, below:



**Image 7.4: oncology clinic /chemotherapy room, showing facilities**

Furthermore, Images 7.3 above and 7.5 below, representing a typical consulting room in PCU and oncology unit, its comparison show some differences and similarities.



**Image 7.5: Doctors' consulting room in the oncology unit**

One might perceive that both consulting rooms looked unclean, with no adequate facilities for patient examinations, an indication that patients were not valued. The consulting room in the oncology unit (image 7.5) had a ceiling fan and appears to be more pleasing, suggesting that it might be the more comfortable for both patients and HCPs, while the only consulting room in the PCU (image 7.3) clearly shows lack of an examination couch and a filing cabinet. This lack of an examination couch compelled the doctor to seek for a space in the oncology clinic to examine patients as indicated by Doctor 1 in the extract above. This might possibly delay the provision of care for



other patients, leading to increased patient waiting time, and potential increased work stress for the doctor and nurses. On a connotative level, one might perceive from the signifiers (objects within the images) that there seems to be lack of place-making (Feld and Basso, 1996), particularly for the PCU. It could be said that PCU has some 'space' used for PC, but not a 'place' that could promote the wellbeing of the service-users or enhance the happiness or job satisfaction of the HCPs. This further indicates that there was lack of 'spaces of representation' in the PCU (Lefebvre, 1991). The label 'oncology unit' on the furniture in PCU signifies that it was borrowed and, together with the absence of basic equipment as highlighted by all the members of PC team, provides evidence that the PC seemed not to be valued in this hospital, perhaps contributed by inadequate knowledge about its relevance, as discussed earlier in chapter five.

Further, regarding the facilities and infrastructures, the floor tiles, side cupboard, beds and bed sheets looked dirty and obsolete, as shown in Images 7.1 and 7.2 above. In addition, the electricity supply was widely reported to be unreliable, as was the water supply with cues shown in Image 7.6, and excerpts below:



**Image 7.6: Washing sinks from two different wards**

*The washing hand sink, walls, glass windows, floor tiles and ceiling looked dirty and old (Field note, F6)*

*A patient relative, who was seen crying, told the doctor that her mother was supposed to do dialysis two days ago but there was no water supply for the procedure. The limbs and abdomen of this patient was swollen, patient*

*appeared to be agitated and died after 5 hours without the procedure (Field note, F29)*

Image 7.6 portrayed that the position of the yellow bucket suggests a leak from under the washing sink, indicating lack of maintenance of the infrastructure. The lack and/or inadequacies of water-supply infrastructure to the wards and clinics could lead to poor personal and environmental hygiene, which may increase the risk of infection for the terminally ill patients, who already had weak body immunity. For instance, one of the terminally ill patients appeared to have suffered poor quality of life due to lack of water for procedures (dialysis) that could have possibly improve her quality of life. In addition, some participants reported that the lack of a reliable electricity supply in the hospital influenced the care of terminally ill patients:

*Power supply goes off sometimes for about 48hours. If there is no power supply, you cannot operate some equipment such as suctioning the patients. During night duty, when there is no electricity supply, we work with rechargeable lantern and phone light (Interview excerpt, Oncology Nurse 3)*

*On arrival at the ward, the ceiling fans were not rotating as there was no electricity (Field note, F13)*

The unreliable electricity supply, as highlighted by 'Oncology Nurse 3', was also observed throughout the nine-month period of data collection, could indicate that it was a persistent problem. Thus, it may be plausibly to argue that environment was unsupportive to both HCPs and service-users in the provision and utilisation of PC. The HCPs attributed the physical environmental inadequacies (poor materials and infrastructure) to inefficient hospital management, but managers of this hospital blamed insufficient political commitment (inadequate funding, lack of, and/or inadequate health policies) by the Federal Government as the factor that impacted on the provision of resources for PC, as explored in chapter six.

Finally, on a personal level, my feeling about the material resources (physical structure and hospital equipment) was that I would certainly try to avoid such a hospital to receive care if I was sick and required PC because of its poor cleanliness and hence risks of infection. In addition, the wards seemed not to provide privacy, dignity, or comfort for service-users and most of the equipment looked old and inadequate. Possibly, the

environmental conditions may have contributed to why so few terminally ill patients sought care in this hospital. Some of the service-users even reported dissatisfaction with some of the facilities, for instance:

*During the ward round, one of the patient relatives complained to the doctor that one of the bed springs was broken and that the bed worsens the pain of the patient. The beds and its mattress looked old and dirty (Field note, F26)*

This provides the impression that lack of, or the poor condition of, facilities affected the physical well-being of the terminally ill and dying patients. It may possibly impact on the emotional and psychological well-being of the patients and their family members. This section has shown that material resources impacted on the provision and utilisation of PC, but data analysis also suggests that human resources influenced PC, which will be explored next.

### **7.2.2 Human resources for palliative care**

This section on human resources is presented in two subdomains: staffing of the PCU, and staff availability for PC.

#### **7.2.2.1 Staffing of palliative care unit**

The staffing level of the PCU was a common concern raised by both the HCPs and the service-users in this hospital. Whereas most of these participants highlighted that this unit was understaffed, my observations, recorded in the field notes, further emphasised the inadequate staffing level for the care of terminally ill patients and their families:

*Four nurses, two doctors; two social workers, a pharmacist, and two physiotherapists constitute the members of palliative care team (Interview excerpt, Doctor1)*

*We do not have pastoral care staff among the palliative care team, though the Head of palliative care unit occasionally invites a catholic priest or pastor to provide spiritual care to our patients. We neither have a doctor who is a specialist in palliative care nor medical officers that work in the palliative care unit (Interview excerpt, Nurse, 3)*

*Two nurses were repeatedly seen during morning duty and a nurse during afternoon shift, but none at night shift. Doctors, social workers, pharmacist, and physiotherapist were not steadily available in palliative care unit (Field note, F35)*

These excerpts showed that PC was provided to terminally ill and dying patients by a small number of clinical staff from nursing, medicine, physiotherapy, social work and the pharmacy, indicating that the team lacked other essential members, such as a chaplain, psychologists, music therapists, art therapists, counsellors, dieticians and volunteers. In addition, the three doctors among PC team were neither employed nor recognised by this hospital for the provision of PC. One of these doctors was a volunteer, while the other was employed by this hospital, but not as a PC physician. This was acknowledged by some of the participants:

*There are three doctors that work in palliative care unit, the head of palliative care unit, a doctor from anaesthesia department and myself who is a volunteer doctor in this unit... (Interview excerpt, Doctor 3)*

*Although I work in a palliative care unit, it is not my primary assignment. My primary assignment is anaesthesia. I was employed as a consultant anaesthetic doctor and for other responsibilities in anaesthesia department of the college (Interview excerpt Doctor 1)*

The Centre for Advanced Palliative Care (CAPC) highlighted that a comprehensive PC team should consist of specially-trained clinical and non-clinical staff, because of the complex needs of people with progressive life-limiting illnesses (CAPC, 2011). In this current study, the composition of the PC team implies that some essential members were missing. However, some of the participants mentioned that priests or pastors were sometimes invited from outside the hospital to give spiritual support. I noted that none of the clergymen were invited to provide this layer of support to the service-users during the period of the fieldwork. It is, therefore, possible that terminally ill patients and their families who sought PC in this hospital may not have received all the specialist care they required to alleviate their suffering and improve the quality of their life.

Furthermore, insufficient staffing was considered by some HCPs to be due to management unresponsiveness to the needs of PCU, PC being perceived as a new area of medicine in Nigeria, with inadequate funding and inefficient management. Some key managers in this hospital agreed that insufficient staffing was due to poor government funding as explored in chapter six, while others added that lack of a residency programme for doctors in PC and lack of an organised educational programme in

Nigeria for training other healthcare providers in PC were the reasons for the shortage in the manpower for PC:

*The head of palliative care unit has requested for doctors and nurses but the management is not just responsive to our need (Interview excerpt, Nurse 4)*

*I will say that the management don't want to employ more staff because of insufficient fund to pay their salary (Interview excerpt, Nurse 2)*

*We cannot employ because there is no money to pay the salary of people that are employed. There is a need for nurses, resident doctors but we cannot employ because there is no money unless things changed (Interview excerpt, Manager 1)*

*This is a teaching hospital; we do not have a structured residency program in palliative care. Because there is no structured residency training, people have no way of getting there. As far as am aware, there is no institution in Nigeria for palliative care training, therefore there is even lack of specialist palliative care professional to employ (Interview excerpt, Manager 2)*

The inadequate funding for, and lack of an educational institution for the training of, PC professionals connotes a failure of the political class and leaders in the healthcare sector of Nigeria to provide leadership, initiative and show commitment to PC development, due to corruption and poor understanding about PC, as explored previously in chapters five and six.

The members of the PC team highlighted the pressures they faced in the provision of care for terminally ill patients because there were too few staff:

*...I am faced with the responsibilities of doing my primary duties which the hospital recognised and rendering palliative care, which is the role I accepted... (Interview excerpt, Doctor 1)*

*I will do double shift today because the other two nurses are on leave (Interview excerpt, Nurse1)*

*I sympathise with nurses because they are overworked (Interview excerpt, Doctor 1)*

The members of the PC team suggested they faced unmanageable workloads that exceed their capacity to cope. Previous research showed that increased workload as a result of poor staffing was associated with back pain, poor emotional exhaustion, job dissatisfaction, and burnout (Nantsupawat *et al.* 2016; Dhaini *et al.*, 2016; Simpson *et*

al., 2016). Specifically, lack of adequate staff for PC appeared to have impaired adequate staff-patient communication, which seemed to have contributed to service-users' poor knowledge of their care, as explored previously in chapter five. Shortage of staffing had also resulted in leaving some patients unattended for long periods of time in the PC clinic and in the wards, without providing the care they required to improve the quality of their life:

*...one of the terminally ill patients entered the palliative nurses' station at 14:30; told me that she had waited since morning to be seen by the doctor.... (Field note, F13)*

*I have waited here since morning to see the doctor but no doctor has come... (Interview excerpt Patient 6)*

*I would have done abdominal tap for this patient so that she will have some relief from the pain but 'I don't want to start what I will not finish'. There is no resident doctor under palliative care unit that will monitor the patients and our nurses do not run night shifts (Field notes, F4)*

These comments indicate that terminally ill patients experienced avoidable delays in receiving services that may have improved their wellbeing, due to a shortage of staff. In some instances, as depicted in Field note (F4), a patient was denied a procedure which would have alleviated her distress because of lack of a resident doctor and nurses that could provide post-procedural care. An indication that some service-users may have experienced poor physical, psychological and spiritual wellbeing due to the unavailability of staff to meet their time specific PC needs. Inadequate staffing of the PCU further impacted on staff availability for PC, which will be explored next.

#### **7.2.2.2 Staff availability for palliative care**

Staff availability in the context of this research concerns healthcare provider's refusal to provide PC services (employee strike), due to disagreement between the employees and the employer. Employee strikes were repeatedly mentioned by all the participants as one of the issues that influenced the provision of PC, and they believed that the frequency of this industrial action by different groups of healthcare workers had negatively impacted on patient care:

*There have been many strikes since this year (Interview excerpt Nurse 4)*

*There was a strike action in almost every quarter of the year lasting between two to three months and we are used to it (Interview excerpt Nurse 1)*

*...from late 2014 through the entire 2015, there were about three to four nationwide strike actions, we all (doctors, nurses and other healthcare professional) participated in these strikes (Interview excerpt Doctor1)*

Work stoppages by the healthcare providers alleged to have regularly occurred in this hospital, signifying a culturally accepted strategy used by the employees to show grievances or to enforce a demand for issues related to their work. As evidence of this, I witnessed two episodes of strikes (work stoppage) within the first six-month period of the fieldwork, which had a negative impact on patients with terminal illness. However, one of the participants (Doctor 1), as shown in the extract above, highlighted that striking was neither peculiar to their hospital nor HCPs involved in the care of terminally ill patients, but that it was a national issue that affected all the healthcare organisations in Nigeria. Although striking is a global phenomenon (Crues and Crues, 2011), meaning that it is a challenge evident in the healthcare sector both in more economically developed countries (MEDCs) and low- and middle-income countries, the difference here appeared to be in the frequency of its occurrence. For instance, in the UK, evidence showed that junior doctors in England went on strike for the first time in forty years in January 2016 (Mckay and Majeed, 2016), while in Nigeria, there were more than eight episodes of strikes by healthcare workers that occurred within 36 months (2013-2015) (Oleribe *et al.*, 2016). In this research, the healthcare providers perceived that withdrawal of healthcare services from the service-users was the only effective method the healthcare workers could use to express their dissatisfaction with their working environment, specifically, the inadequate staffing, poor incentives, poor infrastructure, and inadequate equipment:

*Nurses working condition is very poor. Most of the strike in this hospital is due to poor working condition, lack, and obsolete resources. It the only method our leaders can respond (Interview except, Oncology Nurse 2)*

*Poor working remuneration, lack of incentives, and shortage of staff contribute to the frequency of the strikes in this hospital (Interview excerpt, Nurse1)*

The rationale for striking provided by participants in this current research was similar to other research previously conducted in Nigeria (Ogunbanjo *et al.*, 2009; Oleribe *et*



*al.*, 2016). These rationales seemed to be rooted in the lack of political commitment and the failure of government in relation to funding the Nigerian health sector, as previously explored in chapter seven. Although, work stoppage disrupted patient care in general, the terminally ill patients were perceived to be mostly affected:

*All our patients in the wards have been discharged because of the resident doctor's strike. Some of them go to traditional herbalists' homes in search for the relief of their symptoms. These patients suffer a lot during strike (Interview excerpt Nurse 1)*

*When our patients are sent home each time there is strike action; some of them return after strike in a worse state (Interview excerpt Doctor 1)*

*... because of the strike, there are no many terminally ill patients in the ward receiving palliative care (Interview excerpt physiotherapist Zoe)*

*We have not regained our usual patient load because of the effect of previous strikes. Someone called me yesterday to ask if we are still on strike. This was the strike suspended over last two months (Interview excerpt Nurse 1)*

The terminally ill patients would arguably experience poorer physical, psychological and emotional wellbeing when they were sent home due to strike. Consequently, some of these patients were alleged to have sought care in non-orthodox centres as their only alternative, thereby exposing them to staff who have not specialised in the provision of PC and this may possibly lead to mismanagement that may result in poor quality of life. In addition, some of the participants stated that the decreased number of service-users that sought PC in their hospital was the consequences of previous strikes. Although, strikes appeared to be an organisational norm in this hospital that negatively impacted on the PC, there were other identified organisational norms that appeared to be either cultural enablers or inhibitors to PC. These norms are explored under in the next domain, named organisational healthcare norms.

## **7.3 Organisational healthcare norms**

### **7.3.1 Financial aid to service-users**

In Nigeria, the service-users pay for their healthcare services, including PC, with the exception of about 5% of Nigerians who are largely Federal Government employees who benefit from social health insurance (Uzochukwu *et al.*, 2015). This indicates that



access to healthcare in Nigeria is mainly through out-of-pocket payments, as previously stated in this chapter. The terminally ill patients and their families are faced with socioeconomic hardship, thereby leaving these vulnerable people with the challenge of accessing the care they need to gain improved quality of life, as previously explained in this chapter. In an effort to reduce the financial distress experienced by these patients, the healthcare providers from the palliative and oncology units reported that they provided financial assistance to them because there was no financial aid scheme available for this vulnerable group in Nigeria. These participants allegedly claimed that they make a financial contribution from their pockets to assist patients to pay for morphine, dressing packs, chemotherapy, transportation fare, laboratory investigations and to buy food:

*The nurses here make financial donation to support patient care in this ward especially when the patient cannot afford the cost of the things require for the maintenance of their life (Interview excerpt, Oncology Nurse 4)*

*We sometimes provide money from our pocket to support indigent patients for their dressing pack, transportation fare and feeding (Interview excerpt, Nurse 1)*

*We use our money to buy food for the patients that complain of hunger because they have no money to buy food for themselves (Interview excerpt, Nurse 2)*

*Am sure the nurses would have told you that they support these patients with their own money. I also give them money to support these patients (Interview excerpt, Doctor 1)*

The claim about financial aid from healthcare providers was also professed by most of the service-users during the interviews. In addition, I witnessed several occasions where the nurses and doctors from the PC and oncology units had to make a financial contribution on behalf of patients:

*The nurses and the doctors provide financial help to us. They gave us money to support the payment of laboratory investigation for my daughter. They are trying beyond my expectation (Interview excerpt, Patient relative1)*

*Nurses and doctor contributed money, gave it to me. One of the doctors gave me ten thousand naira and this reduced my worry. I am not regretting my coming to this hospital (Interview excerpt, Patient 5)*

*One of the patients in oncology clinic was seen crying, and the nurses from palliative care and oncology unit including one of the doctors present in the*

*oncology clinic donated some amount of money, gave it to her to support the payment for her chemotherapy. She stopped crying ... (Field note, F43)*

The financial aid provided by the PC and oncology teams to support the care of terminally ill patients could be regarded as a unique attribute of these professionals, suggesting their commitment to, and passion for, PC. This was also demonstrated in the way that the financial support given by members of the PC team was not limited to some service-users who were impoverished and unable to pay for their services, but extended to the funding of patient follow-up and home care:

*The nurses use their money to supplement with buying of recharge card (top-up) for the unit mobile phone, to follow-up the outpatients receiving palliative care (Interview excerpt, Nurse 4)*

*We make expenses like phone calls with our personal money (Interview excerpt, Doctor 1)*

*We sometimes pay our own transportation fare to visit our patients at their homes because hospital did not provide mean of transportation for home visit (Interview excerpt, Nurse 2)*

It seems socially acceptable for a healthcare provider to give personal money to a patient or patient's relative; an act possibly rooted in the Africa ethos of collectivism/communitarianism (Coetzee and Roux, 2002; Ezekwonna, 2005) but this may be considered as unethical and unprofessional in healthcare settings in western countries. For instance, a physician who gave money to a patient to help pay for medication was reprimanded for unprofessional boundary-crossing behaviour in the US (Gordon, 2013). In this current research, the members of PC team may be considered to have extended their care to lessening the effect of the service-users' social circumstance in order to alleviate suffering. However, there could be potential risks arising from these practices, as recognised by Gordon (2013), such as inappropriate expectations, over-dependency for help, and confusion of personal and professional relationships. Although, risks for this practice are possible, this caring relationship did not cause harm to any of the service-users; instead it reduced their suffering, consistent with the purpose of PC:

*We contribute money to assist these patients to make sure they receive adequate care. They appreciate our help for reducing their burden (Interview excerpt, Nurse 1)*

*In palliative care unit, we spend our personal money to help poor patients because we cannot watch them suffer without care. When we render this help to them, you will immediately see laughter on their face and change of their mood (Interview excerpt, Nurse 4)*

*...sometimes, the palliative care team contribute money to assist with patient care so that they can receive the requires services that will promote their well-being (Interview excerpt, Social worker 1)*

Overall, the act of financial aid seemed to be a cultural enabler for PC in this organisation; however, it signifies the irresponsibility and complete failure of the government to support the needs of this vulnerable group through provision of a financial aid scheme or by subsidising the costs of their care, especially for households with poor socioeconomic status. The insensitivity of the government to support the care of terminally ill patients was also demonstrated by the managers of this hospital, who admitted that they had no budget for PC, as identified in chapter six, indicating a culture that does not value the care of terminally ill patients, both in this hospital and in the wider Nigerian society.

### **7.3.2 Interdepartmental collaboration for palliative care**

Interdepartmental collaboration in the context of this research refers to the teamwork among departments within the hospital for the care of terminally ill patients, leading to attainment of specific goals that were not achievable by one department. One core element of PC is the collaborative practice of the interdisciplinary team (Meier and Beresford, 2008), because the quality care of terminally ill patients and their relatives is complex, requiring skills beyond one profession and/or a department. Although the PC team in the studied hospital consisted of multi-professionals, such as a doctor, nurses, a physiotherapist, social workers and a pharmacist, analysis showed that terminally ill patients not only received care from members of the PCU, but also from other departments/units within this hospital. Interdepartmental collaboration was an important norm to understand in this hospital because the PCU depended on referral from other departments/units and, therefore, this norm impacted on the service-

users' access and utilisation of PC. This section explores the perception of collaboration between the PCU and other departments, the actual collaborative practice that existed in this hospital, and how it influenced the provision and utilisation of PC.

The members of PC team expressed two views about interdepartmental collaboration. Firstly, some perceived that some departments of the studied hospital managed terminally ill patients without collaborating with them to gain access to their expertise:

*Many doctors in different department are reluctant to refer patients to palliative care unit for collaborative care (Interview excerpt, Pharmacist Lily)*

*There are many patients that need palliative care in this hospital but other units are unwilling to refer these patients to palliative care unit for collaborative care (Interview excerpt, Doctor1)*

*...we don't get a referral from all the units that should refer patient that will benefit from palliative care services. Some unit that refers, don't refer the patients early (Interview excerpt, Nurse 3)*

Whilst this view was widespread among the professional in PCU, others highlighted that some department/units referred terminally ill patients to them for collaborative care, although the referral was often late:

*Another problem is late referral, the patient is only referred at the third stage of cancer when patient is gasping (Interview excerpt, Nurse 4)*

*Late referral is a problem that affects the services of all the palliative care team members, for instance, during ward round we see many patients that should need palliative care but they are not referred to palliative care unit. Most times, the few of the patients referred to palliative care unit are in their late stage of illness (Interview excerpt, Social worker 1)*

The views about lack of, and late, referral of terminally ill patients to PC were stated by some doctors from other departments. For instance, some of the participants, when asked about how they took care of terminally ill patients in their units, and also about collaborative care with the PCU, said:

*We care for terminally ill patients in our department, though sometimes we refer our patients to palliative care unit especially when it is concerned with pain management ... (Interview excerpt, Head of Department 4)*

*...Eeeh, (Period of silent) .... palliative care unit is still a bit new in this hospital. We do not involve members of the palliative care team with the care of our patients ... (Interview excerpts, Head of Department 2)*

*We do not usually involve them (palliative care unit) until the late stage but they keep informing us of the need to involve them early... (Interview excerpt, Oncology Doctor 1)*

These excerpts are an indication of limited collaboration between the PCU and other departments in the care of terminally ill patients and their families, suggesting that service-users in this hospital may have been unable to access services from experienced and/or specialised PC professionals due to the inadequate collaborative network. For instance, while participating in the daily activities of PC and oncology units, I observed that many patients in the oncology ward and across other wards were not co-managed with the PC team:

*All the beds in oncology ward were occupied by terminally ill patients but palliative care team cared for only two patients in this ward (Field note, F35)*

*Ward 10 was fully occupied by patients but palliative care team provided care to only two patients but there are other patients that looked physically ill appeared to have life-limiting illness (Field note, F32)*

*On arrival, we (palliative care team) saw an unconscious patient, gasping for breath. There was one female patient relative that sat by the patient bedside. One of the palliative care nurses frown her face, lamented that the patient was referred to palliative care unit at her dying stage (Field note, F24)*

My observations confirmed the organisation's norm of lack, and late referral, of patients to the PCU for integrative care, as claimed by the members of the PC team. Interestingly, inadequate knowledge of PC among HCPs, as previously discussed in chapter five, was identified as one of the reasons for this norm. Other identified reasons were struggles for the ownership of patients and lack of awareness about the services of the PCU:

*Patients diagnosed with cancer and other terminal illness are not referred to palliative care unit for collaborative management by the primary unit doctors because of ignorance about palliative care (Interview excerpt, Nurse 4)*

*Palliative care unit is still new. We do not know the extent of things they do and how well they are organised. I am not aware of what services they can offer. If*

*we get to know what they do, they get more involved. If they build their capacity very well, we will partner with them (Interview excerpt, Head of Department 4)*

*...many of the doctors usually say this is my patient, I know what to do! (Interview excerpt, Pharmacist Lily)*

*...they think that we want to take away their patients from them (Interview excerpt, Nurse 2)*

Inadequate knowledge about PC seems to be the core reason for poor collaborative practice in the care of the terminally ill patients. This is perhaps surprising because one would expect that healthcare providers' lack of knowledge and skills in PC should trigger a referral to the PC team for expert management, in consistent with the findings that severity and complexity of symptoms triggered referral to PC team (Johnson *et al.*, 2011). Contrarily in this current study, inadequate knowledge about PC rather hampered the recognition of the necessity to refer terminally ill patients to PCU for co-management. However, previous research has supported the idea that professionals' lack of knowledge or skill may facilitate or hinder referral of terminally ill patients (Bestall, 2004; Aitken, 2006). In addition, it appeared that referral practice was tailored to knowledge about the services of the PC team, indicating that poor understanding by doctors from other departments about the services provided by PCU hampered collaborative networks in the care of terminally ill patients. This was similar to findings by Walshe *et al.* (2008a) and Schenker *et al.* (2014) about issues that influence referral within community PC services and subspecialty PC clinics.

In my own view, based on my observations, the long waiting time for patients referred to the PCU to receive care due to a shortage of manpower, as explored earlier in this chapter, may have also contributed to the reluctance of HCPs from other departments to refer patients to the PCU for collaborative care. It is possible that professionals from other units may have perceived that members of the PCU had no expert knowledge and skills in PC, due to their lack of additional education in PC, as explored previously in chapter five. This may have hindered their zeal to refer patients for co-management. Previous research has supported the theory that professionals' appraisal or judgment about the competence and performance of other professionals to whom they are referring patients influences the decisions about referral and ongoing collaboration in

patient care (Walshe *et al.*, 2008a, Walshe *et al.*, 2008b).

Furthermore, the first part of the statement '*This is my patient, I know what to do*' from Pharmacist Lily, as quoted above, seemed to be a claim for the ownership of the patient, while the second part of this quote suggests a feeling of defensiveness related to perceived criticisms of their clinical professional knowledge of PC. The HCPs chose to be defensive instead of collaborating with members of PC team, perhaps, due to a thought that they would lose control of their patients if they collaborated with the PC team. The decision about referring terminally ill patients to the PCU was, therefore, within the absolute power of the primary physicians, indicating a power imbalance between the PC professionals and providers from other departments. Another possible explanation for '*I know what to do*' could be a feeling that referring a patient to the PCU meant giving up on a patient because of deficient knowledge about their care. It could also mean that HCPs may have felt that they were providing a good standard of care without collaborating with members of the PC team. Based on this finding, there seemed to be interdepartmental conflict regarding role competition, overload and confusion between members of PC units and other departments. Previous researchers, Schenker *et al.* (2014) found similarly that some oncologists considered themselves to have the knowledge and skill to provide PC, while others thought that referring patients to PCU was equivalent to relinquishing their professional responsibilities.

Finally, it is important to note that, in this current research, pain seemed to be a compelling factor for referring a patient to the PCU for collaborative care, as evidenced by some members of the PC team highlighting that patients sent for a consultation were mostly patients experiencing severe pain. They also alleged that other units referred patients to them as a last resort:

*Patient is usually referred to the palliative care unit if they experience serious pain (Interview excerpt Nurse 2)*

*They refer patients to us when they feel they can no longer do anything for the patient (Interview excerpt Doctor 1)*

*...for palliative care team to be involved with the care of a patient, it is either the primary unit has exhausted their care options and then send the patient off to*



*palliative care unit or that the patient is not responding to their pain management (Interview excerpt, Oncology Nurse 1)*

*Some people think that palliative care should be considered as a last resort when other management becomes unsuccessful (Interview excerpt, Physiotherapist, Zoe)*

The referral culture which could be termed as 'pain-based-referral' in the studied hospital indicates that those patients without severe pain but perhaps other unmet care needs, may not be referred to PCU as psychosocial wellbeing is not a primary concern of non-PC professionals. In addition, the act of referring terminally ill patients to the PCU as a last resort further suggest an inappropriate referral culture, which arguably centres more on personal and interpersonal factors between the professionals instead of patients' clinical need for PC. The delayed and/or lack of referral, as alleged by some of the participants exacerbated patients' suffering:

*Most of the doctors that don't refer terminally ill patients to palliative care unit, usually prescribe the wrong regimen of oral liquid morphine. Therefore, the pain of these patients is not relieved (Interview excerpt, Pharmacist Lily)*

*We have seen that most of the terminally ill patients increasingly suffer due to poor pain management and lack of psychological support from other managing units (Interview excerpt, Doctor 2)*

This provides insight that terminally ill and dying patients not co-managed by the PC team tended to experience poor pain relief, because they were deprived of expert pain management and psychological support. Signifying that some terminally ill patients may not have attained an improved quality of life, due to physical distress caused by uncontrolled pain. The interdepartmental collaboration for PC appeared complex in this hospital and seemed to have impacted negatively on the utilisation of PC. However, home-based PC seemed to be a unique practice in this hospital that appeared to be a cultural enabler for the utilisation of PC, which is discussed next.

### **7.3.3 Follow-up for home-based palliative care**

The members of the PC team reported that they routinely visited terminally ill patients, as well as used a mobile phone to contact the service-users while at home, to render support to improve their wellbeing. This claim was reinforced by the service-users, who



reported that nurses from the PCU visited their homes to provide services such as wound dressing, counselling, bed bathing, medication advice and emotional support:

*We, the nurses, routinely visit our patients at home every Wednesday for palliative care. After the home visit, most of the patient relatives usually call us to express their thanks for the visit (Interview excerpt, Nurse 1)*

*The nurses have been very helpful because they often make a phone call to encourage me and find out how am feeling. I call them anytime I have any problem and they provided solutions to my problems. Some of the nurses have visited me too, I felt very happy and encouraged (Interview excerpt, Patient 4)*

*I feel very happy when the nurses visit us. They spend time to discuss with my mother, assisting in bathing, feeding and wound dressing (Interview excerpt, Patient relative 8)*

The service-users felt excited about the practice of home-based care because it provided an opportunity for the nurses to give care which seemed to have improved their physical and emotional wellbeing. Home-based care is intended to improve symptom control and quality of life while the patients are in their homes (Dhiliwal and Muckanden, 2015), and is a practice that is well established in most MEDCs, such as the United Kingdom, and even some less economically developed countries, such as India, but despite the reported good relief of physical symptoms and a significant improvement in overall quality of life (Thayyil and Cherumanali, 2012; Dhiliwal and Muckanden, 2015), this service was reportedly limited for service-users in this current research due to purportedly lack of means of transportation and lack of financial support from the management:

*No vehicle for home visit and I sometimes use my own car (Interview excerpt, Nurse 4)*

*We visit families living in town and the close-by villages because there is no financial support or vehicle to travel to far locations for home visit (Interview excerpt, Nurse 1)*

*There is no vehicle. We need a vehicle to cover both urban and surrounding villages. We need dedicated drivers and vehicle. Our enrollment will increase if we are able to acquire a vehicle for a home visit. Majority of our patients are rural dwellers (Interview excerpt, Doctor 1)*

The members of the PC team were most likely keen to provide wider home-based PC follow-up, but the managers of this hospital were unable to provide the necessary

resources to facilitate its wider coverage due to poor government funding, as explored previously in chapter six. This indicates that the effectiveness of PC practice is, to a great extent, rooted in the economic and political context of the Nigerian healthcare sector.

#### **7.4 Summary of the chapter**

This chapter has clearly demonstrated that the environment within which the PC was set had a great impact on the HCPs, as well as the terminally ill patients and their relatives, in agreement with Environmental Docility Theory. The physical structure for PC was found to be untidy, while the architecture of the space seemed not to support privacy, dignity, and comfort, indicating a symbolic manifestation of lack of '*spaces of representation*' (Lefebvre, 1991), and an uncaring and unideal environment for PC. Given the lack of basic clinical equipment, including poor infrastructure as found in this chapter, it was therefore not surprising that terminally ill patients suffered poor quality of care. In addition, this chapter has shown a gross shortage of manpower for the provision of PC, with the available staff frequently engaged in temporary stoppage of work as a result of the poor working conditions.

Furthermore, this chapter has not only revealed the environmental issues related to human and material resources, but has also shown the complexity of PC provision in this hospital, through the identified unique healthcare norms. Remarkably, it was found that healthcare providers routinely provided physical cash to some terminally ill patients to pay for their medication and other needs, with the intention of alleviating their suffering, although with some naivety regarding the possible risks of doing this. The findings related to interdepartmental collaboration could also be considered alarming, given that decisions about referral of terminally ill patients to the PCU were not mainly based on the clinical needs of the patients, but on what could be referred as the professionals' biased judgements, rooted in their lack of knowledge of the benefits of early collaborative cancer care. Lastly, it was reassuring to find that members of the PC team showed dedication to the PC service, to the extent of using their personal resources to conduct follow-up for home-based PC in an effort to

improve the service-users' quality of life, despite the lack of logistics, such as vehicles, and encouragement from the hospital. In a nutshell, it can be deduced that the components of a physical environment (pure air, pure water, cleanliness, efficient drainage and light) noted by Florence Nightingale (1964) in her thoughts about the necessity for improving patient wellbeing were inadequate in this hospital, indicating that the hospital's environment for the care of terminally ill patients required improvement. The chapter produces some interesting findings that may be used by policymakers as indicators of how to plan or modify a physical environment in order to enhance quality of life and ensure a good death for terminally ill patients.

### **ORGANISATIONAL ETHNOGRAPHY OF PALLIATIVE CARE: DISCUSSION OF THE KEY FINDINGS AND CONTRIBUTIONS**

#### **8.0 Introduction**

This chapter presents a discussion of the key findings of the cultural themes which provided rich and holistic insights into the cultural, social-political, environmental and organisational dynamics that influenced the provision and utilisation of palliative care (PC) in a Nigerian hospital. The key findings have been grouped into three sections to distinguish between the cultural elements related to the service-users, the professionals and the governance/administration whilst focusing on the three questions explored in this study: what are cultural and socio-political factors that influence the provision and utilisation of PC, how do cultural and socio-political complexities influence behaviours towards provision and uptake of PC and in what ways do environmental and organisational dynamics shape the professionals' and service-users' provision and use of PC.

This chapter also draws all the cultural elements together, presented in form of conceptual framework explaining the provision and use of PC in the studied hospital. This was followed with a discussion of the theoretical and practical implications of the ethnography, specifically, considering the contributions to knowledge of this field this study makes and offers recommendations for health care practice, policy and education. Some of the study's limitations are articulated in the final section of this chapter. The holistic cultural scene about the culture of PC is discussed in the following section.

#### **8.1 THE CULTURE OF PALLIATIVE CARE IN A NIGERIAN HOSPITAL**

##### **8.1.1 Elements of the culture related to the healthcare providers**

The healthcare providers were found to possess sets of beliefs which were rooted in societal cultural and religious beliefs, and these beliefs pertained to the purposeful intervention of either supernatural/nonhuman beings or agents acting for the beings. For instance, some of the participants (two doctors, a physiotherapist and a nurse)

repeatedly affirmed their belief in spiritual attack by nonhuman beings, such as ancestors, a ghost or evil spirit, or a supernatural being, such as a deity, being the cause of terminal illnesses. For these healthcare providers, their sense of reality and their perception of the causes of terminal illness were deeply embedded in their cultural and religious beliefs. This concurred with previous literature, which argued that religion, as well as culture, plays a crucial role in shaping the perceptions of life and death, including the approach to end of life care (Crawley, 2005; Edward *et al.*, 2010; Loiselle and Sterling, 2011; Phelps *et al.*, 2012; Scott *et al.*, 2014; Renz, 2016; Fang *et al.*, 2016).

However, it was only a minority (four out of twenty-three) of the healthcare providers that based their understanding of terminal illness in their belief systems rather than in the western biomedical model of disease causation. Those that subscribed to these belief systems, surprisingly, perceived themselves as an instrument being used by a supernatural being (God) to offer miraculous healing to patients. Thus, for these healthcare providers, care delivery for terminally ill or dying patients was aimed towards curative measures rather than palliation, signifying the use of beliefs to foster unrealistic hopes while denying the reality of death and dying. This finding fits well within terror management theory which is grounded on the basic idea that humans are motivated to suppress the potential for terror inherent in their awareness of mortality by investing in cultural worldviews that imbue life with meaning in order to maintain the standard upon which self-esteem is based (Greenberg *et al.*, 1986); it provides a theoretical basis for understanding the behaviour of the healthcare providers who have developed and maintained their constructed beliefs (cultural worldviews) which shaped their actions/practices in providing care to terminally ill and dying patients. Broadly, this also aligned with the indigenous culture of the Igbos in south eastern Nigeria, who believe in the celebration of life, while despising death (Chuku, 2013). Furthermore, this aligns with the mortality salience hypothesis which is one of the fundamental propositions of TMT (Pyszczynski *et al.*, 2015), in that some HCPs increased their commitment to protection provided by their cultural worldviews as their awareness of potential death from life-limiting illnesses increased.

It could be argued that the majority of the clinicians may have replaced the power of religious beliefs to influence their thinking and behaviour by power of the biomedical knowledge. Thus, provision of PC was largely based on conventional medical practices in this hospital. The shift from using cultural worldview to biomedical knowledge by most of healthcare professions in shaping the behaviour regarding PC practice corroborates with Blumer's theoretical proposition that shared meaning could be recreated and modified based on fresh perceptions and interpretation people give to the world of their objects (Blumer, 1969). It also agrees with the predictions made by Weber (1963) and Durkheim (1965) in their respective writings about religion, that scientific thinking would replace religious thinking as society modernises and that the world would increasingly become secular. Giddens and Sutton (2013) noted that the secularization debate continues to reverberate, even after more than a century of theorising about it. The findings of the current research concurred with other proponents of secularisation, that religion was far more important in people's daily life in the past than it is today. However, this was applicable to healthcare professionals whose social metrics, particularly, higher education attainment and socioeconomic status, seemed to exert meaningful influence on their behaviour towards PC, unlike the service-users, as discussed earlier in chapter five. In support of this finding, the Gallup poll on the global perspective of the importance of religion showed that a high percentage of people in the poorest Sub-Sahara Africa and Asia areas considered religion to be crucial in their daily lives, unlike wealthier countries, with exception of the USA (Crabtree, 2010). This confirms the conclusion that belief systems (religious and cultural beliefs) remain stronger in circumstances of poor levels of education and hardship, but as socio-economic development improves, belief systems tend to modify.

Furthermore, it is perhaps interesting to note that some of the healthcare providers (HCPs) experienced a dichotomy between biomedical knowledge and 'ethno-religious knowledge' about terminal illness and approaches to care delivery. For instance, 'Nurse 3' and 'Doctor 3', who agreed on the supposed reality of spiritual attack, stated that they did not believe that all illnesses were caused by spiritual attack, especially when

there was an understanding of medical causes and treatment. This clearly disclosed that some HCPs applied their indigenous beliefs, or what I have termed 'ethno-religious knowledge', to understand and interpret a life crisis (terminal illness) when they lacked scientific understanding (biomedical knowledge) of the problem, contributed to by their inadequate training and education regarding PC, as highlighted previously in chapter five. It is plausible to reason that when the HCPs lacked scientific rationality or biomedical understanding about the care of terminally ill patients, they tended to negotiate meaning by using their cultural worldviews to form a situational or appraised meaning upon which PC would be based. Thus, they relied on supernatural powers for divine intervention while tacitly supporting practices such as prayers, fasting or sacrifice to achieve healing or cures, rather than focusing on the medical measures or practices that would relieve suffering, enhance quality of life and promote good death.

Secondly, education and training were key aspects of cultural understandings related to healthcare providers. Sociologists have argued that education and training is an important social institution that perpetuates and reinforces social rules for action and behaviour (Giddens and Sutton 2013; Little and McGivern, 2013). Similarly, the proponents of functionalism, such as Durkheim (1965), argue that education contributes to manifest functions (intended and visible functions of education, such as socialisation, transmission of knowledge and skills) and latent functions (hidden and unintended functions such as formation of social networks). This denotes that education is not only crucial for the transmission of a society's values (cultural and religious beliefs), moral rules and the acquisition of knowledge/skills required in a highly specialised occupation such as PC, but that it also facilitates the development of social ties and tacit knowledge. In Nigeria, the educational curriculum has been designed to inculcate religious and cultural values to pupils and students, reinforced through the compulsory teaching of social studies and religious knowledge, both in primary and secondary schools (Ikwumelu and Oyibe, 2015), thus facilitating cultural reproduction. Therefore, Durkheim argued that each culture has a network of self-referential logic grounded in the reality of their respective social framework that create truth which are legitimate. Foucault (1980) presented a contrasting view, contending

that 'truths' are negotiated in discourses and discourses form what could be perceived as acceptable and or forbidden in any society, thus suggesting that discourses convey and order realities which regulate an individual's ways of thinking (Cheek, 2000). Interestingly, discourses may include bodies of knowledge or sets of acceptable norms at any particular time in a given society and are used to determine realities (Foucault, 1977). Therefore, a set of identified cultural and religious beliefs about terminal illness, including palliation, as presented in chapter five, may have been learnt within both informal and formal education.

Healthcare professionals in this society were found to have internalised these belief systems and used them as social codes for behaviour, informing decisions about the care of terminally ill patients when discrepancy existed in the general orienting system when viewed in line with theoretical construct of shared meaning in accordance with SI as well as meaning making model (Park, 2009; Park and Folkman, 1997) or simply when their biomedical knowledge was not sufficiently well developed to understand the pathology of terminal illness. For instance, all the healthcare professionals were found to lack the specialised PC knowledge and skills such engaging with difficult conversation required to deliver quality PC, except for the two nurses who stated that they had undertaken brief general training in PC in an institution abroad. The document on APCA standards for providing quality PC across Africa (APCA, 2010), specified that a hospital that provides tertiary/specialist level PC should: meet the complex communication needs between service-users and the HCPs; have some professionals qualified at specialists' level; support the development of PC curricula; and the HCPs support and deliver PC education/training programmes for secondary and primary levels of care. These criteria were found to be lacking in the studied hospital. Other researchers in Nigeria also have acknowledged the absence of a PC training institution/university in Nigeria (Soyannwo 2007; Onyeka *et al.*, 2013; Oyebola 2017), and this may have militated against clinicians' lack of intermediate and specialist knowledge about PC, as identified by this current research and other previous research conducted in Nigeria (A Moran *et al.*, 2012; Fadare *et al.*, 2014a; Fadare *et al.*, 2014b),



thus, providing an understanding as to why some healthcare professionals used cultural discourse to construct a truth which governed their PC practices.

Inadequate PC education and lack of university curricula/training programme have been widely identified, even in some high-income countries, such as Germany, Malta, Finland, Austria, Belgium, Greece, France, Italy, Norway, and Luxembourg as one of the barriers to PC development in consort with provision of PC by healthcare professionals (Lynch *et al.*, 2010; Fink *et al.*, 2013). What appeared unique in this current research was a total lack of a PC training institution/university in Nigeria contrary to APCA standard 4.1 for providing quality PC across Africa (APCA,2010), rooted in lack of political will and commitment by the political leaders, as previously discussed in chapter six. Unlike studies conducted in MEDCs that found that some professionals, especially in rural areas, had inadequate education and training in PC due to insufficient PC training institutions (Lynch *et al.*, 2010; Fink *et al.* 2013), most African countries, like Nigeria, seemed to also completely lack educational programmes, except Uganda and South Africa that have integrated PC training programme into their universities, as elaborately discussed in the literature review chapter of the thesis. It may be reasonable to argue that most of the healthcare professionals involved in the care of terminally ill patients and their relatives in Africa, including the studied hospital, performed their work (PC) without adequate knowledge and skills, as was also found by previous researchers (Uwimana and Struther, 2007; van Gurp *et al.*, 2015; Akinyemiju *et al.*, 2015), who reported that healthcare professionals in Rwanda and Nigeria discharged their duties without formal training in PC. Nevertheless, it is encouraging to note that members of the PC team in this current research, in keeping with the findings of Fink *et al.* (2013), repeatedly emphasised their passion and interest in acquiring specialist PC knowledge about communication techniques, pain management and end-of-life care issues.

The healthcare providers' limited knowledge and expertise, identified in this current research, caused additional difficulty for the service-users. For instance, many of the doctors and some nurses repeatedly admitted that they withheld information from

service-users about their diagnosis, management and prognosis, similarly to the findings of a study conducted in Ethiopia by Kass *et al.* (2014) but against criteria for achieving APCA principle 2, standard 2.3 for providing quality PC across Africa (APCA, 2010), suggesting a manifestation of their lack of effective communication skills to engage in difficult end-of-life discussions, though this may also be connected to beliefs about information sharing in end of life cases. In relation to the former, the clinicians avoided or deferred these discussions to prevent the associated negative reactions, which they had no adequate skills to manage. Non-truth telling, associated with inadequate education of the professionals, appeared to be embedded in the clinical practice of PC in the studied hospital. As previously identified by several studies conducted in the same hospital as this current study, physicians did not disclose information about diagnosis and prognosis to cancer patients, despite the perceived readiness and desire by the service-users for this information (Nwankwo and Ezeome 2011; Nwankwo *et al.*, 2013). This highlights that delivering of diagnostic and prognostic information continued to be problematic in the studied hospital.

Medical paternalism including non-disclosure or withholding of information about cancer diagnosis and prognosis used to be a practice in MEDCs, such as the UK, Canada, Finland and USA (Garrett *et al.*, 2009; Will, 2011). Albeit, this situation has changed. For instance, in 1961, 90% of 219 physicians in the USA reported their preference not to disclose diagnosis of cancer to their patients (Oken, 1961). Almost two decades later, 97% of the 264 physicians used in a study in the USA were communicating a diagnosis of cancer to their patients (Novack *et al.*, 1979) and this is still a strongly held ethical principle in the USA (McCabe *et al.*, 2010; Sisk *et al.*, 2016; Rising, 2017). This showed a shift in culture of care but may particularly indicate a change in approach towards truth-telling of terminal diagnosis/prognosis in the USA, but this situation is not reflected in all the MEDCs countries, since telling the truth to terminal cancer patients is still not completely acceptable in some cultures especially those with deepened ethos of family-centeredness or collectivism such as China, Croatia and most of the Asian countries (Li *et al.*, 2008a; Khalil, 2013; Murgic *et al.*, 2015; Liu *et al.*, 2018). In the UK, Bailey *et al.* (2018) highlighted that doctors who

practiced in the memory clinic expressed dilemma between honesty, hope and uncertainty in communicating diagnostic, prognostic and treatment information. Although this finding was in relation to dementia, it may be extrapolated to other illnesses that require palliation, suggesting that sharing information to patients and their families with serious illnesses is challenging to some HCPs even in MEDCs. Communicating terminal diagnostic, prognostic and treatment information should be a process (Bailey *et al.*, 2018) instead of one-time event as was done during 'family meeting' organised occasionally by members of PC team in the current study. It also requires skilled and sensitive practice by the clinicians (Bailey *et al.*, 2018) yet, the healthcare professionals in the current research demonstrated no such skill rooted in their inadequate education and training as previously discussed above.

Healthcare providers' inadequate knowledge and expertise were also found to be part of the complexity related to interdepartmental collaboration among healthcare professionals, which played a role in communication styles or end-of-life discussions. As presented previously in chapter six, there was weak collaboration between the PCU and other departments/units, which was manifested by lack of, and late referral of, terminally ill patients to the PCU. This resulted in what could be termed as 'situational deprivation' of the service-users from access to, and utilisation of, PC. This organisational norm was found to be rooted in role competition, complexity, overload and confusion amongst the different departments/units who were involved in the provision of care to terminally ill patients. However, French *et al.* (2011) and Ram *et al.*, (2011) noted that conflicting role demands is a common organisational culture amongst team members of different departments/units. One of the striking revelation in this current study was that the Heads of these departments and their members, including the managers of this hospital, had not identified role conflict, overload or ambiguities as an issue and, therefore, had not undertaken any action to clarify role expectations for the care of terminally ill patients in this hospital. The dissention that existed amongst the different departments/units and the irresponsibility of the heads of department and the managers of this hospital to address these issues can be attributed to the widespread inadequate knowledge of PC, thus leading to the failure

of this hospital to formulate guidelines or protocols for interdepartmental collaboration contrary with APCA criteria for standard 1.1, 1.3, 2.1 and 2.2 which underpin the principles of governance, leadership, management and holistic PC provision across Africa (APCA, 2010). Consistent with the finding of this current study, lack of knowledge of PC contributed to by inadequate training was an obstacle that has been widely identified to impede referral to PCUs or collaboration by other professionals with a PC team (Brickner *et al.*, 2004; Fadul *et al.*, 2007; Hardy *et al.*, 2008; Bradley *et al.*, 2011; Horlait *et al.*, 2016).

This current study, however, provided new insights, namely, that the environment presented constraints, such as the absence of a means of communication (lack of telephones and organisational emails), which appeared to add to the complexity of the collaboration between the PCU and other departments/units. Previous research has shown that communicating clearly and effectively is one of the indicators of successful collaborative practice (Suter *et al.*, 2009). However, drawing from the theoretical insights of motivational theories, particularly reinforcement theory (Skinner, 1953) and expectancy theory (Vroom, 1963), the managers of this hospital could improve interdepartmental collaboration regarding the care of terminally ill patients. Reinforcement theory, also known as behavioural modification, is based on the idea that behaviour is learned through the operant condition of positive reinforcers, which in this instance could be providing essential training for the staff, and conditions (resources and policies) that will facilitate effective collaboration. Rewards (which might either be praise or recognition) could also be given to departments or to the unit if they achieve improved quality of care for the terminally ill patients and their families through interdepartmental collaboration, in line with expectancy theorists, who believe that rewards will stimulate positive behaviour. This section has shown that cultural elements peculiar to the healthcare providers were interlinked with a wider spectrum of cultural, socio-political and organisational issues, which influenced provision and uptake of PC. The next section discussed and summarised the key cultural elements peculiar to the service-users.

### **8.1.2 Elements of culture related to the service-users**

The majority of the terminally ill patients and their relatives in this study were found to have used their cultural and religious beliefs in constructing meaning about their terminal illness and palliation and this influenced their actions or behaviour towards the use of PC. Specifically, the service-users consistently provided two causal explanations for terminal illness: that terminal illness was attributed to 'evil others', and mystical or supernatural causes, which fits into one of the perspectives about disease-theory system. Foster (1976), writing about the disease-theory system, explained that all cultures have attributional concepts to identify, classify and explain illness causality. He acknowledged that various disease causation theories exist but argued that the two broadly held explanatory philosophies which many people use to account for the causes of illness/diseases could be identified as naturalistic and personalistic (Foster 1976). In naturalistic theories, disease causation tends to be viewed as when there is imbalance or disharmony between human being and his or her environment. While personalistic paradigm attributes the cause of illness to the intervention by agents such as a supernatural force (deity) and another human (evil persons) or non-human (evil spirits) forces, and this appeared congruent with the beliefs of the service-users about terminal illness in this current research. In addition, Read (1966) noted that there were three groups of illness that existed in the African context, and these were trivial illness (illness that can be treated by home remedies), European disease (a disease that can respond to Western scientific treatment) and African disease (a disease not likely to respond to Western medicine).

Remarkably, the ancient belief about African disease or personalistic causality was still being upheld by service-users because they perceived that PC or conventional treatment was inappropriate to produce their desired outcome, which was a cure. This could be surprising because, in the 21<sup>st</sup> century, one would not expect people challenged by illness to attribute the causes of their condition to issues which lacked scientific credence. Drawing from the theoretical insights of S.I, this could indicate that defining process, shared meaning and interpretations about the causes of terminal illness have not been reconstructed or modified by most of the service-users, possibly

because they have not been exposed to conditions (such as adequate information) that could change their perceptions and process of indications as found in chapter five. However, these findings correspond with previous research, that people from African cultures (black African, African American, and Ethiopians) attributed causes of chronic progressive illnesses to destiny, the will of God, spiritual attack, and evil spirits, rather than biomedical causes, as in accordance with the naturalistic paradigm (Mulatu, 1999; Waldron-Perrine *et al.*, 2011; Koffman *et al.*, 2015; Hayward *et al.*, 2016). Thus, the ancient African culture of using a belief system to explain the causes of illness is still evident in modern African society today, but this was more evident for the service-users that had no, or only a low level of, education. Ezeome and Anarado (2007) found that cancer patients from the University of Nigeria Teaching Hospital who had had no formal education were more likely to have used complementary and alternative medicines than those who had had up to post-primary education, and more. This confirms the findings of the current study that educational status contributed to the perception of terminal illness and the use of PC, which concurred with Albert *et al.* (2008), who found that African Americans would be more likely to construct meanings that were not based on scientific reasoning than Caucasians, due to their poor level of education. This clearly shows, in line with the findings of this research, that service-user knowledge about terminal illness was rooted in their cultural and religious philosophy and why cultural driven perceptions impacted on the demand for PC. However, the current research also found that for some individuals, the use of a cultural lens to perceive illness was regardless of the level of education and other social metrics. It may be interesting to point out that the HCPs, who were supposed to educate service-users about their illness, were, instead, withholding information about their diagnosis, management and prognosis for the reasons discussed above (see section 8.1.1).

Furthermore, as a consequence of the service-users' cultural perception and attribution of the causes of their terminal illness, most of them resorted to denial because they preferred curative care even when PC was more appropriate. They pursued non-orthodox care, perceived to be a life-prolonging treatment. Ajzen and

colleagues in their theory of planned behaviour highlighted that some psychological variables (intentions, attitude, subjective norms, social norms and perceived behavioural control) underpin many behaviours, including healthcare utilisation (Ajzen and Fishbein, 1980; Ajzen, 1985;1991). Thus, drawing from this theory, the explanation for most of the service-users' unwillingness to utilise PC could be that it was considered as giving up hope of a cure. Ajzen (1985) stated that attitude is the degree to which one has either negative or positive evaluation of behaviour. The service-users who considered that the outcome of the performing behaviour (use of PC) would not yield their intention (a cure) would not seek PC services, while some of those already admitted for PC even requested to be discharged. Service-users' expectations of a cure rather than palliation indicate a lack of understanding of what can be gained from the palliation of symptoms. It may also indicate an attempt to protect their sense of self-preservation and self-esteem, thereby subduing mortality awareness while increasing their commitment to psychological security by clinging to the cultural worldviews that give life meaning, purpose and significance in line with TMT (Pyszczynski *et al.*, 2015).

Continuing on the insight from planned behaviour theory, Ajzen (1985) defined subjective norm as a belief about the normative expectations of other people. He argued that this shapes human decisions regarding an action or behaviour on the basis of whether significant others approved or disapproved of the behaviour in question; this was the case in this current research. The service-users were found to be socially influenced by other people, such as friends, family members, neighbours, peers within their social networks, and this network of relationships influenced their decisions about the use of PC. It was found that the social interactions and cordial relationships that existed between the service-users and the members of their social circles yielded social support, particularly informational support in terms of advice, suggestions and recommendations to the ill members within the social network. The service-users learnt the social rule or customary code for behaviour (use of PC) through their interactions with the network members. This concurs with symbolic interactionism (Blumer, 1969), which was based on the premise that meanings ascribed to things come from our interactions with others, which, in turn, influences ones' behaviour or

actions due to the shared meaning of a phenomenon. Consequently, relationships amongst individuals in society seem to be fundamental to explaining an individual's action or behaviour. In this research, most service-user attitudes of non-acceptance and reluctance to use PC were attributable to the information made available to them by the members of their social network, who they appeared to trust.

Interestingly, it appeared that the level of knowledge held by members of the social network about terminal illness and palliation had a contributory connexion with the information provided to the terminally ill patients. Whilst individuals with social connections with the service-users appeared to genuinely want to help through informational support, they unintentionally passed on erroneous information that predominantly discouraged the service-users from accepting and using PC. As stated earlier in this section, many people from this ethnic group held a personalistic view of terminal illness. Thus, the advice and recommendations readily available for the service-users about terminal illness and the place for care were based on their indigenous belief systems. The negative impact of social networks in the use of PC was similarly reported by Horlait *et al.*, (2016), who highlighted that interactions with family members hampered oncologists from discussing PC with the service-users. However, social networks can produce a positive impact, as seen in the work by Hyde *et al.*, (2011), where the relationship which developed among the service-users with members of their social network that sought palliative day-care in the UK promoted positive healthcare seeking behaviour. Notably, Dame Cicely Saunders founded the modern hospice movement in the UK over 51 years ago (Saunders, 1967); thus, public knowledge about palliation, which may have influenced relational process, would be at a much higher level.

Although the uptake of PC was influenced by the knowledge and complex social interaction that existed among service-users and members of their social circle, it is essential to highlight that another additional concern, namely, their economic situation, was also found to influence options service-users may have had, despite their desires. Many of the terminally ill patients and their relatives belonged to the lower



socio-economic class, and this intersected with the choice they could make regarding uptake of PC. Consistent with Ajzen's (1985) theory of planned behaviour, the extent to which people have requisite resources and consider that they can manage any obstacle they may encounter will boost their confidence in performing the action or behaviour. Thus, level of economic status also shaped behaviour regarding the use of PC and this coincides with Ajzen's supposition that perceived behavioural control may facilitate or impede the performance of behaviour. The out-of-pocket payment system that was operational in this hospital, in conjunction with the service-users' poor economic status, was found to impede the use of PC. To further substantiate this assertion, most of the service-users repeatedly stated that their lack of money to pay for care made them look for non-orthodox care, since it was cheaper. Poverty or low economic status was similarly identified as a risk factor for poorer health among uninsured or underinsured individuals in the USA (Artnak, *et al.*, 2011). The absence of government subsidies or insurance cover for cancer and PC in the studied hospital and other hospitals in Nigeria, as also revealed in 2015 Quality of Death Index (EIU, 2015), contributed to a poorer quality of life for the terminally ill patients because they had limited access to PC, due to their inability to afford the cost of care. The APCA document for providing quality PC across Africa, under standard 2.7 (psychosocial care), recommends that patients and their families should be given opportunity to discuss their social/practical needs and options to address these needs are identified and implemented to alleviate their social burden (APCA,2010), but such system of support were unavailable in the studied hospital. Although, some service-users may genuinely have been unable to afford the cost of their care, the findings in this current research suggest that the underlying beliefs about terminal illness, including the attached 'label' of the high cost of cancer care in this cultural environment, were a more critical issue that deterred the willingness to use PC.

Finally, unemployment prior to, and as a consequence of, the illness was unanimously mentioned by the service-users and the healthcare providers as contributory to the underlying cause of the service-users' poor economic status. Remarkably, the socio-political factors were found to be a more complex issue that generate and maintain

poverty at both individual and the hospital levels, and this impacted on the use, as well as the provision, of PC. These complexities are discussed next.

### **8.1.3 Elements of culture related to governance**

The managers and the HCPs unanimously perceived that those who controlled political power and their allies (the bureaucrats) were the basic obstacle for healthcare provision, including PC, in Nigeria. Weber (1978) argued that bureaucracy is indispensable in modern societies since it is designed to attain rational objectives in the most effective and efficient way. However, Weber's viewpoint about bureaucracy was not consistent with the findings of this current research, because it appeared that the Nigerian bureaucracy was characterised by lack of transparency, unaccountability and unresponsiveness, which suggests a state of poor governance. As previously presented in chapter six (see 6.1.1), the participants alleged that state bureaucracy comprised a system within which bureaucrats used their political power to control and use public resources for their personal interest. In addition, these participants further highlighted that most of the political leaders manipulated the political system to attain a position of leadership and that they also appointed people to positions of leadership based on sentiment rather than merit. This indicates that the government did not appear to have carried out their responsibilities effectively, such as management of the country's resources and formulation of policies that would improve the wellbeing of their populace. The findings about the inefficiency of the political actors may not be surprising, especially to people familiar with Nigeria's socio-political circumstances, since several scholars, researchers and international agencies have documented that Nigerian bureaucracy is riddled with nepotism, incompetency, misappropriation of funds, ethnic loyalty and other forms of corruption (Achebe, 1984; Khon, 2008; Arowolo, 2010; Nwaza, 2012; Okorontah and Odionye, 2015; Transparency International, 2018). Importantly, this finding provides evidence that may enhance understanding of the underlying conditions that facilitated the poor development of the healthcare delivery, including PC, in Nigeria.

The tacitly accepted cultural-political norm, in which bureaucrats use their political positions to accrue wealth for personal interest, seemed to reduce the ability of the

government to finance healthcare services such as PC. Overall, national governance was found to have impacted on the healthcare delivery with regard to structural organisation and funding. Firstly, it was revealed that the healthcare delivery system in Nigeria comprised both orthodox and non-orthodox pathways, with multiple subdivisions in each category. This finding may not be new, since several research and opinion papers have underscored that Nigeria operates a pluralistic healthcare system comprising alternative, traditional faith-based, spiritual and conventional medical care (Adefolaju, 2014; Uwakwe *et al.*, 2015; Adeloye *et al.*, 2017; Adekannbi, 2018). However, what seemed new about multiple healthcare deliveries in Nigeria was the uncovering of its impact on care of terminally ill patients, such as difficulties with decision-making about care and confusion about appropriate place for care, which influenced the use of PC. Thus, it can be construed that the heterogeneous structural system of healthcare delivery in Nigeria has made access to healthcare unnecessarily complex and has negatively influenced the behaviour of the service-users in the use of PC.

A more disconcerting finding about the multiple healthcare delivery was its defective nature, or what the participants termed as a 'dysfunctional system'. Both orthodox and non-orthodox pathways were alleged to be ill-functioning in terms of inadequate resources to meet the healthcare needs of the service-users. This was linked to lack of political will by the bureaucrats to formulate and implement policies to synchronize the two structures that operated alongside each other in the Nigeria healthcare delivery system. The HCPs and members of the hospital management also believed that this situation (dysfunctional system) was rooted in leadership failure, particularly in the political norm, where the bureaucrats misappropriated the public funds allocated to the healthcare delivery. This finding reflects those of other scholars who have noted that the high level of corruption and bad governance has led to an economic downturn affecting every aspect of social life in Nigeria, but especially healthcare delivery (Ejimabo, 2013; Gberevbie *et al.*, 2014; Ijewereme and Dunmade, 2014; Kemp, 2017). In support of the findings of this current study, these scholars argued that corruption has long been persistent in Nigeria, due to the incompetency

of the leaders and lack of drive to formulate policies that will minimise corrupt practices. It was particularly striking to note that the bureaucrats appeared to be reluctant to address the dysfunctional multiple structure of the healthcare delivery because they benefited from this ineffective system through receiving bribes, therefore, becoming unconcerned about the performance of both orthodox and non-orthodox pathways.

Secondly, inadequate funding for healthcare delivery by the bureaucrats was another finding which influenced the provision and use of PC. It was not unexpected to hear from all the key managers and most of the HCPs that there was insufficient national budget for the health sector, which influenced the performances of hospitals in Nigeria. Literature on healthcare system financing in Nigeria has consistently acknowledged that the healthcare system is challenged by poor budgetary allocation, a high rate of out-of-pocket payment, the lack of a public social safety net and/or poor social health insurance coverage (Onoka *et al.*, 2011; Riman and Akpan, 2012; Olakunde, 2012; Obansa, 2013). Although, poor healthcare financing impacted on the adequate provision of all aspects of healthcare services in Nigeria, PC was found to be especially affected. The HCPs and managers of the study hospital unanimously stated that PC was not recognised in the national healthcare budget, implying that no funds were allocated for this service, unlike other aspects of healthcare. However, it was unexpected that no money from the healthcare funding received from the Federal Government by the managers of the studied hospital was allocated to the PCU. In addition, the conceptualisation of PC by some of the managers as the '*dead end*' of healthcare services explains this unexpected norm whereby funding was spent on the care of patients believed to have potential for recovery over patients that were dying, signifying their lack of knowledge of the benefits of PC. Arguably, this norm could be situated in the longstanding Western-based medicine being practiced in Nigeria, with a core goal directed to saving life rather than palliation.

Furthermore, the behaviour of the managers and the political actors regarding how the limited funds were allocated to different aspects of health care services can be

understood based on the Maslow's motivational theory on the hierarchy of needs. Maslow states that people are interested to achieve certain needs and that some needs are highly prioritised over another; noting that order of need might differ due to individual differences or external situations (Maslow, 1987). Drawing from this theory, it could be that PC was a lower priority for the managers in the studied hospital, as well as the national government; consequently, funding of other healthcare services took precedence over it. It is plausible to infer that national, as well as the organisational, culture placed higher value on curative measures and provided more resources towards achieving this need rather than the need for palliation. Insufficient funding of PC compelled terminally ill patients in this current research, as well as in previous research (van Gurp *et al.*, 2015), to present late or not at all for PC, due to the absence of health insurance coverage for, and lack of subsidy for the care of, the terminally ill.

Additionally, poor funding also influenced the human and material resources, reflected in the environment for the provision of PC in the studied hospital. The UK hospice movement has been applauded for its recognition of the importance of environment for the service-users approaching end of life (Warpole, 2009). However, it was disappointing in this current research that the physical environment for PC was found to be a source of added distress experienced by the terminally ill patients and their families. This is because the material resources, such as physical structures, clinical equipment, ward layout, and the interior and ambient features, were either lacking or poorly maintained. In this hospital, a clinician had previously documented that their patients were nursed in large open wards with little privacy and that there was no pipeline to deliver oxygen to service-users (Onyeka, 2011). This was still the situation in this current research, which suggests that there had been no improvement in the material resources for the provision of PC in this study setting. The deprived condition of the physical environment in relation to material resources signified lack of place-making or what could be termed as 'nobody's business', since the National Government, as well as the managers of this hospital, had failed to allocate funds, or to formulate and implement policies aimed at enhancing PC development which could

contribute to improved quality of life for the terminally ill patients and their families, as previously explored in chapter seven of this thesis.

Although the inadequate physical environment had clearly had an impact on the terminally ill patients, the hospital environment also appeared to be suboptimal for the provision of care by clinicians. In addition, the environmental needs of the families appeared to be neglected in this hospital. For instance, the HCPs consistently stated that they worked in uncontrolled high room temperatures and were faced with the problem of inappropriate ward layout, including shortage of equipment, which increased their work stress, suggesting their lack of satisfaction with the care they provided. The ambient environmental condition was found by Shepley *et al.* (2012), and in this current research, to impede staff from functioning effectively, and this, as well as a shortage, or the poor condition, of hospital equipment, could decrease the quality of care given to the service users. It was also found that there was no space for the family relatives to grieve or relax, but more remarkable was that there were no recliners for the families who spent days and nights caring for their dying family member. Instead, the family relatives were repeatedly observed to have to sit or sleep on the floor at the back of, or within the ward in, the hospital, which further supported the claim about lack of care for the caregivers.

With regard to the human resources for PC, the HCPs repeatedly mentioned that staffing was inadequate, especially for the PCU. It was perhaps shocking to find that only one physician mainly worked in the PCU, with four nurses, two social workers, and a physiotherapist. However, what appeared more astonishing was that the doctors who worked in this unit were not employed by the hospital managers for PC but, rather, were employed for other services. This implied that there was no physician being paid for the provision of PC in this hospital; rather, the managers of the hospital appeared to recognise these physician as volunteers in the PCU. Furthermore, it was found that all the members of the PC team had no formal training in PC, with the exceptions of two of the nurses, who had received six weeks training in PC abroad. This showed that the studied hospital operated below the APCA standards for providing

quality PC across Africa, particularly standard 4.1 (training for professional care providers) which stressed that some HCPs in the tertiary care level must hold specialist PC qualification that enable them to practice within competency level that promote safe and quality PC for patients and their families (APCA, 2010). This finding is consistent with that of the Economist Intelligent Unit's Quality of Death Index, which showed that Nigeria scored 2 out of 5 indicators in the human resources category, signifying a '*shortage of specialised palliative care professionals, and accreditation of specialist palliative care is not the norm*' (EIU, 2015:32). Only five formally qualified physicians and four formally qualified nurse specialists were noted to practice PC in Nigeria as at 2011 (Lynch *et al.*, 2013). The comparison of the 2015 Quality of Death Index with this current research indicates that Nigeria appears not to have made any significant progress in improving human resources for PC. Several other Nigerian studies, although opinion papers, similarly acknowledge the shortage of manpower and the absence of a PC training institution as a challenge for its development in Nigeria (Onyeka, 2011; Shambe, 2014; Ojimadu and Okwuonu, 2015; Oyebola, 2017). The shortage of staffing for PC was found to be the result of joint irresponsibility by both the political actors and the managers of the studied setting in terms of poor funding of the entire healthcare system and unwillingness to allocate funds for PC. The insufficient staffing contributed to staff unavailability through work stoppages (strikes), with various identified negative impacts on the service-users, as previously presented in chapter seven.

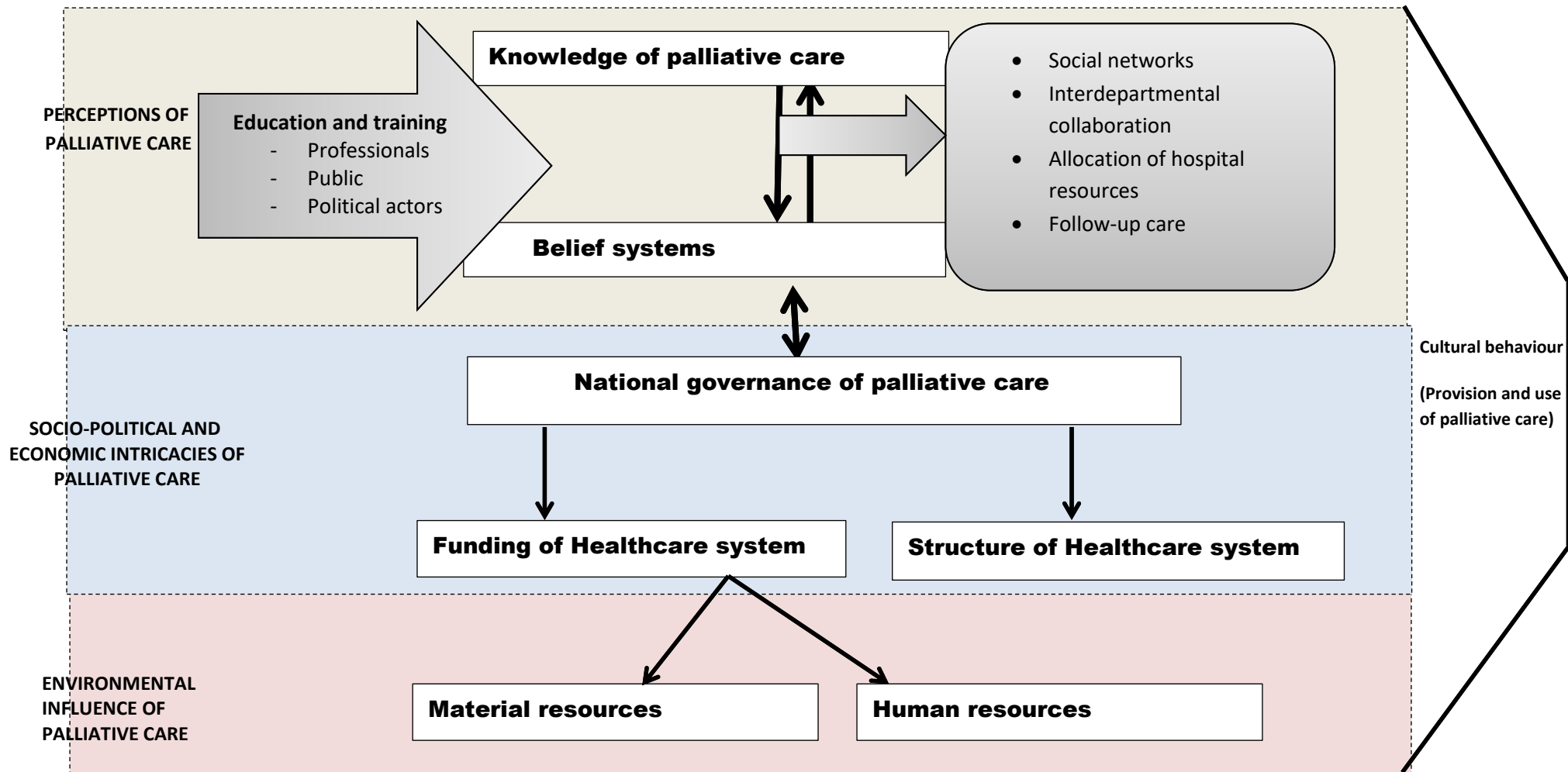
## **8.2 Summary of the organisation's cultural scene**

This organisational ethnography of PC in a Nigerian hospital has uncovered knowledge which has contributed to understanding the cultural, socio-political, environmental and organisational dynamics that influenced the provision and use of PC. The various cultural elements have been represented as a holistic cultural scene, as shown in Figure 8.1, below.

In summary, this research revealed that professionals and service-users cultural and religious beliefs about terminal illness and palliation were informed by, as well as

impacted on, their knowledge of PC. Based on the findings of this current research and available evidence from previous research conducted in Nigeria, it was inferred that belief systems may have shaped the public and policy makers' perceptions of terminal illness and palliation. As a result of the culturally-based perception of PC, contributed to by poor education and training in PC of the HCPs, the service-users, political actors and the managers of the hospital considered PC to be of a lower priority than other healthcare services. This was demonstrated through lack of policy and funding for the development of PC both in the studied hospital and Nigeria overall. Poor knowledge of PC by the professional and the public further impacted on the interdepartmental collaboration, leading to weak collaboration between the PCU and other departments/units. It also contributed negatively to support received by the service-users from the members of their social network, which, in turn, influenced decisions about the use of PC. Finally, the culturally-based perceptions, reinforced by poor knowledge and embedded within culture and religion, contributed to, and resulted in, inadequate political and socio-economic commitment, which translated into an environment which constituted inadequate material and human resources for the provision of PC. This nuanced organisational story of PC has made tacit knowledge more explicit and is hoped to encourage innovation and stimulate change in the cultural behaviour of the provision and use of PC in the studied hospital and the wider context of Nigerian healthcare organisations.





**Figure 8.1: Conceptual framework explaining the use and provision of palliative care in Nigeria**

### **8.3 Contributions of the ethnography to the existing knowledge: theoretical implications**

Having discussed the key findings of the research, I will emphasise that the results presented are broadly consistent with many findings in the literature on the issues influencing the provision and uptake of PC. However, two components of the ethnography offered a novel contribution to knowledge of this field and are discussed in this section. Firstly, meaning-making in illness and PC, and, secondly, the socio-political complexities shaping the provision and use of PC.

#### **8.3.1 Meaning-making in illness and palliative care**

Meaning has been defined as the '*shared mental representation of possible relationships among things, events, and relationship*' (Baumeister, 1991:15). It involves searching for a more favourable understanding of the situation which one has encountered (Park, 2013a). In general, terminal illness or suffering tend to undermine one's broad assumptions or predominant discourse about the nature of the world (Janoff-Bulman, 1992; Park and Folkman, 1997). Therefore, most people tend to re-define or re-negotiate meaning when they are challenged by adverse situations, such as serious illness (Baumeister, 1991; Park *et al.*, 2008; De Luca Picione *et al.*, 2017). This implies that serious illness may trigger the need to find meaning, in terms of making sense of the illness itself and this could be situated within the relational process rather than a sole individual affair, as found in this current research. Several scholars (Koenig *et al.*, 2012; Master and Hooker, 2013; Park 2013b) have argued that religion is central to the meaning systems of many people, although this can vary from one individual to another. This idea was long reiterated by theorists who reasoned that religious meaning systems stem out of the human need for understanding of the deepest problems of existence (Geertz, 1966). In this current research, culture and religion were the two perspectives primarily used by most of the participants in meaning-making about their illness and care. These two perspectives are discussed in this section in relation to their original contributions to the knowledge of this field.

Cultural beliefs, as a meaning-making system, have formed an aspect of the novel contribution to the knowledge of this field. Culture could be referred as a pattern of explanatory models, beliefs, values and customs and this pattern can be expressed materially (in the form of ritual practices, diets, dress, buildings) and non-materially (in the form of abstract idea or ways of thinking that make up a particular culture) (Rao *et al.*, 2008). It is argued that culture may be of relevance at end of life because it influences the meaning and experience of dying and death (Crawley *et al.*, 2002) and could shape healthcare utilisation (Johnson *et al.*, 2011). Most of the previous studies about culture in end of life/PC have focused on several issues, such as the association of racial difference in the completion of advanced directives (care planning) or willingness to use hospice care (Ludke and Smucker 2007; Johnson *et al.*, 2011; Garrido *et al.*, 2014; Hlubocky, 2014; Koss and Baker, 2016; Huang *et al.*, 2016), communication style and information sharing (Deschepper *et al.*, 2008; Kreling *et al.*, 2010; Bahrami *et al.*, 2017), and place of care, death and dying (Fisher and Duke, 2010; Pivodic *et al.*, 2014; Gomes *et al.*, 2015, Natsume *et al.*, 2018).

Generally, studies on the cultural construction of death and dying and how culture shapes experience of serious illnesses and dying is limited, but more particular is the dearth of research about cultural meaning systems in serious illnesses. For instance, only one study (Traister *et al.*, 2018) has reported specific details, in that a male Guatemalan stated some unique cultural beliefs, such as that death begins at the feet and that no one should sit at the end of the bed because this would not permit death to enter, that half of candle would need to be changed or else other family members will die, and that lemon is a poison to the body in the final stage of dying and helps a person to die. This current research showed that terminally ill patients and their families, including some healthcare professionals, culturally constructed various meanings of terminal illnesses, which I have divided into two categories. The first category is that 'evil others' was responsible for the cause of terminal illness while the second category was the purposeful intervention of either supernatural/nonhuman beings or agents acting for the beings caused terminal illnesses, as discussed in chapter

five. This has contributed in enhancing the limited knowledge of how patient's cultural beliefs and practices informed the meaning of illness. This finding is particularly novel because such knowledge is not previously explicated in any of the Nigerian cultures or elsewhere in Africa. Powell *et al.* (2014) emphasised that ways in which people make meaning of their illness and end of life care was particularly lacking in Africa; this was also highlighted by Cain *et al.* (2018) in their integrative review. It may be important to state in support of my claim for the novelty of the findings that the world population is made up of diverse geographically racial/ethnic groups with unique cultures (Pew Research Centre, 2013; Cain *et al.*, 2018; Office for National Statistics UK, 2018). Thus, several studies have acknowledged disparities in the worldview about serious illnesses, suffering, death and dying which shape meaning system existence (Koffman *et al.*, 2008; Johnson, 2013; Romain and Sprung, 2014; Carrison *et al.*, 2016). For this reason, Kagawa-Singer *et al.* (2015) and Cain *et al.* (2018) argued that elements of a cultural system must be analysed as an ecological framework and in the context in which its members live and refract their ability to 'see' the world. This research provided a unique perspective used by the service-users and the healthcare professionals in meaning-making during serious illness and provision of care.

Secondly, the use of religious beliefs as a source of coping and meaning-making in illness and palliation has featured in many articles conducted in the United States, though research in this area is consistently increasing in other parts of the world. For instance Branch *et al.* (2006); Bourjolly and Hirschman (2007); Bullock (2011); Harris *et al.* (2013); Hamilton *et al.* 2013; Hamilton *et al.* (2015); Patel-Kerai *et al.* (2017) reported that patients with cancer and other serious illnesses constructed meanings depicting illness as God's will, that death is a passage to another life and, therefore, surrendered themselves to their fate while engaged in prayer and other religious practices which in some cases resulted in either delayed or non-use of PC, as was also found in this current research. Using religion as meaning-making and coping was also reported among Turkish, Egyptian and Iranian women with breast cancer and their families, as well as in a study that used Sub-Saharan migrant women with HIV/AIDS in

Belgium (Cebeci *et al.*, 2012; Gunusen *et al.*, 2013; Elshshtawy *et al.*, 2014; Hajian *et al.*, 2017). Although, there have been concerted research efforts in this field which have confirmed the use of spirituality/religion to understand and cope with serious illness, these studies focused on patients and their family members. However, the study conducted in New Zealand by Frey *et al.* (2018) used staff working in residential care homes for older people, focused on the role of spiritual/religious beliefs, particularly among nurses and healthcare assistants, in coping with death and dying. This study found that the participants utilised spiritual/religious beliefs to a varied degree and highlighted that the level of these beliefs made some difference in the strategies employed by the staff to cope with death and dying (Frey *et al.*, 2018).

Furthermore, Ugandan nurses were reported to have used their religious belief in their everyday life activities and that they perceived their religiosity affected them positively in their job performance such as self-care and coping with their job stress (Bakibinga *et al.*, 2014). Other studies conducted within Africa continent (Otegbayo *et al.*, 2010; van Gorp *et al.*, 2015; Opuku, 2014) showed that religious belief was an obstacle to PC because patients tended to use these beliefs to form protective mechanisms during end of life care, although these studies did not shed light on what these beliefs were and how they influence coping, perhaps due to methodological limitations of these studies, as explained in chapter two of this thesis. This current research found that some doctors constructed a meaning that God has the ultimate power to cure terminal illnesses and perceived themselves as an instrument used by this supernatural being to provide healing to the patients. This further supports the theory that religion shaped the explanatory framework and contributed for the first time to our knowledge of religion in meaning systems during serious illness in Africa. It also extends the knowledge that some doctors, just like nurses and service-users, could also use their religious beliefs to construct meaning in PC. Thus, this current research has demonstrated that a religious meaning system in terminal illness could be constructed by anyone irrespective of their level of education or other social metrics and documented how this meaning system influenced the provision and use of PC.

In relation to serious illness, this current research has enhanced understanding of the meaning making model which consists of two levels of meaning: global and situational (Park and Folkman, 1997). Cultural and religious beliefs seem to be inherent and fundamental in human existence but were dormant for most people among the cultural group studied in the circumstance of many illness but were reactivated in serious illness to challenge the general discourse or individuals' general orienting system and views (global meaning). This led to appraisals of the illness, forming situational meaning in terms of causal attributions that existed among the service-users and the healthcare professionals due to their limited knowledge of the illness. This could be enlightening and possibly may portray how culture and religion are still powerful in influencing thinking in modern societies. This may be extrapolated to the entire African culture and perhaps other cultures.

### **8.3.2 Socio-political complexities of palliative care**

In the section above, I have argued how a meaning system rooted in religion and culture contributed to the knowledge of this field; this research goes beyond cultural understanding because issues concerning the provision and uptake of PC in a Nigerian society was found to be complex as it also stemmed from socio-political, environmental and organisational dynamics. Funding, policies, opioids availability or accessibility, and the education and training of healthcare professionals were amongst the socio-political and environmental issues identified in previous research, both in Africa, as discussed in the literature review chapter of this thesis, and around the world, that have influenced PC (Lynch *et al.*, 2010; Gardiner *et al.*, 2011b; Carter *et al.*, 2017; Sharkey *et al.*, 2018; Haines *et al.*, 2018). However, this research showed distinctively, and for the first time to the best of my knowledge of literature of this field, that the healthcare organisation was 'auto-inhibitory' to PC, a negative feedback that occurred in response to the Nigerian bureaucracy characterised by lack of transparency, unaccountability and irresponsiveness. Recall that it was found that structurally heterogenous healthcare delivery, comprising both orthodox and non-

orthodox delivery systems, which were poorly organised/managed, existed in Nigeria. This caused confusion and difficulties for the service-users regarding decisions about appropriate places to seek care, and contributed either to late presentation or non-use of PC. This finding contributes a new understanding, that PC may not thrive in a society such as Nigeria and, perhaps, other countries with plural and dysfunctional healthcare systems and especially if corruption has been tacitly accepted as a social norm or if the expected benefits of corrupt practice are perceived to outweigh the expected consequences.

#### **8.4 Practical implications/relevance and recommendations**

This research has not only made theoretical contributions to existing knowledge but also holds practical implications. In relation to the latter, I show these implications by discussing its relevance to healthcare practice, policy and education and as well as providing some specific recommendations for either change to, or improvement in, practice.

##### **8.4.1 Health care practice: cultural competence towards improving palliative care practice**

The uptake of PC by diverse groups of people with serious illnesses is improving across the world; however, disparities still exist (Lynch *et al.*, 2013; Economist Intelligence Unit, 2015; Connor and Gwyther, 2018). Overall, several studies have shown that these disparities mean that people of African race, ethnic and cultural background are less likely to receive care that aligns with their wishes than western white people (Rhodes *et al.*, 2012; Fang *et al.*, 2016; Koss and Baker, 2016; Worster *et al.*, 2018). Cain *et al.* (2018) argued that cultural differences in communication and meaning of illness are the drivers of these inequalities. Therefore, there is need to improve PC practice, aiming to benefit service-users regardless of cultural background as this could contribute to improved satisfaction with care (Crawley, 2005). This may be unachievable if the healthcare professionals lack cultural competence, a term which encompasses awareness, knowledge, sensitivity and skills to unique aspects of individual culture (Betancourt, *et al.*, 2003; Johnston, 2013). Laudably, this study

identified a common set of cultural and religious beliefs amongst service-users and the healthcare professionals that informed the meaning system in illness and influenced the provision and use of PC. This, therefore, provided evidence which clinicians that practice in a Nigerian healthcare system may use to improve their cultural competence in order to improve patients' satisfaction with their care.

In addition, the current study provides clinicians around the world with further understanding of meaning making in illness from the perspectives of Nigerian culture, which may be applicable to other people of African lineage. It may be important to highlight that the world population, especially in MEDCs such as the Australia, US and UK, continues to grow in diversity of language, country of origin, religion and culture (Australian Bureau of Statistics, 2018; Pew research centre, 2018; Office for National Statistics UK, 2018), possibly because of immigration. For instance, it is stated that 4.2 million black immigrants were living in the US as at 2016, with Nigeria being the top three birth-place (Pew Research Centre, 2018). As would be expected, this diversity could cause differences in the values, patterns of behaviour, attitudes and beliefs which could be different from the western-based values, attitudes and beliefs. It has been acknowledged that issues about the end of life in any society reactivate people's identity (Sigrist, 1996) and could raise differences in the way people view or experience end of life care (Hruy and Mwanri, 2018). In this context, it is important that all clinicians should understand the values and beliefs of various ethnic groups, as doing so will promote cultural competence that supports the provision of culturally appropriate PC. Schrader *et al.* (2009) underscored that cultural awareness and sensitivity begins by understanding the uniqueness of each ethnic groups regarding terminal illness, dying and death. As stated earlier, this research extends the limited knowledge about meaning-making in serious illness and could boost the healthcare professionals' sensitivity and competence while providing PC to individuals of African descent, especially Nigerians, in foreign countries.



Culturally sensitive care could promote people's trust in the healthcare, which is likely to encourage the use of PC (Johnston *et al.*, 2013), thereby reducing the existing disparity in the uptake of this care. However, due to individual differences in beliefs that exist in the same culture because of differences in experiences and social metrics, I acknowledge that evidence about meaning systems may not be rigidly used in clinical practice to avoid stereotyping and prejudice, although the findings are still clinically relevant in providing broad awareness and understanding of how people of African ancestry could make meaning in serious illness to better comprehend individual perspectives.

Lastly, it is important that clinicians should understand that various PC delivery models should meet the need of diverse people. Thus, I recommend that PC practitioners, irrespective of their country of origin or place of practice, should be prepared to equip themselves with theoretical cultural knowledge of various ethnic groups, but also should take a more individualised stance by asking questions about what patients and their relatives believe and desire during end of life/PC care. By doing so, the ranges of individual religious and cultural beliefs, values and preferences will be accommodated and this may trigger more utilisation of, and improve satisfaction with, PC.

#### **8.4.2 Health care policy**

The inclusion of PC in national health policy is largely ignored, especially in Africa (Uwimana and Struthers, 2007; van Gurp *et al.*, 2015; Rhee *et al.*, 2018), even though the WHO governing body (World Health Assembly, WHA67.19,) passed a resolution in 2014, requiring governments in all the member states to recognise PC and to make provision for it in their national health policies (WHO, 2018) to improve access, thereby enhancing the wellbeing of people with serious illness. The government in the MEDCs such as the UK responded to this call and demonstrated their commitment for improving care by either formulating of new, or reviewing the existing, policies, frameworks and guidelines for PC development such as a strategic action for palliative and end of life care, choice in end of life care, palliative and end of life guidelines (Scottish Government, 2015; UK, Department of Health, 2017; NHS, Northern England

Clinical Network 2016). However, the findings of this current research show that PC policies were lacking in the studied hospital and in Nigeria in general, particularly in the areas of funding, opioid availability and accessibility (Taylor *et al.*, 2014). This lack of policies had consequences for both the service-users and the healthcare professionals, reflected in the impact on socio-economic and environment, as previously discussed in chapter six and seven of the thesis. My findings indicate that terminally ill patients and their families, including the clinicians providing care for this group of patients, are likely to experience operational difficulties that could hinder provision and uptake of services in any society where policies about PC are lacking.

Nigeria should be a society where someone with serious illness can have access to PC regardless of where such person lives, socio-economic background or other circumstances. This could be achievable if the bureaucrats at both governmental and hospital levels in Nigeria respond to the WHO call for integration of PC into mainstream of healthcare delivery by utilising evidence generated from a rigorous research such as the current study to formulate policies, frameworks and guidelines to improve palliative and end of life care. Specifically, I recommend a formulation of national policy that would dedicate a certain amount of fund yearly (for instance £10 million) for over ten years for the development of PC because funding was found, in this current research, to be central in influencing behaviour regarding the provision and use of PC (see chapters six and seven). Adequate funding will enhance procurement of necessary resources (material and human) that could enhance provision and use of PC. By extension, this policy could allocate funding for research in PC and encourage exchange of knowledge across regions of Nigeria by taking further action to establish Nigeria Research Forum for palliative and end of life care.

It may be particularly important to make access and use of this specialised care 'free for all' because this study revealed that financial requirements for managing terminal illness created situational poverty, thereby causing unnecessary financial hardship that affected every aspect of the wellbeing for individuals with serious illnesses.

Alternatively, health insurance policy in Nigeria should be made more comprehensive to include individuals with serious illness such as cancer because doing so will improve the uptake of PC. Although the recommendations above may sound overambitious for some individuals, it is achievable because Nigeria has a substantial resource to make this possible or attainable if there is a political will to do so. Scottish government though in good pace with PC development, proposed additional £3.5 million funding over four years to drive education and training in PC as well as improvement across other areas of palliative and end of life care to achieve the vision for making PC accessible to all who requires it, as documented in their strategic framework for action on palliative and end of Life care 2016-2021 (Scottish Government, 2015). This policy if formulated and implement may scale up the availability and uptake of PC in Nigeria to include children as PC for this age was found unavailable in the studied setting and perhaps the entire Nigerian hospitals. It will be crucial to set up accountability structures within the healthcare system for funds utilisation and the development of the legal framework to support such a structure because of dominant discourse of corruption in the Nigerian societies as found in this current study and other previous studies as previously discussed in this chapter.

Opioid availability and accessibility is improving in Nigeria (Oyebola, 2017) as the studied hospital was found to have a unit with responsibilities to reconstitute morphine powder into oral liquid morphine. However, pharmacist Lily and other healthcare professionals who participated in the current research emphasised that morphine powder is sometimes out of stock due to regulatory barriers and other complexities related to supply from the Federal store in Nigeria. Therefore, it may be useful to formulate policy that will strengthen the availability/accessibility of morphine and other strong opioids such as oxycodone, fentanyl and methadone which was surprisingly found to be unavailable in the studied hospital. Guidelines and policy for opioids availability will enhance its adequate access and utilisation, this will reduce or prevent unnecessary suffering of the patients and might also contribute to improving their quality of life (Bosnjak *et al.*, 2011).

Lastly, the organisational clinical guidelines for PC was found to be lacking in the studied hospitals. Likewise, national guidelines for palliative and end of life care does not exist to the best of my knowledge and was also reiterated by other Nigerian PC advocates (Onyeka *et al.*, 2013; Oyebola, 2017), regardless of being a useful tool that can reduce healthcare variations and improve patients' outcomes (Melnyk, 2015). The formulation and launch of the clinical practice guidelines at both organisational and national levels will guide PC practitioners and other professionals collaborating with the care of patients with serious illness and their families to maintain safety and clinical competency that would improve the quality of life for the service-users (Melnyk and Fineout-Overholt, 2014). More fundamental to the studied hospitals, clinical guidelines could promote efficient interdepartmental collaboration; to improve organisation culture of referral of patients to PC team and minimise role confusion, competition, overload, and complexities found to exist in the studied hospital.

#### **8.4.3 Education**

As stated earlier, this study revealed that professionals' and service-users' cultural and religious beliefs about terminal illness and palliation were informed by, as well as impacted on, their knowledge of PC. There is also an indication that this belief system shaped the public and policy makers' perceptions of terminal illness and palliation rooted in poor awareness and knowledge about PC, which was further complicated by lack of an educational programme or training institution that provided PC education in Nigeria. Like Nigeria, many countries in the African continent (Rawlinson *et al.*, 2014; Hannon *et al.*, 2016) and other continents (EIU, 2015; Lynch *et al.*, 2010) lacked adequate awareness and knowledge of this field. I acknowledge that issues of religious and cultural beliefs may not be easily or instantly changed by a one-time intervention. Instead, such issues change gradually over time through cultural transformation and the deculturalisation of beliefs which are not based on scientific evidence or modern reasoning. This can be achieved with information dissemination and individuals interacting with other cultures which have different perspectives about serious illness,

dying and palliation. There are some practical steps that could be undertaken to improve knowledge about PC and this could lead to positive behaviour towards the provision and uptake of services. These are outlined as follows:

Firstly, the complexities, confusion and misunderstanding about the use of the word 'palliative care' continue to exist globally (Hui *et al.*, 2013) but, more significant is that some ethnic groups appear to lack cultural wording for this specialised care, as became evident in this current study. In consequence, there seemed to be sense of alienation from this aspect of care in some healthcare professionals and the public. However, the concept of PC is not so difficult that it cannot be broken down for understanding at the required different levels of stakeholder engagement. Thus, the first step should be that PC advocates from different cultures should formulate a local word for PC, if it has not been already done, and use this to disseminate information about its benefits. Furthermore, I recommend the use of mass media as a tool for information dissemination about PC, because many people are influenced by this and this could lead to behavioural modification about serious illness and palliation. The PC advocates could come together to institute an association which should be commissioned with a mandate to foster collaboration with the media and engage the public in issues relating to serious illness and palliation. They will serve as a 'strong force' of advocates fighting the course of the vulnerable and voiceless group (people with serious illness in Nigeria) and, by extension, increase awareness and interest in PC. This may also create an enabling environment to validate or refute preconceived ideas and escalate the issue of PC to attract public and policy attention.

Secondly, there should be orientation programs for managers at different hospitals and government agencies on the role of governance and policies in improving the availability and quality of PC, especially drawing their attention to the evidence that this service could save money for both government and the public while also improving the wellbeing of those that are challenged by serious illness. The advocates need to engage more with government on these issues not only at the policy forum

but at any social events to increase their awareness in the hope of triggering adequate government support for PC.

Finally, the lack of an educational programme in PC for healthcare professionals, as found in this study, is one of the key barriers that should be addressed. Interestingly, all the healthcare professionals in this current study expressed their desire for formal education in PC. Therefore, one realistic way to improve knowledge, as well as local workforce for PC practice in Nigeria, would be to develop a palliative and end of life care educational framework which could be by designing a curriculum for a post-registration educational programme in PC for nurses and other healthcare providers and to introduce it into universities or other training institutions. The education could be delivered in partnership with some universities in the UK or other countries with a developed PC. Recall that some professionals stated they were not keen to travel abroad for study due to family, job and financial reasons. There should also be a resident programme in PC for Nigerian doctors wishing to specialise in this field as this will increase the much-needed manpower. I conclude with the argument that the development of PC education would be contingent to the improvement of practice and policy.

### **8.5 Summary of the unique contributions to the field and its practical application**

This thesis enhanced understanding of the salient areas within patients' and families' experiences of suffering and end of life care, thus revealing that issues concerning the provision and uptake of PC in a Nigerian society were complex and stemmed from socio-political, environmental, cultural and organisational dynamics. Firstly, it extends the findings by Otegbayo *et al.* (2010) and Van Gurp *et al.* (2015) who broadly mentioned that religion was an obstacle to PC in Nigeria, by identifying sets of religious beliefs and clarifying how this impacted on provision and uptake of PC.

Secondly, it uncovers evidence regarding cultural perspectives of meaning-making during life-limiting illnesses in a Nigerian context, exposing that culture and religion were fundamental to human existence, but were particularly reactivated in the circumstances of serious illness to challenge individual general orienting systems or views. Thus, the patients and their families including some professionals, refracted on their cultural worldviews to make meaning that influenced decision-making about provision and uptake of PC. Again, no research in Nigeria or any other African country has uncovered this evidence.

Thirdly, this research provided in-depth understanding that behaviour regarding the provision and use of PC was also conditioned by economic conditions, social relationships and knowledge rooted in bureaucratic system failures. Thus, it showed distinctively, and for the first time to the best of my knowledge of literature of this field, that healthcare organisation was 'auto-inhibitory' to PC and that political culture was insensitive to formulate policies to promote this specialised care.

Overall, this ethnography revealed that inadequate understanding by the public, political actors and the professionals about the benefits that could be gained from PC mainly accounted for inadequate support for its development. Therefore, information generated from this thesis has been used to develop a practical application strategy, as shown in Table 8.1, below, which may be utilised to advance PC development in Nigeria and other similar contexts.

<b>Target group</b>	<b>Areas of information and/or focus</b>	<b>Potential implications</b>
<b>Public</b>	<p>Health education regarding:</p> <ul style="list-style-type: none"> <li>• Life-limiting illnesses</li> <li>• Benefits of palliation</li> <li>• Early access of PC</li> </ul>	<p>will improve understanding and would inculcate positive re-interpretation or reappraisal of meanings associated with terminal illness and palliation, thereby promoting its utilisation.</p>
<b>Professionals</b>	<p>Formal education/continuing professional development in the areas such as:</p> <ul style="list-style-type: none"> <li>▪ Communication in palliative and end of life care</li> <li>▪ Breaking bad news</li> <li>▪ Cultural awareness and sensitivity about beliefs regarding cancer and other life-limiting illnesses</li> <li>▪ Realist medical approach to PC</li> <li>▪ The need for more research into PC and evidence based practice</li> </ul>	<ul style="list-style-type: none"> <li>▪ could promote people’s trust in the healthcare, which is likely to encourage the use of PC</li> <li>▪ Recognition and respect for cultural values and preferences may trigger more utilisation of, and improve satisfaction with, PC</li> </ul>
<b>Policy makers and Political actors</b>	<ul style="list-style-type: none"> <li>• Sensitisation about burden of life-limiting illnesses, benefits and early access to PC</li> <li>• Expanding on home-based PC delivery models to meet individual needs</li> </ul>	<p>Guidelines and policies for these areas may:</p> <ul style="list-style-type: none"> <li>- scale up the availability and uptake of PC in Nigeria</li> <li>- promote opioids availability and enhance its adequate access</li> </ul>



<ul style="list-style-type: none"> <li>• Integrating PC into mainstream of healthcare delivery and making it a priority for every healthcare organisation in Nigeria</li> <li>• Adequate funding for PC</li> <li>• Establishment of Nigerian PC research forum and funding PC research/programmes</li> <li>• Making PC ‘free for all’ or to make health insurance policy in Nigeria to cover individuals with serious illness</li> <li>• Policy that will strengthen the availability/accessibility of morphine and other strong opioids</li> <li>• Need for clinical practice guidelines at both organisational and national levels</li> <li>• Need for palliative and end of life care educational framework/curriculum</li> </ul>	<ul style="list-style-type: none"> <li>- could promote efficient interdepartmental collaboration</li> <li>- will maintain safety for service-users and clinical competency that would improve the quality of life for patients and their families</li> <li>-enhance professional job satisfaction</li> </ul>
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**Table 8.1: Practical application strategy**

### **8.6 Limitations of the ethnography**

This research took an organisational ethnographic approach, aiming to understand the cultural, socio-political, environmental and organisational complexities influencing the provision of PC and the patients’ and their relatives’ behaviour towards the uptake of this services in a Nigerian hospital. This current study has been shown to meet all the ‘good fit’ criteria for ethnography in relation to relevance or value, as discussed in chapter three (see 3.8). It has provided ‘thick description’ and has explicated knowledge about culture of PC in a Nigerian context. Also, it has particularly increased

understanding of the intricacies/context underlying human behaviour regarding provision and use of this specialised care and the interrelationships among several dimensions of group interaction, satisfying all the criteria required to establish the relevance of ethnography (Hammersley, 1998). However, as with all research, there are methodological limitations which need to be acknowledged because this is specifically significant to the findings or knowledge claims of this current research.

Firstly, given that this study was conducted in one hospital with a sample size which may not be representative of the population of persons with serious illness and the professionals that provide care to such population, all the conclusions presented herein cannot be generalisable in any strong sense, because of the ethnography feature of contextualisation (Wiersman, 1986). However, ethnographic findings may be generalisable with reference to similar contexts (Nurani, 2008). In addition, this current study may not be replicated and this is consistent with general limitations of ethnographic research. Several authors highlighted that ethnographic research occurs in natural settings and focuses on processes (Wiersman 1986; LeCompte, and Schensul, 2010; Goodson and Vassar, 2011), and because social life is continuously changing rather than being fixed, structures and identity are changeable and events may not be reproduced. Thus, meaning may be redefined or renegotiated (Goodson and Vassar, 2011). As suggested by Nurani (2008), this limitation was minimised through detailed description of the methods used to gather and analyse data, so that the next researcher, if he/she so wishes, can reconstruct the original analysis. It may also be important to mention that subjectivity is certainly a limitation of ethnography (Goodson and Vassar, 2011). This implies that interpretation of culture may possibly vary among researchers (Nurani, 2008), probably due to the length of time spent in the field to understand the context. I engaged in the field for a period of nine months to facilitate accurate description and interpretation of the studied culture.

Secondly, and more exclusive to this current study, was the impact of myself on the ethnography. Generally, in qualitative research, the researcher is the primary research tool and, as such, the entire project is subject to the processes and interpretations

developed by the researcher. My positionality in relation to my educational training as a professional nurse and being a member of the wider ethnic group researched, played a constitutive role in the knowledge claim of this research. There were some moments when my expressed disappointment/cultural shock about the cultural practice observed and other personal idiosyncrasies impacted on the research and it would be careless to overlook the consequences of this. For instance, the Hawthorn effect (Mayo, 1949) was noticed to be reawakened after I made exclamation (ha!), when a member of PC team on our way to conduct a ward round stated that he will be very fast because he was in a hurry to attend other personal appointments. However, my personal limitations were minimised by constant reflection and engagement in reflexivity all though the stages of research process.

Finally, despite the limitation of ethnography in general and of this current research, the knowledge constructed herein remained valuable for theoretical advancement of knowledge in this field and contributed in providing insights to the practical realities about provision and use of PC including proffering recommendation for improvement.

I will now provide the conclusions of the ethnography, direction for future research and my final reflections, including the knowledge mobilisation and strategy in plan in the next chapter.

## CHAPTER NINE

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### SUMMARY AND CONCLUSION

This research is the culmination of my clinical experience of how my best friend with cancer experienced an agonising death and many years of reflection on how millions of individuals with serious illness in Nigeria and other countries may be dying in a similar way. It was born from my desire to improve the wellbeing of this vulnerable group, so that adequate care to alleviate their suffering could be made available and accessible and, above all, so that they can die well. Also, it was an effort to contribute to the knowledge of this field by filling some of the identified gaps from the existing literature. Turning the spotlight to the healthcare professionals, the managers of the studied hospital, the patients and their families' experiences and perceptions, as well as personal observations of the intricacies surrounding the culture of care given to this vulnerable group, this research aimed to understand the cultural, socio-political, environmental and organisational dynamics influencing the provision of PC, and the patients' and their relatives behaviour regarding the use of PC in a Nigerian hospital.

As a social scientist, I attempted to construct reality and knowledge about provision and use of PC with a stance that reflected a belief that reality is multiple and that individuals will offer multiple social constructions in relation to their context and culture (Guba and Lincoln, 1994; Crotty, 1998; Patton, 2002). This research was firmly based on the epistemological stance that human life exists as it does due to social and interpersonal influences; therefore, my chosen methodology of ethnography fitted into this stance because it unravelled the complexities of human interaction and relations (Rock, 2001). Overall, I learnt a particular construction of reality from varied perspectives situated in performance about the provision and use of PC among the participants in the studied hospital. I first conducted participant observation and engaged with the professionals while they performed their daily rituals, to understand the complexities surrounding what they did. This was followed by documentary analysis and one-on-one interviews, which clarified what was observed and facilitated a more in-depth understanding of the cultural domains. Using Spradley's framework

for ethnographic analysis (Spradley, 2016), I derived cultural themes which provided insight into the studied culture.

The findings from this current research have shown that shifting focus to the interaction within a group and the society, and considering the cultural, socio-political, environmental and organisational complexities, revealed insight into the strategies that could be relevant to minimising the global disparity in the provision and use of PC. Previous evidence has shown that cultural beliefs and practices are particularly salient within patients' and families' experiences of suffering and end of life care, yet these are poorly understood by clinicians (Periyakoil *et al.*, 2016). The knowledge about professionals' beliefs and how it impacted on the palliative or end-of-life care is currently lacking, whilst Worster *et al.*, (2018) argued that this may have contributed to the global inequalities in PC. This current study provided further understanding of this salient area, showing that both the healthcare professionals and service-users constructed a system of beliefs, values and practice style that provided them with an acceptable practice norm, a sense of safety and a meaning of terminal illness and palliation, which shaped culturally-bound attitudes and behaviours. There was a dichotomy or disconnect among some healthcare professionals in the use of their belief systems, whilst the majority of the service-users subscribed to indigenous beliefs in the decisions regarding the use of PC, driven by expectations for a cure. This contributes to our understanding that variability in social metrics, such as education attainment, social networks, economic status, social class, accounted for perceived differences in the use of belief systems, in a meaning system, and decision-making, for the provision and use of PC in this ethnic group. However, further study adopting a quantitative method would be necessary to test this correlation among the larger population of this culture.

This study explains PC beyond cultural complexities, and exposes a complex interaction of socio-political, environmental and organisational forces that interplay in shaping the provision and uptake of PC. It was found that behaviour regarding the provision and use of PC was conditioned by economic conditions, social relationships and knowledge.

Importantly, the hospital managers and the clinicians steadily reiterated that the bureaucrats offered little or no support for PC because of the political culture, which was insensitive in formulating policies that would make this specialised care thrive. However, this group of participants appeared to have lacked insight on how they had also contributed to the poor development of this service, particularly by making no funding available, as well as by what appeared to be a mixture of deliberate and unconscious bias in formulating clinical guidelines for provision of quality PC. Therefore, the environment for care in the study hospital represented a space, rather than a place, that could support the wellbeing of service-users. This environment also constituted an obstacle for the professionals in providing suitable care for this vulnerable group, which led to some organisational cultural norms, for instance, an incessant work stoppage that further contributed to the poor quality of life for the service-users. These findings have revealed that behaviour and decision-making regarding the provision and use of PC is complex and stems from both cultural and contextual factors.

From these findings, I draw several conclusions. Firstly, that the cultural and religious meaning system was reinforced during serious illness, mainly by the service-users with a few of the clinicians. These belief systems were created to protect life sustainability and to maintain psychological security. This dominant discourse thrives in a Nigerian society mainly due to bureaucratic system failures. It requires understanding by the healthcare professionals as well as the policy makers to plan effectively or to respond respectfully toward meeting the needs of people from various ethnic backgrounds in a manner that recognises, protects and preserves their dignity as they journey through their end of life. I, therefore, argue that failure to recognise these cultural differences in the appraised meaning of serious illness can consolidate a view which stereotypes certain groups and may deflect attention from meeting individual PC needs and, thus, could strengthen the existing inequalities and discourage the use of PC.

Secondly, when compared to the relevant literature, the current research revealed that what is specific to PC development was beyond or deeper than the structural factors,

such as opioids availability/accessibility, funding and policies, but that it was deep-rooted into a political and organisational culture that did not value PC. This seemed to have stemmed from a combination of inadequate understanding about the benefits that could be gained from provision of PC and inadequate knowledge embedded in the lack of an educational programme in PC. These call for massive sensitisation of both the political actors, the professionals and the public to change their mindsets and to make cultural and religious positive reappraisals of the meaning of terminal illness and palliation.

Lastly, I feel that this research has achieved its aim, by providing knowledge and understanding of the cultural, socio-political, environmental and organisational dynamics influencing the provision of PC, and the patients' and their relatives' behaviour for the use of PC in a Nigerian hospital. The ethnographic approach was appropriate for this research since it facilitated cultural understanding about provision and use of PC. I believe that this study has made some novel theoretical and practical contributions that could aid towards abridging the disparity and inequality in the world provision of PC. It has also contributed to the on-going debate that culture, race, and ethnicity have a strong influence on different aspects of PC, such as the meaning of suffering, communication patterns and decision making in end of life care. Despite the perceived relevance of this research, an inductive explorative research such as the current study can generate a multitude of findings, and a further limitation is that I was unable to explore all aspects of the findings in a considerable more depth. This has provided direction for future research which will be outlined next.

### **9.1 Directions for future research**

The scoping literature review presented in chapter two, which explored what is known about palliative care in Africa and how it has been studied, identified that no research existed about organisational dynamics and how culture and religion may be influencing the provision and use of PC in Nigeria or any other African country. The current study was conceived to fill this research gap. There were other research gaps that emerged from scoping review as presented in chapter two, these remaining gaps, those

generated by conducting the current study will be discussed by making suggestions for future research.

Given that transferability is somewhat a limitation of this study and the unique and/or evolving nature of culture, I first propose that similar qualitative study should be conducted in other geopolitical zones of Nigeria as well as other African countries. Recall that culture threaded in all the finding of the current study, implying that it is central in shaping behaviour regarding provision and uptake of PC, more enquiry of this type could identify some other unique belief systems about palliation, death and dying which will extend understanding, thereby increasing the knowledge that will boost cultural competence in PC. It may also illuminate other cultural specific complexities which may be used to plan for PC development.

The current research sought the experiences and perceptions of service-user and HCPs and provided knowledge on the meaning systems in serious illness and socio-political, environmental and organisational dynamics that impacted on behaviour regarding the provision and use of PC. It did not directly assess the perceptions of the political and national policymakers on the issues impacting PC in Nigeria. It would be useful to understand their perspectives and also conduct policy analysis in the area as this may add to the knowledge of this field. Such research offers potential insights into the political culture from the perspective of the political-actors which may extend the knowledge about the social behaviour regarding support for PC.

The spatial layout (room-type) was one of the environmental complexities found to have impacted on the provision and use of PC in the studied hospital. Although the service-users did not comment on the room-type for their care, the analysis of their interactions and behaviour was suggestive that Nightingale style ward without curtains that can be pulled round to provide privacy was undesirable. However, further qualitative study is required to explore service-users' preferences of room-type for hospital-based PC in the Nigerian context because such research will give voice to the participants, provide opportunity to gain further information about their preferences and to understand thoughts behind their choice. This will consolidate finding of the



current study and could enhance understanding that may be used to improve environment for PC. The proposed study will also contribute to the debate about the use of a single versus a shared room for PC (Spichiger 2008; Rowland and Noble, 2008; Williams and Gadiner 2015).

It has been acknowledged that communication is vital in PC and a '*vehicle through which the skills of practice and the humanity of care are conveyed*' (Duke, 2010:262). Unfortunately, inadequate communication or information sharing was found to be a predominant practice in the studied hospital. An additional study about communication is required to understand the complexities surrounding information sharing during serious illness in Nigeria and other African countries. The level of information service-users may require from professionals varies across cultures; for instance, Mexican and Arab participants in the study by Perkins *et al.* (2002) desired full and honest information about their diagnosis, treatment and prognosis, whereas Chan and Kayser-Jones (2005) reported that Chinese social workers purported that Chinese people do not want to be told about dying, which was similar for a Filipino woman in the study by McGrath *et al.* (2001). Some cultures prefer clinicians to first initiate discussion with their families (Schrader *et al.*, 2009). It could be relevant to assess this complexity in a Nigerian society as this knowledge may add to clinicians' cultural competence.

A feasibility study and later clinical trial about extending the model of PC delivery to community-based care may be necessary. This would be required to develop an indigenous framework that could provide training to community volunteers to be able to identify and encourage people to seek PC in the hospital, thereby facilitating community partnership and ownership. It could be a step towards promoting awareness of PC and changing the predominant discourse in the meaning system during serious illness.

Finally, a quantitative study would be useful to assess whether services-users and clinical staff from other hospitals within the south-east geopolitical region hold a similar set of beliefs as found in this current study and this could be conducted across

other regions of Nigeria for comparative analysis. This kind of study would proffer an opportunity to test correlations of social metrics to the cultural meaning system, thereby providing greater insight into this specific area for a larger population. The leaders and policy makers among the professional bodies in Nigeria, such as the Nursing and Midwifery Council, and the Nigerian Medical Association, could be assessed on their opinion regarding their willingness and perceived obstacles about formulating, or adopting and integrating, a curriculum for PC education into Nigerian universities. This may reveal an insight of 'what next' about PC education in Nigeria.

## **9.2 Final reflection**

Reflecting on the course of the research, and particularly about challenges and opportunities in conducting ethnography in a Nigerian hospital, I have gained a greater knowledge of the cultural nature of this research journey, especially with regards to the research process itself and the sensitivity of the topic that was investigated in relation to the ethical debate such as vulnerability of patients with life threatening illness, the benefits of the research for the immediate participants and other issues, as articulated in the narrative review conducted by Duke and Bennett (2010). Every decision I made during this research and the corresponding actions were hugely shaped by the research/cultural context and my cultural background in terms of education and ethnicity, as Rogoff (2003) rightly described, everything is culture. In this section, I reflect on the key aspects of my learning over the past four years, highlighting the way this would likely improve my future research practice.

Considering the long immersive nature of ethnography and a PhD journey, one of the elements I found paramount concerned creating and maintaining a good interpersonal relationship with all those involved in this research process, such as the supervisory team, the ethics committee, the terminally ill patients and their families, the healthcare professionals and the Hospital's managers. Although, I had initially failed to recognise the dynamics inherent in groups of this nature, which caused some difficulties for me, research relationships improved, especially among the supervisory team and the participants because I was able to practice what Goffman (1959) regarded as impression management. Neill (2011) suggested that such relationships

are likely to be more relaxed in the long term (albeit in the context of family interaction). I will build on this skill in my future research and would recommend this for other researchers, especially PhD students, because it is critical for research success in terms of completion. I will not fail to mention that I felt coerced and strained in an attempt to maintain good research relationships among the participants during field work; this happened on some occasions when gatekeepers made me to participate in their daily activities which I perceived were not of relevance to my research. However, I realised that being compliant though assertive, during fieldwork contributed to forming my holistic understanding about the culture that was investigated.

One of the highlights in this journey was the research design. I initially designed this study to include members of PC team, without a critical thought of who else might be relevant for inclusion in order to gain comprehensive understanding of the culture that was investigated. This could imply that I was a little naïve in thinking, although as a novice researcher, this is bound to occur and I learnt from it. As the study progressed, it became obvious from the data that information was needed from another group of participants (other professionals, members of the hospital management, patients and their families) to achieve data saturation. Although these participants were assessed in my second field work after I gained further ethical approval, If I were to start again, I would take longer time to think about all the potential participants to elicit information for a comprehensive understanding of the phenomenon under investigation. Over the past four years, I have become a more analytical and reflective person. I am much more critical in thinking which I could argue to have stemmed from the research processes such as my field work, more reading, writing my own work where I had to think about every word used, and learning through interactions and feedback from my supervisory team. Generally, I feel better equipped to analyse tacit and/or spoken words of others during communication and to see others' point of view. Thus, I have impression that though I am still somewhat a novice researcher, I have developed as a person and a professional with some research expertise in my chosen area as a result of this PhD journey and well placed to continue improving in my research and writing skills.

I have also learnt from my encounter with the hospital managers in Nigeria. Access to this group was particularly challenging, in that there were no formal means of communication such as an organisational email, to secure appointments to discuss the research and negotiate their participation. Several times I felt disappointed by being stopped by their secretaries from meeting them, but even after the initial access was gained, it took me two to three months to gain appointments for interviews. Most remarkable was accessing the Chief Medical Director that took longer; I had nearly given up because I felt exhausted and frustrated after making concerted efforts with no success. However, I successfully interviewed him in the seventh month. The richness of the information gained from him compensated for my frustration and reflected the importance of being resilient and focused towards achieving a set goal. Other challenges I encountered while conducting this research were associated with issues related to industrial strikes, listening to patients' sad stories, difficulties in getting the research proposal to the hospital committee due to absence of online application platform, and financial expectations of the participants due to lack of social welfare service in Nigeria. These were all distressing but have positively contributed to my problem-solving skills and other personal/professional development.

Finally, I would confess that I started my PhD journey with little knowledge of what it entails but have come to realise that this journey is characterised by 'ups and downs' and has been, in my personal view, a period of unconscious bias and paranoid feelings as well as periods of self-accomplishment. Fortunately, the 'negative hunches' of this journey were short-lived and far outweighed by my commitment and passion, which was reinvigorated by my eye witnessing of the humiliation and pain which the service-users went through. I was committed to complete the research in order to open the dialogue for positive change in practice for the dying of serious illness in Nigeria and beyond. I have learnt greatly from undertaking this research and am very grateful to my supervisors and all the participants, including others who have provided me with inspiration and support along the way.

### **9.3 Knowledge mobilisation, strategy and action plan**

There is a growing recognition of the gap between research evidence, policy and practice (Dobbins *et al.*, 2009; Norton *et al.*, 2016), with a corresponding raising of interest and desire to bridge this gap across sectors, disciplines and organisations (Pablos-Mendez, 2006; Bullock *et al.*, 2012; Traynor *et al.*, 2014; Shrubsole *et al.*, 2018). Knowledge mobilisation or translation is one of the approaches which is gaining wider recognition and is being used for facilitating the integration of evidence-informed decision making (Ferlie *et al.*, 2012; Davies *et al.*, 2015; Norton *et al.*, 2016; Langley *et al.*, 2018; Barnes *et al.*, 2018). This concept could be referred to as the wide range of activities relating to the production and use of research findings, knowledge synthesis, dissemination, transfer, exchange, and partnership by researchers and knowledge users to create a positive impact, such as improved health outcomes (Munerol *et al.*, 2013; Canadian Foundation for Healthcare Improvement, 2018). This could be simply regarded as making information understandable, useable and accessible through working collaboratively to encourage end-users' participation whilst focusing on bringing the intended change into reality. In a more simplistic expression, Knowledge mobilisation is moving knowledge to where it can be mostly useful (Ward, 2017).

Knowledge brokering is one of the approaches being used in MEDCs such as the UK, US and Canada to ensure that research findings/results are usable in order to create the greatest possible impact through evidence based policy and practice (Ward *et al.*, 2009b; Chew *et al.*, 2013; Davies *et al.*, 2017). Knowledge brokering is often implemented by a third party, regarded as a knowledge broker or mobiliser, aimed to mediate the sharing of knowledge between the research producer and research users, such as healthcare professionals or others who can benefit from the research findings (Traynor *et al.*, 2014). Indeed, it would be expected that a knowledge broker should perform duties including, but not limited to, knowledge management in terms of dissemination, linkage and exchange (linking and connecting people who could benefit from the research evidence) and capacity building (Ward *et al.*, 2009a). However, evidence indicates that knowledge brokering is yet to be recognised or implemented in most of the low- and middle-income countries (Norton *et al.*, 2016), although

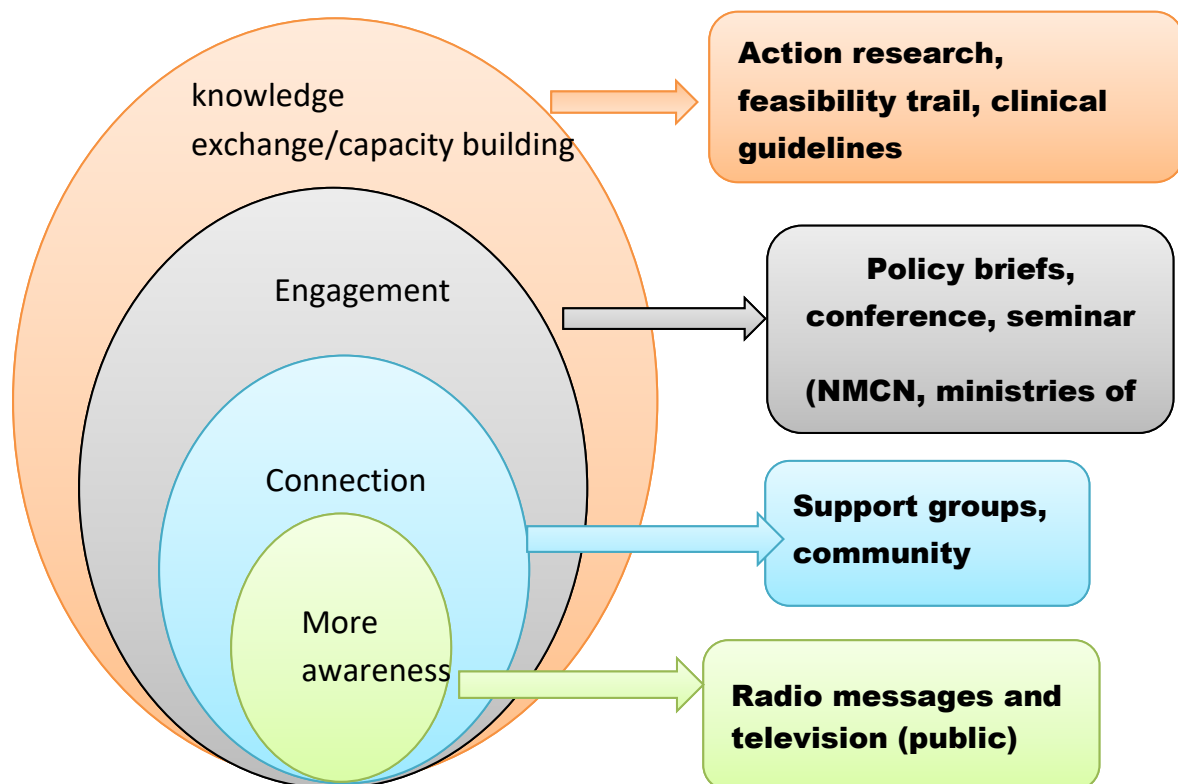
Dobbins *et al.* (2009) found that in some circumstances, tailored or targeted messages at specific behaviour are more effective than knowledge brokering. This implies that researchers in a country such as Nigeria would need to function as a knowledge broker or engage in a tailored-targeted message transmission to increase the chances of research evidence being utilised in informing health policies and change in practice. Although, I had earlier identified and discussed the implications and recommendations of the current study for practice, policy and education, these would not be relied upon because there is no certainty that these recommendations will translate into action/implementation around improvement in public health policy, education and practice. This is not surprising because much of the previous research consistently reiterated that evidence-based healthcare practice is not widely embraced in Nigeria (Akinbo *et al.*, 2008; Eneku, and Igbinosun, 2012; Adamu and Naidoo, 2015). Furthermore, Uneke *et al.* (2012) reported that policy makers and other stakeholders in Nigeria's health sector emphasised that communication gaps and poor networking between policy makers and researchers, and the non-involvement of healthcare recipients in identifying and planning care delivery needs, were some of the key barriers for the use of research-based evidence in decision-making. Therefore, this section highlights personal action plans and key strategies to facilitate knowledge mobilisation/translation into changes in practice and policy.

Firstly, there is on-going drafting of many academic papers generated from the current study including, but not limited to, topics such as:

- Exploring the organisation and scope of palliative care services in a Nigerian hospital: an ethnographic study
- Understanding meaning-making in serious illnesses and its impacts on palliative care: an ethnographic study in a Nigerian hospital
- The influence of knowledge on the use and provision of palliative care: an ethnographic study in a Nigerian hospital
- Provision and use of palliative care in Africa: a scoping review
- The service-users' and healthcare providers' views of political influence on palliative care in Nigeria

- The impact of social and economic complexities on service-users' behaviour towards utilisation of palliative care in Nigeria
- Exploring the impacts of resources on palliative care in a Nigerian hospital: an organisation ethnography
- Organisational cultural enablers for palliative care: a perspective from healthcare professionals and service-users in a Nigerian hospital
- The influence of interdepartmental collaborative practice for palliative care in a Nigerian hospital
- Improving palliative care workforce in Nigeria: views and recommendations of the members of palliative care team in a Nigerian hospital

It is hoped that when completed these articles will be published in peer reviewed journals, such as International Journal of Palliative Nursing, BMC Palliative Care, Journal of Palliative Care, Journal of Hospice and Palliative Nursing, BMJ Supportive and Palliative Care, Journal of Pain and Symptom Management, Pan African Medical Journal, Nigerian Journal of Clinical Practice and Journal of Palliative Care and Medicine. Publishing these articles is a strategy aimed to disseminate the research findings and it is hoped they will be available and accessible to the audience interested in these topics and will contribute in advancing the knowledge of this field. However, I plan to go beyond the above mentioned passive strategy (Traynor *et al.*, 2014) to involving in active strategies, such as building more awareness, developing connections, establishing engagements and knowledge exchange, as shown in the diagram below.



**Figure 9.1: Proposed knowledge mobilisation framework of the current study**

**More awareness:** I will engage with the use of social media, such as radio and television, to create further awareness, tailoring the message and knowledge I want to share to fit the needs of different audiences, such as local community members, groups with life-limiting or chronic illnesses, such as cancer. This unidirectional transmission of knowledge is hoped to be achieved by negotiating a time slot in the existing health programme in various private and public radio and television stations in Nigeria. I will also independently source funds to buy a time slot in these media platforms to propagate the knowledge generated from the current study, because it may contribute to changing the existing cultural discourse about terminal illness and palliation, thereby promoting positive adjustment in social rules for behaviour regarding service provision and utilisation.

**Connection:** This phase involves interactive knowledge transfer by linking directly with different actors in the real world, such as groups with cancer and other life-limiting illnesses, opinion leaders, such as village Heads, religious leaders, women leaders, youth leaders, and other local pressure groups. In this interactional relationship, I will engage with these groups by providing informational support about terminal illness and



palliation through interactive small group meetings, workshops and presentations. Interpersonal contact is suggested to improve the likelihood of behaviour change (Thompson *et al.*, 2006). Thus, I will work in partnership with the local communities to formulate an indigenous strategy to promote use of PC services. This strategy may foster change in the existing culturally bound perceptions about terminal illness and palliation. In addition, I will strengthen and expand the breast cancer support group, which I initiated with one of the physician during my fieldwork. Members of this group are used to sharing their experiences with other individuals with similar illnesses, as well as communicating the benefits of using PC, thereby encouraging change of behaviour towards service utilisation.

**Engagement:** At this stage, I will engage with policy makers and other stakeholders in Nigeria's health sector, such as members of hospital management at local, State and Federal levels (see Appendix H: overview of Nigerian health care system), Hospital Management Boards, State and Federal Ministries of Health, the Nursing and Midwifery Council of Nigeria (NMCN), the Nigeria Medical Association, the Nigeria Budget Office, management of academic institutions and Hospice and Palliative Care, Nigeria. The engagement will be in form of presenting policy briefs, conferences to further share knowledge generated in the current study. This approach could awaken their consciousness and may trigger discussions about PC, which may lead to policy formulation and developing training programmes that will drive change in practice. I acknowledge that meeting and initiating engagement with some of these stakeholders may be challenging, due to the bureaucratic complexities in Nigeria, but I will be resilient and persistent in achieving this goal, in line with one of the lessons gained from conducting the current study.

**Knowledge exchange/capacity building:** Consultations, meetings and presentation of policy briefs to the policy makers and other stakeholders in Nigeria's health sector may not be enough to guarantee the success of the knowledge implementation for change in practice, education and policy. I will continue networking and initiate knowledge exchange through collaboration in further research, such as conducting a feasibility trial or action research in various areas. For instance, I will suggest to the relevant

committee in the NMCN that they look for international support in formulating or adopting a curriculum for a pre-registration or post-basic nursing programme in PC, and to conduct research to test its workability. This would be followed by an official launch and its inclusion into other nursing programmes in Nigeria. At the studied hospital as well as other hospitals in Nigeria, I will initiate the formulation of PC clinical guidelines based on the evidence generated from this research and other existing evidence. A feasibility trial may be conducted to assess the applicability of the proposed guidelines, leading to its adopting as a protocol for PC practice at the studied hospital and, perhaps, at national level.

Finally, the knowledge mobilisation framework discussed above is mainly focused on instrumental use (Degenais *et al.*, 2015), implying integration of the knowledge generated in the current study into decision-making, with problem-solving perspectives centrally aimed to change practice and improve knowledge of PC. However, my proposed knowledge mobilisation strategies could also contribute to conceptual and symbolic knowledge use (Degenais *et al.*, 2015), indicating that it can be used to enhance the general understating of the context of PC. Additionally, it could be used to validate and support prior decisions, actions already underway and to modify existing interventions/strategies for PC development in Nigeria.

#### **9.4 Concluding thoughts**

The central goal of medicine is to preserve life but every human life will cease at a certain point, despite the advancement of technology to prolong life. There is need for a healthcare system that does not deny this fact. It could be reasonable and beneficial for everyone to support efforts towards healthcare reform aimed to benefit all dying persons, especially those with serious illnesses, regardless of their cultural background and circumstances. Culturally appropriate care should be encouraged because it may lead to good outcomes and could motivate individuals to use PC. Education in PC is contingent to improving clinical excellence in the provision of PC and may also inculcate positive re-interpretation or reappraisal of meanings associated with terminal illness and palliation, thereby promoting its utilisation.

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## Appendices

### Appendix A: Data extraction table for articles meeting inclusion criteria

S/N	Authors(s); Year of publication	Country	Title	study methodology	Study aims/objectives	Relevant Key Findings
1	Elumelu <i>et al.</i> , 2013	Nigeria	Palliative care experiences in breast and uterine cancer in Ibadan, Nigeria	Retrospective review (case file review)	To assess palliative care in a day care hospice centre from June 2008 to December, 2010	178 patients with advanced cancer accessed palliative care services within 30 months of its establishment All the patients were glad to have been introduced to palliative care service of the hospital 25 of the patients lived around the hospital environs while the 83 (46.6%) of the patient who accessed the services regretted non-availability of similar services at their home base for continuum of care 100(56.2%) of the patients who accessed the PC were referred to different parts of the country. All the patients accepted PC services Pains and other symptoms presented by the patients were controlled prior to their discharge
2	Fadare <i>et al.</i> , 2014a	Nigeria	Health workers' knowledge and attitude toward palliative care in an emerging tertiary	Cross sectional study using adapted questionnaire from previous	To investigate the knowledge and attitude of healthcare workers in a tertiary level hospital in Nigeria where a palliative	Majority of participant (70%) understood PC to be about pain medicine 49.9% considered PC to be geriatric care while 82.3% felt PC is about active care of the dying. Majority of the participants had good understanding about philosophy

			centre in South-West Nigeria	similar study to collect data from 225 healthcare workers (Nurses, Doctors, Pharmacists, Social Workers and Clinical Psychologist  Questions pre-tested in another healthcare facility before it was used.	care unit is being established	of PC. Majority also recommended PC for all dying patients and disclosure of the prognosis
3	Kolawole et al., 2013	Nigeria	Palliative care in developing countries: University of Ilorin teaching hospital experiences	Review of case note for 113 patients case notes with various forms of malignancy	To investigate experiences over a period of 20 months (May 2009 to December 2010) and highlight the challenges of providing palliative care in a hospital primarily set up to provide curative and preventive healthcare	Pain was the commonest indication among all the 113-patient referred for PC. Pain and symptom controls, psychotherapy, counselling, spiritual support, home care and bereavement support were services provided to the patients. Inadequate awareness of the services, patient drop out due to financial constraints to pay for care, lack of vehicle for home visit were the challenges

4	Fadare <i>et al.</i> , 2014b	Nigeria	Perception of Nurses about palliative care: experience from south-West Nigeria	Cross sectional study using adapted questionnaire administered to 100 different cadre of Nurses (NO, SNO, PNO, ACNO, CNO and DDN)	To investigate the knowledge and attitude of nurses toward palliative care in a tertiary hospital in Nigeria	Majority of participant (71.8%) understood PC to be about pain medicine 55% considered PC to be geriatric care while 90.2% felt PC is about active care of the dying. Majority of the participants had good understanding about philosophy of PC.
5	Otegbayo <i>et al.</i> , 2010	Nigeria	Palliative care needs evaluation in untreated patients with hepatocellular carcinoma in Ibadan, Nigeria	Modified Needs Questionnaires on pain and psychological assessment, thoughts and feelings and spiritual concerns were administered by one of the author for 205 patients between February 2007 and May 2009.	To evaluate the physical, psychosocial and spiritual needs of untreated patients with hepatocellular carcinoma, in order to determine effective palliative care approach and therefore improve their quality of life when curative therapy is elusive.	71 (35%) of patients were satisfied with pain relief while 117 (57%) were dissatisfied Some patients felt frustrated, incapacitated and could not cope well with the illness 129 (63%) knew their diagnosis while 37% did not know what they were being treated for 95% had no problem with communication with healthcare providers. 70% had fear of death while 89% hoped for healing. Some patients believed that God is a doer and could heal them

6	Omoyeni <i>et al.</i> , 2014	Nigeria	Home-based palliative care for adult cancer patients in Ibadan- a three years' review	Retrospective review	To review the spectrum of adult cancer patients involved in home-based palliative care, the services provided, outcome and benefits	60 adult cancer patients enrolled for home-based care out of total 787 adult patients enrolled for palliative care between March 2009 to January 2013 Pain was major complaint for most of the patients (86.3%) Pain relieved within two weeks of treatment Services provided are symptoms management, psychosocial counselling, drug administration, safe patient handling, provision of fund and comfort pack for indigent patients
7	Gurp <i>et al.</i> , 2015	Nigeria	Telemedicine 's potential to support good dying in Nigeria: A qualitative study	Qualitative study using FGD and interview for data collection	To explore Nigerian healthcare professionals' concepts of good dying/ death and how telemedicine technology and services would fit the current Nigeria palliative care practice	Reported barriers to palliative care provision were socio-economic consequences of being seriously ill, taboos on dying and being ill, equation of religion to medicine, poor implementation of palliative care policy and restricted access to adequate medical-technical care
8	Akinyemi ju <i>et al.</i> , 2015	Nigeria	Palliative care awareness among health care professionals in Nigeria	Cross sectional study (questionnaires distributed to 100 participants)	To assess the awareness of palliative care among some health care professionals in Lagos, Nigeria	98% has heard of palliative care 72% had learnt some aspects of palliative care job without any formal training but 90% desired training

<b>9</b>	Badru and Kanmodi (2017)	Nigeria	Palliative care awareness among religious leaders and seminarian: a Nigerian study	Cross sectional study (questionnaires distributed to 302 religious leaders and seminarians)	To determine the level of awareness of religious leaders and seminarians in Ibadan, Nigeria.	Only 31.8% have heard of palliative care 12.6% knew hospitals where palliative care is provided 21.6% knew that chaplains are members of palliative care team
<b>10</b>	Downing et al., 2014	Kenya	Public preferences and priorities for end-of-life care in Kenya: a population-based street survey	Cross sectional study (questionnaires distributed to 201 participants)	To explore public preferences and priorities for end-of-life care in Nairobi, Kenya	Majority (56.7%) said that would want to be informed if they had time left The participants preferred that their friends and family's needs for worry met over their personal need for pain relief Home was the most preferred place for death
<b>11</b>	Harding et al., 2011	South Africa and Uganda	The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries	Survey using The Memorial Symptoms Assessment Schedule Short Form	To determine the symptom prevalence and burden amongst advanced cancer patients in two African countries	The five most prevalent symptoms among the 112 patients recruited for this study were pain, feeling drowsy, sad, worrying and lack of energy with pain weight loss, sexual problems, lack of energy and I don't like myself being the most severe symptoms
<b>12</b>	Selman et al., 2011	South Africa And Uganda	Quality of life among patients receiving palliative care in South Africa and Uganda: a multi-centered study	Cross-sectional survey using the Missoula Vitas Quality of Life Index (questionnaire)	To describe QOL among patients with incurable, progressive disease receiving palliative care	Out of the 285 that were recruited, patient scored most poorly on function, wellbeing, symptoms, transcendent and interpersonal. These patients exhibited significantly poor quality of life

<b>13</b>	Grant et al., 2011	Uganda, Kenya and Malawi	Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field study	Field study using interview, observation and documentary review to collect data	To describe the patient, family and local community perspectives on the impact of three community based palliative care intervention	Patient valued being treated with dignity and respect, being supported at home which reduced physical, emotional and financial burden of travel to, and care at the health facilities. Mobile phone facilitated rapid access to clinical and social support network
<b>14</b>	Downing et al., 2015	Kenya and Malawi	Understanding models of palliative care delivery in sub-Saharan Africa: leaning from programs in Kenya and Malawi	Case study evaluation	To define the models used, contextualise them, and identify challenges, best practices, and transferable lessons scale-up	Specialist, district hospital level and community level were the three identified models of palliative care delivery Models closely associated with physical settings of services.
<b>15</b>	Ndiok and Ncama (2018)	Nigeria	Assessment of palliative care needs of patients/families living with cancer in a developing country	Descriptive study using questionnaire to collect data from 455 patients from two teaching hospitals in Nigeria	To assess palliative care needs of patients with cancer from the perspectives of the patients themselves	The most commonly needs of patients were information on possibilities of treatment and side effects, diagnosis, testing, physical symptoms. Psychological, spiritual and financial needs were identified as a stressor for patients and their families.
<b>15</b>	Olaitan et al., 2016	Nigeria	Palliative care: supporting Adult Cancer Patients in Ibadan, Nigeria	Retrospective study (reviewed case noted for patients enrolled from January to December, 2013	To describe activities of the Ibadan palliative care group and review one-year holistic care programme offered by the team to support patients and their families	Hospital based care, day care centre and home-based care commenced in 2008, being the first in Nigeria. 189 patients were provided with palliative care in one year  Pain and symptoms control, financial and spiritual support, counselling, education for patients and families

						were offered despite the major challenge of late referral and financial constraint
<b>17</b>	Rhee et al., 2017	African countries	Palliative care in Africa: a scoping review from 2005-2016	Scoping review	To gain a broad overview of the medical literature regarding palliative care development in Africa and to provide an analysis of this literature alongside the WHO public health strategy dimensions (services, education, policies and medicine availability and the activities of professionals and advocates.	<p>Service provision and implementation</p> <p>Medicine availability</p> <p>Policies</p> <p>Education</p>
<b>18</b>	Tapsfield and Bate 2011	Malawi	Hospital based palliative care in Sub-Saharan Africa; a six-month review from Malawi	Retrospective review of the case note (April-September 2009)	To review the six months of in-patient palliative care services at Tiyanjane clinic	<p>137 out of 177 patients case notes were retrieved and reviewed</p> <p>Pain was the most commonly reported symptoms, followed with others such as unable to walk, shortness of breath, weakness, anxiety and depression.</p> <p>Analgesic drugs were prescribed to 117 patients</p>

						<p>89 (65%) of the patients were discharged home but follow up planned for only 45 (51%) patients while 26% died during hospital admission</p> <p>The palliative care team was involved with provision of care for the average of 6.3days (between 1-39 days)</p>
19	Katumbo et al., 2017	Congo	The nurses' knowledge and attitude towards the palliative care in Lubumbashi Hospital	A cross-sectional descriptive study (questionnaires administered to 112 nurses)	To assess the nurses' knowledge and attitude towards PC among nurses working in selected hospitals in Lubumbashi	<p>69 (70.5%) out of 112 had poor knowledge level of palliative care. Only 33% had good knowledge</p> <p>Most of the nurses' attitude towards palliative care was favourable</p>
20	Agodirin et al., 2017	Nigeria	Pattern of breast cancer referral to palliative care and the complimentary role of a palliative care unit in a resource limited country	<p>Retrospective review of breast cancer patients referred to pain and palliative care unit between May 2009 and June 2014</p> <p>Interview by the nursing staff to shed light on some of the record and clarify the findings</p>	To describe the pattern of referral and the complimentary role of palliative care	<p>94% of 101 patients reviewed was found to have presented to PAPU in advanced stage most at stage 3 and 4</p> <p>Communication and counselling, pain control, home visitation, telephone contact and sourcing for financial aid were the services provided by the palliative care team</p>



<b>21</b>	Lakew et al., 2015	Ethiopia	Assessment of knowledge, accessibility and utilisation of palliative care services among adults cancer patients at Tikur Anbesa specialised hospital, Addis Ababa, Ethiopia, 2014; a cross-sectional institution based study	Survey (Cross-sectional institution based study using questionnaire to collect data from 384 patients with cancer)	To assess the knowledge, accessibility and utilisation of palliative care services for adults cancer patients by their perspective at Tikur Anbesa specialised hospital (TASH), Addis Ababa, Ethiopia	62.2% of 384 had previous knowledge for cancer PC services 89% reported problem with accessibility of PC services
<b>22</b>	Kassa et al., 2014	Ethiopia	Assessment of knowledge, attitude and practice and associated factors towards palliative care among nurses working in selected hospital, Addis Ababa, Ethiopia	Survey (a cross-sectional quantitative study design using questionnaires to collect data from 341 nurses)	To assess knowledge, skills, attitudes and associated factors with PC in nurses working in selected hospitals in Addis Ababa, Ethiopia	104 (30.5%) of 341 nurses had good knowledge while 259 (76%) had favourable attitude towards PC. Working in medical and surgical wards, individual's level of knowledge, participation in PC training were positively associated with knowledge and attitude of the nurses 76.2% of the nurses had poor knowledge towards PC Only 54.2% of them initiated PC discussion during diagnosis while 285 (83.6%) reported hiding truth from patients
<b>23</b>	Allsop et al., 2018	21 countries in African region	A survey of mobile phone use in the provision of palliative care services in the African region and priorities for future development.	Survey	To identify the current mHealth use in PC service delivery, potential barriers to mHealth use and provider priorities for research development	mHealth approaches were reported across 71.4% of services in which respondents were based Barriers to mHealth research include patients not having access to phones, mobile network access, and limited access to expertise and hardware required for mHealth. Research priorities were identified which included exploring ways of incorporating mHealth into patient

						care and ensuring access and relevance of mHealth for patients and health professionals.
24	Harding et al., 2014	Kenya and Uganda	Palliative care-related self-reported problems among cancer patients in East Africa: a two-country study	Cross-sectional design (Adults with advanced malignant disease gave self-reported data to the African Palliative Outcome Scale (POS))	To measure the three-day period intensity of multidimensional problems (physical, psychological, social and spiritual) among advanced cancer patients in Kenya and Uganda	The worst ranked POS items were pain and information
25	Clark et al., 2007	26 African countries	Hospice and palliative care development in Africa: A multi-method review of services and experiences	Review of literature, in-depth qualitative interview with key personnel  Field visit to Uganda, South Africa, Zimbabwe, Tanzania, Kenya, Malawi and Botswana	To provide a fuller evidence base concerning what palliative care provision presently exists in the countries of Africa and to generate intelligence on barriers to development and how they may be overcome	Opioid availability  Categorisation of development

<b>26</b>	Opoku (2014)	Ghana	Health and care development: An exploration of factors that hamper better palliative care in sub-Sahara Africa	mix-method design using interview and questionnaires to collect data from 65 healthcare professionals and 50 members of the general public	To identify the factors that are impeding palliative care development in Ghana	<p>Many respondents from general public had little knowledge about PC</p> <p>Religio-cultural attitudes towards death and dying, high cost of care and lack of fund for the provision of palliative care were identified as hampering palliative care in Ghana</p>
<b>27</b>	Mkwinda et al., 2016	Malawi	Palliative care needs in Malawi: care received by people living with HIV	A qualitative explorative design, using interview to collect data from 18 patients across three healthcare facilities	To explore the needs of PLWHA concerning care received from primary caregivers and palliative care nurses in Malawi	PLWHA needed knowledge from nurses in several areas which affected decision making and also need proper care, financial and nutritional support from the nurses
<b>28</b>	Uwimana and Struther, 2007	Rwanda	Met and unmet palliative care needs of people living with HIV/AIDS in Rwanada	Descriptive cross-sectional study using questionnaire and interview to collect data from 306 participants	To identify palliative care needs of PLWHA in selected areas of Rwanda	<p>Over 50% of PLWHA reported particularly the need for pain relief, symptom management, nutritional support, financial assistance</p> <p>Inadequate policy and resources were the main obstacle to the provision of optimal palliative care</p> <p>Over 50 of the professionals reported that they were not trained in palliative care</p>

<b>29</b>	Harding and Higginson 2005	Sub-Saharan Africa	Palliative care in sub-Saharan Africa	Review of paper from 1966 to 2003	To describe the African context for palliative care, identify factors that lead to sustainability, maximum coverage, and efficient referral systems, and highlight examples of good practice through analysis of models of palliative care and evaluation findings	Home and community-based care has been successful but community capacity and resources and clinical supervision necessary to sustain care are lacking.  Opioid availability is a barrier  Service model  Policy
<b>30</b>	Sharket et al., 2018	Around the world	National palliative care capacities around the world: Results from the World Health Organisation non-communicable diseases country capacity survey	Survey	To monitor the global status of palliative care and evaluate the progress	Findings related to African region are  There was 40% funding for palliative care in AFR  54% OF AFR have national policy for NCD includes palliative care and policy is operational  Only 14% of AFR have oral morphine in more than 50% pharmacies  9% of AFR have home-based or community palliative care
<b>31</b>	Rhee et al., 2018	7 African countries	Factors affecting palliative care development in Africa: in country experts' perceptions in seven countries	Qualitative design using interview to collect data from 16 palliative care experts	To identify key factors affecting PC development in African countries from in-country PC experts' perspective	Lack of palliative care education, limited availability/accessibility to morphine, lack OF standardisation in implementation, lack of funding, poverty and disease burden were the identified challenges

<b>32</b>	Lynch et al., 2013	40 countries of the world	Mapping levels of palliative care development: A global update	Multi-method approach (review, in-country experts were asked to provide information,	To categorise palliative care development, county by country, throughout the world, showing changes over time	In Africa, no palliative care services could be identified in 28 countries  Uganda was only African country in group 4b while other African countries were categorised in group 4a, 3a, 3b, 2 and group 1
<b>33</b>	Nwabuko et al., 2017	Nigeria	Multiple myeloma in Niger Delta, Nigeria: complications and the outcome of palliative interventions	Retrospective study (A ten-year multicentre review)	To bring to the fore the complications experienced by people living with MM in the Nigeria-Delta region of Nigeria and the outcome of various palliative intervention	Majority (61.5%) presented in Durie-Salmon stage III Pain, anemia, nephropathy, and hemiplegia were the complications presented by the patient Inadequate PC account for major complication (their conclusion)
<b>34</b>	Wright et al., 2008	234 countries around the world	Mapping levels of palliative care development: A global view	Multi-method approach (reviews, grey literature, opinion of experts)	To categorise palliative care development, county by country, throughout the world, and then depict this development in a series of world and region map	Palliative care was found to be unavailable in most of the African countries though there some evidence of capacity building and localised palliative care provision is some African countries
<b>35</b>	Adenipekun et al., 2005	Nigeria	Knowledge and attitudes of terminally ill patients and their families to palliative care and hospice services in Nigeria	Survey (questionnaires administered to 130 participants)	To assess the knowledge and attitudes of patients and their relations to palliative care and hospice services and to fashion out appropriate services for the patients	94 (72.2%) had no knowledge of palliative care regardless of level of education and social status 106 (83%) desired to have hospice established in every community, this again was regardless of tribe

<b>36</b>	Omidamide et al., 2013	Nigeria	Palliative care: An alternative to euthanasia	Qualitative design using interview to elicit data from terminally ill patients	To show case palliative care as an efficient alternative to euthanasia for terminally ill patients	The request for euthanasia and or assisted suicide, are largely due to the fear of being a burden and abandoned by families and relatives
<b>37</b>	Lewington et al., 2012	Uganda	Provision of palliative care for life-limiting disease in a low-income country national hospital setting: how much is needed	Qualitative design using interview to elicit data from 78 life limiting patients	To measure the magnitude of palliative care needs among hospital inpatients	Social problems included an inability to work, having unaffordable medical expenses, limited access to food and need to increase faith support were the needs expressed by the patients
<b>38</b>	Fraser et al., 2017	Uganda And Kenya	Palliative care development in Africa: lesson from Uganda and Kenya	Review	To examine and compare strategies used to promote the development of palliative care in Uganda and Kenya in relation to five domains (education and training, access to opioids, public and professional attitude, integration into national healthcare systems and research)	Both countries have implemented all five domains to develop palliative care Both countries have integrated palliative care into the national healthcare system and educational curricula, the training of health care providers in opioid treatment, and the inclusion of community providers in palliative care planning and implementation. Research in palliative care is the least well-developed domain in both countries
<b>39</b>	Hannon et al., 2016	Low- and Middle-income	Provision of palliative care in Low- and Middle-income countries: overcoming	Review	To examine approaches to overcome barriers that continued to affect the availability of palliative	Health care delivery and integration into National health systems Access to opioids medications Research Education and training

		countries	obstacles for effective treatment delivery		care Low- and Middle-income countries	Attitude towards palliative care
<b>40</b>	Nnadi and Singh, 2016	Nigeria	Knowledge of palliative care among medical interns in a tertiary health institution in Northwestern Nigeria	Quasi-experimental interventional study	To ascertain the existing knowledge of palliative care among medical interns and determine the effect of a structured educational intervention on improvement of their knowledge level	11 participants out of 49 had poor knowledge level of palliative care in the pretest but this improved with only 2 medical interns still with poor knowledge after postintervention Good knowledge appreciates from 18.4% to 28.6% while very good knowledge rise from 20.4% to 38.9% after intervention. 57% had had poor knowledge of the constituents of terminal care. They exist positive relationship between the number of sources of information and the knowledge level of palliative care.
<b>41</b>	Eke <i>et al.</i> , 2016	Nigeria	Knowledge and perception of healthcare providers towards palliative care in Rivers State, Nigeria	Cross-sectional study	To evaluate the knowledge and perceptions towards palliative care among healthcare providers in Rivers State	88% had previously heard of palliative care but less than 47.4% were aware of the interdisciplinary facet of this service. 83.3% believed that terminally ill patients should benefit from palliative care whereas some believed that everyone should benefit from palliative care

## Appendix B: Project risk assessment

### Degree of risk

<b>Unlikely</b>	<b>Possible</b>	<b>Highly likely</b>	<b>Inevitable</b>
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>

Description of potential risk	Persons at risk	Degree of risk	Potential impact/ consequences	Control measures/precautions to be taken
<p><b><u>Travel risk</u></b></p> <p>This involves potential travel risk to study site for data collection (from the United Kingdom to Nigeria. It also involves local travel risk from area of residence to study site within Nigeria</p>	<p>The researcher</p>	<div style="background-color: #4a7ebb; color: white; padding: 5px; width: 20px; margin: 0 auto;">2</div>	<p>Physical injury</p>	<p>The researcher will travel only when necessary. The precaution of using trusted and a well-known airline like British airline will be taken during travel to Nigeria. Local travelling will be minimised by residing close to the study site.</p>



<p><b><u>Nosocomial infection</u></b></p> <p>Healthcare workers are at risk of hospital-acquired infections. This is because they are exposed to the care of patients with different kind of diseases and hospital environments. The researcher will be prone to this risk because he will be immersed with the oncology care team at the study site.</p>	<p>The researcher and other healthcare workers</p>	<p>2</p>			<p>Disease condition</p>	<p>The following precaution will be taken by the researcher to avoid nosocomial infections.</p> <ul style="list-style-type: none"> <li>• Observe universal precaution measures such as the use of hand gloves, washing of hand regularly etc.</li> <li>• Avoid unnecessary contact of patients with infectious diseases.</li> <li>• Changing of nurses' uniform after each day work</li> </ul>
<p><b>Risk of activity of armed group (Boko haram) and Biafra agitators</b></p> <p>There are activities of Boko haram in Nigeria but it's predominant at North East. The risk of the researcher been attacked is minimal because the study site region (South East) is free from this</p>	<p>The researcher and other healthcare workers</p>	<p>1</p>			<p>Physical injury</p>	<p>The researcher will be always alert to the happenings in his environment. Avoid movement in the night.</p>

<p>insurgency. However, the researcher is prone to the activities of Biafra agitators predominantly in the Eastern part of Nigeria</p>						
<p><b><u>Emotional distress</u></b></p> <p>Observing the care of terminal and dying patients has potential to reawaken negative feelings and emotional suffering. Also, discussing terminal illness, listening to the interview tape during transcription is another typical activity that may arouse strong negative feelings.</p>	<p>The researcher , patients, patients' relatives and other healthcare workers.</p>		2		<p>Negative feelings, emotional distress, depression.</p>	<p>The following precaution will be taken by the researcher to avoid emotional distress.</p> <ul style="list-style-type: none"> <li>▪ Exhibiting quality of a nurse such as empathy</li> <li>▪ Using diversional therapy like watching television after each day work</li> <li>▪ Building up self to be aware and to expect such feelings at the study site</li> <li>▪ Use of psychological and emotional therapy located in the oncology complex on the organisation if emotional distress occurs to the participants or the researcher</li> <li>▪ Ask only necessary questions to the participants during interview</li> </ul>

## Appendix C: Ethical approval letters

1



Our Ref: ..... Date: 25<sup>th</sup> June, 2015

**NHREC/05/01/2008B-FWA00002458-1RB00002323**

**ETHICAL CLEARANCE CERTIFICATE**

**TOPIC:** EXPERIENCES OF PALLIATIVE CARE TEAM ABOUT FACTORS INFLUENCING THE CARE OF TERMINALLY ILL AND DYING PATIENTS IN NIGERIA: AN ORGANIZATIONAL ETHNOGRAPHY.

**BY:** *DAVID A. AGOM*

**FOR:** A PH'D THESIS OF THE SCHOOL OF HEALTH, UNIVERSITY OF NORTHAMPTON, PART CAMPUS ENGLAND, UK.

This research project on the above topic was reviewed and approved by the University of Northampton Teaching Hospital Health Research Ethics Committee. This certificate is valid for **one year** from date of issue.

  
Pfc  
Chairman, Health Research Ethics Committee

Date: *11/07/15*

Our Ref: CSA/329/OL.5

Date: 27<sup>th</sup> March, 2017

**NHREC/05/01/2008B-FWA00002458-1RB00002323**

**ETHICAL CLEARANCE CERTIFICATE**

**TOPIC:** EXPERIENCES OF PALLIATIVE CARE TEAM ABOUT FACTORS INFLUENCING THE CARE OF TERMINALLY ILL AND DYING PATIENTS IN NIGERIA: AN ORGANIZATIONAL ETHNOGRAPHY (Renewed for 2017)

**BY:** DAVID A. AGOM

**FOR** A PH.D THESIS OF THE SCHOOL OF HEALTH, UNIVERSITY OF NORTHAMPTON, PART CAMPUS ENGLAND, UK.

This research project on the above topic was reviewed and approved by the [REDACTED] Hospital Health Research Ethics Committee. This certificate is valid for **one year** from date of issue. Please note that the Committee Reserves the Right to monitor the Conduct of the study at any time for strict Compliance to the Protocol.

[REDACTED]  
Chairman, Health Research Ethics Committee

Date: 29/03/17

## **Appendix D- Participant information sheet (version 2.0) January 2017**

Study title: Socio-political, cultural, environmental, and organisational factors influencing the care of terminally ill patients in a Nigerian healthcare organisation: An organisational ethnography

### **Purpose of the research**

The purpose of this research project is to generate evidence concerning factors influencing the provision of palliative care services in Nigeria and to use this evidence to promote positive change in palliative care service delivery and education through evidence-based report to relevant authorities (Federal ministry of health, State ministry of health, hospitals management boards, medical and nursing professional bodies) in Nigeria about the factors influencing the provision of palliative care in Nigeria

### **Who the researcher is:**

The researcher is David. A. Agom, a Ph.D. student at the University of Northampton, United Kingdom. He is a registered nurse in Nigeria and holds a Bachelor of Nursing Science degree (BNSc) and Masters in Nursing Science degree (MSc Nursing).

### **What the study involves:**

This is a qualitative study using participant observation and interview as methods to collect data from the participants. You will be observed while providing care to terminally ill and dying patients and/or invited to participate in formal interviews where questions around the care of terminal illness will be asked and interview will be recorded using voice recorder.

### **What happens to you if you take part?**

You will be asked for consent to be interviewed and/or observed. You will either be observed while providing care to terminally ill patients or be invited to be interviewed about terminal illness and its management.

### **What are the risks?**

No highly likely or inevitable risks have been identified as a consequence of your involvement in the project. You will be asked to suggest a place for the interview which will be risk assessed to ensure that it will be comfortable, safe and secure for you and the researcher.

### **What happens to the information?**

The information given will be stored in a computer which is password protected. The identity of each participant (you) will remain anonymous throughout the research process and in the report. I will do this by assigning a number to you. From then on, you will be known only by your number. Once the research is completed, the information will be kept for some years (about 10 years) before it is destroyed. Keeping of the data for some years is necessary as it will be used to substantiate the finding in a situation where the finding is challenged in future.

When I write any report of the study, it may not be possible to identify you or anyone else who participated in the study.

The information you give will be for research purpose only. It will not be given to any other party but the supervisory team for this project may need to see it for necessary guide towards successful project completion.

**Not sure about participating? Or do you have to take part?**

If you do not want to participate, that is fine; you have right not to participate. You can also stop at any time if you do not want to finish the study; just let me know when you are ready to stop. If you decide to stop before completion, your personal contacts or data will be destroyed. Please note that data collected from you may not be destroyed at the point where it has been transcribed and anonymised because it will not be possible to identify and disentangle such data. All your data before this stage will be destroyed if you decide to withdraw from the study.

**Who has checked this research?**

The research degree board and research ethics committee at University of Northampton, England, United Kingdom

**Who to contact in your organization, if you have any concern about the study at any point**

You should contact the chairman, Hospital Research Ethics Committee.

**Contact details for the researcher**

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+44(0)7442975948

<p><b>Supervisory team</b> <b>Director of Studies</b> Dr Stuart Allen Head of Sport, Exercise and Life Science School of Health stuart.allen@northampton.ac.uk Tel: +44 (0)1604 892642</p> <p>Dr. Sarah Neill Associate Professor in Children's Nursing School of Health sarah.neill@northampton.ac.uk Tel: +44 (0)1604 892871</p>
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Thanks.

## Appendix E: Participant consent forms

**Interview consent form (version 2.0) January 2017**

**Title of the study:** Socio-political, cultural, environmental, and organisational factors influencing the care of terminally ill patients in a Nigerian healthcare organisation: An organisational ethnography

**Researcher:** David A. Agom

**Please initial each box if you agree to take part in this study**

Your initials here ↓

1	I confirm that I have read and understood the participant information sheet version 2.0 dated January 2017 for the above study.	
2	I have had sufficient information about this study to enable me to make a decision about taking part	
3	I have spoken to the above researcher and understand that my involvement will involve being interviewed about care of terminal illness and/or beliefs about terminal illnesses	
4	I understand that the discussion will be audio recorded throughout	
5	I have had the opportunity to consider information, ask questions about this study and have had these answered satisfactorily.	
6	I understand that my participation is voluntary and that I am free to physically withdraw at any time, without giving a reason.	
7	I understand that data collected during the study will be used to write evidence-based report to Federal ministry of health, State ministry of health, hospitals management boards, medical and nursing professional bodies in Nigeria for service and educational improvement in my organization and beyond.	
8	I understand that the data collected during the study may be looked at by the supervisory team from The University of Northampton.	
9	I understand that any information given by me may be used in future reports, articles or presentations by the researcher in professional journals, at conferences or used in health care professional education programs.	
10	I understand that my name will not appear in any report, articles or presentations	
11	I understand that the researcher will report any disclosed information that may constitute harm to the appropriate authority	
12	I understand that the information I provided will be transported to the United Kingdom for analysis by the researcher	
13	I understand that anonymised data will be retained if I withdraw my participation in this study.	
14	I agree to take part in the above study	

.....

.....

.....

Name of Participant

Date

Signature

Participant contact detail (if you wish) .....

..... Date Signature

**Participant observation consent form (version 2.0) January 2017**

Sociocultural, environmental, and organisational factors influencing the care of terminally ill patients in a Nigerian healthcare organisation: An organisational ethnography

**Researcher: David A. Agom**

**Please initial each box if you agree to take part in this study**

Your initials here

1	I confirm that I have read and understood the participant information sheet version 2.0 dated January, 2017 for the above study.	
2	I have had sufficient information about this study to enable me to make a decision about taking part	
3	I have spoken to the above researcher and understand that my involvement will involve being observed and/or interviewed about care to terminal and dying patients	
4	I understand that the discussion will be audio recorded throughout	
5	I have had the opportunity to consider information, ask questions about this study and have had these answered satisfactorily.	
6	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	
7	I understand that data collected during the study will be used to write evidence-based report to Federal ministry of health, State ministry of health, hospitals management boards, medical and nursing professional bodies in Nigeria for service and educational improvement in my organisation and beyond.	
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12	I understand that the information I provided will be transported to the United Kingdom for analysis by the researcher	
13	I understand that anonymised data will be retained if I withdraw my participation in this study.	
14	I agree to take part in the above study	



.....  
Name of Participant

.....  
Date

.....  
Signature

Participant contact detail (if you wish) .....

## Appendix F- Sample of field notes

### Condensed note

Start 10:00  
Pain demonstration: The problem of how to make nurses to be satisfied with keeping at the chart. He said that some nurses are un-enthusiastic ~~to~~ especially at (personal) keeping. The reason could be communal & more after the first batch of the training.

Sex - influenza  
- 3 classes  
- 2 nurses  
- one pharmacist

Friday 16/10/2015  
Pain Unit Observation (FIELD NOTE)

On my way to the Oncology complex at 8:15, I met Mrs. (P.N.). I greeted her and we walked together to nurses station. Most of the door were still locked including Palliative care clinic and palliative care nurses station. The nurses went to get the key, opened the nurses station and start cleaning the chairs and table. I offered to assist her but she said that I should wait for the

cleaners to come and into their unit.  
✓ Sat down at the table and told me they had emergency family meeting yesterday and also two patient referred by Gastroenterology Unit and General Surgery Unit. She gave me all the forms and the paper works to read. As I was reading the report of the family meeting they had yesterday and the two other referral letter, Another palliative care nurse (Mrs.) came inside the clinic & greeted her and she started telling me that she had come as early as 7:15 but everything were locked. That the cleaners that supposed to clean everything don't do their job. that it is already their culture not to do their job of cleaning. She further said that she has reported Assistant director nursing services that mandated her to issue a query to them why they have refused to do their jobs.

Review of Report of family meeting held yesterday  
patient's diagnosis: Metastatic Anorectal Carcinoma

Meeting requested by: PC Team  
 Family caregiver present are

- Elder Sister
- Male Cousin (care giver)
- Younger Sister

Topic discussed: Prognosis + end-of-life care  
 The younger sister of the pt is a trained nurse and had excellent knowledge of prognosis and prognosis.

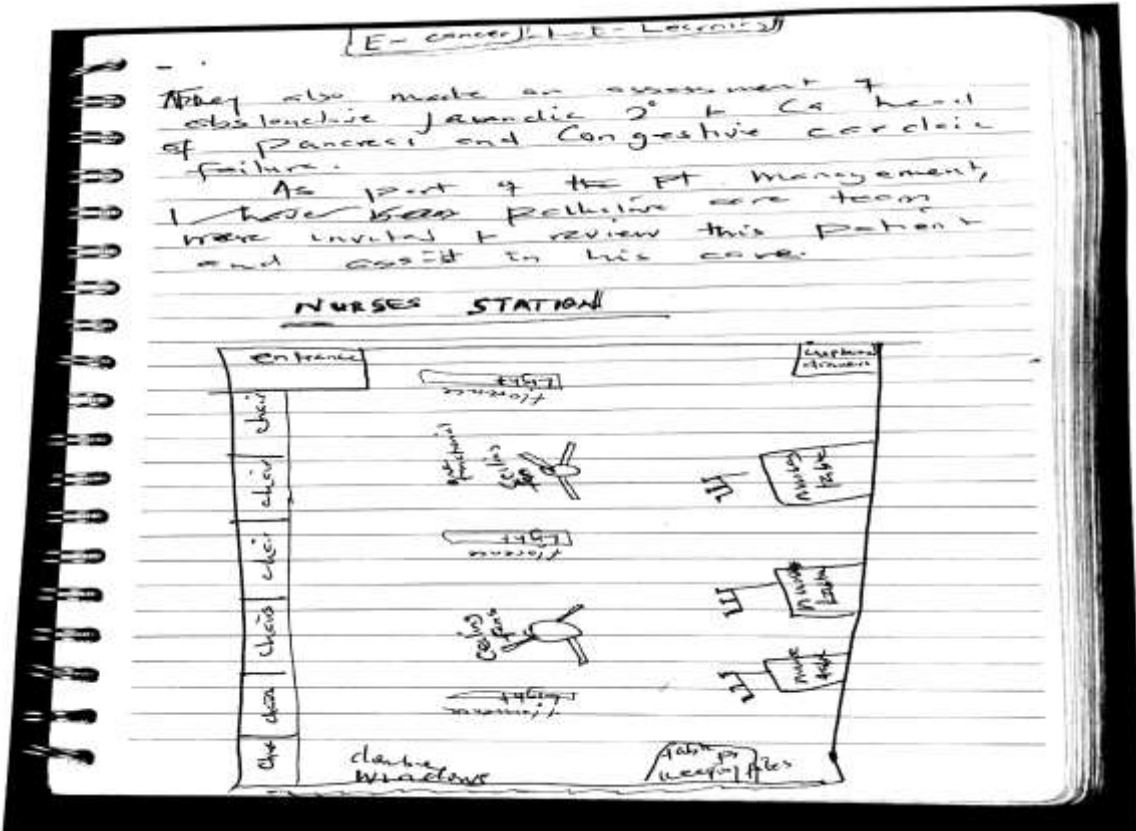
- my concern of diagnosis + prognosis. They are of the opinion that the pt brother should be told about the diagnosis + prognosis but PC team should organize such meeting with patient for the pt to discuss details and prognosis before death.
- Younger Sister was invited and wanted the meeting to end privately.
- The Elder Sister of the pt said that pt is presently has fear of death and should not be informed about the condition while the younger sister prefer that the patient should be informed about the diagnosis + prognosis.

- Elder Sister want brother to be prior free with the cultural beliefs of a man who is dying, he will not be happy in the next world.  
 PC team is of impression that

- younger sister wants end to issue so as to go back to normal family + work life.
- family don't want to know so they want get his business done, leads to meet the together before she will be aware.
- Elder Sister want brother to die quietly + peacefully.

Review of THE TWO Referral LETTERS TO PCU.

- One of the pt was admitted 4/2 ago and after investigation, the diagnosis of suspected male likely cancer with hepatic and pleuropulmonary metastasis was made. The surgical team reviewed the patient and concluded that he will not benefit from surgery. Palliative care team was therefore invited to take over management of this patient.
- Another patient was admitted 3/2 ago under general surgery unit I. After lab investigations, and Abdomino-pelvic USS and CT Scan, the impression of Ca of head of pancreas was made.



## **Expanded note**

### **Field note on 2016-01-18**

I met two palliative care nurses on arrival to the palliative care nurses station at 8:30. They laughed as they discussed with me and with each other. At 9:30, the Head of palliative care unit (HOP) rang me, said she will be in the palliative care nurses station by 10:00 to lead ward round. At 10:10, someone from physiotherapy unit entered palliative care nurses station, said she came to find out the time for palliative care ward round.

At 10:25, the HOP arrived and the team that comprised of two palliative care nurses, two palliative care physiotherapists, a social worker and myself proceeded for a ward-round. The team cared for terminally ill patients in oncology ward, ward 1, ward 2 and ward 10. During the ward round, the following were noted;

- The nurses that work in ward 10 did not administer oral morphine as prescribed. One of the patient said that she reminded a nurse to administer the oral morphine to her but the nurse ignored her.
- The palliative care nurse counselled the patients and with their relatives
- Ward 10 and oncology ward were filled with many patients
- The physiotherapists made contributions for the patient pain management during the round
- Palliative care team members engaged with each other in discussion about the patient care. The HOP provided opportunity to discuss each patient management.
- The HOP arranged for family meeting the next day with a patient relative (her husband) in ward 10. The patient relative pleaded that the meeting should hold that day because he will not be available the next day. The HOP agreed that the meeting will hold after the ward round.
- The ward round ended at 12:15.

### **Family meeting**

The family meeting with patient relative and the palliative care team members commenced by 12:45 at palliative care nurses station. The meeting started with opening prayer made by the palliative care nurse. The HOP welcomed the patient relative and asked him to tell us what he know about the wife disease condition. The man said the followings;

- He is aware the wife has breast cancer because it was diagnosed ten years ago.
- That it started as a breast lump and he took the wife to this hospital and it was diagnosed as a breast cancer

- That when the diagnosis was made, it seemed as a death certificate. He cried with the wife.
- They later accepted the diagnosis and strictly followed the doctor's advice. The wife received chemotherapy and later had mastectomy.
- That the wife has lived for 10 years since the diagnosis was made

When the man finished the explanation of what he knew about the diagnosis, the HOP thanked him, said he has basic knowledge of the condition. She asked the man if he know why the wife is currently having pain on the face, eye and the mouth. The patient relative replied no, said he believed that they should be a solution. The HOP explained that the cancer has spread to the head, eye and the facial bones, that the patient will lose her sight on the affected eye. The HOP went further to explain the role and responsibilities of palliative care team. Said that the palliative care team was involved in the care of the patients so that they will treat pain and any other distressing symptoms the patient may develop.

The patient relative asked how long the patient will receive care from the palliative care team. The HOP said as long as the patient lives. She also said that the palliative care nurses will visit the patient home some days to continue with palliative care services if the patient is discharged home. The palliative care mobile number was given to the man, told him he can contact the unit to discuss or report any symptom the patient may develop when they are discharged home.

The man thanked the HOP, said he was happy with the services rendered to his wife by the consultant and the palliative care team. The man went further to say that 'the wife condition at the moment seems to be beyond medical science. That he has planned to take the wife to somewhere else for cure because he has strong faith that the will disease will be cured. That he believed that God who added 10 years to the live of the wife since the diagnosis was made will add another 15 years to the live of his wife. That God did it before and he can do it again. That he believed that it is God's will for the wife to live long'.

The man continued, said that 'they want to adventure into spiritual. They want to seek care from man of God. That pastor Adeboye will hold crusade on Friday at Anambra state. That he will take the wife to the crusade ground for prayer and healing. That he and his wife have strong faith that God will cure this condition. That he kept on hearing in his spirit and his mind that devil cannot win over this battle. That God will win'.

The HOP said that she is a Christian and believed that God can do all things but he should continue with the medical care while he seeks for spiritual care. One of the palliative care nurse

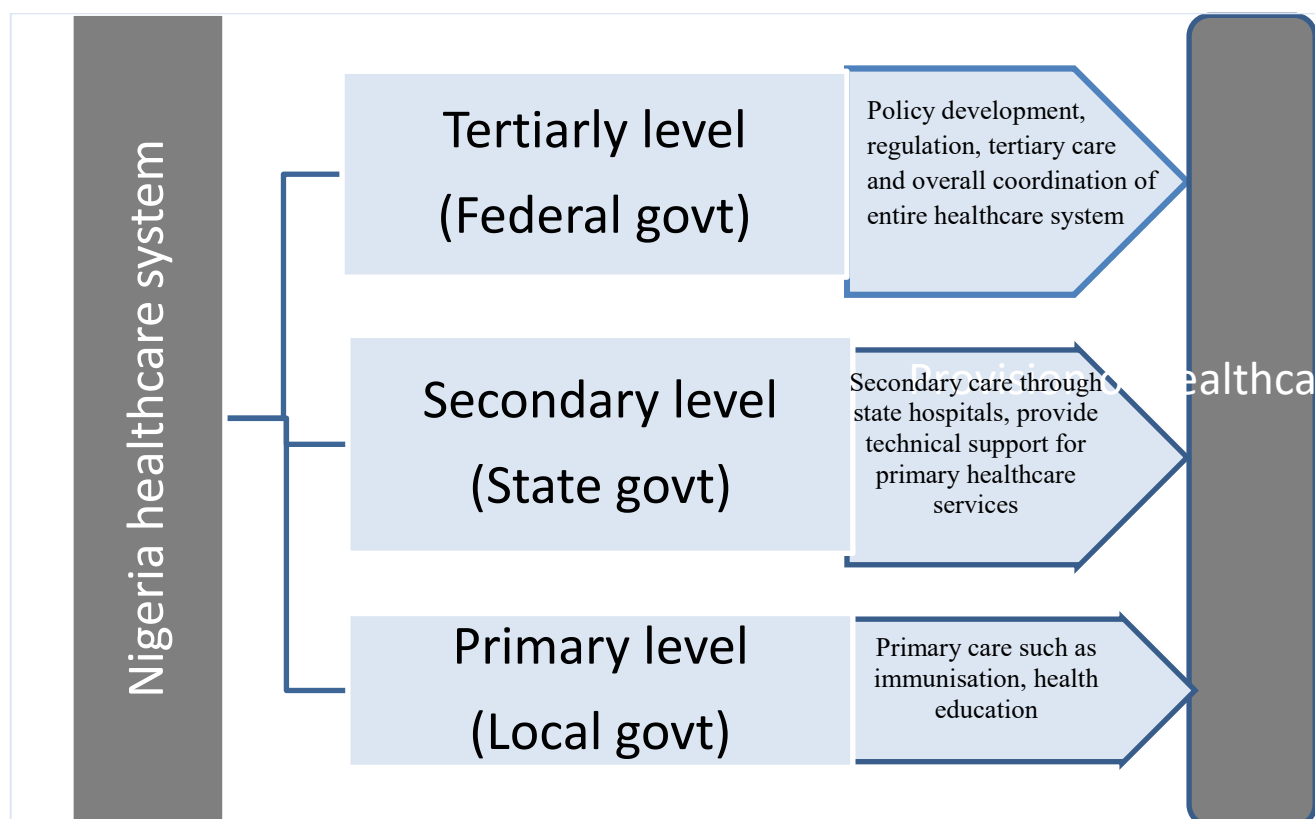
also supported what the HOP said and told the man to continue with the services render by the palliative care team because the aim is to improve the quality of the wife's life. The man thanked the team members and the HOP asked me to close the meeting with prayer.

### **Fieldwork journal on 2016-01-08**

The nurse expressed concern about the terminally ill patients that were referred to palliative care unit but did not received care from palliative care team because no doctor was available to lead palliative care ward round. Are palliative care nurses not allowed to independently render any palliative care services to terminally ill patient? There is shortage of palliative care doctors and the available doctors are seemed not fully dedicated to palliative care services. The absence of palliative care doctor affects the palliative care services render by palliative care nurses and other members of palliative care team. This is because no palliative care services have been rendered to five terminally ill patients that were referred to palliative care unit since 4<sup>th</sup> January. One of the palliative care nurse earlier told me that 'palliative care nurses are not allowed to lead palliative care ward round or to prescribe medications for the care of terminally ill patients. This could be a case of power struggle that exist in Nigeria health care system? Palliative care services were not rendered to terminally ill patients because no palliative care doctor came to work. This suggests that provision of palliative care services depend greatly on the availability of palliative care doctors in this hospital. There should be palliative care doctors readily available and committed to provision of palliative care services to terminally ill patients. I felt bothered when a doctor entered in the palliative care nurses station to complain that palliative care team has not cared for terminally ill patient referred since 4<sup>th</sup> January. These doctors reported that the patient is currently in severe pain. What are the reason for the shortage of manpower especially palliative care doctors?

## Appendix G: Overview of Nigerian health care system

The healthcare delivery system in Nigeria is organised into primary, secondary and tertiary healthcare levels, as shown below.



The Federal and State government, through health ministries, parastatals, boards and agencies provide management of the healthcare system and with various responsibilities, as shown in Figure 1.1, above, whereas Local Government, through health authorities, deliver primary healthcare services (Nigeria Health Sector, 2015; Okpani, and Abimbola, 2015; Federal Ministry of Health 1999). However, this depiction of a straight-forward three-tier structure of Nigerian healthcare delivery system is accurate only in principle; in reality, it is pluralistic, comprising alternative, traditional faith-based, spiritual and private healthcare systems that operate alongside the three tier-structure (Adekannbi, 2018; Adeloye *et al.*, 2017; Uwakwe *et al.*, 2015; Adefolaju, 2014),

Lastly, the healthcare is financed by a combination of budgetary allocation, out-of-pocket payments (OOP), donor funding, and health insurance. A low budgetary allocation at all levels of government, high OOP, and poor health insurance coverage was found in a recent review of healthcare system financing in Nigeria (Uzochukwu *et al.*, 2015). Remarkably, despite the Nigerian government signing the Abuja Declaration in 2001 and agreeing to allocate 15% of the total budget to health, less than 10% of the national budget has been allocated to health since this declaration to date; specifically, it was 4.23% in 2016 and 4.7% in 2017 (Nigeria



Budget Office, 2018). Therefore, OOP seems to be the key source for healthcare funding, estimated at more than 70% of healthcare financing in Nigeria (Aregbeshola and Khan, 2018; World Bank, 2018). It is estimated that only 5% of individuals, mainly Federal and State workers, are currently covered by the National Health Insurance Scheme (Onwujekwe *et al.*, 2012; Onoka *et al.*, 2013), in sharp contrast to the key objectives to secure universal coverage and access to adequate and affordable healthcare for all Nigerians (NHIS, 2018). The current research was conducted in one of the hospitals in Nigeria; therefore, providing context related how the healthcare system is organised and managed could offer useful insight upon which to understand the current research.

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