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Exploring the process and experiences of nursing care of patients at the end of life: nurses', patients', and family carers' perspectives

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Responses to the recommendations of the viva held on 3rd April 2019. Several suggestions were addressed as shown below:

Comments/Recommendations	Responses	Page
In Chapter 3, please expand your section on reflexivity a little (3.2.8) to include a more in-depth consideration of positionality and identity (e.g. as a nurse, as a lecturer, as a Nigerian – i.e. as an 'insider') and how this may have influenced what you observed and how you interpreted your data.	Section 3.2.8 was expanded to include my positionality and identity as a nurse, a lecturer, and a Nigerian, and the influence on the data observed and interpreted.	59 - 60
In Chapter 4, please include a short section explaining how the 'cases' were analysed and used to inform the development of the themes. We feel it would be helpful to have more detail here on what value was added to your work by using a case study approach - i.e. how did this influence your understanding and analysis It would also be helpful to briefly justify why cases were restricted to three individuals when many other actors play a role in this setting (doctors, ancillaries, other families etc.).	In section 4.2, I explained how the cases were analysed and used to inform the development of the themes. The influence of the cases on the data analysis was also included. The justification on why cases were restricted to three individuals was highlighted.	75 – 76 76 76
We felt that the findings would be easier to understand if there was more detail on the 'cases' that you observed. Hence, in Chapter 5 (or in an Appendix), please create a section in which the cases are described more fully (for example, by creating a table documenting a 'case triad summary' for each one in which we find out more about the patient, their diagnosis, their illness & hospitalisation trajectory, their main symptoms and problems, and what ultimately happened to them. These should include a similar description for the main (linked)	Case profiles were created and included in the appendices. See appendix Six	217 - 230

family carer and nurse. The case summaries or descriptions should include some reflections on the interactions between the three key individuals within the case and how this influenced nursing care and care experiences.		
In Chapter 9, we would like to see a little more discussion of the 'nurse-FC model'. This discussion should include some critical consideration of how it might be elaborated and implemented; including ways in which it may (or may not) be acceptable to staff and carers, and what some of the barriers might be and how these might be overcome. E.g. possibly referring to some of the literature on positive outcomes related to caregiving (e.g. work by Peter Hudson). The discussion should include a critical consideration of similar models of care that have been implemented in other settings (e.g. in Uganda or South Africa) and an evaluation of whether or not they might be adapted to a Nigerian context.	A further discussion of the 'nurse-FC model on how it might be elaborated and implemented was include in section 9.1.1 Similar care model in Uganda was also examined and included in section 9.1.1	171 – 173 173
We felt that the final section on 'Implications' was a little short and under-developed. We would like to see more specific recommendations for policy, education, research and practice that link to wider developments in the field. The candidate discussed some innovative ideas for future developments in the field during the viva, and we would like to see some of these documented.	Specific recommendations for policy, education, research, and practice were included in section 9.5	193 - 196

ABSTRACT

Background: Nurses, patients, and family carers in Nigeria face several challenges associated with inadequate resources to care for patients at the end of life. This is evidenced in the recent ranking of palliative and end-of-life care across the world for the 2015 Quality of Death Index by the Economist Intelligence Unit; where Nigeria is at the position 77out of 80 countries. There is a dearth of literature relating to palliative and end-of-life care in Nigeria. A systematic review of end-of-life care in sub-Saharan Africa reveals that most of the studies in sub-Saharan Africa (SSA) were centred on HIV/AIDS, and the majority were in South Africa. No studies were from Nigeria nor found to explore the nurses' experiences and understanding of caring for patients in hospitals during the end of life. To the researcher's knowledge, this is the first study to explore the process and experiences of nursing care of patients at the end of life in a hospital from the perspective of nurses, patients, and family carers which justifies the current study.

Research Question: How is nursing care delivered to patients in the hospital at the end of life from the perspective of nurses, patients, and family carers?

Purpose: To explore the process and experiences of nursing care of patients at the end of life from the perspective of nurses, patients, and family carers.

Methodology and Methods: A qualitative ethnographic case study design was employed for the study. Participant observations consisting of 188 hours of observation, and semi-structured interviews with 40 participants (fourteen nurses, twelve patients, and fourteen family carers) were undertaken. Data analysis follows an inductive thematic approach using NVivo 11 qualitative data management programme, guided by an analytical framework identified by Roper & Shapira (2000) and Braun & Clarke (2013).

Findings: The nurses, family carers and other healthcare professionals play significant roles in delivering care to patients. The pattern of care

discovered in the study was presented in the form of nurses-family carers care model describing care in three dimensions: care by nurses, care by family carers, and collaborative care. The nurses delivered care to patients at the end of life without a clear pathway or a definitive approach, due to the absence of policies and guidelines. Palliative and end-of-life care is not included in either undergraduate or postgraduate medical and nursing curriculum and is not integrated in the mainstream healthcare system in the country. Both nurses and family carers experienced distress and inadequacies, and are often faced with numerous conflicting situations when the plan of care is perceived to be shifted to end-of-life care. The findings also show expression of mixed feelings about the care, in which the majority of patients and their family carers expressed negative emotions, while others with positive feelings felt that the nurses could do better if provided with the enabling environment. Some of the patients and family carers complained about healthcare professionals withholding information from them. This inadequate information generates tension and anxiety for both patients and their family carers because of fear of unknown circumstances. The participants highlighted several factors that affected the provision of quality patient care such as a shortage of nurses, logistical problems, poor conditions of service, decayed infrastructure, security laxity, and language barrier. Finally, all the participants perceived that the improvement of drug supplies, improvement of staffing levels, provision of rewards/incentives, and continuing education and training of staff could promote good end-of-life care.

Conclusion: The findings showed how nurses and family carers delivered care to patients at the end of life; they carry out various activities to ensure the wellbeing of patients. Both nurses and family carers have varying experiences during end-of-life care ranging from degrees of discomfort and emotional distress to a feeling of fulfilment. It was clear from the findings that most of the patients have their needs unmet at the end of life. Financial problems were a major concern among patients and their family carers because healthcare expenses

are paid out-of-pocket. The findings also show that patients and family carers receive insufficient information regarding patient care. While the patients and their family carers expressed dissatisfaction about the care they received, the nurses attributed the poor quality of care to inadequate staffing, decayed infrastructure, logistical problems and poor conditions of service. The study implies that nurses need to engage actively in the care of patients, especially fundamental care. This would provide them with an opportunity to carry out physical assessment during the fundamental care thus reducing the risk of pressure ulcers and other conditions related to immobility and improve interaction with the patients and family carers. Healthcare professionals, policymakers, and all stakeholders need to collaborate on how best to help patients and their family carers and strengthen the healthcare institutions. This could be achieved by introducing palliative and end-of-life care in both undergraduate and postgraduate medical and nursing curriculum, development of policies and guidelines, and integrating palliative and end-of-life care in the mainstream healthcare system in the country.

SCHOLARLY OUTPUTS FROM THE STUDY

Published abstracts:

1. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. 2018. *Nurses' caring experiences during the end of life in a resource-poor setting*. Palliat Med, 32, 3-330. http://www.ncbi.nlm.nih.gov/pubmed/29676654

2. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. 2018. *Family carers' experiences during the end-of-life care in a resource-poor setting.* BMJ Supportive & Palliative Care, 8, A24-A24. http://spcare.bmj.com/content/bmjspcare/8/Suppl1/A24.1.full.pdf

3. KHALID, D. S., HIGGINBOTTOM, G. & COX, K. 2017. *Nursing care of patients during the end of life in sub-Saharan Africa: A (systematic) literature review. West African Journal of Nursing*. http://www.wacn-online.com/journalN.php

4. KHALID, D. S., JOHNSTON, B. & SEYMOUR, J. 2016. Dignity to the care of dying Patient in end of Life care: A concept analysis. Palliat Med, 30, S1-S130. http://www.ncbi.nlm.nih.gov/pubmed/27509596 http://journals.sagepub.com/doi/pdf/10.1177/0269216316631462

Conference presentations:

1. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. *Patients' experiences of receiving care during the end of life in a resource-poor setting.* 22nd International Congress on Palliative Care October 2 - 5, 2018 Palais des Congrès, Montréal, Canada.

2. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. *The challenges of Hospital-Based Palliative and End of life care: a case study of a Nigerian Teaching Hospital.* The University of Nottingham in association with the Palliative Care Research Society PhD/ MD Student Conference Research in the field of supportive, palliative and end-of-life care. Thursday 21st June 2018, University Park Campus, University of Nottingham.

3. KHALID, D. S., HIGGINBOTTOM, G. & COX, K. *Nursing care of patients during the end of life in sub-Saharan Africa: A (systematic) review.* West African College of Nursing 14th Biennial General Meeting and 23rd Scientific Session 1st to 8th July 2017. ECOWAS Conference Centre, Abuja, Nigeria.

Conference posters:

1. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. *The Challenges of Hospital-based Palliative and End of Life Care: A Case Study of a Nigerian Teaching Hospital*. 16th World Congress of the EAPC. 23-25 May 2019 Berlin, Germany.

2. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. *Straight from the horses' mouth: perceived factors for promoting palliative and end of life care; the perspective of nurses, patients, and family carers.* The APM's Annual Supportive and Palliative Care Conference (ASP Conference), 21 - 22 March 2019, Harrogate Convention Centre.

3. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. *Nurses' Caring experiences during the end of life in a resource-poor setting*. 10th World Research Congress of the EAPC. 24-26 May 2018 Bern, Switzerland.

4. KHALID, D. S., BAILEY, C. & HIGGINBOTTOM, G. *Family carers' experiences during the end-of-life care in a resource-poor setting.* The APM's Annual Supportive and Palliative Care Conference (ASP Conference), In Association with the Palliative Care Congress, 15 - 16 March 2018, Bournemouth International Centre.

5. KHALID, D. S., JOHNSTON, B. & SEYMOUR, J. *Dignity to the care of dying patient in end of life care: A concept analysis*. The 11th Palliative Care Congress Wednesday 9 - Friday 11 March 2016. The Scottish Exhibition and Conference Centre, Glasgow.

6. KHALID, D. S., JOHNSTON, B. & SEYMOUR, J. *Nursing care of the death and dying: the Islamic perspective.* The Palliative Care Research Society in conjunction with the Sue Ryder Care Centre for the Study of Supportive, Palliative and End-of-life care at the University of Nottingham, PhD/MD Student Conference. 8th December 2015, University of Nottingham. (3RD prize position)

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LIST OF ABBREVIATIONS

A&E	Accident and Emergency unit
B.NSc	Bachelor's degree in Nursing Science
Case 1 –N	Nurse in case study one
Case 1- FC	Family Carer in case study one
Case 1 - P	Patient in case study one
Case 1- O	Observation in case study one
CPCN	Centre for Palliative Care Nigeria
CIDP	Chronic inflammatory demyelinating polyneuropathy
CMD	Chief Medical Director
FC	Family Carer
GCS	Glasgow Coma Scale
GDP	Gross Domestic Product
GOPD	General Out Patient Department
HIV/AIDS	Human Immunodeficiency Virus /Acquired Immunodeficiency Syndrome
HPCAN	Hospice and Palliative Care Association of Nigeria
NACA	National Agency for the Control of Aids
NCDs	Non-communicable diseases
NICE	National Institute for Health and Care Excellence
NMCN	Nursing and Midwifery Council of Nigeria
PCIN	Palliative Care Initiative of Nigeria
RM	Registered Midwife
RN	Registered Nurse
SSA	Sub-Saharan Africa
UCH	University College Hospital
UN	United Nations
UNICEF	United Nations International Children's Emergency Fund
WHO	World Health Organisation

CHAPTER ONE: BACKGROUND TO THE STUDY

1.0 INTRODUCTION

The 67TH World Health Assembly Resolution (2014) recognised palliative and end-of-life care as a core component of integrated, people-centred health services, not an optional extra, and called on countries to strengthen services. The World Health Organisation [WHO (2015) estimates that 40 million people worldwide require palliative care, but only about 14% of people in need at the end of life are currently receiving it. In spite of increasing global attention, the issue of palliative and end-of-life care receives little formal attention in Nigeria.

From my personal experiences as a secondary care nurse, nurses in Nigeria face several challenges associated with inadequate resources to care for the dying patient. This is evidenced in the recent ranking of palliative care across the world for the 2015 Quality of Death Index by the Economist Intelligence Unit; the UK tops the Index, followed by Australia and New Zealand, while Nigeria is at the position 77 out of 80, and the last among African countries (Economist, 2015). This also reflects the WHO public health strategy in palliative care, where a policy framework is one of three essential foundations (along with drug availability and workforce) (Stjernsward et al., 2007).

Among African countries, only two countries make it into the top 35, with South Africa at position 34 and Uganda at position 35 (Economist, 2015). Studies across sub-Saharan Africa (Grant et al., 2011, Harding and Higginson, 2005, Grant et al., 2003) show that living and dying with incurable illness in poverty and pain is common, there are minimal resources and huge shortages of health workers in Sub-Saharan African countries.

The idea of this study “Exploring the process and experiences of nursing care of patients at the end of life: nurses’, patients’, and family carers’ perspectives” was developed during my clinical experience in an oncology unit of one of the Nigerian University Teaching Hospitals due

to the personal experiences earlier mentioned. To set the scene of the study, I will briefly highlight my biographical sketch, Nigerian mortality and morbidity rates, nursing in Nigeria, and palliative and end-of-life care in Sub-Saharan Africa and Nigeria.

1.1 Biographical sketch

Following the completion of my Basic nursing programme (Diploma in Nursing) in the year 2000, I started my career as a general nurse in a secondary care hospital in the same year. In 2002, I proceeded to enroll for a bachelor's degree in Nursing Science (B.NSc) while at the same time working as a secondary care nurse. I developed my interest in oncology nursing during these student years. I graduated in 2006 and became an academic staff member at the Department of Nursing Sciences, Ahmadu Bello University Zaria involved in teaching, research and community development. I obtained a Masters in Disaster and Risk Management in the year 2013. I came across palliative and end-of-life care in my time as a nurse academic, even though palliative and end-of-life care was not in the curriculum of nursing in Nigeria. I became more interested in the area because of the prior knowledge I have about end-of-life care from the Islamic perspective gained from 'Islamiyah.' Islamiyah is a traditional Islamic school where Muslims acquire Islamic knowledge on personal, social, political, economic, moral and spiritual affairs of life.

During my clinical years I realised that patients at the end of life do not receive adequate care and attention, they were cared for just like all other patients in conventional wards. Therefore, there is a need to collate baseline data from an evidence-based study to inform an appropriate approach and best quality of care during the end of life. This informed the idea of this study "Nursing care of patients at the end of life from the perspectives of nurses, patients, and family carers."

1.2 Nigeria: facts and figures

Nigeria covers an area of 923,768 square kilometres; its boundaries border the Gulf of Guinea to the south, Benin from the west, Cameroon to the east, Niger and Chad to the north with Abuja as the capital city (see Figures 1 and 2) (Wright et al., 2006). The 2013 country statistics and global health estimates by WHO and UN partners rank Nigeria as the most populous country in Africa and the seventh most populous country in the world with a total population of 173,615,000 (WHO and UN, 2015). Life expectancy at birth is 54 and 55 years for males and females respectively (UNICEF, 2013, WHO and UN, 2015).

The Central Intelligence Agency (CIA, 2015) shows that Nigeria had its GDP estimated at US$479 billion in the 2014 statistical rebasing exercise and emerged as Africa's largest economy with oil as the main source of government revenue. Nigeria is a multi-religious country with more than 250 ethnic groups. Fifty percent of the population practice Islam, which is well established in the northern part of the country, 40% Christianity dominates the southern states, while the remaining 10% of the population adheres to traditional religions and beliefs. In Nigeria, religion plays a significant role in the lives of people, and some consider it a light that sharpens their lives, giving them an instinct, an acumen, and wisdom (CIA, 2015).



Figure 1: Map of Africa (Source: GraphicMaps.com 2016)



Figure 2: Map of Nigeria (Source: GraphicMaps.com 2016)

1.3 Disease burden and mortality rates in Nigeria

The WHO Global Health estimates in 2016 showed that there were 56.87 million deaths worldwide, with 71% of these deaths due to non-communicable diseases (WHO, 2018). In Nigeria, cardiovascular disease is the main cause of the death among the four major non-communicable diseases (NCDs) 7%; followed by malignant neoplasms (cancer) 3%, Diabetes 2%, chronic respiratory disease 1% and other NCDs 11% (WHO and UN, 2015). In 2014, the WHO report on the burden of diseases in Nigeria showed that 66% of deaths result from communicable, maternal, perinatal and nutritional conditions, and 10% from injuries (WHO, 2018). The National Agency for the Control of Aids (NACA) reported that Nigeria is one of the countries with the highest number of people living with HIV/AIDS in the world with an estimated number of 3,391,546 and a total of 174,253 deaths from AIDS-related causes in 2014, this constituted 10.4% of the deaths from communicable diseases (NACA, 2015). Other major causes of deaths from communicable diseases include lower respiratory infections 13.9%, malaria 8.7%, and diarrhoeal diseases 6.3%.

In 2013 the probability of death per 1000 populations/year in Nigeria was 357 and 325 between ages 15 and 60 years for males and females respectively (UNICEF, 2013, WHO and UN, 2015). The probability of dying before the 15th year of life from all causes is 40% and 36% for males and females respectively. Eighty percent of males and 76% of females die before their 70th birthday. The percentage of women of reproductive age (15 – 49 years) who died from maternal causes in 2013 was 38% (WHO and UN, 2015). The 2014 age-specific mortality rate for age 15-49 years is slightly higher among women (3.5 deaths per 1,000 population) than among men (3.3 deaths per 1,000 population) (National Population Commission) (NPC, 2014). The increase in the number of death among women age 15-49 years was due to death from maternal causes. The increasing mortality rate from the four major non-communicable diseases raises a great concern most

especially for the hospitals, and this called for the need to explore and understand how nurses deliver care to dying patients in the hospital. The healthcare system in Nigeria is structured into three levels: primary, secondary and tertiary healthcare levels. The Local Government Areas are responsible for funding the primary healthcare centres, the State Governments are responsible for financing the secondary care hospitals (general hospitals), while the Federal Government is responsible for the funding of the tertiary hospitals. Despite financing by the government, patients still pay for services.

1.4 Nursing care/practice in Nigeria

Nursing care approaches which Nigerian nurses have used to organise their activity traditionally and until now include: case nursing, functional nursing, primary care nursing, and team nursing (Archibong, 1999, Agbedia, 2012). The most prevalent in most health institutions in Nigeria is the functional approach to care because is the most efficient way of getting through the work in resource-constrained contexts. Evidence has shown a negative impact on best practice, standards, and quality of care rendered because care is not person-centered (Agbedia, 2012). However, many nurses are not willing to accept the challenges of staying up-to-date with education and developing new skills in their various levels and settings of nursing practice (Agbedia, 2012). A functional approach nursing care is task-oriented where nursing care is assigned to nurses based on their skills, experience, and complexity of the nursing task (Duffield et al., 2010).

The educational level of many nurses affects their proper understanding and utilisation of the most current concepts in nursing such as nursing process, evidence-based practice, advanced nursing practice, and reflective practice which are designed to improve the quality of care rendered by nurses (Agbedia et al., 2014). Some nurses in Nigeria are reluctant to engage in knowledge updates and acquiring new skills because the working hours are not flexible to accommodate further training (Agbedia, 2012). However, the Nursing and Midwifery Council

of Nigeria (NMCN) have recently addressed this issue by making continuing professional education mandatory for all nurses.

Despite increasing urbanisation in Nigeria and other countries of Sub-Saharan Africa (SSA), most patients prefer to die at home (Downing et al., 2015). There is a dearth of literature related to hospital admissions turnover in Nigerian teaching hospitals. However, a retrospective study on the pattern of death in a Nigerian teaching hospital for three decades (1978 to 2006) by Adeolu et al. (2010) shows a decreasing trend in the number of deaths recorded; out of eleven thousand six hundred and twenty-one (11,621) deaths, 3,825 (38.5%) were in the early decade, 3,867 (38.9%) in the middle decade while 2,255 (22.7%) in the recent decade. There is a fundamental gap affecting palliative and end-of-life care approach in our hospitals. Therefore, I sought to understand how nursing care is delivered to patients at the end of life in a hospital.

1.5 Palliative and end-of-life care in Sub-Saharan Africa and Nigeria

Evidence suggests that there is increasing recognition of the need to develop palliative and end-of-life care worldwide in response to people's needs and wishes (WHO, 2014). The need for palliative care is increasing due to rapidly increasing ageing populations and rates of non-communicable diseases and some communicable diseases mainly HIV/AIDS (WHO, 2014). However, there is a relative lack of evidence within Africa of individuals' preferences and priorities for palliative and end-of-life care.

Various palliative care programmes have been developed, and national palliative care associations have emerged, but despite this positive change, palliative care is still only available to less than 5% of Africans who need it (Grant et al., 2011). In a study looking at public preference and priorities for end-of-life care in Kenya by Downing et al. (2015), 201 respondents were interviewed in a population-based street survey. The results suggest that 96% of the respondents want to be informed about the symptoms they could experience when receiving care, 56.7%

like to be informed that they had limited time to live and 51.1% would prefer to die at home (Downing et al., 2014). Palliative and end-of-life care research is needed in Western Africa for policy development and allocation of limited resources which must be informed by reliable evidence and guided by proven best practice (Ajayi et al., 2014).

Policy makers and the general public in Nigeria formally came into contact with palliative care in 2003 through the Palliative Care Initiative of Nigeria (PCIN) now the Center for Palliative Care, Nigeria (CPCN), located at the University College Hospital (UCH), Ibadan (Oyebola, 2017). The Centre for Palliative Care Nigeria is a non-governmental and non-profit organisation, having a multi-disciplinary team of health professionals. CPCN works in collaboration with University College Hospital Ibadan to provide services such as pain and other symptom control, counselling, and support for carers at home (Onyeka et al., 2013). Before this period, only a privately-owned and a missionary hospice existed in the country (Onyeka, 2011). A national medical or nursing academic curriculum for palliative care at both undergraduate and postgraduate levels is lacking, and research into palliative and end-of-life care is just evolving (Onyeka et al., 2013).

In January 2007, the Hospice and Palliative Care Association of Nigeria (HPCAN) was formed to stimulate palliative care practice and make it affordable and accessible all over the country (Oyebola, 2017). HPCAN have already inaugurated local chapters of the Association in all the tertiary health institutions in the country to accelerate the dissemination of palliative care awareness across the nation, although there are no national policies or programmes on cancer pain relief, and palliative and end-of-life care in Nigeria at present (Onyeka, 2011, Oyebola, 2017). The HPCAN collaborates with CPCN to organise workshops, seminars, and conferences.

Palliative and end-of-life care is not integrated into the mainstream health system in Nigeria which is a major challenge as described by Kajang et al. (2015). Other significant challenges include lack of

human/material resources, lack of receptivity by the government, absence of curriculum in medical and nursing training institutions, and lack of public awareness. These challenges could be overcome through sensitising the policymakers, stakeholders, and educational institutions on the need to include palliative and end-of-life care into the mainstream of the national health care system.

1.6 Study concepts

There is a lack of consensus in defining some of the concepts related to this study (Hui et al., 2012). However, an effort was made to draw literature from varying sources and authors to define and explain the concepts used in the current study.

1.6.1 Palliative care

The WHO established a revised definition of palliative care adopted by the Global Atlas of palliative care at the end of life as:

> *"an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual" (WHO, 2014).*

Due to the comprehensive nature of palliative care, the definition extends further to clarify the nature of illnesses as chronic and life-threatening/limiting conditions with no time or prognostic limit on care delivery, and at all levels of care and settings (WHO, 2014).

Palliative and end-of-life care is a relatively new healthcare discipline that originated as a response to the inadequate provision of mainstream services for the dying patient (Watts, 2009).

1.6.2 End-of-life care

According to Hui et al. (2014) end of life refers to the:

> *"Final period - hours, days, weeks, and months in a person's life in which it is medically obvious that death is imminent, or a terminal moribund state cannot be prevented." (Hui et al. 2014, p. 82)*

End-of-life care has no clear-cut definition according to CARESEARCH (2011), but it is referred to as the care of people at the last few days of life when death is irreversible, also known as the terminal phase. Although some diseases have a natural history of progression and exacerbations that makes the transition to the terminal phase difficult to identify, yet there are many situations in which it is possible to identify the terminal phase (CARESEARCH, 2011).

In the UK, the General Medical Council (GMC (2010)) defines end-of-life care as care of patients who are approaching the end of life, when they are likely to die within the next twelve months. This includes patients whose death is imminent (death expected within a few hours or days), those with advanced, progressive, incurable conditions, general frailty and co-existing conditions that are expected to die within 12 months, existing conditions at risk of dying from a sudden acute crisis and those with life-threatening acute conditions caused by sudden catastrophic events (GMC, 2010). The current study will adopt the definition of end-of-life care as the care received by people whose death is imminent and are likely to die in the next few months, as well as care in the last days and hours of life, and immediate care after death.

1.6.3 Care of the dying

The National Institute for Health and Care Excellence (NICE, 2015) describes a good quality of care to patients in their last days and hours of life as involving respectful communication and involving patients and those important to them in decision making, and by maintaining their

comfort and dignity, and management of hydration and commonly experienced symptoms.

Caregiving for dying patients and their relatives covers the physical, psychological, social and spiritual aspects as described by Ellershaw and Ward (2003). Physical care involves regular observation, good pain and symptom control, and conversion of essential oral drugs to subcutaneous. Psychological care involves exploring issues related to dying and death appropriately and sensitively. Social care has to do with assessing and appropriately addressing the family's insight into the condition of the patient and spiritual care deals with the cultural and religious background of the patient; the latter has great influence in the dying phase and the care of the body after death. Compassion is required when dealing with the patient's relatives (Ellershaw and Ward, 2003).

It was pointed out by Corr et al. (2011) that to provide adequate care to dying patients and their relatives is to address fear, anxiety, and distress. However, Jevon (2009) viewed it from the perspective where patients' and family's perceptions of what is considered to be a good death must be explored to allow holistic care planning to meet the need for a good death. There is strong evidence that nurses are confronted with the care of patients during the last days of life (Bam and Naidoo, 2014), nurses individualise care to dying patients (Costello, 2001), dying patients are highly dependent upon the nurses and require constant nursing care (Dunn et al., 2005). The above statements show a corresponding increase in nursing care demand on nurses because of increasing nursing care needs of dying patients, whereas the needs for good medical care continues. The study explored the process and experiences of nursing care of patients at the end of life in the hospital from the perspectives of nurses, patients, and family carers.

1.7 Thesis structure

The thesis is structured into nine chapters. Chapter One is the background to the study that gives a brief overview of the research, including a biographical sketch of the researcher, Nigeria facts and figures, disease burden and mortality rates in Nigeria, nursing care/practice in Nigeria, and palliative and end-of-life care in Sub-Saharan Africa and Nigeria. The chapter also addresses the definition of the study concepts such as palliative care, end-of-life care and care of the dying.

Chapter Two is the literature review that provided a contextual background for the empirical studies. This chapter examines the nurses' knowledge and perception about palliative and end-of-life care in Sub-Saharan Africa, their experiences of care at the end of life, and their emotional stress when caring for dying patients and their perceptions about dying. Family carers' experiences of care at the end of life and barriers to palliative and end-of-life care provision are also discussed in the chapter.

Chapter Three discusses the research methodology and methods. The methodological approach covers the philosophical underpinnings of the study which is an interpretivist/constructivist paradigm, addresses the choice of qualitative research design, and explains the rationale for the choice of ethnographic case study design. The chapter also provides a detailed account of the methods concerning the research process used in the study include study setting, participants, sampling, access and gate-keeping, recruitment strategies. The chapter also describes in detail how data were obtained, including the ethical principles involved in the data collection, as well as rigour and reflexivity.

Chapter Four presents the data management and analysis in the study. It provides the detailed technique and analytical process in which a large volume of the data was reduced to a more manageable form using thematic analysis. Finally, four themes were generated and

presented as qualitative findings in the subsequent chapters (five to eight).

Chapter Five: The first part of the chapter presents a contextual description of the medical unit (study setting), and some related events that unfolded during the period of observation. The second part of the chapter presents the first finding which is the caring roles of nurses, family carers and other healthcare professionals in the study. Nurses' and family carers' roles were examined, these include fundamental and routine nursing tasks and are presented as the nurses-family carers care model.

Chapter Six presents findings on the nurses', patients', and their family carers' experiences and feelings about care, and their level of satisfaction about care. It also examines nurses' and family carers' views with regards to separating the patient who is dying and recognising the dying, as well as dying with dignity.

Chapter Seven describes communication among nurses, patients, and family carers as a vital component in the provision of end-of-life care. Patients and family carers described their relationships with the nurses as cordial. It also focuses on the educational needs of the participants, creating awareness in family carers and patients, and family carers' lack of knowledge about care. The chapter further highlights patients' and family carers' support needs, balancing family carers' job and caring, and reassurance of patients and their family carers.

Chapter Eight illuminates the participants' views regarding factors that hinder or facilitate effective end-of-life care. Participants highlighted several factors that affect the provision of quality end-of-life care such as problems from the hospital management which include a shortage of nurses, logistical problems, poor conditions of service, decayed infrastructure, security laxity, and language barrier. The chapter also highlights the factors that provided the nurses with additional strength to continue to deliver their care and the perceived factors that can promote end-of-life care such as improvement of drug supply, improvement of

staffing levels, provision of rewards/incentives, and continuing professional education.

In Chapter Nine, the findings are analysed in relation to relevant literature. The chapter discusses the caring roles of both nurses and family carers, and by other healthcare professionals. Experiences and feelings about care among nurses, patients, and their family carers are discussed. Also, nurses' and family carers' feelings about dying patients, nurses' workload, stress, and burnout were further discussed. Communication among nurses, patients, and family carers as a key component to the provision of end-of-life care are also described, in which some of the patients and family carers complained of withholding of information by healthcare professionals. Participants' views regarding factors that hinder or enable effective end-of-life care are also discussed. Throughout the study, participants highlighted several factors that affect the provision of quality end-of-life care. Finally, the chapter concludes the study with an overview of the implications of the research findings for practice, education, research, and policy, and also the strengths and limitations of the research.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter seeks to explore what published research evidence exists about the nursing care of patients at the end of life in hospitals in Sub-Saharan Africa and Nigeria as described in the previous chapter. A literature review to identify and synthesise research evidence about the nursing care of patients at the end of life in hospitals of Sub-Saharan Africa was conducted.

2.1 Reviewing the literature

The literature review followed an approach similar to that of Grant and Booth (2009). A form of evidence assessment using systematic review methods to search and synthesise existing research literature. Though not a systematic review, but the review drew upon systematic review principles. The methodology involves a careful focus on the review question, using broader or less sophisticated search strategies than the traditional systematic review (Grant and Booth, 2009).

2.2 Aim of the review

To identify and synthesise research evidence on the nursing care of patients (adult) at the end of life in hospitals in Sub-Saharan Africa.

2.3 Review question

What evidence is there about nursing care delivered to patients (adult) at the end of life in hospitals in Sub-Saharan Africa?

2.4 Search terms

Table 1: Search terms

1- "End of life" OR **2**- "End of life care" OR **3**- "Palliative care" OR **4**- "Terminal care" OR **5**- "Terminal illness" OR **6**- "Care of the death" OR **7**- "Care of the dying" OR **8**- "Care of the dying patient" OR **9**- "Dying with dignity." **10-**1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9	**11**- "Nursing care" OR **12**- "Nursing practice" OR **13**- "Hospital care." **14**-11 OR 12 OR 13 **15**-10 AND 14 **16**-"Sub-Saharan Africa" AND 15	**17**-Angola **18**-Benin **19**-Botswana **20**-Burkina Faso **21**-Burundi **22**-Cameroon **23**-Cape Verde **24**-Central African **25**-Republic **26**-Chad **27-**Comoros **28**-Congo B **29**-Congo DR **30**-Côte d'Ivoire **31**-Djibouti **32**-Equatorial Guinea **33**-Eritrea **34**-Ethiopia **35**-Gabon **36**-The Gambia **37**-Ghana **38**-Guinea **39**-Guinea-Bissau **40**-Kenya **41**-Lesotho **42**-Liberia **43**-Madagascar **44**-Malawi **45**-Mali **46**-Mauritania **47**-Mauritius **48**-Mozambique **49**-Namibia **50**-Niger	**51**-Nigeria **52**-Réunion **53**-Rwanda **54**-Senegal **55**-Sierra Leone **56**-Somalia **57**-South Africa **58**-Sudan **59**-Swaziland **60**-Tanzania **61**-Togo **62**-Uganda **63**-Western Sahara **64**-Zambia **65**-Zimbabwe **66**-17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR 54 OR 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62 OR 63 OR 64 OR 65 **67-** 16 AND 66

2.5 Selection Criteria

- Research conducted in Sub-Saharan Africa
- Research involving adult patients receiving palliative and end-of-life care
- Papers related to care at the end of life
- Research conducted in hospital settings
- Research published in English

2.6 Methods

The literature search was carried out using 4 electronic databases; these are Citation Index for Nursing and Allied Health Literature (CINAHL), EMBASE, MEDLINE (OVID) and Web of Science. Total search from the databases yielded 37620 articles, two articles extracted from Google Scholar were added and 14 duplicates removed. Two

hundred and fifty-eight articles were related to Sub-Saharan Africa. One hundred and eighty-three articles were rejected because they were not related to adult, and studies not conducted in a hospital. Seventy-five articles were further screened based on the title and abstract, 58 were excluded. Full texts of the remaining 17 articles were finally scrutinised, and 12 articles were found relevant for the study (See Figure 3).

2.7 Search strategy

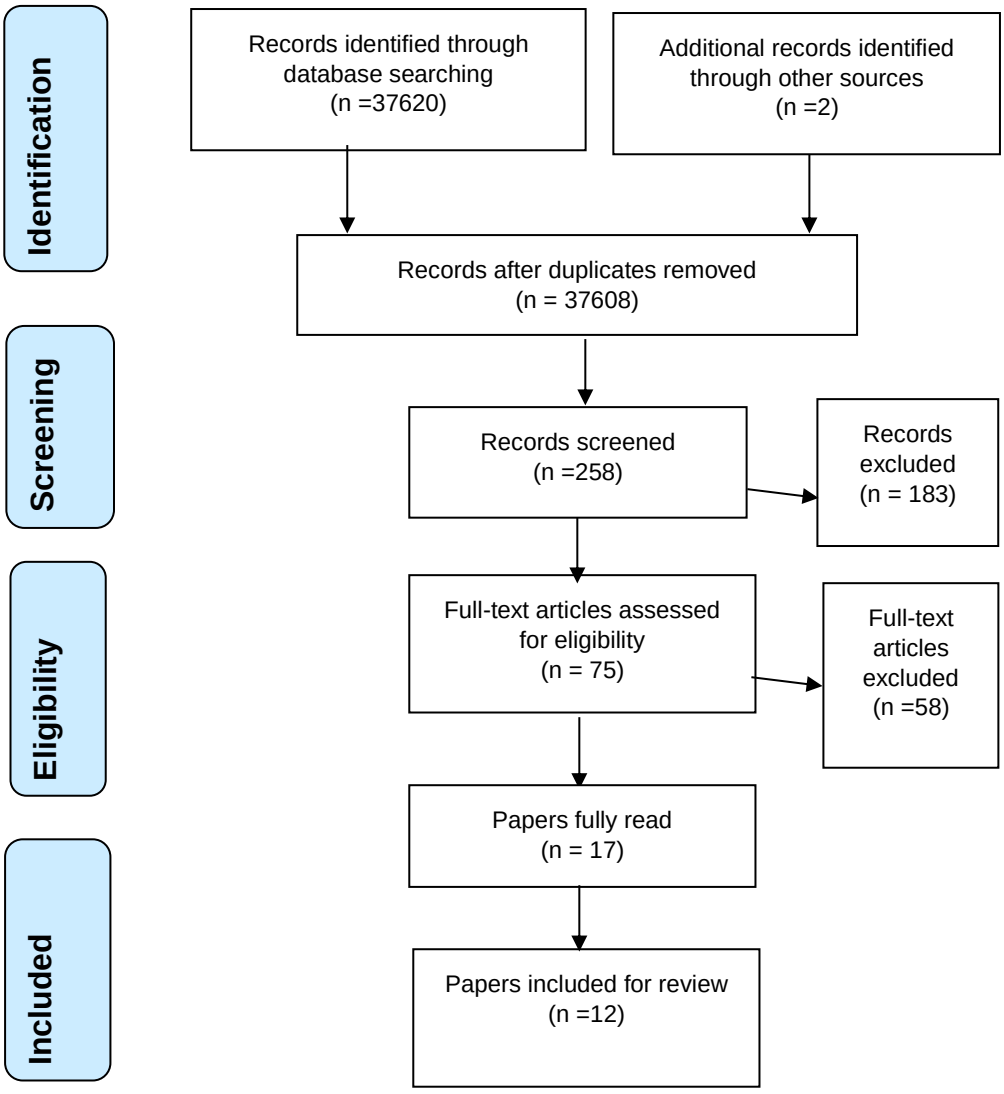


Figure 3: PRISMA flow for searched articles

Table 2: Summary of reviewed articles

AUTHOR YEAR COUNTRY	JOURNAL	ARTICLE TITLE	AIM	METHODOLOGY	SAMPLE SIZE	REPORTED MAIN FINDINGS	NOTES AND CRITIQUES
BAM AND NAIDOO (2014) **SOUTH AFRICA**	*Curationis*	Nurses experiences in palliative care of terminally ill HIV patients in level 1 district hospital	To explore and describe the lived experiences of nurses caring for patients with terminal HIV illness	Qualitative research, using the interview	Ten nurses	Themes: Conceptualization of caring and terminal illness, experiences of caring, factors hinder palliative care, a mechanism for adjusting in caring for terminally ill,	There is no ethical approval for the study, the location of interviews was not mentioned
BESTER ET AL. (2006) **SOUTH AFRICA**	*Health SA Gesondheid*	Professional nurses' experience of the dying process of the terminally AIDS patient	To explore and describe the nurses' experience of the dying process of the terminally AIDS patient	Qualitative research design using an in-depth interview	Ten professional nurses	Categories: Experience regarding the course of dying process, Medical treatment during the dying process, Specific behavioural needs for patients, Specific behaviour of the nurse, Nurses' emotional experiences, Value judgement by the nurse	No ethical approval for the study, Number of participants not clearly stated, venues of the interview were not mentioned
COENEN ET AL. (2007) **(ETHIOPIA, INDIA, KENYA AND UNITED STATE)**	*Oncology Nursing forum*	Nursing intervention to promote dignified dying in four countries	To describe nursing intervention to promote dignified dying as identified by nurses in four countries	Qualitative analysis of open-ended question	560 nurses from four countries	Themes: Symptom management, Communication, Family care, Spiritual comfort, Environmental management	Design/method not clearly defined
DEKKER ET AL. (2012) **SOUTH AFRICA**	*Journals of pain & palliative care pharmacotherapy*	"What is killing me most": Chronic pain and the need for palliative care in the Eastern cape, South Africa	To investigate patient experiences and health care provider attitudes towards chronic pain and palliative care	Mixed method approach using questionnaire and in-depth interview	Patients - 45 Doctors - 7 nurses – 11 Physiotherapist – 3 Occupational therapist – 3 Social worker – 1 Pharmacist – 1	Themes: pain and patient experiences, predictors of pain, pain prescription patterns, Palliative care training, and providers understanding of palliative care.	No basis for sampling, No justification for chosen design
FADARE ET AL. (2014) **NIGERIA**	*Annals of Medical and Health Sciences Research*	Perception of Nurses about Palliative care: Experience from south-western Nigeria	To explore nurses knowledge and attitude toward palliative care	Questionnaire-based cross-sectional study	120 Nurses	Experience- 46% practice for >10 years, Knowledge- 71.8% said palliative care is about pain medicine, 55% geriatric medicine, 90.2% active care of the dying,	Random sampling was used instead of quota sampling, number of participants not clearly stated.

						64.6% rehabilitation medicine	
GYSELS ET AL. (2011) **SSA**	*BMC palliative care*	End-of-life care in Sub-Saharan Africa: a systematic review of the qualitative literature	To synthesize qualitative research on end-of-life care in SSA to inform policy, practice and further research	Systematic review	51 articles	Burden of end of life care, Training, support needs and tools, Place of care, Good death versus bad death and stigma, Bereavement, Culture-specific experiences and approaches to symptoms, illness, death and caring	
KASSA ET AL. (2014) **ETHIOPIA**	*BMC Palliative care*	Assessment of knowledge, attitude and practice and associated factors towards palliative care among nurses working in selected hospitals in Addis Ababa	To assess the knowledge, skills, attitude and associated factors with palliative care in nurses working in selected hospitals in Addis Ababa	A cross-sectional quantitative study using questionnaire	365 nurses	Knowledge- 76.2% of the respondents had poor knowledge, Attitude- 76% had a favourable attitude towards palliative care	
KELL AND WALLEY (2009) **LESOTHO**	*BMC palliative care*	Palliative care for HIV in the era of antiretroviral therapy availability: perspectives of nurses in Lesotho	Understand the perceptions of nurses of palliative care in Lesotho Discuss the need for palliative care through analysis of the components of the WHO definition	Qualitative semi-structured interviews	Ten nurses and six key informants	Themes: palliative care: end of life or chronic care, The need for palliative care, Integrated management of adolescent and Adult illness (IMAI) as a tool for palliative care provision	No justifications of choice of methodology and sample selection
MACHIRA ET AL. (2013) **KENYA**	*International Journal of palliative nursing*	Impact of an educational pain management programme on nurse' pain knowledge and attitudes in Kenya	To implement and evaluate a pain management programme for nurse in Kenya	Quasi-experimental pre-post-test design	27 nurses	Kenyan nurses' pain knowledge and attitudes are far from ideal (47.5%),	No pilot study was conducted to test the applicability of the instrument to Kenyan nurses
SMIT (2004) **SOUTH AFRICA**	*Journal of Advanced Nursing*	HIV/AIDS and the workplace: perceptions of nurses in a public hospital in South Africa	Investigate the perceptions and experiences of nurses in the public health sector with regard to their attitudes towards caring for patients with HIV/AIDS	In-depth semi-structured interviews	Nurses - 35	Themes: Helplessness, Emotional stress and fatigue, Fear, Anger and frustration, Empathy and Self-fulfilment	Design of the study not defined, name of the university that approved the ethical clearance was not mentioned.

VAN GURP ET AL. (2015) **NIGERIA**	*PLoS ONE*	Telemedicine's potential to support good dying in Nigeria: A qualitative study.	To conceptualize good dying and or good death among Nigerian health care professionals in palliative care and explore how telemedicine fit the palliative care practice	Qualitative study using focus group	Doctors – 11 Nurses – 7 Pharmacists – 5 Medical social worker – 1 ICT staff – 3	Themes: Good dying and or good death, Barriers to palliative care provision, Telemedicine in a Nigerian care	
VAN ROOYEN ET AL. (2009) **SOUTH AFRICA**	*Health SA Gesondheid*	Caring for terminal AIDS patients: The experiences of caregivers in a palliative care institution	Explore and describe how caregivers in a formal setting (palliative care institution) experience caring for patients dying from AIDS, and develop broad guidelines for support and optimising nursing care for patients dying from AIDS	Qualitative, exploratory, descriptive, and contextual research with phenomenological approach	13 Caregivers	One theme: Challenges experience by caregivers in dealing with dying patients Five sub-themes: Emotional challenges for caring of the dying patients, Differences in death and dying of adults compared to children, Rationalization of death and dying, Strength to cope with death and dying from having faith in God, caring for the dying is self-fulfilling and meaningful despite the sadness	The identity of caregivers not define, no ethical approval, no justification for the purposive sampling which was based on the researcher's assumption

2.8 Quality Assessment

Of the twelve articles included in the review, seven were qualitative studies, three quantitative, one mixed-method and one was a systematic review as described in Section 2.9. A traditional approach to assessing more than one study by narrative discussion was used (Hawker et al., 2002) (see Table 2).

There were certain limitations in some of the qualitative studies (Bam and Naidoo, 2014 and Bester et al., 2006); these include lack of reports of ethical approval from ethical reviewing board or committee and ethical considerations. In some of the articles study design and approach were not specified (Coenen et al., 2007 and Smit, 2004), sample size selection not justified (Dekker et al. 2012), and the locations of the interviews were not mentioned (Bam and Naidoo, 2014 and Bester et al. 2006). Characteristics of caregivers were not defined in one of the studies and were selected based on the assumption of the researcher (Van Rooyen et al. 2009).

In the three quantitative studies, two (Machira et al., 2013, and Fadare et al., 2014) have questionable generalisability due to small sample size, selection bias and pilot study was not conducted. This may affect the internal and external validity of the results. Also, one of the studies (Fadare et al., 2014) was a cross-sectional survey among different categories of nurses in a hospital, yet a random sampling method was used to select respondents instead of a quota sampling, thus affecting the distribution of the respondents.

The mixed-methods study (Dekker et al., 2012) has a small sample size limiting the power of detecting statistically significant differences, while the convenience sampling approach prevents a fair representation due to selection bias. In the systematic review (Gysels et al. 2011) there was no summary table to show the articles reviewed, show up only the locations for data collection, participants and illnesses.

2.9 Findings

Of the twelve articles in the review, five were from South Africa (Smit, 2005, Bester et al., 2006, Van Rooyen et al., 2009, Dekker et al., 2012, Bam and Naidoo, 2014), two from Nigeria (Fadare et al., 2014, van Gurp et al., 2015), one from Lesotho (Kell and Walley, 2009), one from Ethiopia (Kassa et al., 2014) one from Kenya (Machira et al., 2013) and one systematic review (Gysels et al., 2011). As noted above, seven of the studies were qualitative (Smit, 2005, Bester et al., 2006, Coenen et al., 2007, Kell and Walley, 2009, Van Rooyen et al., 2009, Bam and Naidoo, 2014, van Gurp et al., 2015), three articles were quantitative studies (Fadare et al., 2014, Kassa et al., 2014, Machira et al., 2013), one mixed-method (Dekker et al., 2012) and one systematic review (Gysels et al., 2011).

Five of the reviewed articles were related to the care of patients with HIV/AIDS (Smit, 2005, Bester et al., 2006, Van Rooyen et al., 2009, Kell and Walley, 2009, Bam and Naidoo, 2014), one article each related to palliative care experience, chronic pain, and death and dying respectively (Fadare et al., 2014, Dekker et al., 2012, van Gurp et al., 2015). Four of the remaining papers report studies on experiences, two on knowledge and attitude, one each on perception, and experiences amongst nurses and conceptualisation of a good death and dying.

Six themes were identified from the studies and presented as follows:

- Nurses' knowledge and perception about palliative and end-of-life care
- Nurses experiences of care at the end of life
- Nurses emotional stress when caring for patients at the end of life
- Barriers to palliative and end-of-life care provision
- Nurses' perception of dying
- Family carers experiences of care at the end of life

2.10 Themes

2.10.1 Nurses' knowledge and perception about palliative and end-of-life care

There is a range of understandings of palliative and end-of-life care among nurses in Nigeria. This is evident in a study of 100 nurses' perceptions of palliative care in South-Western Nigeria by Fadare et al. (2014), where results show that 71.8% of the respondents said that palliative care is about pain medicine, 55% felt that it is about geriatric medicine, 90.2% said it is about active care of the dying, and 64.6% said it is synonymous with rehabilitation. These results raise concerns about the level of knowledge of nurses about palliative and end-of-life care since a significant proportion (46%) of the respondents have had more than ten years of experience working with patients with palliative and end-of-life care needs (Fadare et al., 2014). Kassa et al. (2014) in their study on the assessment of knowledge, attitude and practice, and associated factors towards palliative care among nurses working in selected hospitals in Addis Ababa, show that the majority of the respondents (76%) had poor knowledge of palliative care. This finding reflects a study in Kenya by Machira et al. (2013) in which the majority of the nurses (93%) reported no knowledge of palliative and end-of-life care. In a qualitative study among nurses in Lesotho by Kell and Walley (2009) some nurses described palliative care as chronic care, while other responses included the following:

> *"It is care given to a patient at home."*
> *"I think it's the care that is given for HIV-positive patients, going together with TB."*
> *"With the palliative care, I don't know anything" (Kell and Walley, 2007 p.3)*

The latter study further shows that knowledge of palliative and end-of-life care is training dependent because two of the nurses who received palliative care training were able to define palliative care like the WHO definition (Kell and Walley, 2009). Similarly, Dekker et al. (2012) report that 9 of the 11 nurses in their study had no palliative care training and

were unable to articulate what palliative care is; rather they made references to the care only of patients diagnosed with cancer.

2.10.2 Nurses experiences of care at the end of life

Three studies (Bam and Naidoo, 2014, Van Rooyen et al., 2009, Gysels et al., 2011) show that some nurses experience positive feelings when caring for patients at the end of life. Bam and Naidoo (2014) reported that some nurses express feelings of joy whenever they help or care for the patients, while Van Rooyen et al. (2009) reported that nurses feel a sense of fulfilment when caring for terminally ill patients and supporting their families. Supporting the bereaved family to deal with loss and grief is a positive experience expressed by many nurses (Gysels et al., 2011). However, some nurses felt concern over the pain and suffering of the patients and their family members (Van Rooyen et al., 2009). Smit (2005) asserts that nurses experience a sense of futility while caring for patients, involving a sense of helplessness and a belief that they cannot change the situation. This is also evident in a study by Dekker et al. (2012) which shows that most patients (46%) experience severe pain in the last month of their life. However, Gysels et al. (2011) observe that the lack of effective pain management was largely due to a lack of standards in practice, knowledge, and resources. The following response shows how helpless nurses can feel when delivering care at the end of life:

> *"… there is nothing I can do to help this guy - he's going to die. I think nurses are these days only nursing for the mortuary." (Smith, 2005 p. 25)*

The above statement clearly shows what nurses are experiencing when caring for patients at the end of life in a resource-constrained context. This experience of futility during the dying process is usually aggravated by the nature in which the patients are admitted, and their socioeconomic status as suggested by Bester et al. (2006) that patients are re-admitted in a debilitated condition. And the pace of dying process is more rapid in patients with lower socioeconomic status than those

with higher socioeconomic status because of their poor nutritional state, difficulty in paying fee-for-service and lack of access to treatment. However, nurses with experience and prolonged exposure to palliative and end-of-life care on hospital wards show more support and care to dying patients when compared with those with fewer years of experience (Bam and Naidoo, 2014).

2.10.3 Nurses emotional stress when caring for the dying patients

Four studies (Smit, 2005, Bester et al., 2006, Van Rooyen et al., 2009, Gysels et al., 2011) reported that death and dying is one of the hardest things that human beings face, while the emotional stress affects the dying patient and all those around him including healthcare professionals. A study conducted by Van Rooyen et al. (2009) in South Africa revealed that many nurses involved in the care of dying patients with AIDS report being emotionally drained due to the suffering imposed by the disease and the dying process. There are many instances where families are reported to abandon patients; this is due to a variety of factors including stigma surrounds AIDS, costs of caring or inability to deal with suffering caused by the disease, inducing feelings of helplessness, anger, frustration, and depression (Van Rooyen et al., 2009). The following nurse's response clarifies that:

> *"I've experienced that sometimes you have to phone to remind them, hullo!*
> *One of your relatives is here; can you please come in and visit?" (Van Rooyen et al., 2009, p.6).*

Another study in South Africa by Smit (2005) shows that providing care to terminally ill especially HIV patients is highly taxing mentally. The patients are helpless and demand more time-consuming care. In addition, some patients are not appreciative and are disrespectful toward the nurses caring for them, there is a negative perception of members of society towards nurses caring for HIV patients, and lack of seriousness in the approach of HIV/AIDS management by the government (Smit, 2005). Emotional demands of caring resulted in loneliness, depression, and isolation (Gysels et al., 2011). Other

compounding factors that are occupationally related and found to increase nurses' emotional stress as explained by Smit (2005) include decay of hospital infrastructure, insufficient medical equipment and understaffing. He also added that there is an increased number of patient admissions in overcrowded wards with a nurse-patient ratio of 1:15 and a task shift – nurses working as doctors, pharmacists, and social workers.

Bester et al. (2006) conducted a qualitative research study using in-depth interviews to explore and describe nurses' experience of the dying process of terminally ill AIDS patients in South Africa where ten nurses expressed powerlessness because nursing care can only support and not cure the terminally ill AIDS patient. The following response is an example:

> *"And your objective at that stage is to do everything we can do. It is as if it just doesn't help. So, it's very difficult" (Bester et al., 2006, p. 47)*

2.10.4 Barriers to palliative and end-of-life care provision

Several challenges to palliative and end-of-life care provision were highlighted in five studies (Smit, 2005, Bester et al., 2006, Gysels et al., 2011, Bam and Naidoo, 2014, van Gurp et al., 2015) these include: socioeconomic burden, restricted access to adequate medical-technical palliative care and poor or non-implementation of palliative care policies. However, families are also facing hard times over the fee-for-service delivery system and mutual dependency on the family's resources. There is a lack of palliative and end-of-life care knowledge and communication skills from the nurses which are complicated by the unavailability of and lack of accessibility of opioids to treat patients' pain. Nigeria and most SSA countries have three levels of healthcare system, namely primary, secondary and tertiary levels, but the systems suffer a lack of funding by the government. Consequently, palliative and end-of-life care resources are only found in some tertiary hospitals (van Gurp et al., 2015).

Evidence shows that some nurses are reluctant to identify their religious faith in care settings; instead, they remain neutral in exploring patients'

beliefs even though religious beliefs strongly influence people's perceptions of dying in SSA (van Gurp et al., 2015). There is a barrier to meeting the spiritual needs of dying patients in hospitals, so dying at home was preferred by most patients and their families. As a result of that, they put pressure on nurses requesting discharge (Bester et al., 2006). Therefore, education for patients and their families is essential in order to accept the serious situation and prepare for it. Smit (2005) stated that some nurses' families or significant others are also barriers to palliative and end-of-life care provision particularly to terminally ill HIV/AIDS patients because of their overwhelming concerns about their being exposed to HIV while providing care. One of the nurses gave the following account of her husband's concern:

> *"He would constantly ask me, are you making sure that you are protected when you work with patients? How many AIDS-people are in your ward? And so on. He's sometimes so paranoid about my safety - I know it is because he loves me, but sometimes he shows so much anxiety that I become stressed out". (Smit, 2005, p. 25-26)*

In another qualitative study on the experiences of nurses of palliative care patients, (Bam and Naidoo, 2014) explore and describe the lived experiences of nurses caring for patients with terminal HIV illness in a level one district hospital of South Africa. The results show that cost of care and overwhelming demand on nurses due to care workload and staff shortages hinder the outcomes of palliative care provision. This is similar to a study by Gysels et al. (2011) that end-of-life care is a significant physical and socioeconomic burden on caregivers. These include physical consequences of caring for someone with end-of-life care needs in the form of exhaustion and pains after patients care and role reversals, where elderly parents care for their adult children, as well as catering for the needs of their grandchildren. Low levels of support from other community members result in a social burden of end-of-life care for caregivers. Funeral costs were also mentioned as a large economic burden on caregivers. While emotional stress, lack of hospital resources such as beds, medicines and staff shortages affect healthcare professionals.

2.10.5 Nurses' perceptions about dying

The perception of what is referred to as good death when an adult died as compared to a child's death was reported by Van Rooyen et al. (2009), that it is more natural and better for adults to die than children. Although some of the respondents were uncomfortable with the death of children, they still viewed death as God's will because nothing could be done to prevent its occurrence. In a qualitative study on telemedicine's potential to support good dying in Nigeria by van Gurp et al. (2015), the results show that dying with one's dream accomplished and being reconciled with God and people is perceived to be a good death by some of the participants. While others said that good death is the consequence of brief illness that leads to death without wasting family resources.

According to Bester et al. (2006), some nurses, on the one hand, are of the opinion that medical treatment is futile and prolongs or complicates the dying process. While some of the nurses, on the other hand, have a contrasting opinion and said that medical treatment should receive attention as it increases hope and reduces suffering, thus leading to a good death. They suggested that investigating the nurse's experience of meaning and purpose while nursing dying patients and understanding their roles within the multidisciplinary team during this process will help to improve the quality of care at the end of life (Bester et al., 2006).

A systematic review by Gysels et al. (2011) suggests that when a patient dies as a result of HIV/AIDS, he or she is said to have lost ancestral status and is denied a befitting burial, thus leading to a private funeral. And the prospect of such burial affects their dignity and causes anxiety to the relatives, complicates grief and negatively influences bereavement. van Gurp et al. (2015) reported that providing adequate information on life-threatening illnesses such as HIV/AIDS to relatives is complicated by taboos because of the direct effect on the dying patient, grief process and bereavement. This is primarily due to people's

awareness of the moral discourse and biomedical explanation of the mode of transmissions of the disease.

2.10.6 Family carers experiences of care at the end of life

Death among patients with terminal illness causes an existential crisis affecting emotions and perceptions for both patients and families. Family members often assume new roles and supportive responsibilities as caregivers, they become exhausted and thus need professional services and support (Iranmanesh et al., 2009). It is evident that families of patients at the end of life always prefer to be with their family member, want to be informed about their patient's condition, be assured of his comfort, and receive support from healthcare professionals (Reisetter and Thomas, 1986, Andershed, 2006). Therefore, nurses need professional skills and attitudes to care for and preserve the dignity of dying patients and their families, as they need active informational and emotional support from nurses.

Patients and their caregivers in South African and Uganda reported several challenges at the end of life as identified by Gysels et al. (2011), these challenges include lack of information regarding symptoms, symptom management, and disease etiology, as well as lack of information on disease progression and treatment. Onyeka (2011) reported that healthcare professionals in many cases censor their information giving to patients and family carers in an attempt not to hurt them with sad or bad news. This practice of trying to shield patients and their family members from the reality of the situation is common in most developing countries. The determinants of attitudes toward death and dying encompass cultural, societal, philosophical, and religious belief systems as well as a personal and cognitive framework (Stanislav (2015)Stanislav, 2015)

Families are affected by the patients' illness, and it is important to involve them in the care (Wallerstedt and Andershed, 2007), but some nurses do not interact with the patient's family (Bloomer et al., 2013).

When family members are not isolated from the dying family member, grief and mourning are more easily resolved (Reisetter and Thomas, 1986).

2.11 Conclusion

None of the studies primarily address nurses' experiences and understanding about nursing care of patients at the end of life. Only one study (Smit, 2005) focused on nursing care, but specifically, patients with HIV/AIDS, other patients with palliative and end-of-life care needs were excluded. Preserving the quality of life of a patient with a terminal illness is perceived to be the role of the nurse (Bam and Naidoo, 2014). There is a need to understand how nurses currently deliver their nursing care to patients at the end of life without pre- or post-registration education in palliative and end-of-life care in Nigeria, before appropriate ways of addressing the gap in knowledge can be devised.

The review reveals most of the studies were centred on HIV/AIDS, even though other conditions have similar needs for palliative care such as cancer, renal failure, heart failure, diabetes mellitus, liver diseases, and chronic respiratory diseases. However, most of the studies were conducted in South Africa, and based on the sample characteristics and other limitations such as sample size and study settings, and the results are not generalisable beyond the participants and the study settings.

One of the two studies conducted in Nigeria (Fadare et al., 2014) uses a questionnaire to explore nurses' knowledge and attitudes towards palliative care in one of the tertiary hospitals. The study lacks the ability to seek a deeper understanding of the phenomena in question because it assessed only the knowledge and attitudes of nurses about palliative care. Therefore, exploring nurses' experiences of patients' care at the end of life in hospitals using qualitative methods will provide a better understanding of palliative and end-of-life care, and inform policy, practice and further research.

In a systematic review, Gysels et al. (2011) synthesise qualitative studies on end-of-life care in SSA; fifty-one articles were reviewed out of which 38 focused on HIV/AIDS, 19 of the articles were from South Africa and none from Nigeria. The systematic review confirms that the research needed to inform adequate end-of-life care in Africa is at an early stage, and many research areas need to be explored.

All the articles reviewed were congruent with the following: that findings of palliative and end-of-life care services are far from optimal. The majority of nurses in the studies had no prior palliative care education, indicating a lack of emphasis on palliative care at pre-registration level and within clinical practice. Information needs of patients during end-of-life care were commonly not met.
The studies recommend in-service training and education for caregivers working with patients dying with AIDS. Enhancing communication skills of nurses when caring for patients with HIV/AIDS, appropriate skills development, education of student nurses on nursing care of HIV/AIDS patients, update courses for registered nurses and more research on nurse's experiences of HIV-related nursing care and other terminally ill patients.

There is a paucity of information on palliative and end-of-life care provision in Nigeria, and there is only weak evidence to build policy and practice development. Nigeria demonstrated evidence of only localized provision of palliative and end-of-life care in a context where small numbers of isolated services have gained a foothold, the ratio of palliative and end-of-life care services to the population in Nigeria, is as low as 1:40 million (Clark et al., 2007).
However, no studies from Nigeria were found to explore nurses' experiences and understanding of caring for patients at the end of life in hospitals. Therefore based on the researcher's knowledge this study will be the first to explore the process and experiences of nursing care of patients at the end of life in hospitals from the perspective of nurses, patient, and family carers which justifies the current study. The study

would like to generate evidence-based data to ensure that end-of-life care service provision is effective, appropriate, acceptable, ethical and culturally competent.

2.12 Research Question

How is nursing care delivered to patients in the hospital at the end of life from the perspective of nurses, patients, and family carers?

2.13 Research Aim

To explore the process and experiences of nursing care of patients at the end of life in Ahmadu Bello University Teaching Hospital Zaria-Nigeria from the perspectives of nurses, patients, and family carers.

2.14 Research Objectives

1. To examine how nursing care is delivered to patients at the end of life in the hospital.
2. To explore nurses' caring experiences at the end of life in the hospital.
3. To explore family carers' experiences of patient care at the end of life in the hospital.
4. To explore patients' experiences of receiving nursing care at the end of life in the hospital.
5. To identify educational and support needs for both nurses and family carers

CHAPTER THREE: RESEARCH METHODOLOGY AND METHODS

3.0 Introduction

This chapter is presented in two parts: methodology and methods. The first part which is the methodology - a framework in which the research was conducted (Braun and Clarke, 2013). It includes the philosophical underpinnings of the study, research design, methodological rigour, and ethical considerations.

3.1 Research Methodology

3.1.1 Philosophical underpinnings

Mackey (2005) stated that philosophical standards and arrangements are central to research, they provide continuity and soundness to its conduct and outcome. Paradigms provide the philosophical and methodological foundations for the research process. The choice of research paradigm is guided by the research question and influences the research design, data collection, data analysis, and presentation of results. The philosophical worldview most appropriate for this study was interpretivism/constructivism.

3.1.2 Interpretivism/Constructivism

The interpretive paradigm relies on the human interpretation of reality as the basis of understanding the world. People construct meaning in different ways, but truth is a consensus formed by co-constructors (Scotland, 2012). Scotland (2012) argues that the social world can only be understood from the standpoint of individuals who are participating in it. Interpretivists aim to bring to consciousness hidden social forces and structures through understanding phenomena from the individual perspective, investigating interaction among individuals as well as historical and cultural context. Their emphasis is on individual cases in which a relativistic social world is embedded, and sensitive to individual meanings that can become buried within broader generalisation. The core understanding in the interpretive paradigm is learning what people make of the world around them, how they interpret what they encounter and how they assign meaning and values to events or objects.

Interpretivism is also termed as constructivism with the idea that the social and natural worlds are different. The social world deals with human beings where values and conscience influence perception of reality. The implication of this perspective for researchers is to look deep inside these understanding and meanings. In the interpretivist paradigm, phenomena are studied from a holistic perspective in their natural setting, and qualitative data are collected to gain in-depth insights to develop knowledge. To understand human experience and behaviour, the study is best situated within the interpretivist worldview (Benton and Craib, 2011). Therefore the interpretivist paradigm is an appropriate perspective from which to address this study's research question.

Ontologically, the study views the social world as multiple realities (Benton and Craib, 2011); individuals create and interpret the world and their experiences through their belief systems. From this philosophical point of view, the researcher's role is to explore experiences and co-construct reality.

Epistemologically, the interpretivist paradigm has its foundation in subjectivism in which the world is viewed independently of the existence of knowledge. Naturalism is the core orientation of interpretivists, and they are interested in real life. The interpretivist stance is suitable for this study because the researcher is interested in making meaning and understanding human behaviour by interpreting participants' subjective accounts (Green and Thorogood, 2014). Therefore, my interpretive stance is based upon interpretation of the subjective accounts of participants in order to provide a conceptual understanding of how nursing care of patients at the end of life was carried out in hospital. For example, by observing care delivered to patients at the end of life by nurses and family carers, and at the same time taking into consideration the interactions between them.

In this study, participant observation and interviews were used for data collection, so my role as a researcher was highly interpretive of the observations based on my knowledge and experience of nursing care of

patients at the end of life. Different groups of individuals with varying experiences (nurses, patients, and family carers) were explored in the study; and they interpreted the world through their own experiences and belief systems. For example, the nurses gave accounts of the nursing care delivered to patients, while family carers were concerned with the wellbeing of their family members. However, the co-construction of meaning by participants is highly recognised in constructivism and knowledge constructed by each participant depends upon their views and meaning giving to the context (Rubin and Rubin, 2012). Therefore, it was appropriate to situate this study in the interpretivist/constructivist paradigm.

3.1.3 Qualitative Research Design

A qualitative research design was used for this study to gain an in-depth and detailed description, understanding and explanation of ordinary occurrences as experienced by those in the field (Weaver and Olson, 2006). The reason for this choice was based on processes and meaning that are not rigorously examined, or measured in terms of quantity, amount, intensity or frequency. Qualitative research is congruent with my philosophical stance and the objectives of the study. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry (Bailey, 1997). A qualitative research design is most suitable when developing an in-depth understanding of an unknown and potentially complex phenomenon, such as nursing care of patients at the end of life in hospital.

Qualitative research answers some questions that quantitative measures cannot answer, for example, quantitative methods may tell you how many people do a certain thing but are unlikely to tell you how or why they do it. So qualitative methods can better answer the how and why questions, and also provide other information in the process. Qualitative research has different approaches. Creswell (2007) identifies five approaches to qualitative research: narrative,

phenomenology, grounded theory, ethnography, and case study. Narrative focuses on the life of an individual; phenomenology focuses on understanding a concept or phenomenon, grounded theory focuses on theory development. Ethnography refers to ‘an integration of both first-hand empirical investigation and the theoretical and comparative interpretation of social organisation and culture’ (Hammersley and Atkinson, 2007). The focus of an ethnographic research design is to understand and gain knowledge of a particular culture-sharing group. While the purpose of case study research design is to provide an in-depth understanding of a phenomenon within a research setting having clear boundaries. Therefore, this study is informed by an ethnographic principle to uncover how nursing care is delivered to patients at the end of life, which is an attitude as well as behaviour of a particular group.

3.1.3.1 Ethnography

Comparative cultural anthropology is the origin of ethnography; in which patterns of behaviour, beliefs, and languages within a cultural group are examined (Hammersley, 2007, Creswell, 2007). It involves living within the culture, making observations and interviews to develop understanding, after which the meaning of behaviour, language and interactions are described and interpreted (Hammersley and Atkinson, 2007, Roper and Shapira, 2000). It is a way in which humans make meaning of their world, and such meaning is collected, described and analysed (Bailey, 1997). Murphy and Dingwall (2007) describe the ethnographic approach as an effective method of generating information that influences the quality of health care, especially in the organisational and interactional processes of delivering health care. Therefore, based on this note the ethnographic approach to data collection combining participant observation and interviews was used in this study. This is because the approach has the ability to uncover attitudes and behaviours in real life situations using first-hand information, which might not be captured using other approaches. The approach also allows the researcher to collect current and reliable data that are comprehensive and exclusive to answer the research question.

3.1.3.2 Case study

A case study is “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (Yin, 2009). The focus of this research is to understand the phenomenon by obtaining in-depth information about contemporary events from participants. Emphasis is usually placed on the phenomenon of interest that involves real-life interactions and relationships, events and behaviours. This explains the objective of the case study research to describe, understand and predict the subject under study, which could be a process, people or an organisation (Gerrish and Lathlean, 2015).

Stake (1995) describes a case study as an approach that allows for a holistic understanding of a phenomenon within real-life contexts from the perspective of those involved. In order to gain an in-depth and a detailed description, understanding and explanation of ordinary occurrences as experienced by those in the field (in this case nurses, patients, and family carers) (Weaver and Olson, 2006), Stake’s approach focuses on the unit of study, or the case, as the defining characteristic (Anthony and Jack, 2009). The epistemological position of Yin is closer to positivism and combined both quantitative and qualitative data sources. While Stake’s position is constructivist and exclusively uses qualitative data sources (Yazan, 2015).

3.1.3.3 Rationale for choosing an ethnographic case study

The purpose of this study, which is to explore the process and experiences of nursing care of patients at the end of life, the philosophical viewpoint (interpretive paradigm), and the research aim governed the selection of the approach. The phenomenon under study also requires real-life investigation, and researcher will have no control over events. A case study is used in practice to address the holistic nature of care and treatment (Walshe et al., 2004). A case study approach provides a standpoint for an in-depth and holistic investigation into a phenomenon (Stake, 1995) achieved through multiple sources of data collection within a time frame (Yin, 2009). This however, allows the

research strategy to be flexible for exploration of a contemporary phenomenon when recognising multiple perspectives that are congruent with clinical practice (Walshe et al., 2004) and addressing complex situations similar to the current study. Yin (2009) asserts that case study is appropriate to study complex conditions with many variables. Therefore, nursing care of patients at the end of life appeared to be a complex situation that requires a robust approach such as case study (Walshe et al., 2004).

Stake (2006), uses the term collective case study to describe multiple case study as an approach that produces compelling and robust evidence because it draws assertions from the similarities or differences in the phenomenon through aggregation of findings across cases. Multiple case design is used in exploring the same phenomena across cases in a diversity of situations (Walshe et al., 2004) and allows for the assessment of similarities and differences (Stake, 2006). Therefore, in this research a collective (multiple) case study approach was appropriate.

Three types of case studies were highlighted by (Stake, 2006): intrinsic, instrumental and collective (multiple) case studies. Intrinsic case studies place emphasis more on the uniqueness of the case, instrumental case study emphasises the issue or phenomenon, while collective case study deals with multiple cases (Baliza et al., 2015) in an effort to recognise a broader perspective of the phenomenon. Yin (2013) recommends two types of multiple case study design: holistic case study examines one unit of analysis and an embedded case study that involves multiple units of analysis. Stake (2006) reported that case study is suitable for understanding reality and discovering external reality, and agrees with Yin (2014) that case study is suitable for addressing research questions on how and why phenomena occur through the use of multiple sources of evidence. Interview, focus group discussion, observation and examining documents or historical records are methods of data collection used in interpretive qualitative research. Stake's approach was followed in this study rather than Yin's because of its flexibility that

allows changes during the research process. Stake's philosophical orientation as being constructivist, and is in line with my research intent.

This study seeks to understand a phenomenon in a cultural context; therefore a contemporary approach suitable for this study will be ethnographic case study approach (Storesund and McMurray, 2009). Generally, a classical ethnography approach requires several months or years of fieldwork (Gallant, 2008). However, the ethnographic principles applied to shorter ethnographic case studies are referred to as micro or mini ethnographies (Storesund and McMurray, 2009) and conducted over a shorter period (weeks or months) (Gallant, 2008).

Ethnography requires the direct involvement of researcher in a systematic data collection of social meanings and daily activities of people in their natural settings, using a combination of participation, observation, and interview (Roper and Shapira, 2000, Van Maanen, 2011). Researchers' involvement in the study setting strengthens ethnographic research (Gallant, 2008). Ethnographic principles are suitable for studies in hospital settings because they apply to different social and organisational situations that involve cultural processes and work experiences. Ethnography also provides an approach that is congruent with the interpretive/constructivist philosophy that underpins this study. This study is short, focussed and time bounded taking place over some months (Gallant, 2008), therefore is situated within the micro or mini ethnographies. This type of study was successfully employed on registered nurses' perspectives on practice quality in an Australian ICU by nurse researchers (Storesund and McMurray, 2009) and is deemed fit for the current study.

An ethnographic lens was used in this study to explore the nursing care of patients at the end of life, which is a contemporary phenomenon in real-life situations within the context of the study (Wong, 2014). This was chosen because it was the best approach to answer the research question. This study aimed to gain knowledge and an in-depth understanding of a sub-group or sub-culture of nursing care at the end

of life; which is a phenomenon within a culture-sharing group (Lambert et al., 2011, Hammersley and Atkinson, 2007), hence referred to as ethnographic case study. It is an ethnographic study because it was conducted in accordance with the principles and methods of ethnographic research. Ethnography looks at the socio-cultural process to uncover and describe the behaviour of a particular group of people (Lambert et al., 2011) through multiple methods of data collection conducted according to the principles and methods of ethnographic research. It is a case study because it involves a holistic examination of cases (Baliza et al., 2015) and analysis of multiple units (Walshe et al., 2004). In this section of the methodological approach, a theoretical description regarding the two methods of data collection was highlighted. The practical aspects of data collection are fully described in the methods section.

3.1.3.4 Participant observation

Participant observation is a form of data collection used to investigate, appreciate, and translate a culture, people, or events being studied from an insider's perspective (Gerrish and Lacey, 2006). The researcher spends a considerable amount of time in the field to examine the practices of different groups, and this sometimes requires an element of participation. Observations usually occur in a natural setting where the activities of such groups are investigated to generate data for the study in question (Silverman 1993). During observations, researchers have the opportunity to observe and generate data on actual behaviours and events as they are occurring without relying on individuals' accounts (Lincoln and Guba, 1985a).

Observational methods in qualitative research and case study research can provide thorough and accurate descriptions of what is observed in the naturalistic setting (Creswell, 2018), although when the naturalistic setting is a hospital or hospital ward, participant observation can be a valuable approach (Salmon, 2015). This is because participant observation has the tendency of addressing discrepancies between what the participants say when interviewed and what they actually do,

and allows the researcher to observe things that may escape conscious awareness among the nurses. Observational methods provide insights into interactions and capture the moments within a context and physical environment of practice (Salmon, 2015).

Structured and unstructured observations

Observations can be structured or unstructured. Structured observations are predetermined observations for what and when to observe. Unstructured observations are undetermined and unspecified without any restrictions on what to observe (Murphy and Dingwall 2003). Creswell (2018) and Roper and Shapira (2000) distinguished the extent to which an observer is engaged in the observation field into four types: Complete participant – where participants are fully engaged by the researcher, thus establishing rapport. Participant as an observer – the researcher is involved in activities within the observational field performing the role of an insider. Nonparticipant or observer as a participant –there is no direct involvement in activities during the data collection by the researcher. Complete observer - researcher observes from a distance, performing the role of an outsider. However, I used participant as an observer in this study because I was fully involved in activities in the observational field, for example, handover, medication, positioning, bed making.

In this study, unstructured observations were used and were considered most appropriate because the researcher enters the field with an open mind without restrictions on what to observe.

3.1.3.5 Interviews

Researchers use interviews to uncover experiences and behaviours of people and their reasons for that (Braun and Clarke, 2013, Murphy and Dingwall, 2007). Qualitative interviews can be structured, semi-structured or unstructured.

Structured, semi-structured and unstructured interviews

Braun and Clarke (2013) describe interviews as structured, semi-structured or unstructured. In structured interviews, respondents are asked questions that are pre-defined with little flexibility and a limited set of responses. Unstructured interviews are referred to as in-depth or open-ended interviews, and they are flexible and undefined without any limitation to the field of enquiry. Semi-structured interviews were considered the most appropriate method for this study because semi-structured interviews are flexible in order to cover fundamental aspects of key topics using an interview guide with some probing questions. A semi-structured interview involves the use of a prepared guide focusing on the topics of the research in a consistent and systematic manner, interpolated with probes intended to elicit more elaborate responses (Sandy and John, 2011). Ryan et al. (2009) stated that the goal of interviews is to explore in-depth participants' perception, views, feelings, and experiences. When a researcher wants to cover specific topics, at the same time to hear the participant's stories during an interview, semi-structured interviews are the most appropriate (Rabionet, 2011).

3.2 Research Methods

The second part of the chapter provides a detailed account of the methods used in the study. These include setting, participants, sampling, access and gate-keeping, data collection, recruitment strategies, rigour, reflexivity, and ethical considerations.

3.2.1 Setting

The research setting is one of Nigeria's first generation teaching hospitals designed to serve as a principal tertiary health institution in the north-west geopolitical region. It has a staff of over 2000, a bed capacity of 1000 and a total patient admission turnover of more than 10,000 annually. The reason for the choice of the study setting is that it is the oldest university teaching hospital in northern Nigeria; and the largest health facility with regard to both size and personnel. The hospital offers health services and serves as a referral centre most especially for

cancer cases from all over the federation; it is referred to as the centre of excellence for oncology. It is expected to have a greater likelihood of transferability of results to other settings because of its diverse nature in terms of patients and personnel.

There are several units and departments in the hospital. However this study was carried out in the adult medical unit which comprises four wards (two male and two female) (see Table 3 below) because the majority of patients with palliative and end-of-life care needs (for example, patients with terminal cancer, renal failure, heart failure, diabetes mellitus, liver diseases, chronic respiratory diseases, and human immunodeficiency virus (HIV)) are admitted to this unit. Each ward is managed by a head nurse supported by other nursing staff, all the four ward heads report directly to the unit manager/sectional head. Other units such as the surgical and intensive care units were excluded from the study because the surgical unit admits patients with acute and short term conditions, who are mainly discharged after surgical interventions, while the intensive care unit admits patients with critical conditions that require specialised care and does not allow the presence of family carers. However, a detailed description of the study context is found in chapter five.

Table 3: Characteristics of the adult medical unit

Ward	Bed capacity	Bed occupancy	No of Nurses	Common conditions
Male ward A	33	88%	18	Cardiovascular, Renal, Endocrine, Respiratory Gastrointestinal, Cancer HIV/AIDS etc.
Male ward B	33	91%	15	
Female ward A	32	84%	16	
Female ward B	32	81%	16	
Total	131		65	

Source: (Field survey, 2017)

3.2.2 Participants

There were 14 cases, each case involved three participants (nurses - 14, patients - 14 and family carers - 14) except for two cases where the patients were unconscious and could not be interviewed, and all the participants were observed and interviewed. Details of demographic

data for these participants and their characteristics are presented in the following tables, (See Appendix Six for the case profiles).

Table 4: Patients' Characteristics

Case	Ward	Gender	Age (yrs.)	Occupation	Diagnosis	Date of Admission
1	MMW(A)	Male	70	Retiree	Type II Diabetes Mellitus	15/12/16
2	MMW(B)	Male	52	Driver	Stroke/ Diabetes Mellitus	06/02/17
3	FMW (A)	Female	53	Housewife	Ischemic stroke	13/01/17
4	MMW(B)	Male	75	Farmer	Sepsis	01/03/17
5	MMW(A)	Male	45	Trader	Chronic Liver Disease	29/02/17
6	FMWB	Female	65	Trader	Right Hemispheric stroke	28/02/17
7	MMW(B)	Male	38	Driver	Tuberculosis/Retroviral disease	30/12/16
8	FWW(A)	Female	60	Hose wife	Sepsis/ Diabetes Mellitus	31/03/17
9	FMW(A)	Female	58	Trader	End Stage Renal disease	26/03/17
10	FMW(B)	Female	57	Librarian	Acute kidney injury	03/04/17
11	MMW(B)	Male	55	Businessman	Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)	17/02/17
12	FMW(B)	Female	47	Teacher	Chronic myeloma	11/05/17
13	FMW(A)	Female	45	Housewife	Diabetic ketoacidosis	28/04/17
14	MMW(B)	Male	46	Civil servant	CIDP	05/02/17

The table above shows the patients' characteristics which include case number, patients' wards, patients' gender and age, occupation, diagnosis, and dates of admission.

Table 5: Family carers' characteristics

Case	Ward	Gender	Age(yr)	Level of education	Occupation	Relationship
1	MMW(A)	Male	31	Diploma	Civil servant	Son
2	MMW(B)	Male	20	Secondary school	Student	Son
3	FMW (A)	Female	24	Masters	Banker	Daughter
4	MMW(B)	Male	33	Masters	Civil servant	Son
5	MMW(A)	Male	30	NCE	Teacher	Son
6	FMW(B)	Female	24	No formal educ	House Wife	Daughter
7	MMW(B)	Male	32	School cert	Businessman	Aide
8	FWW(A)	Female	25	HND	Student	Daughter
9	FMW(A)	Female	30	School cert	Businesswoman	Daughter
10	FMW(B)	Male	28	B.Engr. (civil)	Self-employed	Son
11	MMW(B)	Female	47	Diploma	FT House Wife	Wife
12	FMW(B)	Female	26	B.A (Ed)	Teacher	Daughter
13	FMW(A)	Male	53	School cert	Driver	Husband
14	MMW(B)	Male	35	Adv. Diploma	Self-employed	Brother

The table above shows the family carers' characteristics which include case number, patients' wards, gender and age, level of education, occupation, and relationship to the patient.

Table 6: Nurses characteristics

Case	Ward	Gender	Age (yrs.)	Qualification	Rank	Years of experience
1	MMW(A)	Female	56	RN[1], RM[2], ADPA[3]	CNO	33
2	MMW(B)	Female	31	RN, RM	NO	5
3	FMW (A)	Female	35	RN, RM	NO	5
4	MMW(B)	Female	36	RN, RM	SNO	9
5	MMW(A)	Female	33	RN, RM	SNO	8
6	FMW(B)	Female	33	RN, RM	SNM	4
7	MMW(B)	Female	45	RN, RM	SNM	4
8	FWW(A)	Female	32	RN, RM	SNM	3
9	FMW(A)	Female	37	RN, RM, RICN[4]	SNO	9
10	FMW(B)	Female	31	RN, RM, BNSC[5]	SNO	4
11	MMW(B)	Male	43	RN, RPSN[6], RPHN[7]	SNO	4
12	FMW(B)	Male	41	RN, RPN[8]	SNO	8
13	FMW(A)	Female	35	RN, RM	SNM	5
14	MMW(A)	Male	39	RN, RPHN	SNO	7

Table 6 above shows the nurses' characteristics which include case number, wards, gender and age, qualification, rank, and years of experience.

[1] Registered Nurse, [2]Registered Midwife, [3] Advanced Diploma in Public Administration,
[4] Registered Intensive Care Nurse, [5] Bachelor of Nursing Science,
[6] Registered Psychiatry Nurse, [7] Registered Public Health Nurse [8] Registered Psychiatry Nurse

3.2.2.1 Recognising persons in the last days of life

According to Hui et al. (2014) end of life refers to a “final period - hours, days, weeks, or months in a person’s life in which it is medically obvious that death is imminent or a terminal moribund state cannot be prevented” (Hui et al. 2014, p. 82). Although it is difficult and complex to be certain that a person is dying, reports have shown that half of all deaths in the UK can be anticipated (Gibbins et al., 2009). To help in the diagnosis of dying Gibbins et al. (2009) suggest the following criteria for entering the last phase of life: bed bound, semi-comatose, unable to take tablets and unable to take fluids. Prognostic certainty is often the most troubling among health care professionals (Christakis and Iwashyna, 1998), uncertainty about the time of death and determining prognosis is more complicated in older patients, life-threatening and non-malignant disease when compared with cancer (Coventry et al., 2005). There are certain clinical changes in the patient’s condition which suggest that a person is entering the last days of life. See Table 7 below.

Table 7: Clinical changes in patient entering the last days of life

Signs	Symptoms	Functional observations
Agitation, Cheyne–Stokes breathing, deterioration in the level of consciousness, mottled skin, noisy respiratory secretions, and progressive weight loss	Increased fatigue and loss of appetite	Changes in communication, mobility or performance status deterioration, or social withdrawal

3.2.2.2 Determining the case

The study is a collective (multiple) case study exploring the process and experiences of nursing care of patients at the end of life in four wards (two male and two female medical wards). The central focus of this study is nursing care, and the units of analysis consist of nurses, patients and family carers, whose experiences of nursing care at the end of life were investigated. The context for the case study is the medical unit where the holistic analysis of all aspects of nursing care at the end of life was undertaken. The study was bounded by time (six months) within which data were collected and was confined to the adult medical of the hospital.

3.2.2.3 Selection criteria

To easily recognise and assess changes in the table seven, an assessment tool is required. Therefore, a performance status score was used as a guide (Picot et al., 2011, Peus et al., 2013, Cardona-Morrell and Hillman, 2015) to determine the patient's condition in the adult medical unit of the hospital. In this case, all the patients were placed on the performance status score, those patients with a Karnofsky performance status score of 10% (see Appendix Four) were eligible for the study. Nurses delivering care to patients who met the inclusion criteria and family members or significant others aged 18 years and above looking after a patient with the inclusion criteria in Box 1 below were also eligible for the study.

Inclusion criteria

Cohort 1: - Nurses delivering care to patients at the end of life in the adult medical wards of the hospital.

Cohort 2: Patients - chosen using Karnofsky performance status score of 10% (See Appendix Four)

Cohort 3: Family member or significant other who is 18 years or above looking after a patient at the end of life in the hospital.

Exclusion criteria

- Nurses not involved in delivering care to patient at the end of life in the adult medical wards.
- Patients with scores above Karnofsky performance status score of 10%.
- Family carer who is less than 18 years of age looking after a patient at the end of life.

Box 1: Selection criteria

3.2.3 Sampling

Purposive sampling is a non-probability means of selecting participants based upon the uniqueness of individuals' understanding of the phenomenon in question and the topic under study (Robinson, 2014). In ethnographic case study research, data are obtained from participants who really have the information, mostly through purposive sampling, in order to ensure the richness of the data (Ali-Khan, 2014).

A purposive sampling technique was used to recruit participants. According to Holloway and Freshwater (2007) and McKie (2012) case study research uses small samples as the main criteria for recruitment of participants, to allow the exploration of a specific research question and generate sufficient data. Wong (2014) and Stake (2006) suggest between four and ten cases. While Yin (2013) suggests that six to ten cases can yield a convincing result. Therefore, 14 cases (42 participants in total: nurses (n=14), patients (n=14) and family carers (n=14)) were used which provided sufficient data to address the research question. Roper and Shapira (2000) suggest that data saturation has been reached and data collection is complete when the researcher recognises that the research question has been answered and no new information is being generated.

3.2.4 Access and gate-keeping

Following ethical approval from the ethical review boards of the University of Nottingham and that of the study setting, I met with the Head of Nursing Services of the hospital. I was referred to the nurse in charge of the medical unit (the medical unit comprised of four wards, two each for males and females) introduced myself and provided information about the research study. I also explained the purpose, procedure, inclusion and exclusion criteria for participants, as well as the period for collecting the data. I then requested the unit head to introduce me to the four ward managers. I met the ward managers with information about the research study and explained the purpose, procedure, inclusion and exclusion criteria for participants. Posters describing the nature of the study were presented to the ward

managers, who asked me to place them on various notice boards of the unit (see Appendix Four). Recruitment was achieved directly through the ward managers.

3.2.5 Recruitment and Consent

The study was introduced to the nurses and the patients by the ward managers. The consent of those willing to participate in the study was obtained by the ward managers, who subsequently allowed me to meet with them. Those that were willing to participate in the study were approached. The purpose and process of the study were explained to them by the researcher, and they were provided with a participant information sheet and my contact details. Those eligible patients that agreed to participate were requested to appoint a family carer to be included in the study and shared the information with them. Once interest was expressed, I went ahead and discussed the study with each of the family carers; those that agreed to participate were given the information sheet and a consent form. A period of 48 hours was also given to ensure reflection on participation in the study.

The information sheet and consent form for the patients and family carers were printed both in English and Hausa languages and shared with them according to their language fluency and literacy level. While the information sheet and consent form shared to the nurses were only printed in English (see Appendices 7-14). The issue of language problem was addressed due to my background and skills as a bilingual speaker. I was able to read out the Hausa version to patients and family carers who could not read or write.

Participants were encouraged to ask questions related to the study and were well informed that participation in the study was entirely voluntary and they were able to withdraw their participation at any time. Participants were reminded that their consent was required for both observations and interviews and that no personal identifiers would be used throughout the study or in subsequent publications. Figure 4

below summarises the recruitment process.

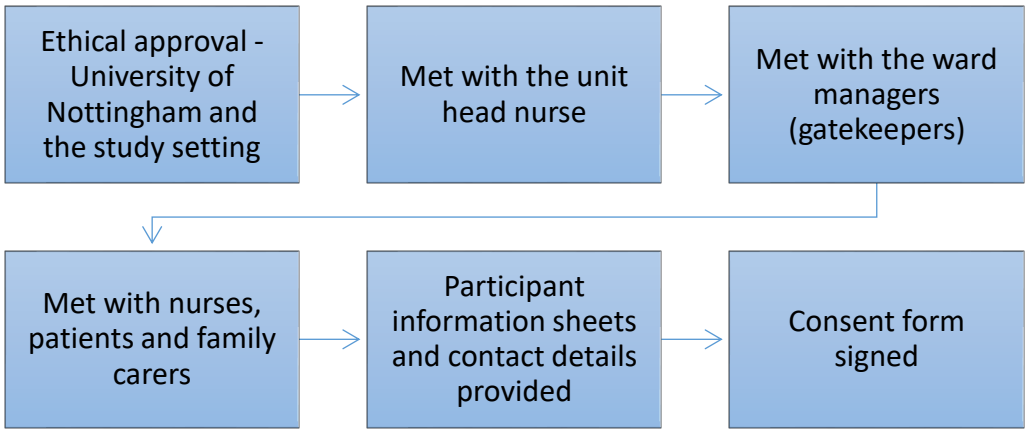


Figure 4: Recruitment process

3.2.6 Data collection

It is important within a case study to create a structure for data collection that addresses the research question and study objectives (Stake, 2006, Yin, 2009). Stake (2006) highlights techniques of data collection such as interviews, observations and document review. Observations and interviews were used for data collection in this study.

3.2.6.1 Participant observation

Participant observation was used in this study to investigate all the aspects of nursing care of patients during the end of life within the study context including the interrelations among nurses, other healthcare professionals, family carers and patients. Participant observation is congruent with the interpretive paradigm, that knowledge constructed by each participant depends upon their views and the meaning given to the context, and the interpretation of the researcher (Rubin and Rubin, 2012). A rapport was established with the participants, and I immersed myself in the wards in order to obtain information about the participants, and the physical aspects of the environment before starting the observation. That gave me a general idea of the entire context;

therefore, I found it easier to document my observations both in writing and using an audio recorder (see Section 3.2.6.1.1). As the study progressed, my observation was more focused on aspects of nursing care of patients at the end of life, recognising the importance of the physical environment and other interactions within the context. I focused more on the nursing care of those patients who met the eligibility criteria.

However, I clarified my role as participant observer during the observation and asked for permission from family carers and patients prior to observing intimate care to protect the dignity and privacy of the patients and their families. I constantly reminded the participants about my role as a researcher to avoid formal nursing roles and reduce the power imbalance between the researcher and the participants. During the observations, there were informal conversations between the researcher and the participants, such conversations built more rapport and were taken as field notes because they were freely and openly carried out.

To ensure privacy and allow a period for the patients and family carers to rest, observation took place during two shifts (morning and afternoon), which was adequate to have full knowledge of what transpired within the study context. The number of hours of observation spent in each ward is as follows: Male Medical Ward (A) 28 hours, Male Medical Ward (B) 65.5 hours, Female Medical Ward (A) 54 hours and Female Medical Ward (B) 40.5 hours. To observe interactions between the nurses during handover, I joined each shift from the beginning. I spent most of my time around the patients and observed interactions among all the participants. I also recorded field notes including verbal and non-verbal interactions as they occurred. However, it was difficult for me sometimes during participant observation to take notes directly; in these circumstances, notes were postponed and recorded immediately afterward.

3.2.6.1.1 Field Notes

I tried as much possible to avoid generating tension, anxieties, and suspense for the nurses while recording field notes. I used pen and paper to record my field notes. Occasionally, I used my digital recorder where writing may generate tension. Memo-writing was an essential aspect of recording observations. Words and phrases of participants were recorded during observations, while detailed accounts of the observations and reflection were written as soon as practicable (see Appendix Five).

3.2.6.2 Semi-structured Interviews

Semi-structured interviews were employed as a method of data collection following the observations, to explore the experiences of nurses, patients and family carers regarding nursing care of patients at the end of life. Details of the interviews were explained on the participants' information sheet and presented to each of the participants before the interviews. An interview guide (see Appendices 8,11 and 14) was used for the interviewing process and this covered general areas related to the research questions.

Case study interviews usually allow for a free expression of participants' views, and for the richness of data, questions are raised with why, how and what (Wong, 2014). Ryan et al. (2009) suggest that to generate useful information, questions generating yes or no answers are not helpful. A cordial relationship with participants and an enabling environment is likely to produce honest responses for the researcher (Cronin, 2014). However, short interviews were conducted with some of the patients whose conditions did not allow me to explore further. The interviews were conducted in both English and Hausa languages depending on the language fluency level of the participants. As a bilingual language speaker of English and Hausa, I conducted the interviews in the participant's preferred language. The venue and time of the interview were determined by the participants, while I ensured that the venues were free from distractions and the time suitable for the interviews. Some of the interviews were conducted at the bedside for

both patients and family carers, during the later part of the afternoon shift after the visiting hours. Interviews with the nurses and some family carers were conducted in a separate room outside the wards. The interviews were recorded using an audio recorder, while field notes concerning facial expression and gestures were documented during the process.

Interviews are important sources of information in case study and should be in the form of guided conversations (Yin, 2009). The interviews were open-ended and in the form of conversation with no defined order of asking questions during the interview. However, I encouraged the participants to talk about their experiences and asked them to make clarifications where necessary.

3.2.7 Ethical considerations

The researcher obtained and gained ethical approval from the ethical review boards of the University of Nottingham and that of the study setting (OVS12092016 and ABUTHZ/HREC/Y4/2016 respectively) (see Appendix 2 and 3). Research into palliative and end-of-life care is difficult to present to participants and involves unique ethical challenges (Henry and Scales, 2012), especially when it involves dying patients. For this reason, I replaced the “dying patient” with “seriously ill patient” in all the documents presented to participants. This safeguarded the information from generating tension and anxiety from patients and their family carers.

3.2.7.1 Informed consent

Those who agreed to participate in the study were asked to sign the consent form using their thumbprint which is a valid signature for official documents in Nigeria. In researching this nature, the researcher is obliged to obtain informed consent from family members concerned, as well as from the patients (Jubb, 2002), or by obtaining assent from someone close to the patients with fluctuating or declining capacity (Gysels et al., 2013). Karlawish (2003) recommends that a close friend or family member can serve as a proxy for a non-competent patient

(who lacks the capacity) as a result of a chronic and progressive illness, but Berg (1996) is of the opinion that families are usually the best suited to make decisions. The family members perform the role of caregivers and serve as knowledgeable informants to health care professionals about the patient's health, make decisions for the patient, and assist the patient in activities of daily living.

3.2.7.2 Confidentiality

The researcher built a rapport with the participants; these relationships were built over the study period. Participants were told that information from one interview is relevant to the whole case; participants were reassured that information from each interview would not be shared with other members of the case. For confidentiality, anonymous labelling (case numbers) was used, and details were only known to the researcher. No participant's name was used on any document traceable to that particular person. Interviews recorded were stored securely on a password-protected computer. Transcripts, the reflexive dairy, and field notes were kept in a securely locked cabinet. Maintaining confidentiality helps to establish trust between the researcher and the participants, reduces anxiety and maintains dignity.

3.2.7.3 Other ethical issues

Research with people approaching the end of life generates a lot of discussions since they are widely believed to be at risk of negative consequences in research participation (Hopkinson et al., 2005, Seymour et al., 2005). Protection of human rights is promoted by ethically sound research that addresses issues of privacy, anonymity, confidentiality, justice, protection from discomfort and harm as described below.

Privacy- The patient has the right to limit access to him by others depending on the circumstances. In this study, privacy was protected by being absent when intimate care was given to patients.

Autonomy- Participants were given the capacity to think independently, freely decide and act by such reflection. For example, participants were

informed that participation in the study was entirely voluntary and they were able to withdraw their participation at any time.

Beneficence- The participants were informed that the study might not be of direct benefit to them, because the benefit is of long-term.

Non-maleficence – The researcher reduced the risk of harm by providing the participants with detailed information about the study.

Justice- The participant received equitable treatment from the researcher without partiality (Hewitt, 2007). No special care or preferences are given to any participant during the study.

3.2.8 Maintaining rigour

The quality of research is determined by the way in which the research was conducted. This involves a detailed description of the entire research process. Lincoln and Guba (1985b) highlighted four key elements of establishing trustworthiness in interpretive research as follows: credibility, confirmability, dependability, and transferability.

Credibility - Ensures that findings are truthful and represent participants' points of view through seeking informants' or participants' feedback on the researcher's understanding of their perceptions. And also spending sufficient time with the participants to develop a sound understanding of them (Lincoln and Guba, 1989, Cronin, 2014). The measures undertaken to improve the credibility of my findings included triangulation of data from different sources, prolonged periods of direct observation, and interviews with participants.

Confirmability - Is the researcher's ability to overcome biases in interpretation of the participants' perceptions by ensuring the findings are obtained from the participants and is achieved through confirmability audit, audit trail, triangulation, and reflexivity (Graneheim and Lundman, 2004, Cronin, 2014). To ensure confirmability in this study, a step by step analytical process is described in the next chapter. The issue of triangulating data sources was also described in the previous section, while reflexivity is discussed in the next section.

Dependability – A means of taking into account those factors such as instability, phenomena or design induced changes that happen over time and the changes from the researcher's decisions during the analysis process (Cronin, 2014, Lincoln and Guba, 1989). To address the issue of dependability in the current study, the entire research process was described in detail. The supervisory team also monitors the processes of data collection and analysis.

Transferability - Shows the extent to which research findings are transferable to other settings with similar characteristics. The researcher proposes transferability of the findings to another context, while the reader decides whether findings are transferable (Graneheim and Lundman, 2004). To improve the transferability of the findings from this study; participants, a method of data collection and analysis were clearly described as suggested by (Graneheim and Lundman, 2004). An in-depth contextual description of the research setting is provided in Chapter Five.

3.2.9 Reflexivity

Reflexivity is defined as "the process of critically reflecting on the knowledge we produce, and our role in producing that knowledge" (Braun and Clarke, 2013). The researcher shares a relationship with the investigating world which is essential for ethnographic research. Researchers describe their ideas and experiences when presenting research reports in order to allow the readers to judge the possible impact of these influences on the study (Reeves et al., 2008). Ethnographers enhance the quality of their work by providing a detailed description of the research participants and the setting, based on hours of observation and interviews with participants.

Creswell (2007) stated that reflexivity is based on researchers reflecting on their backgrounds, including social and cultural aspects, which may influence their interpretation of study data. The viewpoints and prior assumptions of the researcher that may influence research findings were addressed by being reflexive. As a professional nurse by

background, my interpretations of observations could have been shaped to suit my understanding. An understanding of how this professional background may have influenced the phenomena is therefore essential to data gathering and analysis. Recording personal impressions and feelings separately as memos ensured a demarcation between what is observed and my personal reflections. My identity as a professional nurse and as a research student was helpful in that it made access easier because the nurses considered me as one of them. I constantly reminded the participants about my role as a research student in order to lessen formal nursing roles and reduce the power imbalance between the researcher and the participants. Despite my position as a researcher, my presence caused a Hawthorne effect at the beginning and gradually faded away as the study progressed. The Hawthorne effect occurs when participants change their behaviours due to an ongoing study. I noticed that the nurses followed the right procedures when giving care at the beginning of my observations.

My position as a former student trained in the hospital and a lecturer from the university may have influenced me as I conducted my observations. However, being an insider created a positive effect which made it easier to develop rapport and elicit information from participants.

As a nurse trained in the same institution where I collected the data, it simplifies my ability to create a rapport with the staff nurses and other healthcare professionals. In addition to that, my appearance in nurses' uniform also helped to improve my interaction with the participants. They felt that I belong to them and that it was easier to communicate with me at their level. If I had dressed in a usual cloth, not a uniform, the participants might have found it difficult to relate with me due to lack of identity. Therefore, I was opportune to closely observe their activities, more especially the nurses were reluctant to carry out their normal activities without thinking about my presence as a researcher. However, it showed that the issue of Hawthorne's effect was not present. On so many occasions, the ward head asked me to carry out some of the

procedures forgetting that I am a researcher which strengthen my role as an insider. I had to tell her that I would rather assist the nurses in carrying out their task, reminding her about my role as a researcher instead of engaging in a formal nursing role. Moreover, qualitative research is new to the participants, especially the experience of being interviewed and observed. I am confident that with time, more qualitative studies will be conducted in the hospital, and the nurses will become more aware of data collection through observations and interviews.

My professional role as a nurse and a lecturer during the data analysis and interpretation gave the ability to fairly judge a 'good and bad nursing care' and was deliberately carried out or done by mistake by the participants.

On the other hand, the patients and the family carers also regarded me as a member of the nursing staff in the hospital. I had to remind them about my role as a researcher constantly. My researcher's position also gave me the opportunity to explore more from the patients and the family carers. They regarded me as someone that was there to act as an advocate for them, and also to rescue them from the situation they have found themselves in terms of care, infrastructure, logistics, and several other problems that hinder the delivery of quality nursing care in a resource-poor setting. Below is a reflexive account of the data collection.

Reflexive account: Data collection

Qualitative research is generally a new approach to inquiry in most of the healthcare institutions in Nigeria. Most of our healthcare professionals are used to responding to researchers through questionnaires. It was not surprised when some of the nurses I approached asked if it was questionnaires I brought, they were ready to fill it instantly. The research process was explained to them, but despite detailed explanation, some of the participants still requested that I should give them the interview guide to answer in writing because they are not used to face to face interviews. Some said that they don't want their voices to be heard, while others said they are afraid the hospital management may hear their voices and such could affect their jobs. After a thorough explanation and full assurance of anonymity, they agreed to participate. Despite the reassurance, some of them were bit reserved to open up and discuss freely because they resisted probes sometimes and refused to comment on certain issues raised. All the nurses interviewed said that they had never been involved in any qualitative observation or interview, but they had answered questionnaires several times from many researchers. I observed that most of the nurses were not confident enough to face challenges because of their low educational qualifications as most of the nurses are diploma holders, very few of them are graduates. Therefore, they may lack the courage to speak against the management on the challenges and barriers to quality nursing care.

In contrast, the family carers were ready to express their views and feelings, some of them even requested that their views should be forwarded to the management in order to address some of the problems affecting the quality of nursing care. Similarly, the patients had the same views as the family carers where some of them requested that the government, not just the management should be informed about their situation. They said they have never had such an opportunity to express their feelings and experiences about the care they are receiving, therefore my presence was a welcome development and they will use it as an avenue to channel their complaints. They said there were a lot of problems in the hospital, but they don't know how and where to report those problems.

Summary

This chapter has outlined the methodology and methods used for this study. An interpretivist philosophical standpoint underpinned the research which explored the process and experiences of nursing care of patients at the end of life from the perspectives of nurses, patients, and family carers. The choice of qualitative research methods (ethnographic case study) using participant observation and semi-structured interviews was based on the assertion that this research design can adequately answer the research questions better than any other research design.

Data analysis was in two stages: the early stage or the initial analysis was concurrent with the data collection (transcription and translation), the second stage or the later analysis was more systematic using NVivo 11 software. The analysis of data followed an inductive thematic approach, and key issues emerged as themes from examined and identified categories of data. Right from the onset of the study, I ensured that ethical principles were followed during the study period, thus minimizing the risk of harm. The next chapter presents the data management and analysis in the study.

CHAPTER FOUR: DATA MANAGEMENT AND ANALYSIS

4.0 Introduction

The chapter presents the data management and analysis. Data analysis is the most challenging aspect of qualitative research (Basit, 2003)**,** with no one technique that supersedes all others (Bradley et al., 2007)**.** It consists of a series of activities that involve selection, abstraction, and transformation of the data from transcripts, documents and field notes; and subsequently data display which involves organisation of information to draw conclusions (Gale et al., 2013). In qualitative research, data analysis is a process in which the researcher systematically organises both textual and non-textual materials to gain an understanding of the phenomenon in question (Wong, 2008). However, (Zamawe, 2015) points out that there is no replacement for qualitative inquiry in the social world when the research intent is to increase understanding of how things came to be**.** Houghton et al., (2015), indicate that qualitative data analysis has no systematic rules, but aims at eliciting themes from data through rigorous and organised patterns. Although a large amount of data is generated in qualitative research in the form of transcripts and field notes (Zamawe, 2015, Cope, 2014)**,** the analytical process reduces the large volume of the data to a more manageable form (Kawulich, 2004). However, the analytical process is usually arduous and requires an extended period (Cope, 2014). According to Stake (2006), analysis also provides a contextual meaning for each report in addition to a list of findings. There are a variety of approaches to data analysis in qualitative research (Braun and Clarke, 2013, Vaismoradi et al., 2013, Smith and Firth, 2011, Thorne, 2000) (see Table 8). Data analysis is an iterative process in qualitative research (van der Eerden et al., 2014). Therefore I conducted the data analysis in two stages: the early stage or the initial analysis was concurrent with the data collection. The data collected for each case were transcribed verbatim, reviewed and kept in a separate folder by the researcher. The nine interviews conducted in Hausa language were sent to a Nigerian and African languages department for

a standard translation. A back translation was carried by the researcher who is a bilingual speaker (Hausa and English) to ensure accuracy and quality of the transcript. Only minor differences were found during the back translation which is mainly related to the choice of words.

The second stage or the later analysis was more systematic after the whole dataset (participant observations and interviews) was collected, transcripts were uploaded into the NVivo 11 qualitative data management programme. All personal identifiers were removed, and case numbers were assigned to each participant to protect confidentiality and ensure anonymity. Data were analysed using thematic analysis.

Table 8: Approaches to data analysis in qualitative research

Type of analysis	Description
Constant comparison analysis	Originally developed for serial data analysis to refine ideas and identify conceptual boundaries in the grounded theory methodology of Glaser and Strauss. Themes are systematically developed from the entire dataset by reducing the data through coding, then identifying the underlying themes in order to develop conceptualisations of the possible relations between various pieces of data.
Classical content analysis	This is referred to as counting the number of codes. It is similar to constant comparison analysis; the major difference is that the number of times each code is utilised is counted instead of developing the themes. The analysis helps to identify which codes are used most and which might be the most important concepts that give information about the data.
Conversation analysis	Analysis is developed from the behaviour of speakers as the central resource. Producing orderly social interaction of people is the goal of this method of analysis. It generally focuses on the conversation of participants.
Discourse analysis	Focuses on the various ways in which people communicate ideas, by selecting a descriptive or distinctive segment of a language used. This may include several lines of an interview transcript, and then carefully scrutinising the chosen segments in detail for a rhetorical organisation, inconsistency, accountability, and positioning.
Narrative analysis	Involves giving meaning to lives of individuals through stories and taking into account participants' own evaluations. It recognises the lived experiences of participants from the stories they provide, thus treating data as stories.
Interpretative phenomenological analysis	Explores how participants make sense of their personal and social world. Focuses on an individual's personal experience and is concerned with perception or account of an object or event rather than attempting to reduce it to predefined or overly abstract categories.
Grounded theory analysis	It is a systematic way of theory generation from data obtained from social research. Data analysis is typically begun during the process of data collection, thus further data collection is guided by initial readings. In grounded theory, the researcher examines and possibly accounts for all instances, and searches for deviant cases in order to develop and refine the theoretical framework.

(Adapted from Thorne, 2000, Smith and Firth, 2011, Braun and Clarke, 2013, Vaismoradi et al., 2013)

4.1. Thematic analysis

Thematic analysis provides a useful and flexible research tool within the constructivist paradigm (Braun and Clarke, 2006, Braun and Clarke, 2014). It is used to identify, analyse and report themes within data. Themes are unifying statements or concepts (Bradley et al., 2007) consistently occurring within the subject of inquiry. In contrast to other analytical methods, thematic analysis identifies themes and patterns across a dataset in relation to research aim and objectives; and is not influenced by an existing theory (Braun and Clarke, 2014). Thematic analysis provides a detailed account of qualitative data, in which the researcher searches for and identifies common ideas that spread across the entire dataset (Vaismoradi et al., 2013). The analytical steps explained by Braun and Clarke (2013) are shown in Table 9.

Analysis of data for ethnographic case studies can follow an inductive thematic approach (Reeves et al., 2008) because themes are generated directly from the data (Pope et al., 2000). An inductive approach involves data analysis where the study phenomenon is not known and uses the actual data to derive the structure of the analysis with few or no pre-defined categories or patterns (Burnard et al., 2008). Although the approach is time-consuming, however, it is comprehensive (Burnard et al., 2008), and therefore most suitable for the current study. Categories of data are examined and identified as key issues and subsequently emerge as themes (Braun and Clarke, 2006). Themes are the outcome of coding, categorisation and analytical reflection from units of data (Saldaña, 2016). Themes can be directly observed from information at manifest level or may be identified underlying the data at the latent level (Saldaña, 2016). Data were analysed using thematic analysis, through identifying and interpreting patterns across the datasets. I used an inductive approach to thematic analysis where codes and themes were developed from the data.

The data analysis appropriate for ethnographic research is conducted through the identification and classification of the data, as well as abstract generalisations and explanation of patterns (Higginbottom et

al., 2013). Although data analysis in ethnography is conducted in several forms (Creswell, 2018, Fetterman, 2010, Braun and Clarke, 2013, Roper and Shapira, 2000), Roper and Shapira (2000) on one hand highlighted six analytical steps for ethnographic study, these are: coding the data, sorting for patterns, identification of outliers, generation of themes, generalising constructs and theories, and memoing of researcher reflections and insight. While on the other hand, Braun and Clarke (2006) outlined six similar steps or phases, these are: familiarising with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report (see Table 9). However, I combined the two approaches (Braun and Clarke, 2013 and Roper and Shapira, 2000) for my data analysis. The study is an ethnographic case study; therefore, a combination of a generic and ethnographic approach to data analysis would be more suitable to address the research question. Therefore, each step/phase was fully described in the following sections.

Table 9: Analytical steps or phases

Braun & Clarke (2013)	Roper & Shapira (2000)
Transcription and Familiarising with data **Data transcription, reading and rereading, repeated listening and noting down initial ideas.**	
Coding **Identifying interesting features of the data relating to research question systematically across the entire data set, and collating data relevant to each code which could be either complete or selective.**	**Coding for descriptive labels** Materials collected in the form of written words are grouped into meaningful categories or descriptive labels to identify patterns.
Searching for themes **Collating codes into a central organising concept containing different ideas that speak about the data. Gathering all relevant data to each potential theme.**	**Sorting for patterns** Sorting or grouping the descriptive labels into smaller sets and more general and abstract pattern. Developing the themes from those groupings and possible connections between the information.
Reviewing themes **Checking whether the themes are related to the coded data and the entire data set and producing a thematic map.**	**Identifying outliers** Identifying cases, situations, events or settings in contrast with the rest of the findings and kept in mind. These may offer information and strengthen analysis.
Defining and naming themes **Generating clear definitions and names for each theme. Continuing refinement of each theme and the overall story that the analysis tells.**	**Generalizing constructs and theories** Connecting findings to theories in order to make sense of the rich and complex data collected.
Writing – finalising the analysis **The final opportunity for analysis. Selection of vivid, compelling extract examples, a final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a report of the analysis.**	**Memoing with reflective remarks** Memos are written for further clarification or testing, and for keeping track of assumptions, biases, and opinions throughout the whole research process.

4.1.1 Familiarising with the data

Familiarisation involves a review of research materials to become immersed in the data through a repetitive reading of the transcripts, listening to the tape and studying field notes from observations (Pope et al., 2000, Furber, 2010). The overall aim of this stage is to become familiar with data for easy coding and further development of an analytical framework (Ward et al., 2013). The interviews in this study were transcribed verbatim, to ensure accuracy, transcripts were read several times while listening to the audio recordings, and this allowed me to become immersed in the data. The data obtained from the interviews and observations were transcribed, and the transcripts were imported into the NVivo software using the Microsoft Word files referred to as internal sources (see Figure 6). I grouped the files into case folders, each case comprising three interviews (nurse, patient and family carer) and an observation. All personal identifiers were removed, and a case code was assigned to each participant for anonymity.

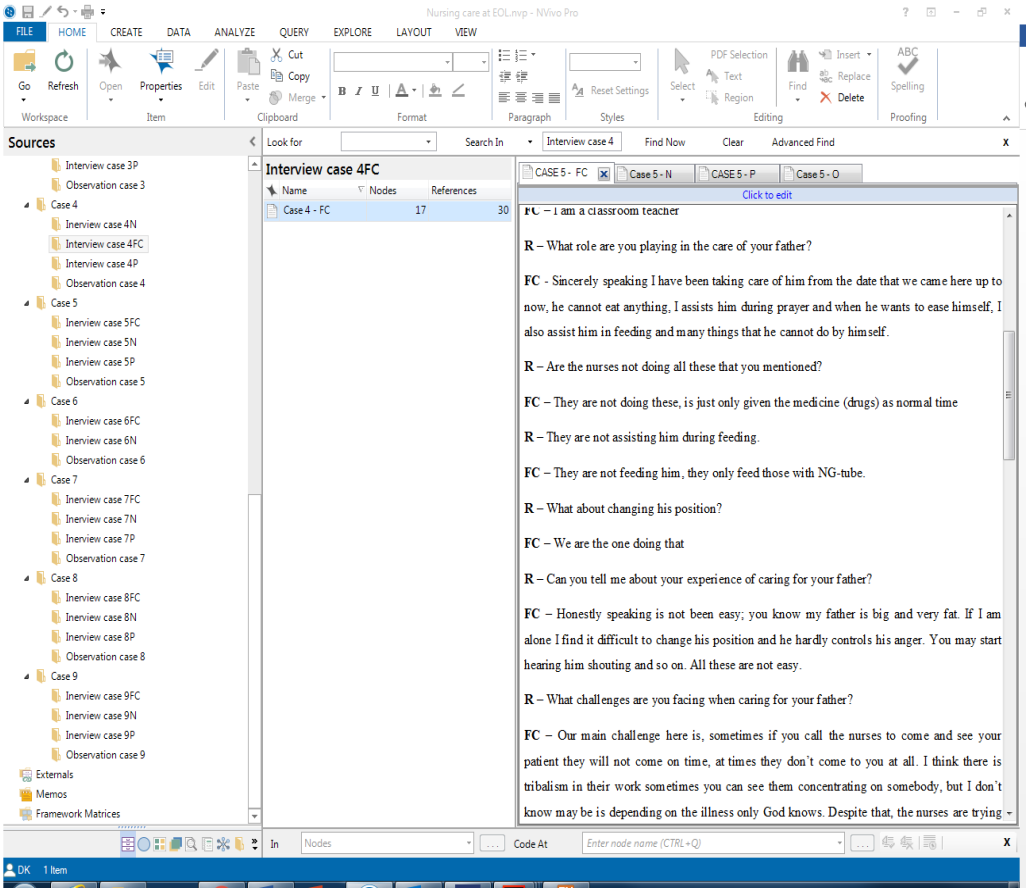


Figure 4: Screenshot of NVivo Data organisation for the current study

I chose to use NVivo 11 because it provides an organised storage system that is readily accessible where units of data can easily be located. The software also enables the researcher to have an unlimited number of codes, so that s/he can retrieve and organise data in any number of patterns and themes. After importing the cases I began by selecting source content and attributing it to a particular code, this is referred to as coding. Coding involves labelling or tagging textual data to allocate meaning to the text or transcripts. Coding can apply to words, phrases or sentences, sometimes even a whole paragraph.

Table 10: Terms used in NVivo data management

Term	Definition
Code	Codes (nodes in NVivo) are tags or labels, which are assigned to words, phrases, sentences or paragraphs to identified topics or themes from the data compiled in a study.
Coding	Coding involves subdividing huge amounts of data into segments, examining the data similarities and differences, and subsequently grouping similar data in the respective nodes.
Node	Represents a code, theme, or idea about the data in a project. A child node is a node extending from another node (parent node) from which a given node has descended. Sibling nodes are two or more nodes under the main node (parent node) that they related to.
Reference	References represent coded sources about a specific node.
Theme	Themes are patterns in the information that evolve from the relationship codes, which tag data that link concepts to each other and provide recurrent and unifying ideas regarding the subject of inquiry.
Sub-theme	A sub-theme exists under the broader theme and inherits the parent theme's resources. It shares the same central organising concept as the theme but focuses on one notable specific element.

(Wong, 2008, Vaismoradi et al., 2013, Sangasubana, 2011, Fereday and Muir-Cochrane, 2016, Bradley et al., 2007)

4.1.2 Generating initial codes / coding the data

After organising the data into case files, transcripts of interviews and field notes were read several times to gain a sense of the whole dataset. The data from each file were coded separately to explore meaning in greater depth. Codes are descriptive labels applied to segments of a transcript and are referred to as nodes in NVivo, while the process is referred to as coding (Green et al., 2007). There are several terms used in data management using NVivo (see Table 10). A direct means of coding by highlighting words, phrases, and paragraphs was used, and then dragged to a node. New nodes were created whenever new ideas were found. For example, in one of the interview transcripts below (Case 1 - N) where I highlighted phrases and coded as fundamental nursing care, that is a child node under the parent node 'nurses' responsibility' (see Figure 7).

> *"Patients that are seriously ill are about to die we try to do our fundamental nursing care as we usually do to our patients.* ***We clear their airways, resuscitate patient adequately, try to inform the doctor to be on ground****, every personnel involved in the care of patient are contacted so that they will be on ground and once the doctor prescribe anything we go ahead to administer and try all our best to see that the patient is kept alive." (Case 1 - N)*

The above excerpt is a sample interview transcript (Case 1 – N)

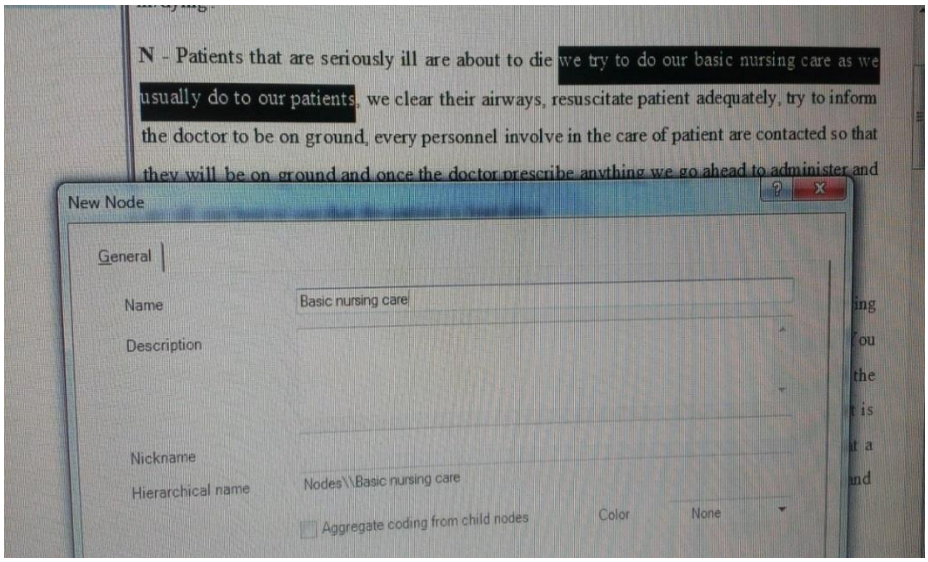


Figure 5: Screenshot of initial coding on NVivo

Any node added is immediately recorded by NVivo, when two or more ideas are present, each of the coded parts becomes a reference (see Table 10). Nodes are categories or files created within NVivo that enable the researcher to store and retrieve coded data. Each time the coded data are stored in a node, it is recorded (see Figure 7), at the same time keeping track of the location in the transcript where such data were coded referred to as a reference (see figure 9). The references gave me the ability to return to the original full transcripts for further information relating to a particular code.

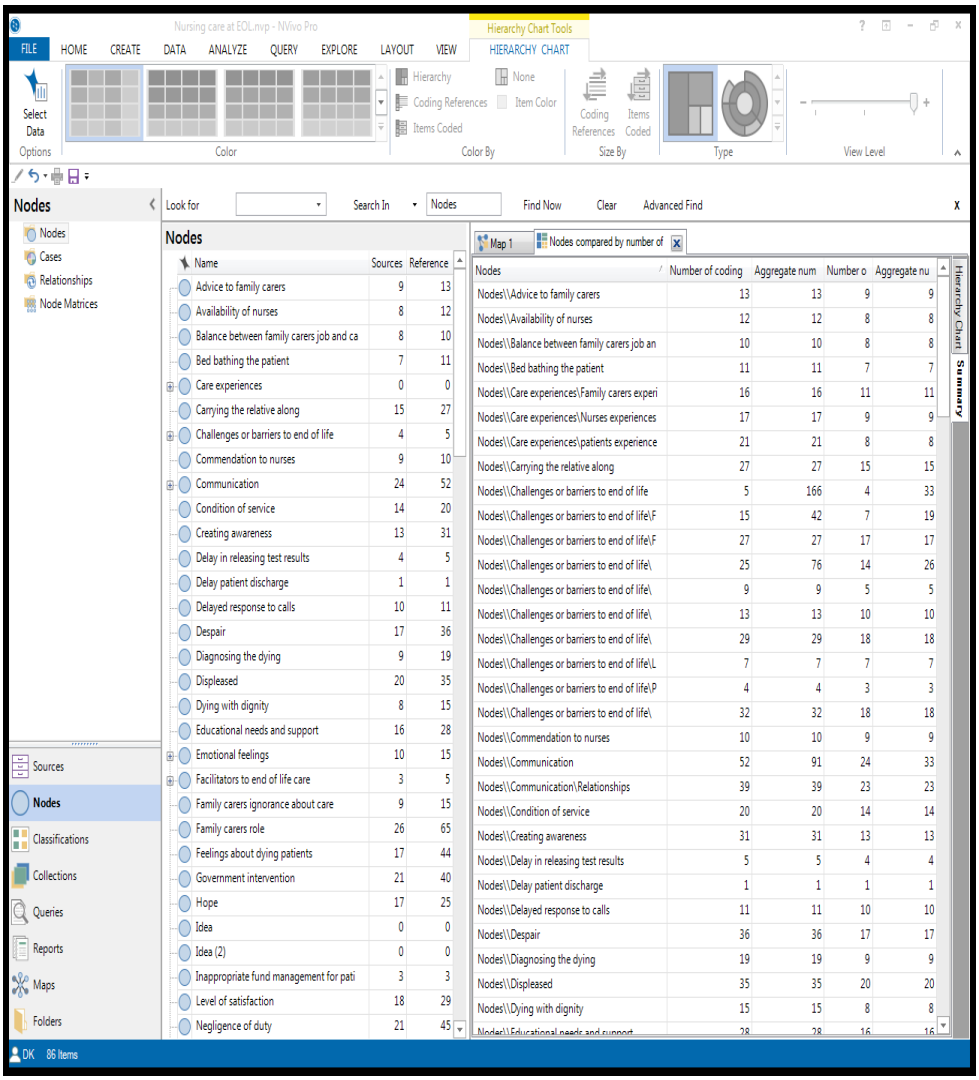


Figure 6: Screenshot of summary of nodes and references from NVivo

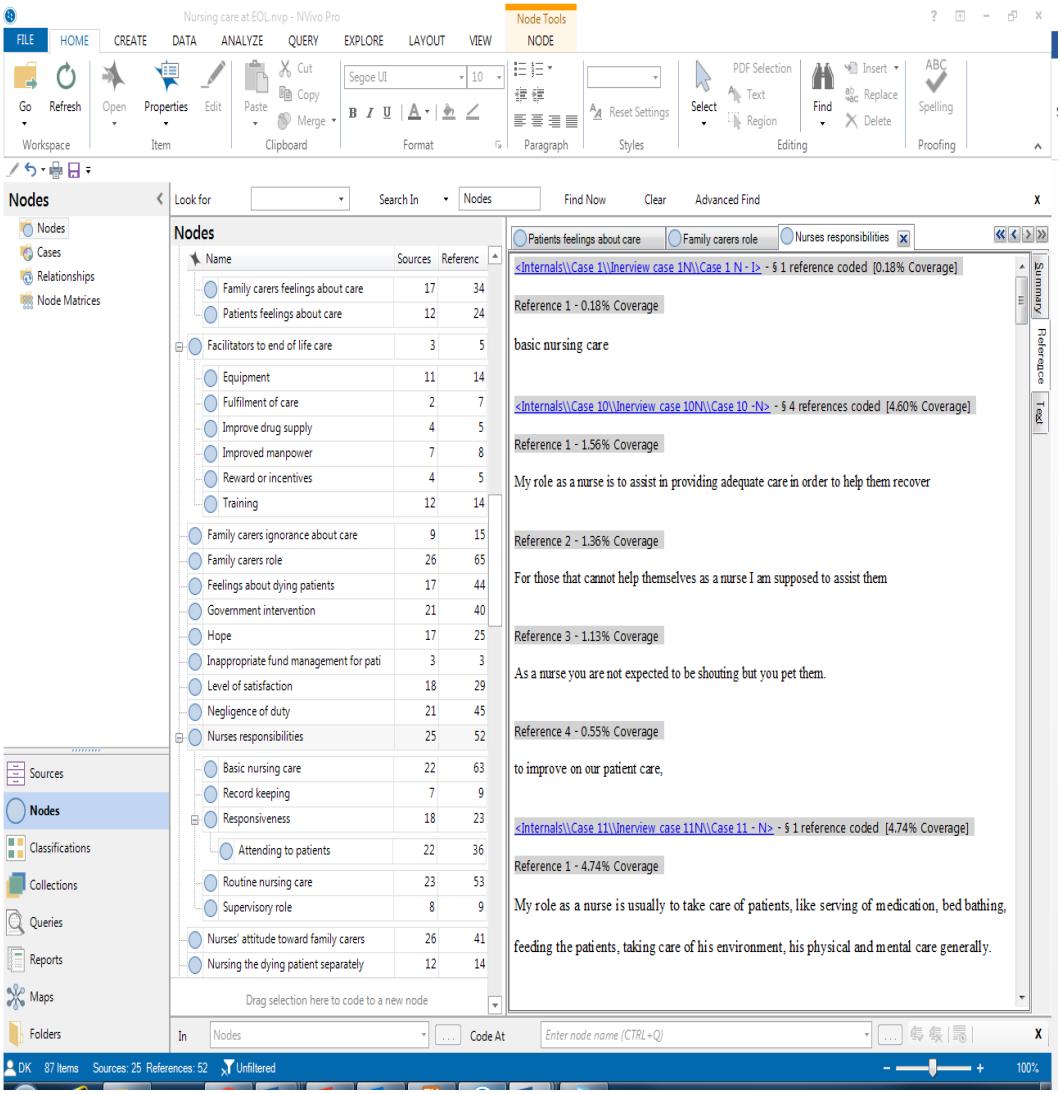


Figure 7: Screenshot showing nodes and references on NVivo

4.1.3 Searching for themes/generation of themes

Themes are described as structures, patterns, differences and commonalities within the data. After the initial coding of the data and the development of the nodes, I examined concepts across the dataset for the emergence of the themes. The nodes were reviewed and sorted out as new insights were made. Some of the sub-nodes that were related to one another were merged to form the sub-themes. Some of the parent nodes addressing similar issues were also merged to become themes (see Table 11).

Table 11: Thematic generation

	Themes	Sub-themes	Nodes	Sub-nodes
1	Caring roles	Nurses caring role	Fundamental nursing care	Bed bathing
			Record keeping	Treacherousness
			Responsiveness	Attending to patients
				Delayed response to calls
			Routine nursing care	
			Supervisory role	
			Obtaining consent for care	
		Other healthcare professionals' roles		
		Supporting role	Being with	
			Patient Custody	
		Family carers role	Reasons for involving family carers in the care	
		Negligence of duty	Task shift	
2	Feelings about care	Family carers feelings		
		Patients feelings		
		Nursing the dying patient separately		
		Workload	Stress and burnout	
			Availability of nurses	
		Level of satisfaction		
		Perception about the end-of-life care	Diagnosing the dying	
			Dying with dignity	
		Feelings about dying patients		
3	Care experiences	Family carers' experiences		
		Nurses experiences		
		Patients experiences		
4	Challenges or barriers to end of life care	Language barrier		
		Hospital management	Doctors	
			Lack of human resources	
			Logistics problem	Delay patient discharge
				Delay in releasing test results
			Inappropriate fund management for patients	
			Decay infrastructure	Condition of service
				Security laxity
		Ward		
		Family Carers	Economic factors	
5	Facilitators to end of life care	Equipment		
		Improve drug supply		
		Improved manpower		
		Reward or incentives		
		Training		
6	Communication	Relationships	Relating with colleagues	
		Carrying the relative along		
		Commendation to nurses		
		Reassurance		
		Teamwork		
		Withholding information		
7	Educational needs and support need	Creating awareness	Ward sanitation	
		Family carers' ignorance about care	Uncertainty	Despair
				Displeased
				Hope
				Fulfilment of care
		Balancing family carers' job and caring		
		Nurses' attitude toward family carers		
		Patient and family carers' needs	Patient expectation	
			Patients' privacy	
			Protection	

As shown in Table 11 above, the sub-nodes were subsidiary to the main nodes and explained further the content of the nodes, thus distinguishing their different levels. The main nodes that showed the characteristics of the activities carried out were grouped to form the sub-themes. Finally, themes (e.g. 'caring roles') emerged from the sub-themes that showed the varying responsibilities of people involved in the study. Similarly, other themes were generated followed the same pattern. Seven themes were generated: (1) Caring roles (2) Care experiences (3) Feelings about care (4) Challenges or barriers to end-of-life care (5) Facilitators to end-of-life care 6) Communication and (7) Educational needs and support (see Table 11).

4.1.4 Reviewing, Defining and Naming themes

The themes generated were reviewed and further refined where some of the themes were collapsed to form one theme. All the nodes under each theme were reassessed to ensure that codes were coherent with the themes. Of the seven themes presented in the previous section, three were collapsed and merged with other related themes with a similar pattern. For example, care experiences and feelings about care were merged to become 'experiences and feelings about care'. Challenges or barriers to end-of-life care and Facilitators to end-of-life care were merged and became 'barriers and facilitators to end-of-life care'. Communication was merged with educational needs and support to become 'Communication, and educational needs and support' (see Table 12). All the themes contained sub-themes due to their complex nature as shown in Table 11.

Table 12: Reviewed themes

S/N	Initial themes generated	Reviewed themes
1	Caring roles	Caring roles
2	Feelings about care	Experiences and Feelings about care
3	Care experiences	Communication, Educational need and support need
4	Communication	Barriers and Facilitators to end of life care
5	Educational needs and support	
6	Challenges or barriers to end of life care	
7	Facilitators to end of life care	

4.1.5 Writing/finalising the analysis

The final phase for thematic analysis involves selection of clear, persuasive examples from the data. The analysis provides a concise account within and across themes in which the data extracts provide sufficient evidence of the themes which were presented in the finding chapters. The extracts were embedded within the analytical narratives illustrating the stories about the research aim and objectives.

The next chapter, which is the beginning of the finding chapters, examines and presents the care delivered by nurses, family carers, and other healthcare professionals in the study.

4.2 Analytical process of the cases

The cases comprised of three units of analysis (nurse, patient, and family carers) grouped as a single folder. The interviews and observations of these units were transcribed into a word document, and the whole transcripts of the dataset (participant observations and interviews) for each case were uploaded into the NVivo 11 qualitative data management programme. Individual units of analysis (nurse, patient, and family carer) were coded separately within the folder to maintain the identity of the case. Each unit of a particular case from a folder shares the general nodes with other units from all other folders containing the cases. At the same time creating new nodes along with new ideas. For example, in figure four that shows the cases folders, and an interview transcript of a family carer for case four, which was coded and assigned to the various nodes. This was preceded by coding of the interview transcript of the nurse in the same case four. Then followed by coding of the interview transcript of the patient, and finally coding of the observational field notes of the case. All other cases were coded in a similar order. The reason why the coding was not case specific was due to the fact that phenomenon of interest was not to determine the similarities and differences among cases, and does not also involve analysis within and between cases, because all the cases have similar characteristics except for the gender. The whole idea of assigning

cases was to enable the researcher to link the units of analysis and their observations. Therefore, thematic analysis was based on the grouping of all the sub-nodes with similar ideas to become nodes, and all the nodes addressing similar issues were merged to become sub-themes. Finally, all the related sub-themes were merged to become a major theme.

The case study approach provided a platform and the bases for my observations and interviews. It might look cumbersome to observe what was carried out on one patient and to interview a different nurse or family carer, and these are two different ideas with a missing link. The idea of the case study approach was to enable me to confine the study to a particular group of people because the study was carried out in a general medical ward having a mixture of both acute and chronic cases. Some of the patients stay in the unit as short as two or three days, while others may stay up to a year. Therefore, the case study was found suitable and appropriate for determining the cases.

The study involved participant observations and semi-structured interviews, and the case study approach played a significant role in linking the observation and interview data to the appropriate participants, which could not be done by general observations and interviews.

During the study, there were several other actors around the patients (doctors, physiotherapists, accounting clerks, record clerks, and welfare staff) that could have been part of the unit of analysis. Although they featured in the observations, however, the study was about the nursing care delivered to patients by nurses and family carers at the end of life. The nurses and the family carers stayed with the patients all the time, while other healthcare professionals visit the patients from time to time, and their roles were acknowledged and reported as a subtheme in section 5.4.

CHAPTER FIVE: INTRODUCTION TO FINDINGS

5.0 Introduction

This chapter presents findings in relation to the care delivered by nurses, family carers and other healthcare professionals in the study. In this chapter, nurses' roles are examined, these include fundamental and routine nursing tasks. Fundamental nursing tasks involved those activities carried out on patients based on demand and or patients' conditions such as feeding, serving meals, changing of positions, and bed bathing. While routine nursing tasks usually have a temporal dimension and are carried out on each of the patients at a specified time, these include drug administration, observation of vital signs, bed making, and wound dressing. Family carers' roles are discussed in the chapter and the reasons for involving them in the patient's care, and a model that describes end-of-life care delivery within the context. However, before presenting the findings in an ethnographic study, it is incumbent on the researcher to set the scene by providing an overview of the entire study context and landscape. Also presented along with the contextual description are some related events unfolded during my observations and presented as field notes.

5.1. Contextual Description

This section presents a detailed description of the study context, which provides a background for the findings chapters (5-8), providing a detailed description of the landscape and ward environment. The section further describes the nature of the shifts[9], handover[10], participants' characteristics and the length of time spent in the field as a participant observer.

[9] The shifts are designed to provide nursing care across 24 hours of the clock each day of the week. The practice typically sees the day divided into set periods of time during which different groups of nurses perform their duties. For example, morning shift -8:00am to 3:00pm, afternoon shift - 2:00pm to 9:00pm, and night shift - 9:00pm to 8:00am.

[10] Handover is a system that enable the nurses communicate and transfer patient information between shifts to ensure continuity of care.

5.1.1 Study Context

In most healthcare facilities in Nigeria, staff nurses are mostly recruited from the RN/RM cadre (diploma-holders). The BNSc graduates are predominantly found in educational institutions in both the public and private sectors. Ethnographers are engaged directly with the world they are studying, and they are involved in recording a variety of elements in their field notes through participant observations of the complex nature of social life. Reeves et al. (2008) described nine observational dimensions in an ethnographic study as follows:

5.1.2 Space — Physical layout of the place

The medical unit is located on the second floor of three storey building, it consists of four wards (Male medical wards A&B and Female medical wards A&B), headed by a unit head (see Figure Four). The wards have similar characteristics. The bed capacity of the wards ranges between 30-33 beds, each of the wards has five cubicles containing five to six beds and a nurses' station. There are also four offices immediately you enter each of the wards; two by the right side, one belonging to the ward head and one for the rest of the staff. The other two offices on the left side, one serves as the record office, and the other serves as a consulting room. There is an entrance that links male wards A and B. Also, there is a similar link between the female wards, but there is no entry between male and female wards. At the end of each of the wards are lavatories consisting of three toilets and three bathrooms (see Appendix Sixteen). The condition of the lavatories was quite horrible, filthy with water flooding all over the floor, and one could hardly breathe due to the strong odour. However, the wards are generally clean, well ventilated and adequately lighted. The wards are usually calm and quiet, although there are no adequate measures to control visitors as they come in and out at any time they wish; despite the presence of security staff at all the entrance to the wards. Doctors and medical students conduct their ward rounds in batches according to their specialities.

5.1.3 Actors — Range of people involved

There are three significant actors involved in the study they include nurses, patients, and family carers. However, others include doctors, physiotherapists, domestic staff (ward attendants) and students.

5.1.4 Activity — set of related activities that occur

Usually, activities start at 8:00 am daily with handing over by the night nurses which is in two parts, and it takes them 30 minutes to one hour. They start with reading from the cardex (details about each patient) at the nurses' station, followed by visiting the patients' beds and checking the bed-head tickets (nurses' note) for the activities carried out on the patients by the nurses. After taking over from the night nurses, the morning nurses continue with the bed making, but sometimes they only gave the bedsheets to the family carers to make the beds for their patients. When they have finished bed making and distributing bed sheets, the most senior among the nurses allocates jobs for the shift.

5.1.5 Object — Physical things that are present

Each ward consists of 30 – 33 beds, a nurses' station with a clean utility room attached to it. A clean utility room is where the emergency tray, medication trolley, dressing trolley, dressing packs, oxygen cylinders, and suction machines are kept. There is also a reservoir of water and a wash-hand basin in the clean utility room, under the wash-hand basin is a waste bin. Wheelchairs, screens, drip stands, bedpans, and urinals are kept in a dirty utility room near the lavatories.

5.1.6 Act — Single actions people undertake

Handover takes place at the beginning of each shift. Nurses from the previous and current shift come together for a briefing about what transpired in the last shift. A nurse of the prior shift leads the handover by reading the report for each patient and then visits patients bed by bed to see the patients and their bed head tickets. Nurses from the current shift may challenge any uncompleted or unrecorded nursing tasks.

5.1.7 Event — Activities that people carry out

These include fundamental and routine nursing tasks. The fundamental nursing tasks involved those activities carried out for patients based on demand and/or patients' conditions such as feeding, serving of meals, changing of positions, and bed bathing. While the routine nursing tasks are carried out on each of the patients at a specified point in time, these include drug administration, observation of vital signs, bed making, and wound dressing.

5.1.8 Time — sequencing of events that occur

The events start in the morning with the handover, followed by bed making, serving meals, drug administration, vital signs, wound dressing, and ward round. However, some procedures may overlap depending on the job allocation.

5.1.9 Goal — Things that people are trying to accomplish

For each shift, the nurses work hard to accomplish their various assigned tasks which are based on job allocation. The tasks include fundamental and routine nursing care as mentioned above. However, the nurses work hand in hand among themselves and the family carers to ensure smooth achievement of their goals towards patients care.

5.1.10 Feeling — Emotions felt and expressed

The nurses expressed mixed feelings regarding patients' care, conditions of service, equipment, educational support, and many other issues. Most of their concerns were attributed to managerial problems. Patients and family carers expressed similar concerns.

5.1.11 Nature of the shifts

The shift patterns for staff are similar within the entire hospital; there are three shifts in a day: the morning shift starts at 8:00 am and finishes at 3:00 pm, the afternoon shift is from 2:00 pm until 9:00 pm and the night shift starts at 9:00 pm and finishes at 8:00 am. At the end of each shift the nurses who have completed their shift hand over to the nurses doing the next shift which takes 30 minutes to one hour. The morning shift usually consists of four to five nurses, including the ward head

carrying out the administrative function, the deputy ward head overseeing the ward activities, attending ward round and assisting the nurses when necessary, and the remaining two or three nurses who continued with fundamental and routine care. This includes feeding, serving meals, recording, and reporting, changing of positions, wound dressing, bed bathing, drug administration, admissions, and discharges. In addition to the nurses in a shift, there is usually a domestic staff member (ward attendant) who runs errands such as taking patients for investigations and carrying samples to the laboratories. The nurses ensure that all care tasks completed are recorded and signed off.

On the afternoon shift which starts at 2:00 pm and finishes at 9:00 pm, there are two nurses and one attendant. The nurses continue with the fundamental and routine care tasks, they write a report of what transpires in the ward and submit it to the hospital matron's office at the end of the shift, while the attendant continues to run errands. The process of writing the report consumes a considerable amount of time and hinders a lot of caring tasks. Although the afternoon shift is lighter than the morning shift in terms of care tasks, the nurses face a lot of distractions and interruptions from visitors because the visiting time is from 4:00 pm to 6:00 pm.

The night shift is from 9:00 pm until 8:00 am, and just like the afternoon shift, there were two nurses and one attendant. The nurses continue with the fundamental and routine care tasks, they write a report of what transpires in the ward and submit it to the hospital matron's office at the end of the shift. The night shift is the lightest of all the shifts regarding care tasks but can be busy at times especially when there are admissions or when a patient's condition becomes critical at night requiring immediate intervention.

For the weekend shifts, usually, there are only two nurses and a ward attendant per shift.

5.1.12 Admissions

When a patient is admitted, the nurses make an initial assessment and put together a care plan that is updated and reported at the end of each shift. The nurses rarely provide direct physical care traditionally considered as nursing tasks, but generally, administer drugs to patients, carry out procedures such as wound dressings, feeding, and other paperwork. It is during admission that nurses usually collate base-line data on the patients from their initial assessment and develop their nursing care plan. At the same time establish rapport with patients and family carers. But the situation was different in some observed cases because the nurses neither assessed the patients nor established rapport. This could affect patients' experiences throughout their hospital stay. Therefore, the nurses need to be trained in basic communication skills, and other continuing professional development regarding admissions. See field notes 1a and 1b below for what transpired during some of the admission processes.

Field note 1a: Admissions process

Admissions process 11:05am - 22/02/2017

During a morning shift at the nurses' station male medical ward (A), three patients were brought on wheelchairs for admission from the accident and emergency unit (A&E) by their family carers accompanied by a nurse carrying their case notes. An attendant pushed one of the patients. The A&E nurse handed the case notes to one of the two nurses sitting at the nurses' station. The nurses went through the case notes to find out whether the patients had paid for their admission, one of the patients did not have his payment receipt in the case note, and the nurse told the family carer to present it before they were admitted. Then the nurse turned to one of the three nursing students present at the nurses' station and asked her to check the admission booklet on the table and write some items for the patients to go and buy as part of their admission requirement. These items included a pack of a latex gloves, a thermometer, a bottle of Jik (cleansing agent) (1.5L), a bottle of methylated spirit (35ml), a roll of cotton wool, a bottle of Savlon (500ml), a bottle of hand wash (500ml), syringes and cannulae. The nurse showed two of the family carers with evidence of payment beds for their patients, and she asked them to clean the bed and spread their bed sheets. The family carers did not come with bed sheets, so they placed their patients on a bare mattress. *No admission procedure was carried out.*

Field note 1b: Admissions process

Admissions process 12:30pm - 24/02/2017
A similar incident occurred in the female medical ward (A), a patient came for admission from the general outpatient department (GOPD), a nurse asked the patient to check a bed whether it has a backrest (cardiac bed), the patient checked the bed and told the nurse there was no backrest. The nurse asked her to check another bed which had a backrest. The nurse went and collected bedlinen from the clean utility room and spread on the bed. The patient told the nurse that she hadn't managed her customer well.

5.1.13 Handover

Handover is a system that enables the nurses to communicate and transfer patient information between shifts to ensure continuity of care. However, a generic description of handover is illustrated following observations: The handover starts with reading a report by the night nurses from the cardex, they said they had a busy shift with two admissions giving a total of 27 patients. After presenting the report at the nurses' station, we moved to patients' bedsides to see their conditions and to check their bedhead tickets (nurses' notes) for what transpired during the night shift. In one of the handovers, the ward head was furious with the night nurses for not properly documenting their actions and because they were too slow in the process of handing over. We met a family carer bathing his patient in bed, and the ward head told him to make it fast because he was exposing the patient to cold. The family carer also showed the ward head some blisters on the patient's left buttock, earlobe and left upper arm which are about to become pressure sores. The ward head told the family carer that they should be turning the patient frequently; meanwhile, he should use spirit on the blisters so that they would dry off. After the handover, the ward head summoned all the nurses for a brief meeting in the clean utility room where she emphasised proper documentation, use of appropriate uniforms and quick handover. An issue was raised regarding doctors' delay in response when they were called to see a patient. The ward head told them to take note of the time they called the doctors, the time

they arrived, and the actions taken. The nurses were challenged for not being observant, the ward head narrated an incident, where a family carer came and was crying while the nurses were sitting at the nurses' station when he was asked, he said, my father, when the nurses rushed to check, they found that he had already died. She concluded the meeting by calling upon the nurses to be vigilant and notice any changes from patients' current conditions. See field notes below for other examples of what transpired during handover.

Field note 2a: Handover

Handover - 08:00am - 22/02/2017
During a handover by the night nurses on the male medical ward (B), the nurses were found not to document the fluid intake and output of all patients. During the round a family carer complained that his patient wanted to remove his urinary catheter, the nurses spoke to him that he should reassure the patient on the need for it. Another family carer was also asked to look for hot water to bath his patient in the bathroom. Another family carer brought his patient from the bathroom on a wheelchair, he asked the deputy ward head to assist him to put the patient back to the bed, but she asked me to support the patient to the bed which I did. A patient needed to be changed to a cardiac bed, the ward head called me to assist in changing the patient's bed and asked the family carer to lift the patient to the bed.

Field note 2b: Handover

Handover - 08:00am - 27/02/2017
During a handover on the female medical ward (A), there was only one night nurse that handed over to the morning nurses. The second nurse was said to have gone to see a doctor for her health condition. During the handover bed linen was brought from the laundry, one of the nurses received the bed linen and shared with the patients. I realised that the bed linen was inadequate and allocated to only those patients whose linen was dirty. I also observed that patients pay for their stationery every Monday (₦100=20p), the ward head asked one of the nurses on the morning shift to go round and ensure that each patient paid. At 9:30am all the family carers were gathered for a health talk by the nurses. The topics covered included personal and environmental hygiene, visiting hours, preparation for morning duty, how to obtain drugs from the pharmacy, and use of lavatories.

Field note 2c: Handover

Handover - 08:00am - 17/07/2017
During a handover on the male medical ward (A), the head of in-service training and another nurse from the same office joined the handover it was quite a challenging one. They emphasised documentation, and they followed patients' records one by one pointing out routine tasks not recorded such as vital signs, fluid intake and output, and changing position. They found that most of the tasks were carried out by the family carers. Although only two nurses covered the night shift with a total of 23 patients, they were questioned for not carrying out their tasks.

5.1.14 Managerial structure in the nursing service department

The managerial structure in the nursing service department of the study setting. Figure 8 below shows how information flows across the department. The unit heads receive information from the head of the nursing service through the hospital matron and pass it to the ward managers down to the ward attendants (domestic staff).

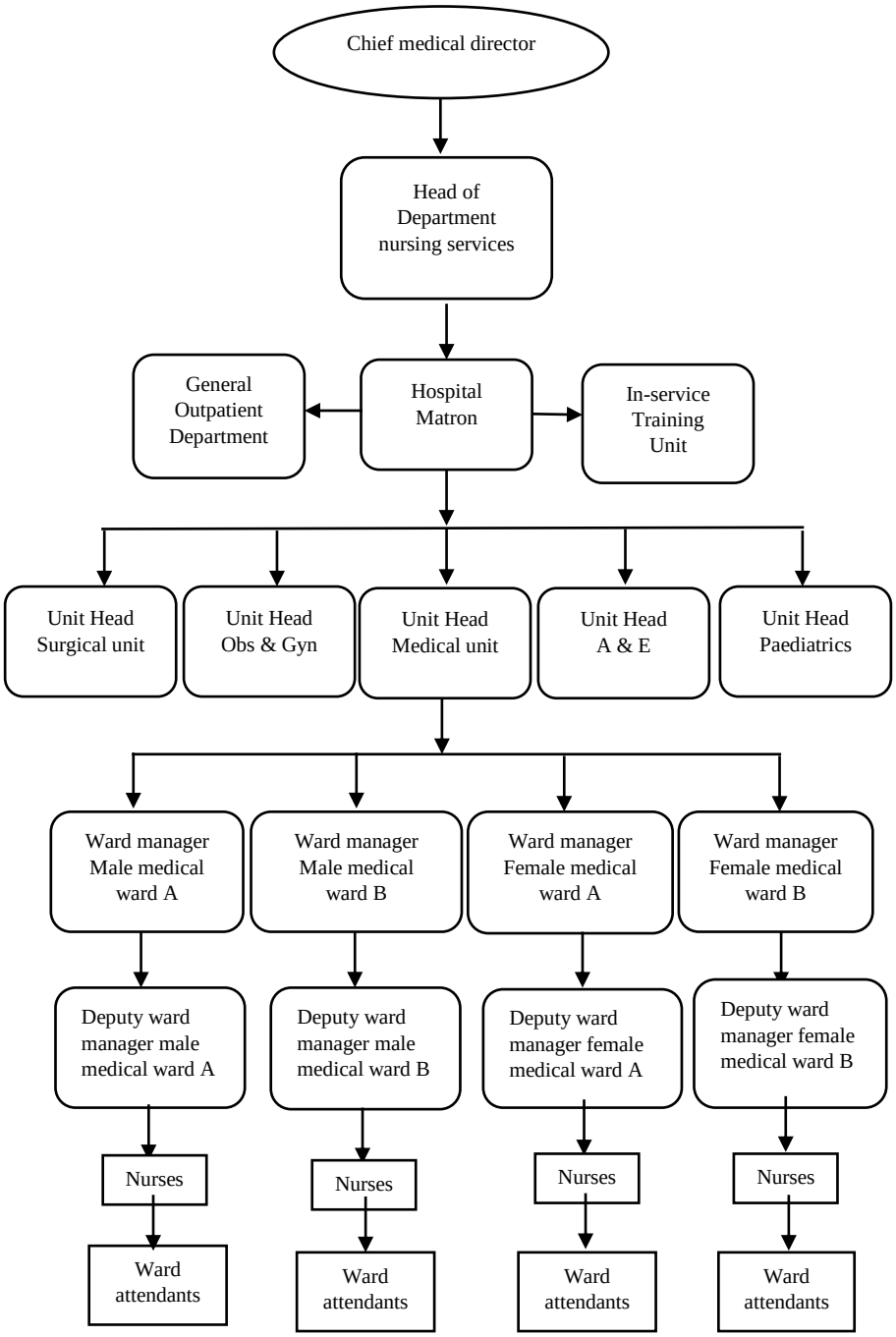


Figure 8: Managerial structure in the nursing service department

5.2 FINDINGS

This section presents the study findings regarding the caring roles played by the nurses, family carers, and other health care professionals. The section also describes the pattern of care in the form of nurses-family carers care model.

5.2.1 Nurses' caring role

Providing quality care to patients is incumbent upon nurses to do so via codes of professional practice. The nurses described their caring roles at the end of life as a form of assisting the patient in maximising their health potential in the final days of life by providing both fundamental and routine care. The nature of the routine and fundamental nursing care was fully described in Section 5.1.4.

5.2.1.1 Fundamental nursing care

Part of the nursing care delivered to patients at the end of life by the nurses is the provision of fundamental nursing care to these patients (see Section 5.1.4). All the nurses described their fundamental nursing care roles carried out to the patients, and they said they carried out such roles diligently, and those fundamental tasks that are beyond their limit they call the attention of the doctors:

> *"We clear their airways, resuscitate patient adequately, and try to inform the doctors to be available, every staff member involved in the care of the patient is contacted so that they will also be available." (Case 1 –N)*

> *"As a nurse, I should do my work perfectly, for instance, oral care, bed bath, changing position feeding them very well, serving of the prescribed drug and ensure all investigations are carried out." (Case 7 – N)*

> *"We assess patient's condition through the use of the nursing process and any change noticed is reported to the doctors or any of the senior colleagues. What we usually do as nurses is to keep observing, keep documenting and keep managing the patient as the need be." (Case 8 – N)*

It was also observed from the statement below that the nurses carried out some of their caring roles diligently. They demonstrated good

knowledge of what is required for the nurse to carry out following observation of abnormalities:

> *"The nurse came and tested the patient's blood glucose, inspect his pressure sore and said that is healing after which she brought a trolley and dressed the patient's wound." (Case 1- O)*

> *"The nurse noticed a rise in the patient's temperature (38.8oc) after taking the vital signs, so she exposed the patient and tepid sponged." (Case 6 – O)*

5.2.1.1.1 Bed bathing the patient

Providing physical care to improve patients' personal hygiene and wellbeing such as bed bathing is one of the fundamental nursing tasks performed mainly on dependent patients. Although the nurses were said to carry out their roles diligently, none of the nurses were found to carry out bed baths for the patients. The majority of nurses when asked could not ascertain the last time they gave a bed bath to a patient. The statements below confirmed that the nurses relinquished such task to the family carers (FC):

> *"I gave a bed bath to a patient not up to 2 or 3 weeks." (Case 10 –N)*

> *"We used to give a bed bath to patients that their condition is critical. At times I use to give it myself but if there are junior ones, we assign them to give them. You know it depends on the number of staff we have." (Case 12 – N)*

> *"There was one unconscious patient we had in February (2 weeks ago) I did a bed bath for him." (Case 5 – N)*

> *"I remember, I did it two weeks ago, when we had an unconscious patient due to diabetic encephalopathy." (Case 7 – N)*

Throughout my observations, there was no single bed bath performed by the nurses; it was the family carers who were doing it. During bed baths and other personal care, the nurses have the opportunity to carry out a thorough assessment from head to toe to monitor the patient's wellbeing. However, from the above statements, it shows that the nurses are missing one of their vital roles that ensure the quality of care

which is the general assessment of the patient. One of the nurses mentioned during the interviews (Case 8 - N), that part of the nurse's role was the assessment of the patient's condition through the use of the nursing process; they were found not to be carrying out such tasks.

5.2.2 Record-keeping

One vital nurse's role is accurate record keeping, the nurses in the study were found to be recording their actions, and this could be seen from the observations below:

> *The nurse gave the patient a drug, recorded and moved to the next patient. (Case 1- O)*

> *The nurse gave the patient intravenous ceftriaxone and left, she returned after 15 minutes and recorded it. (Case 4 – O)*

> *While administering the drugs, the nurse asked the FC to prepare the food for the patient, after administering the drugs she served the food and documented. (Case 6 – O)*

5.2.2.1 Lack of trustworthiness

One of the qualities of nurses is trustworthiness which should be manifested in their actions. Patients and their families rely upon the abilities and the confidence of nurses when receiving care. This relationship and the trust developed during the end-of-life care makes the care easier, patients and family carers look up to the nurses for support. However, one of the patients narrated his experience on the contrary where some of the nurses' actions differed from their reports, and this can be seen in the statement below.

> *"Sometimes, the nurse will not come and see you but can tell that or report that you slept well, he/she didn't even greet you, but they can say you slept well. But it's not true because they don't even know your condition. The observation of the patient is not there." (Case 11 – P)*

The patient's statement above was confirmed from various observations highlighted below, where nurses were found to have recorded both fundamental and routine nursing tasks carried out by family carers. The most surprising aspect was that even the family carers were very much

aware of what was happening. My attention was drawn to such an act by one of the family carers after she treated the patient's pressure areas and changed the patient's position, the nurse only came and recorded this task on the nurses' note.

> *FC changed patient position and rubbed some talcum powder on her back. She said now that she changed the patient position, I should watch if the nurse came around, she would chart on the paper that patient position was changed. The nurse came to observe the patient's vital signs after she recorded the vital signs, she looked at the patient's position and recorded it. I looked at the chart, and I found that patient position was recorded to be changed at two-hour intervals. I asked the FC who was changing the position she said she changed the position every 2 hours, but the nurses record that they change the position without even asking her who changed the position. (Case 3 – O)*

> *The nurse observed the patient's body temperature, pulse, and respiration, and recorded. However, I found that blood pressure was recorded but was not observed. The same recording of the 6:00 am (140/70mmHg) was copied to 10:00 am. She also documented that she changed the patient's position which in reality was not done. (Case 6 – O)*

These examples of untrustworthiness were not limited to the ward or only to the nurses but involved even the security staff around the hospital. A patient narrated an incident where his sister's bag disappeared after an encounter with security men while trying to come to the ward. The patient also added that a similar incident happened where some group of people allegedly dressed like ward attendants broke into the pharmacy department and ran away with laptops.

> *"The security men around have become thieves, I am telling you from experience, they stole my sister's handbag in a car. We just returned from home, as they were trying to put me on a wheelchair and bring me in, the security man came around and said you are not supposed to park here. My sister said yes, I know, I am a staff here I want to drop the patient and leave please let me do, before you know it they stole my sister's bag in the car with money, though we later found the bag. So, the people that are given the responsibility of securing your life are the ones after your life." (Case 14 – P)*

> *"Some people came to the hospital dressing in attendant's uniform like attendants and went stealing around all in the name that they are attendants, but they are not. They went as far as stealing a laptop from the pharmacy department. Well, anybody on duty in the pharmacy would think it was an attendant. But how many attendants can you identify around in a facility as big as this? When all attendants can wear any shirts made of brown materials, I don't know if you understand what I mean? Brown is of different colours, an attendant can decide to wear a light brown, and another one can decide to wear an ox bood brown." (Case 14 – P)*

This lack of trustworthiness has a negative impact on the well-being of the patients, for instance during an interview with one of the patients (Case 11 - P) who said that some of the nurses could write a full report that a patient slept well without having contact with the patient. This act means that the patients are at risk of having their problems underreported. During one of my observations (Case 6 - O), the nurse was found to have recorded a blood pressure that was not measured without taking account of the implications of doing that. Such circumstances could put the patient's life in danger. A similar incident that happened during another observation (Case 3 - O) where the nurse recorded that the patient's position was changed, which was not done. The implication of this was that some of the patients developed pressure sores as a consequence of the nurses' action. This act of untrustworthiness was not limited to the nurses alone but involved even the security personnel that are responsible for looking after the lives and properties of the nurses, other staff, patients and family carers. A patient (Case 14 - P) narrated how security men in the hospital stole a handbag belonging to his sister (a nurse). However, the situation of these security men in the hospital was problematic, because I learned that they spent eight months without having their wages. Although this does not warrant their wrong action, the hospital management contributed to that. The implication is that the safety of lives and properties of patients and their family carers are not guaranteed.

5.2.3 Responsiveness

The majority of patients and their family carers expressed their views regarding nurses' delay in responding to calls when they needed their attention. They said that the nurses usually waste time before they responded to patients' needs. Although most of the patients and their family carers expressed negative feelings regarding nurses' response to calls, this was determined by the situation on the ward the nurses found themselves in at the time of the call. Sometimes a shift could be very busy with few nurses, yet some nurses might be found sitting at the nurses' station. In such instances, patients and family carers experienced a delayed response from the nurses as mentioned by some of the patients and family carers (e.g., Case 11 – P, Case 7 – FC, Case 5 – FC and Case 2 – FC). Such delays by the nurses caused the family carers to go ahead and carry out the nursing task as observed in one of the cases (Case 2 – O).

> *"Whenever your drip finished, and you sent for them (nurses), they will come after 10 – 20 minutes, so they are not doing their work." (Case 11 – P)*

> *"The nurses waste time, and sometimes they take up to 10 to 15 minutes before they come." (Case 7 – FC)*

> *"The only thing is that they don't respond to your calls promptly." (Case 2 – FC)*

> *"Our main challenge here is, sometimes if you call the nurses to come and see your patient they will not come on time, at times they don't come at all." (Case 5 – FC)*

The above statements were confirmed through series of my observations where family carers asked the nurses to come and change the patient position but delayed responding, the family carer went ahead and changed the patient's position himself. Likewise, another patient vomited blood at night and doctors were informed, but by morning they hadn't arrived:

> *"The family carer said is time to change the patient position, he went and informed the nurse at 11:00 am, up to 11:30 am the nurse didn't come, the FC decided to do it himself, and I assisted him." (Case 2 – O)*

> *"I asked the FC about patient's condition he said the*

condition has changed because patient vomited blood in the night and his doctors were informed but are yet to come and see him." (Case 5 – O)

5.2.3.1 Contact with the patients

The nurses came in contact with patients mainly when they were carrying out their nursing tasks. Most of the times they were at the nurses' station and attended to patients on demand as described by the patients and their family carers.

"When it is time for medication they come and administer it, from time to time they come and observe my BP and other vital signs, sometimes they don't come at all." (Case 10 – P)

"If they set an intravenous fluid infusion, we call them to come and check, but sometimes if they set it in the night, you may not see them until morning." (Case 8 – P)

"When they want to administer a drug, they come on their own, but there are certain times when she needs something I have to go and call them. There was a time I want to give her food, but she refused to eat. I had to call the nurses, they talk to her, and she agreed." (Case 8 – FC)

The nurses were always at their station, and they don't usually go to the patients' bedsides unless they are administering drugs or when they are carrying out other fundamental or routine tasks. Most of the times they wait until the patients or family carers called their attention. This attitude shows that nurse-patient interaction is quite limited which often generates anxiety for both the patients and their family carers.

5.2.4 Routine nursing care

Routine nursing care was discussed in the previous section. However, the nurses described how they carried out such tasks for the patients.

> *"Once the doctor prescribes anything we go ahead and administer." (Case 1- N)*

> *"As a nurse, I do my work perfectly. For example, doing the vital signs - BP, pulse, respiration, and temperature." (Case 13 – N)*

Some of the family carers testified that the nurses were carrying out their routine tasks such as administering medication and feeding patients with a nasogastric tube.

> *"They feed him and give him medication before the doctor comes." (Case 1 - FC)*

> *"But the routine things they do, like administering medication." (Case 3 – FC)*

These routine tasks carried out by the nurses were confirmed by observation as they were being carried out. The nurses were observed to be administering drugs regularly, checking patients' vital signs and feeding those that could not feed themselves.

> *The nurse came and observed patient's vital signs, and later came with her trolley and asked the FC for drugs, she administered Augmentin 500mg I.V. (Case 2 – O)*

> *The nurse came with a mortar and a pestle she crushed some drugs (locovid 100mg and cognitol 5mg) and administered via NG – tube after feeding the patient with pap[11] mixed with milk. (Case 3 – O)*

> *The nurse fed the patient with about 300 – 400ml of pap mixed with milk via the N.G tube. The nurse later wheeled a dressing trolley to the patient's bedside and said that she wants to dress the patient's wound (pressure sore) She did the dressing, changed the patient's position and left. (Case 1- O)*

[11] A staple food in Nigeria and other African countries. It is white in colour porridge-like, thick in consistency and made from cereals (maize, millet, guinea corn and rice). When mixed with milk it becomes watery and suitable for nasogastric-tube feeding.

These routine tasks are mainly the technical aspect of nursing care carried out by nurses and could not be performed by the family carers. Therefore, the nurses ensured that they carried out such roles without leaving them to the family carers. Some of the family carers interviewed (Case 1 – FC and Case 3 – FC) testified that the nurses were carrying out the routine nursing care such as drug administration and feeding, which was also confirmed during observations mentioned above.

5.2.5 Supervisory role

The head of nursing services and the unit head visited the ward from time to time to find out what was going on in the wards, and to ask if any issues needed prompt attention. This role was seen during the observation sessions. The head of the nursing service department visits the wards once every week while the unit head nurse enters the wards regularly.

> *The head of the nursing department visited the ward and met the nurse observing the patient's vital signs, and she asked the nurse if there were any problems, the nurse complained that the sphygmomanometer was faulty. (Case 1- O)*

> *The unit head came around and found the family carers bathing the patient, and she called the nurses to take over from the family carers. (Case 4 – O)*

It is a tradition on the part of the head of the nursing department to go around all the wards in the hospital weekly to find out problems at the ward level. During one of my observations, a nurse complained to the head of the nursing department during a visit, that a blood pressure apparatus was faulty, but that problem was not addressed throughout the period of the study. There were many problems in the unit as a whole during the study period that were reported by the nurses but were not addressed.

5.2.6 Disregard of duty

The nurses were found to have refrained from their responsibilities of caring during the study, thereby leaving the burden of care on the family carers. Patients and family carers expressed concern over this inability

of nurses to carry out their roles especially fundamental nursing care. One of the family carers interviewed (Case 1 – FC) attributed the pressure sore developed by his patient to the inability of the nurses to change the patient's position as prescribed. He further stated that the nurses also delayed the patient's feeding causing unnecessary hardship to the patient. Another family carer (Case 3 – FC) was angry with the nurses because they didn't usually find out the situation of the patients. Some of the patients (Case 10 – P and Case 13 – P) were of the opinion that the nurses neglected their fundamental responsibilities and allowed the family carers to perform such roles. Although these family carers did not have the required training to care for their patients, they could not sit down and watch their loved ones suffering, even though they might harm the patients themselves:

> *"You can see he has a bed sore because the nurses are not changing his position, even to assist me to change the position is a problem to them, there is also a delay in feeding the patients sometimes an hour later than scheduled." (CASE 1 – FC)*

> *"At first I was kind of getting angry with them when I came, the few that don't do their work I usually get angry with them and ask them I am supposed to come and tell you what you're supposed to do? They don't usually come and check the patient to see how patients are doing. I don't know, seriously this neglect of responsibilities has been there for a long time." (Case 3 – FC)*

> *"No, they don't bath her, I am the one doing it, sometimes in the bed, and other times in the bathroom. Mostly what they do is to come and administer drugs and gives her injection. Not long ago I changed her bedsheet and took her to the bathroom for a bath." (Case 8 – FC)*

> *"I can say if they know it is their work and they don't do it because of their selfish interest that is negligence." (Case 4 – FC)*

Patients also had similar concerns regarding this disregard of duty. Although some of the patients never asked the nurses to care for their personal hygiene because of the presence of their family carers, the

nurses nevertheless never attempted to do this:

> *"I expected them to care for my body, but I didn't see them doing it for anyone, and my husband was willing to do it, so we didn't bother." (Case 13 – P)*

> *"They don't care about my personal hygiene; it's my son that is taking care of that." (Case 10 – P)*

Patients and their family carers narrated several instances where the nurses refrained from carrying out their duties, even though some of the patients and the family carers were aware that such duties are nurses' responsibilities. This attitude increases the burden on family carers and affects the wellbeing of the patients.

5.2.6.1 Task shift

Apart from disregarding their responsibilities, the nurses usually asked the family carers to perform some of their tasks, which was confirmed by several observations (Case 1- O, Case 2 – O and Case 6 – O). In one of the observations, the nurse asked the family carer to prepare food for the patient who was on nasogastric feeding, which the family carer did. The nurse served the food without putting into consideration the mode of preparation, the amount and the temperature, which may have had an adverse effect on the patient's wellbeing. During another observation, a nurse brought a bed-sheet to the family carer and asked him to make the bed. This act means that the nurse shifted her responsibility to the family carer who had no idea of how to make an occupied bed, thus causing unnecessary discomfort to the patient. One of the family carers (Case 3 – FC) said that the nurses shifted their responsibilities to them and told them if there is any problem they should call them.

In caring for patients and their families at the end of life, nurses are the pivot in the healthcare team. Their complex roles include symptom management, administering medications, information dissemination, handling equipment and carrying out procedures, as well as coordinating patients' care. This task shift was confirmed by several

periods of observation where the nurses asked the family carers to perform such tasks.

> *"The nurse told the family carer that it was time for feeding and asked the FC to prepare the food for patient, the family carer prepared pap and milk in a cup and informed the nurse. The nurse came and fed the patient." (Case 1- O)*

> *"The nurses brought a bed sheet to the FC, and he made the bed. I asked the FC why is it that the nurses are not making their bed, he said, that is what some of them do, they sometimes give them the bed sheet to make the bed. The FC observed patient was exerting pressure on the ankle joint, the attention of the nurse was drawn in which she asked the FC to blow air into two surgical gloves which she put between the two legs at the ankle joints". (Case 2 – O)*

> *"The nurse asked the FC to check if the patient opens her bowels, the FC found that the patient opened her bowels and the nurse did not do anything about it. The FC went ahead and cleaned the patient." (Case 6 – O)*

One of the patients complained about how the senior doctors shift their responsibilities to the junior ones who are supposed to work under supervision, but they are left to work independently.

> *"Another thing is this, now look around, you don't see any of the senior doctors around, you don't, all you can find is the house officers who haven't hatched yet. Even the so-called senior registrars, you don't find them around only during the ward round or when they bring their students around for bedside teaching." (Case 14 – P)*

The family carers and the patients explained how nurses' responsibilities were pushed to them, and how they are carrying out those tasks. Most of the activities carried out by the family carers involved care for personal hygiene which cannot be performed by the patients at the end of life. All the patients studied were dependent upon the nurses and the family carers for their care because they were unable to help themselves:

"Mmm, I don't know if it's because I am the son or whatever, or because I am the one that came to look after her in the hospital? But there are some if I told them they would ask me to bring a screen and set it up and bring all the necessary things, I only assist them to hold her, they clean her and put Sudocrem on her wound from prolonged lying down on one side." (Case 10 – FC)

"They shifted those responsibilities to the carer, and they will tell you if there is a problem you come and tell them. All they do in the morning is vital signs, i.e., take the BP, temperature, they ask you to bath her and clean her, empty her urine bag things like that." (Case 3 – FC)

"Yes, I am the one doing it, there was only a day that she was confused and defecated on her body, the matron came and assisted me to put her in a wheelchair to the bathroom, but I did all the cleaning." (Case 8 – FC)

"Yes, my family, I will do the toilet here, my family will clean it up, my family does everything for me. There aren't any nurses that did something for me regarding personal care for one day." (Case 11 – P)

Most of the duties neglected by the nurses were carried out by the family carers. This situation increases anxiety for the family carers which leads to hostility and results to family carers assuming the caring roles.

5.3 Family carers' role

It was a routine task for each of the family carers to wake up early in the morning to bath their patients before the nurses' handover. Often family carers needed to compete for the screens to provide privacy. Therefore, the earlier they did that, the better because those who were not able to do the cleaning before the handover had to wait until after the handover. Several observations confirmed family carers carrying out certain tasks which I believe are nurses' tasks. For example, in one of the observations (Case 4 - O) two family carers bathed their patient, changed his clothes and repositioned him, while in another observation (Case 6 - O) the family carers put the patient on a chair and changed the bed sheet and placed a wide polythene as mackintosh on top of the

bed sheet to prevent it from soiling:

> *"FC and his brother screened the patient's bed cleaned him up and changed his clothes. They made the bed and put the patient in a comfortable position." (Case 4 – O)*

> *"FC changed patient position and rubbed some talcum powder on her back." (Case 3 – O)*

> *The FC used wide polythene at the middle of the bed to cover the bed sheet (as Mackintosh) to prevent it from soiling, and also placed a wrapper on the polythene (Case 6 – O)*

> *"The FC prepared food (pap + milk) and informed the nurse who came and fed the patient. The FC changed the patient's clothes and cleaned him up. The FC changed the patient's position and applied Sudocrem on his earlobe to prevent pressure sores." (Case 2 – O)*

The family carers were fully involved in the care of the patients, and they carried out various activities to ensure the wellbeing of their loved ones especially physical care because they could be with the patients all the time. These could be seen from the following statements:

> *"I woke up early clean my mum and make her comfortable, I don't wait for them, and you know neatness contribute to their health and wellness." (Case 8 – FC)*

> *"I empty the urine bag, clean him up after defecating and bath him as well. The doctor wrote that his position should be changed every 3 hours. I do it alone except for one nurse who does assist me when on duty." (Case 1 – FC)*

> *"I do everything, bath her, clean her mess up, and wash her clothes. Sometimes I call them to change her position, but if they are not responding, I will do it myself." (Case 10 – FC)*

> *"It is more or less anything I do out of love. In the first place, she is my wife, whatever I do with regards to her health is my responsibility. So, I have to do everything*

to make sure she is well. Apart from the practical medical aspects which I don't know about, any other thing that could bring her sound health I do it. I bath her, I take her to the toilet, buy food and drugs for her." (Case 13 – FC)

"I take care of everything and meet all her needs. The drugs and injections I get them ready, I clean her up, change her position at 2 hourly intervals, as a carer we won't leave her like that, that is why I am here. All that is not done I want to get it done." (Case 3 – FC)

"I also turn him side-by-side and rub barrier cream for him on areas of pressure sore which occurred due to being bedridden." (Case 4 – FC)

The family carers were highly enthusiastic about carrying out whatever tasks needed for their loved ones to get well. Despite their limitations, they sometimes 'went the extra mile' to carry out specific professional duties described above.

5.3.1 Reasons for involving family carers in the care

The roles played by the family carers in the care of patients during the end of life cannot be underestimated, because they contributed significantly to the wellbeing of the patients. During an interview with one of the family carers (Case 1 – FC), he mentioned that he emptied the urine bag, this means that the nurses were not keen about assessing the intake and output of the patient. He further stated that the patient's position was to be changed every three hours, but he did it on his own because the nurses were not doing it. Another family carer (Case 13 – FC) said apart from the practical medical aspects which he doesn't know; he did all the other things that could bring sound help to his loved one. The statements made by the family carers were confirmed by several observations, where I witnessed the family carers bathing their patients, changing bed linen, feeding patients, and so many other fundamental care responsibilities. Apart from direct patient care by the family carers, there was additional support they gave to maximise patients' wellbeing. These supporting roles included running errands, washing clothes and feeding utensils, and financial support.

The reasons why family carers were involved in the care of their patients were mentioned by some of the nurses and family carers during the interviews. For example, one of the nurses (Case 8 – N) said that they involved family carers in patient care because they didn't have enough pairs of hands to offer their best to the patients, despite being aware that the family carers would not be able to carry out the care effectively. Another nurse (Case 9 – N) said that it was the hospital management that allowed one family carer to a patient. However, it is not an ideal practice to allow family carers to be with their patients for 24 hours. Involving relatives in the care of patients is a common phenomenon in Nigerian hospitals. During the interviews, some of the nurses explained the reason why family carers were involved in patient care:

> *"It's because we don't have enough pairs of hands. Ideally, the relatives are not even supposed to be with their patient for 24 hours. Because of our environment, you know our Africa environment relatives always want to stay with the sick person, and if you deny them that opportunity, they feel that you don't want their patient to get well. Sometimes even the patients like to see their people there." (Case 8 – N)*

> *"…of course, the patient will not get the best of care, and that is why we involve a patient's relative which we're not supposed to. The management said one patient relative should be by the patient's bedside, and sometimes you have the attendant to help us." (Case 9 – N)*

A family carer said that there is a potential risk of not involving family carers in the care of patients. He described an incident that happened to his wife when he went to buy some drugs outside the hospital. When he returned, he found his wife sweating profusely indicating hypoglycaemia, and this happened without the nurses noticing it:

> *"There is a risk when leaving the patient because there was a time I went to buy drugs in the town before I returned she was hypoglycaemic. I found her sweating, I quickly brought out her glucometer and tested her sugar level, and then I discovered it was below the*

normal level, based on the little experience I have, I was able to overcome that without drawing the attention of any of the nurses or doctors to it. They didn't notice it because they thought she was sleeping." (Case 13 – FC)

5.4 Other healthcare professionals' roles

Other healthcare professionals such as doctors, physiotherapists, and social workers contributed significantly to the wellbeing of the patients. Several observations (Case 1- O, Case 3 – O, Case 4 – O and Case 6 – O) have shown how these healthcare professionals carried out their various roles for example in one of the observations doctors came for a ward round and assessed a patient's pressure sore which had developed due to prolonged immobilisation and irregular changes of the patient's position. They encouraged the nurses on the need for daily wound dressing and frequent change of position. Another observation showed how physiotherapists performed their role for a patient who had a stroke. From the observations carried out, nurses were found to have a cordial relationship with other healthcare professionals:

"Doctors came for the ward round, they reviewed the patient's condition and added a drug to his treatment. They inspected the pressure sore and said that is healing after which the nurse dressed the wound." (Case 1- O)

"A doctor from the oncology team visited the patient to find out about the review by the neuro-surgeons, the doctor went through the patient's case notes, jotted some things down and left." (Case 3 – O)

"Doctors came to see patient, reviewed his laboratory results and studied the X-ray disc in their computer and said that the chest is clear." (Case 4 – O)

"The physiotherapy team came and exercised the patient's limbs applied some powder and changed her position." (Case 6 – O)

Apart from nurses, other healthcare professionals played a significant role in the care of patients at the end of life. Their roles were identified

in various observations as they worked hand in hand with nurses to ensure that patients were adequately cared for.

5.5 Nurses-Family carers care model

Patient care at the end of life entails physical, psychological, and spiritual needs. Both nurses and family carers meet these needs. Findings from this study show that patient care was in three parts: care by nurses, care by family carers and care by both nurses and family carers (collaborative care) (see Figure 10).

Care by nurses

The care provided by nurses at the end of life is in the form of assisting the patient in maximising their health potential in the final days of life by providing both fundamental and routine care which are basic human needs. Abraham Maslow asserts that human desires are similar and hierarchical, fulfilment of lower needs is fundamental to actualisation of higher needs (Zalenski and Raspa, 2006). Therefore, optimal care cannot be achieved until these needs are satisfied. Maslow's approach provides nurses with the opportunities to address physical, psychological, social, and spiritual needs thus fulfilling patients and family carers' wishes at the end of life.

Nurses deliver care to patients based on their professional training and are expected to extend care to involve the family carers for optimal care. Optimal nursing care is the care delivered to meet a patient's individual caring needs during a given period of time (Fagerstrom and Rainio, 1999). And this consists of the following subsections: planning and coordination of care, breathing, blood circulation and symptoms of disease, nutrition, and medication, personal hygiene and excretion, activity, movement, sleep and rest, as well as teaching, guidance in care, and emotional support.

In this study, nurses' caring roles included but were not limited to medication, observation of vital signs, nasogastric tube feeding, and oxygen administration. However, the study shows that the nurses were

not carrying out some of their vital roles to ensure the quality of care. For example, in the aspect of physical care, nurses relinquished personal care to family carers, while the nurses did not address psychological and spiritual issues of the care. This may be because nurses used some mechanisms to protect themselves from anxiety, emotional, and moral distress, and thus distanced themselves from the patients. There were factors perceived by the nurses to restrict them from carrying out their nursing responsibilities leaving family carers to step-in and fill the gaps. These perceived factors in this study are referred to as barriers to end-of-life care, and they contributed to the poor quality of care received by the patients: a shortage of nurses, lack of palliative and end-of-life care education, lack of training, poor communication skills, inadequate logistics, and lack of motivation. However, there are perceived factors that can promote good end of life care, and these are improvement in drug supply, improvement of human resources, provision of rewards/incentives, and staff training.

Care by family carers

Providing physical care to improve patients' hygiene and wellbeing such as bed bathing is one of the fundamental nursing tasks performed mainly on patients with compromised physical abilities. Family carers performed their caring role within their scope and mainly occupied by the physical care involving care of personal hygiene, change of position and provision of other care needs. Family carers also provided both psychological and spiritual support to the patients, which is ideally supposed to be provided by the nurses. Because patients' care needs were unmet due to those barriers perceived by the nurses, the hospital management allowed family carers to be present at the patients' bedsides to provide the necessary support. During this period, spiritual caring actions are very important, reciting the Shahadah (testimony of faith) as the last word is the most important caring action that every Muslim is craving to have at the end of life. Therefore, allowing the family members to be as close as possible at this time is essential. In Islam, death is to be accepted as the will of God and should neither be

resisted nor fought against it. It was revealed in the Holy Quran (Q3: 139) “It is not possible for a soul to die except with the permission of God at a term set down on record” (Ali-Khan, 2014, Al-Hilali and Khan, 2006). Islamic laws and teachings are derived from the Holy Qur’an and the Sunnah of the prophet Muhammad (Peace be upon him). The spiritual dimension of health is an essential component of Muslim health beliefs and Muslims are obligated to maintain their spiritual health and wellbeing. However, death is a natural and inevitable phenomenon, so illness, distress, and dying are life processes, and Muslims face them with patience, meditation, and prayer. The family provides physical as well as psychological support (Lovering, 2012), and provides a source of strength, hope and connectedness (de Pentheny O'Kelly et al., 2011) particularly during the end of life care.

In this context, caring for a patient has a strong cultural and religious dimension because caring is regarded as a divine duty, most especially caring for parents or spouse. As a result of that, family carers took over the nursing responsibilities and delivered care to their loved ones, while most of the nurses considered it as a form of relief. Similarly, findings from the study show that there were factors perceived by the family carers as barriers to good end-of-life care, and these include financial problems, ignorance about care, language barrier, and lack of care support.

Care by both nurses and family carers (collaborative care)

There were certain aspects of patient care where both nurses and patients jointly performed such tasks, for example when feeding patients via NG-tube, the nurses usually asked the family carers to prepare the food for the nurses to serve. When administering drugs, sometimes the nurses handed the pill to the family carers to give the patients. There were many aspects of care in which the nurses asked the family carers to assist in delivering care. During my observation, I found out that collaborative care was the best because the family carers felt that they were involved in the care. The family carers were highly

enthusiastic about carrying out whatever tasks were required for their loved ones to get well, while the nurses felt a sense of relief from their workload as they carried out their responsibilities.

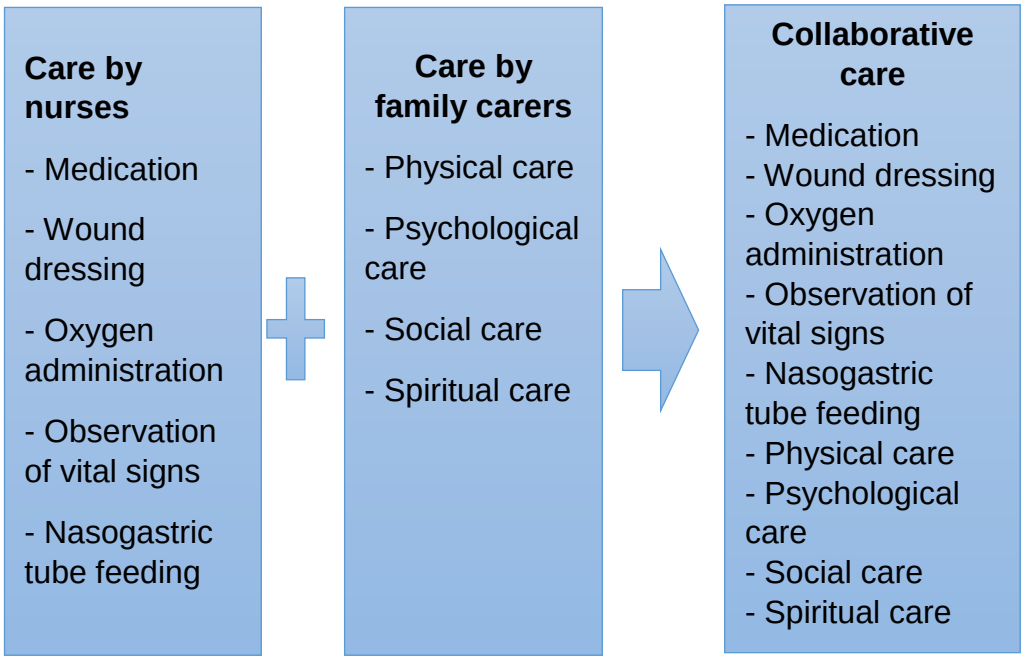


Figure 9: Nurses-Family carers care model

5.6 Chapter summary

This chapter highlights caring roles from the perspectives of the nurses, other healthcare professionals, and the family carers. It details the processes of delivering both fundamental and routine nursing care, highlighting how nurses deal with patients' records, response to calls and how they attend to patients' needs. Both patients and family carers expressed their views about these issues either positively or negatively. However, the chapter also focused on some of the reasons why family carers were involved in the care of their loved ones, even though the care was delivered in a hospital, not at home. Finally, the chapter presented a nurses-family carers care model describing care in three parts: care by nurses, care by family carers and care by both nurses and family carers (collaborative care). Islamic perspectives on sickness and caring roles were also discussed, because caring is regarded as a divine duty, most especially caring for parents or spouse. In the next

chapter, findings related to experiences and feelings about care amongst nurses, patients, and their family carers are presented.

CHAPTER SIX: EXPERIENCES AND FEELINGS ABOUT CARE

6.0 Introduction

This chapter presents the findings in relation to experiences and feelings about care amongst nurses, patients, and their family carers. The chapter also describes nurses' and family carers' feelings about dying patients, nurses' workload and stress. It further explores participants' views regarding nursing the dying patient separately and their level of satisfaction with care. Finally, the chapter demonstrates how nurses recognise a dying patient and dying with dignity.

Experience in this context refers to the occurrences and incidents related to real-life events that happen when nurses and family carers provide care to patients. While feelings are the notions or perceptions of what the care entails and are highly subjective and not always accurate.

6.1 Care experiences

This section highlights the experiences of delivering care to patients by nurses and family carers and the patients' experiences of receiving care.

6.1.1 Nurses' experiences

Nurses have diverse experiences when caring for patients at the end of life, ranging from some degree of discomfort to emotional distress and feelings of fulfilment. When a patient's condition was deteriorating nurses experienced distress and felt that they required more support to care for such patients, but when they are powerless, they showed a variety of emotions such as anger, frustration, guilt, resentment or sorrow. These situations are reflected in the following examples:

> *"Mhmm, various experiences, there was a patient during my previous night shift, the patient was dying actually. We checked the oxygen saturation which was low (68%), so we commenced oxygen administration immediately, the Spo^2 increased to 93-94 after we started the oxygen, but despite that the patient was still gasping, and we sent for the doctors, and they came. CPR was done every effort was made to resuscitate the*

patient despite the oxygen therapy, at the end of the day the patient died." (Case 10 –N)

"It is devastating because at times you may end up alone during a shift or two of you, with so many patients to take care of, so you will not find it easy even though we prioritize our care just like the case of triage. The patients that are seriously ill are given more attention." (Case 12 - N)

"I had good experiences of caring for patients who are dying. I was able to attend to them on time and institute resuscitative measures and was able to revive the patient. But for the one that did not have prompt attention we lost him." (Case 9 – N)

Some of the nurses described patient care at the end of life as highly demanding, involving working round the clock and requiring a biopsychosocial approach – a systematic approach to complex interactions involving biological, psychological, and social factors in delivering care. There are feelings of inadequacy when the nurses are helpless and unable to carry out their tasks particularly when caring for the dying patient.

"The care is both physical and mental. Physically, we take care of patients as if he/she is not dying, because you will not tell a patient that he/she is dying, so all the physical needs like bed bathing, giving out drugs and meals and ensuring that the environment is clean. For example, if a patient needs oxygen you have to give because you cannot say he/she is dying so I won't give it." (Case 11 – N)

"This is a patient who is not able to do anything, confined to bed, so we make sure we do everything for the patient. Even if the patient's relative is there, as a nurse there are some things you will do to back up your profession." (Case 13 – N)

"My experience of care is not easy especially turning the heavy patients and washing them, sometimes if you finish they mess up the place and you start cleaning all over again. Nursing work is not easy I don't like to see patient dying during my shift, is not a good experience. At times you want to use oxygen, but the cylinder is leaking." (Case 4- N)

Nurses providing care at the end of life are often faced with numerous conflicting situations when they perceived that the plan of care has shifted to preparing the patient for death. One of the nurses said that sometimes the patients throw questions at them which are difficult to answer:

> *"My experience of the care of patients who are dying is that some of the patients do not believe that they are going to die from their disease condition, they always ask questions that the nurse cannot answer, e.g., Nurse, can I survive this condition? I also noticed that dying patients tend to be very aggressive, so as a nurse I have to be very careful in taking care of them." (Case 5 – N)*

> *"The most annoying thing is when a patient dies, and he/she owes money to the hospital, he must pay that money. Put yourself in that position is it the pain of the death or what they are owing? The hospital policy is that a body should not be left for more than an hour in the ward, and we have different religious beliefs, Muslims doesn't want their body to be taken to the mortuary, they usually bury the body immediately. While Christians leave their bodies in the mortuary for two to three months." (Case 12 – N)*

The nurses described their experiences of delivering care to patients at the end of life with various responses. For example, one of the nurses (Case 12 –N) considered it as devastating despite prioritising the care. According to the nurse, there were many patients to attend to, but due to the shortage of the nurses, they end up having one or two nurses per shift making the entire process complex. Another nurse (Case 11 – N) said care entails all aspects of patient care such as physical, emotional and social care.

6.1.1.1 Workload and stress

Nurses and family carers recognised that high workload was significantly contributing to their stress. This pressure is what often resulted in nurses losing a sense of control and certainty. Nurses said that caring for dying patients was quite stressful and required working round the clock, but sometimes their hands were tied due to inadequate staff and equipment:

> *"You know it is time and energy consuming, by the time you finished nursing such patients you are fatigued even morally because you know that patient will not recover except a miracle happens. Nursing the dying patient is not easy, the relations are there standing and crying which will even make someone emotionally disturbed. You get burnout easily because you are on your feet constantly taking care of such patients." (Case 8 – N)*

> *"Sometimes it can be stressful, the burnout, there was a time I was on night duty we lost three patients because our hands are tied down, we don't have the equipment and the technology to asses our patients." (Case 9 – N)*

> *"The care of dying patient is a burden to the nurse, not only the nurse but also other care providers." (Case 3 – N)*

> *"It is extremely stressful, round the clock." (Case 5 – N)*

On one occasion, a family carer came and called a nurse to attend to the patient while feeding another patient; she completed the feeding and left, she then returned after 10 minutes and then gave the patients his drugs. While she was giving the drugs, another family carer informed the nurse that her attention is needed to check an intravenous line that had stopped running. Some of the family carers acknowledged the nurses' workload and their level of stress:

> *"Some of them came frowning I don't know maybe they are not happy with the job or something. But now let me say I am getting used to it, and I'm getting to understand that is the workload that is making them angry." (Case 3 – FC)*

> *"The work is too much for them." (Case 2 – FC)*

> *"Sincerely speaking from all indication there is inadequate staff. I don't blame them sometimes because at times in a shift you see two nurses for many patients." (Case 7 – FC)*

The level of the workload on the wards affected the output of the nurses which significantly affected the quality of care delivered to patients. One of the family carers (Case 3- FC) said some of the nurses appeared gloomy when delivering care, which may have been due to stress, or they are unhappy with the working conditions. When nurses are stressed or when they were not happy with their working conditions, it

means the outcome will be a poor quality of care and patients are at the receiving end.

6.1.2 Family carers' experiences

Watching a loved one crying and suffering in pain throughout the night and imagining how that patient felt could be devastating for family carers, especially when someone is experiencing such circumstances for the first time and was not able to help the situation. Caring for patients at the end of life may sometimes be for an extended period, family carers became fatigued and exhausted. One of the family carers (Case 12 - FC) narrated how she spent her first night as a family carer in agony watching her loved one crying in pain and could not help. She informed the nurses that her mother was restless due to pain if they could assist. But to her surprise, one of the nurses responded by saying that every patient is restless. That was how that night passed, the family carer reassuring her mother.

Similarly, Case 11 – FC said a patient might be in severe pain, but the nurses do not bother to check. Another family carer (Case 10 - FC) said things were so difficult for him due to the condition of his mother when the junior doctors were unable to establish an intravenous line for drug administration. He said he had to call one of the doctors (a nephrologist) who rescued the patient from countless needle pricks by inserting the cannula at his first attempt:

> *"I came and met her in this condition, I know the condition is serious, but I didn't cry in order not to break her spirit and discourage those who were around. The whole of that day she was in pain groaning and mourning with pain and each time I called the nurses please my mother is restless, there is pain could you please attend to her and know what is wrong? They dismiss it like is a normal thing. One of the nurses said that every patient is restless that was the response. But anyway, I watched my mother in that condition which was not easy for me. That was the most difficult aspect of caring for my mother since I came. I don't know how to help her, she was crying in pains all through the night, and that was my first night which I had to accompany her in that pain holding her hand and telling*

her sorry in the morning we shall see the doctor." (Case 12 – FC)

"Patient can be in serious pain, but the nurses do not bother to check." (Case 11FC)

"There was time thing was so difficult to me I had to call one doctor that I knew very well (a nephrologist), when he came he didn't give anything he just raised her hand clean with cotton wool and spirit and inserted the cannula, he got the vein. The junior ones had already damaged the other hand and everywhere swelled up, but he just got the vein with one attempt." (Case 10 – FC)

Most of the family carers found caring for patients at the end of life frustrating, challenging, highly demanding, and requiring a lot of sacrifices. Some of the family carers said it has not been easy for them to take care of their loved ones, a carer needs to be tolerant to look after a patient:

"What I will say about the experience here is very hectic, mosquitos are too much. I can't even sleep any time the mosquitos are biting her I will be killing some of them." (Case 10 – FC)

"It is not easy especially in the hospital because where we stay is not comfortable, but we put all those aside and took the challenge and everything you do as long as you have an open mind you have a focus, which is the sound health. Whatever it takes to do I put away the stress and see everything as an easy thing to do." (Case 13 – FC)

"Honestly speaking it has not been easy; you know my father is big and very fat. If I am alone, I find it difficult to change his position, and he hardly controls his anger. You may start hearing him shouting and so on." (Case 5 – FC)

"My experience is not funny because you have to sacrifice, I am a student, I left my school, and I also had to suspend other issues. I haven't taken my bath for the past two days. You will not eat well, you will not sleep well because in the middle of the night they will get up, you have to follow them gradually, and they will say they need this, and they need that. It has not been funny; someone that is impatient will not be able to tolerate these." (Case 8 – FC)

However, some family carers described their caring experiences as a mixture of feelings, some of them considered caring for their loved ones as an obligation, they were happy to do it without any reward from anyone:

> *"So, the experience has been that of pain, fear, anxiety, worry, tensed, fearful, helplessness also because you can't do anything. On the other hand, I have a deep sense of joy and happiness that my religious order allowed me to come and take care of my mother, so for me is a great privilege, for that one I am happy." (Case 12 – FC)*

> *"I did not consider this any difficult responsibility because I regard it as an obligation on me and I need no commendation from anyone." (Case 4 – FC)*

Like many other family carers, Case 12 – FC and Case 4 – FC said they were happy and privileged to care for their loved ones. This situation might be connected with the religious teachings in which caring for the sick is considered to be rewarding, especially for children who care for their parent. That was the reason the family carers tried to remain positive all the time despite the negative experiences.

6.1.3 Patients' experiences of receiving care

It was clear that many patients at the end of life have their needs unmet. Some patients perceived that the doctors were less accessible, and nurses were too busy to provide quality care for them. They were unhappy with the quality of care they received and expressed frustration with healthcare professionals who failed to carry out their tasks. One of the patients (Case 11 – P) described some of the nurses as administrative nurses because they were not doing their work and were only concerned with the ward environment and paperwork. According to the patient, some of the nurses were only charting during their shifts. This means that they paid less attention to the patients' needs but wrote pages about the patients.

Similarly, Case 14 – P said that patients are dying like rats in the hospital just because the doctors and nurses do not have the patients in mind. He narrated an incident were his catheter was blocked by debris

from the urine at 11:30 pm but could not see the doctor on call to change the catheter until 4:00 am. This is one of the reasons that the patients questioned the competencies of the nurses because the hospital policy does not allow nurses to insert or remove a catheter. Ideally, this should not happen because nurses are taught catheterisation during their training. Another patient (Case 7 - P) said he had his drugs with him which he gave himself without the knowledge of the nurses. He said both nurses and doctors didn't care for him, and they only practised on him while students asked unnecessary questions:

> *"Yes, I have good and bad experiences. Most of the nurses nowadays are not fully nurses; most often they are administrative nurses because they are not doing their work. Few of them are doing their work, some can only chart, make noise, make the bed, in reality, the nursing system is poor because there is no practical care but only documenting, everything is documenting. They can write from night to morning, but the practical care is not there." (Case 11 – P)*

> *"So the issue is that both nurses and doctors don't have the patients in their minds, why won't people die like rats. There was a time when my catheter got blocked as a result of debris in the urine, and all that I needed was the catheter to be changed at around 11:30 pm, 12:00 am, 1:00 am and 1:30 am. Do you know the house officer that was on call, do you know that he was only sleeping I didn't get to see him until around 3:30 – 4:00 am. What kind of doctors are we training"? (Case 14 – P)*

> *"I have my drugs where are they when I am taking the drugs? They don't care about you, and they only do their practice on you. The doctors don't care about you, and students will come and ask you silly questions. You can see this tube (pointing at his chest tube) I spent 12 days with it. Is not draining anything, there was a day that the water in the bottle started flowing backward towards my chest, it's only Allah that helped me, someone came and removed the bottle and threw away the content. If it had succeeded in getting into to my body, I would have died by now." (Case 7 – P)*

Although some patients expressed dismay about the care they received, some of the patients said they experienced good care from the nurses. However, one of the patients who had received adequate care was said to be a relation of one of the senior nurses in the hospital.

> *"They are doing their work regularly. They always serve us drug at regular times. At least they are doing their best." (Case 12 – P)*
>
> *"They used to come and check my body, and also come with an instrument for measurement, they used to take care of me very well." (Case 5 – P)*
>
> *"Honestly to be fair, the nursing care has not been bad. The care I received from the nurses is something commendable. I appreciate their efforts toward ensuring that I get all the necessary nursing care, at any given time. Going by the diagnosis and all that, my case is that I need help around me all the time, sometimes when I need to defecate because I use diapers. So, when I do that I call them, and they do the cleaning and all that irrespective of the fact that I am a younger brother to one of the chiefs (a senior nurse) around here, I mean in this facility. But the truth is that I received almost all the necessary care from them." (Case 14 – P)*

One of the patients (Case 14 - P) who happened to be a younger brother to a senior nurse in the hospital reported that he received excellent care from the nurses. The patient was diagnosed with chronic inflammatory demyelinating polyneuropathy (CIDP), a condition that rendered him entirely dependent upon the nurses and family carers for care. The excellent care and full attention he received might be connected with his relationship with a senior nurse in the hospital as mentioned above. So, if this patient perceives to have received the care he needed merely because of his status, it means that other patients could receive the same type of care as he received, except the nurses are biased as perceived by one of the family carers. "I think there is tribalism in their work sometimes you can see them concentrating on one patient, but I don't know maybe it depends on the illness only God knows." (Case 5 - FC)

The hospital environment especially the wards were busy and noisy in most cases with little or no space for privacy. A patient described his experience when another patient came for admission with many family carers occupying the small space within the ward:

> *"A patient having seven people to take care of him. When they came into the ward luckily for them all the patients in that cubicle has been discharged except for one person, so all the seven caregivers took the remaining beds. They all slept on the bed because there were no patients. Why? If everyone would have to come with two, three, seven caregivers how would the ward look like? You understand this goes on and on." (Case 14 – P)*

The goal of nursing care is to ensure that patients and their family carers are adequately cared for, but when death is inevitable, the nurses should try to ensure that the patients die a peaceful death. The way the patients and family carers were managed during the period of stay in the hospital played a significant role in the wellbeing of both the patients and their family carers. Although caring for patients at the end of life is highly demanding and requires dedication, some patients were unhappy about the quality of care they received. They described some of the modern nurses as callous and not committed to their work:

> *"The caring you are talking about nurses is no more, a nurse can shout at you, she is not caring before a nurse can wash you, clean you, change your bed, change your position, but now they are not doing. They are not doing their work. You know, I know, the nurses of those days cleaned you up; they take you to the bathroom and wash you. Then what are they doing? Why are you paying them? I am telling you the nurses are not doing their job. I am telling you they are rubbish, lip service, selfishness, laziness, so this is what I can tell you." (Case 11 – P)*

One of the patients described his encounter with the doctors during a ward round where the junior doctors were not able to describe a simple procedure to be carried on him. He expressed dismay about the situation and said if they could not carry out such a simple task, then what about a more challenging one:

"I am to go through bladder training, and they came around during their ward round, the senior doctor who brought them was asking the house officers how do you do bladder training for a patient? None of them could say anything good. Even the right word for clamping the urine they didn't know. The truth of the matter is that I have a condition called Guillain-Barre Syndrome, CIDP (Chronic inflammatory demyelinating polyneuropathy), so there is this numbness that set from the lower limbs unto the upper limbs. But that is not even the main issue, I want to make a complaint, but even the so-called house officers don't know how to do bladder training. They don't even know the right word for it. So, if a house officer cannot properly address a case of bladder training, do you think he can handle more challenging issues?" (Case 14 – P)

Some patients commended the role played by their family carers, and highly valued and appreciated the care they received from their respective family carers.

"He is giving me food all the time and taking care of my body. He is trying his best." (Case 5 – P)

"He is doing his best, everything I need." (Case 10 – P)

"So lovingly, he baths me, cares for my feeding, washes my clothes, and everything that I need." (Case 13 – P)

Part of the experiences shared by the patients was the kind of care they received from their loved ones. They said their family bathed them, fed them, washed their clothes, in fact, they did everything for them.

6.1.3.1 Availability of nurses

Patients and family carers expressed concern about the inability of the nurses to be with the patients all the time, especially when there was a sudden change in the patient's condition or when the patient was in pain. However, family members and patients said that the nurses were always there at their station, but they didn't usually go to patients unless they were called or when they were administering drugs:

"Yes, at least I have never gone out to look for them. If they are not in their station, they are somewhere around the ward." (Case 12 – FC)

"They are always available at their station." (Case 5 – FC)

“They are always available at the nursing station. They are not there when they are serving medication, they will be around the ward, but anytime if they are not serving medication they are always in their station. They don’t, on an ordinary occasion come and see the patient. They only get up from their station to serve their medication and go back there, if you need their attention you go to their station and call.” (Case 3 – FC)

“No, not always, especially in the night. Before my hand was operated on, it used to hurt me a lot, I will be doing mhm, mhm, mhm or be shouting, but I will not see any of the nurses there to see what is happening to me. Whenever I look, they are not there. But when I shout so loud, and it’s disturbing other patients, they will wake up and come to see me. Let me not put it as sleep because they are on duty, and maybe they are not close by.” (Case 13 – P)

It was observed that there was no framework or pattern to deliver end-of-life care during the study. Although patients were found to be at the end of life, it was established that an organised end-of-life care was not practiced in the setting. The nurses experienced distress and inadequacies and were often faced with numerous conflicting situations when the plan of care was perceived to be shifted from conventional fundamental and routine care to end-of-life care. Therefore, the nurses resorted to carrying out routine tasks and procedures that were quite crude which reflected an organisational gap, and failure on the part of the management to provide a clear pathway for good end-of-life care see Section 8.1.2.

Family carers narrated their experiences of watching a loved one crying and suffering in pain throughout the night and imagining how that patient felt said to be devastating. They experienced fatigue and exhaustion when caring for patients at the end of life for an extended period. They said it was challenging, highly demanding, and required a lot of sacrifices. Because of its connection with religious teachings, caring for the sick is considered to be rewarding. However, the family carers remained positive about the care they delivered despite the negative experiences, while most of the patients experienced

disappointment about the quality of care they received from nurses and other healthcare professionals. However, few patients and family carers said they had a positive experience. Among these patients was a brother to a senior nursing sister in the hospital (Case 14 – P), while other patients (Case 5 – P, Case 12 – P, and Case 13 - P) with positive experiences were those without knowledge about nursing care.

6.2 Feelings about care

This section describes the patients' and family carers' feelings about the standard of care delivered by nurses and other healthcare professionals, and the level of satisfaction about the care. It also examines the nurses and family carers' views with regards to separating patients who are dying and recognising the dying, as well as dying with dignity.

6.2.1 Patients feelings about care

Although patients expressed negative feelings about the care they received from the nurses, some of them considered the problem to be beyond the nurses' control. The hospital management was not doing enough to provide an enabling environment for the nurses to put in their best, and this means if the nurses were given the opportunity they would have done far better as mentioned by one of the patients (Case 14 – P) during the interview. Another patient (Case 11 - P) said lack of seriousness from the Chief Medical Director (CMD) resulted in the poor quality of care delivered by the nurses and other healthcare professionals. He added that if the CMD was serious everyone in the hospital would be serious in carrying out their responsibilities:

> *"The nurses would have done far better if the entire hospital management puts what is supposed to be in place. They have so many cases that they have to attend like mine and even those worse than mine. If the necessary things that are needed are in place, I am sure the nurses will do better." (Case 14 – P)*

> *"When you have the zeal to do your job, you will do it, but if you don't have the zeal, you will not do it. On the other side, this man, this my friend (Chief Medical Director) is killing the hospital. No nurses, doctors are*

not serious, nurses are not serious, and no one is serious because he is not serious too. Because whenever you are serious in your house, everyone will be serious." (Case 11 – P)

"It is only the nurses, and the house officers are left to battle with lives, so what do house officers know? I am only giving you an example. If a simple matter, a simple case cannot be given the right decision by a house officer then how much more of those problems that are bigger when he is being confronted with, how does he manage them?" (Case 14 – P)

Most patients expressed negative feelings about the care they received. They attributed the problems mainly to the bureaucratic nature of hospital policies and poor managerial processes in the hospital. For example, one of the patients lamented restrictions that prevented nurses from carrying out some tasks even though they were competent to do them.

6.2.2 Family carers' feelings about care

Family carers are significantly affected when their loved ones are admitted to a hospital, caring for a patient at the end of life can impose significant burdens on them. Most family carers in this study expressed negative feelings about the care provided by healthcare professionals, especially nurses. They felt that neither nurses nor doctors were up to the task of providing the care required by patients:

"On my knowledge, I feel that if the senior doctors, the qualified ones will be coming to see her every day, since they admitted her they have not come. They left her in the hands of these young ones that are using her for their practice damaging some of her veins as you can see all over her hands. At least if the adult ones can come, her condition is critical we need the attention of the main consultants to come and see her, let the pains of inserting the needles be reduced, attend to her and prescribe more things needed or examine her to find out her main problem." (Case 10 – FC)

"The nurses hardly spend two minutes with patients but can write for 30 minutes about the patient. They only come for medication, and they never change the patient's position." (Case 11 – FC)

> *"It doesn't go well to the caregiver when a doctor comes and tells you what the other doctor did is null, how do you feel yourself? Your hope is your loved one to gain health, but this makes you lose confidence in the medics themselves it is like they don't know what they are doing." (Case 12 – FC)*

One of the family carers had a different opinion about how he felt about the care his loved one was receiving. He said he was satisfied with the work the nurses were doing because of the number of patients in relation to the number of nurses:

> *"Ordinarily most of the care if we said we are to put it upon the nurses, I think it will be too much for them. How many patients and how many nurses do we have, we appreciate the level of work they are doing. On a lay man's aspect, I have no grudges I am satisfied with what they are doing." (Case 13 – FC)*

6.2.2.1 Level of satisfaction about care

Family carers play an important role in end-of-life care, and they frequently linked their level of satisfaction with the ability of healthcare professionals – mainly the nurses – to provide high-quality end-of-life care. Some family carers expressed dissatisfaction especially in the area of pain relief and other complex procedures involving doctors. For example, Case 10 – FC described how he was angry with the nurses and other healthcare professionals because he bought a drug for his mother, but they were unable to administer it at the right time, and she was left screaming in pain. While on the part of Case 11 – FC, she expressed her dissatisfaction with the manner in which the nurses gave more emphasis to making payment instead of saving patients' lives. She gave an instance where a patient needs oxygen but could not have it until the family carer went to the cash office paid the money for the oxygen and brought a receipt before the patient had the oxygen administered:

> *"The injection they supposed to give her at 10 am, but it was giving to her at 2:00 pm due to their inability to get the vein. I said "haba"[12] how can I afford money to buy the drug, but they abandoned her screaming passing*

[12] An expression of feeling disturbed

through pains, so that was the time I was angry. I told them if it is beyond their knowledge they should look for the one above to assist rather than allowing her to stay like this." (Case 10 – FC)

"Their priority in this hospital is making payment, even if the patient is dying. For example, if a patient that is in need of oxygen, the relative is asked to go and pay, bring the receipt and then have the oxygen in situ. Patient buys what he needs in this hospital. If one is to compare what is done to a patient and his record, two parallel things will be seen." (Case 11 – FC)

"Sincerely speaking we are just managing, except two nurses I told you earlier. I was satisfied with what happened the previous shift, but apart from that there is a problem." (Case 4 – FC)

The feeling of dissatisfaction expressed by some of the family carers was due to their negative feelings about the care received by their loved ones. One of the family carers noted with concern the junior doctors' lack of knowledge and skills to provide the needed care to his mother.

Despite the discontent expressed by family carers, many of them showed some level of satisfaction, acknowledging what the nurses were going through, especially when numbers of nurses were compared to numbers of patients in the wards:

"Yes! To Allah be the glory, they are always there for us despite some challenges which are common in these types of situation. The nurses are trying as you can see when you compare the number of nurses with the number of patients." (Case 1 – FC)

"It's not something to describe as long as we don't have any case to report that you are neglected, so I say everything is quite normal. That is why I am satisfied with every aspect. But had it been there is any reason to question anybody's activity and that this is wrong." (Case 13 – FC)

"I am satisfied with their work most especially the nurses. For the doctors, I will say I am satisfied a little because if you complain to the doctors, they only answer you, but you understand that their mind is not with you." (Case 5 – FC)

Some of the patients were satisfied with the level of care they received from the nurses especially when compared with the amount of the work they were doing:

> *"Yes, I am satisfied, because I observed that the work is too much for them, and they are only a few. There is so much work on so many patients, but only two nurses are involved in the care." (Case 10 – P)*

> *"Yes, they are trying, they check your BP and serve drugs. I didn't see anything wrong in their work. That is for me I don't know about others." (Case 12 – P)*

There were mixed feelings from both patients and family carers regarding their level of satisfaction about the care delivered by the nurses. The majority of them were not satisfied with the care as described above, while only a few of them were happy about the care.

6.2.3 Feelings about dying patients

Death is a natural phenomenon that often has emotional and psychological implications for both nurses and family carers. Nurses felt that caring for patients at the end of life was frustrating and heartbreaking, especially when the patient dies. The attitude of nurses toward death and dying has a significant influence on caring for patients who are dying. The feelings of nurses can be perceived in the following statements:

> *"I used to put myself in their shoes, I have the thought that one day I may end up like this, and certainly one must die. I feel for them, with that condition they can't do anything everything has to be done for them, you know the patient may not come out from that condition." (Case 5 – N)*

> *"When you try all possible best to manage patient but no improvement you feel bad. Our aim is not to lose the patient, but to assist the patient to be well." (Case 7 – N)*

> *"Well it is not encouraging, you are trying to do your best for the patient, but your patient is not getting the best in you because the hospital is constrained, and the patients lack enough finance, so we have mixed feelings. I am not happy about it." (Case 9 – N)*

> *"I feel terrible when my patients are dying because I feel all my interventions and nursing care are in vain. I feel so bad I feel as if I could have a soul to give to them or perform a miracle. When you see your patient dying, you will be demoralized. That little courage needs to be given to you because it is not only the relatives that are losing that patient. The nurses see it as if they haven't done enough and that kills our spirit." (Case 3 – N)*

Nurses are usually the ones who are always with patients and their family carers at this time, and therefore are more exposed to an emotional imbalance caused by the death of the patient. Some nurses expressed feelings of dissatisfaction when they were unable to provide the desired care to the patient. All the nurses said they had the feelings of empathy toward the family carers when they lost their loved ones.

6.2.4 Nursing the dying patient separately

Most nurses and family carers want patients at the end of life to be cared for in separate wards because of their particular needs. They always require close monitoring and the presence of loved ones. Therefore, separating them from other patients who are recovering will benefit both patients:

> *"They supposed to give him special room for special care because we are doing everything to him." (Case 5 – FC)*

> *"These dying patients need all the care and attention. They need to be nursed in a separate ward or a separate room with a nurse if you want to achieve your goals." (Case 4- N)*

> *"Caring for those that are dying need close monitoring and putting them in a ward with a capacity of 30 patients they will not have the best care. So they need skilled nurses trained in advanced technology, not just the general nurses." (Case 9 – N)*

However, some nurses were opposed to separating patients at the end of life from other patients, since a patient's condition can change very quickly. They said it means that when the patient entered the last days, they would have to be transferred to an end-of-life care ward for further care:

"It can help, but it is possible even the stable patients to see changes in their condition within the next five minutes, so in that case will they rush the patient to end-of-life care unit to be attended? I had a patient; he was very stable a GIT case (liver cirrhosis) he said, he wants to ease himself, he came down out of bed and used a bedpan, and he was unable to get up again, that was all." (Case 10 –N)

"I don't think they need their ward, because of close monitoring once you isolate them they may not have that. Except they have the nurses that will care for them." (Case 5 – N)

"I don't think that, even patients that are critically ill would like to be with those that are getting better, it will somehow encourage them. Because their care is highly demanding, so it is better to keep them together with other people, it also builds hope." (Case 8 – N)

Some of the nurses believed patients at the end of life should not be separated from other patients. For example, Case 8 – N said that even the patients at the end of life would like to be with those that are getting well to build hope. Another nurse (Case 5 – N), said the patients might not have the necessary time from the nurses for adequate monitoring when separated considering the number of nurses when compared to the patients.

6.2.4.1 Recognising the dying

A variety of perspectives was expressed on how to recognise the dying patient, with nurses mentioning several different clinical manifestations. However, most of them laid more emphasis on a low Glasgow Coma Scale (GCS) score and low oxygen saturation as the most frequent indicators that a patient was dying:

"We check the respiratory level; the rising and falling of the chest will not be too pronounced, and also when eyes are static. There is restlessness and checking the saturation level $SP0^2$ using pulse-oximeter that will give up a clue." (Case 10 –N)

"There are many clinical manifestations like the GCS will read 8/15 and below, changes in breathing, patient unable to talk, cannot swallow, and SPO^2 below 22%." (Case 12 – N)

"For instance, the GCS is very low that the patient cannot respond to pain, sound, and stimuli. The patient cannot eat nor do anything. Even if you take the vital signs they are abnormal, the patient has a hunger for air and does not recognize those around them." (Case 13 – N)

"The patient may be unconscious, may be gasping for air, the eyes will just be open, and he is not looking at you; you know that the patient is going." (Case 5 – N)

The nurses mentioned some of the clinical manifestations based on their experiences that a patient might be dying when those features are apparent. When a patient was observed to have reached this stage, it is essential for the nurses to ensure that the patient dies a dignified death by allowing the family to be closer to the patient.

6.2.4.2 Dying with dignity

The nurses described dying with dignity as good control of both physical and psychological symptoms, intervening in physical distress such as pain and symptom management, spiritual comfort and support, not interrupting the dying process with unreasonable life-supporting activities such as tubes, intravenous fluids, and ventilators. Dying with dignity was also described as being in the company of family and significant others at the end of life, and allowed to make their own choices. The nurses have a common view that even if a patient is going to die there should be some level of comfort so that he/she dies a peaceful death. Also, if nurses were not in a position to change the patient's circumstances, they tried their best to see that patients died with dignity:

"Once is going to die let him die a peaceful death. When a patient is dying is to make him as comfortable, as possible." (Case 1 - N)

"At least we assist him to a peaceful death." (Case 10 – N)

"You do all that you suppose to do so that the patient dies a peaceful death." (Case 4- N)

"Also, I told you about a spiritual leader who will prepare them towards death. We want them to have a peaceful

death that is why we encourage them to have a spiritual person." (Case 9 – N)

"The time that you suppose to use to nurse the patient even if the patient is dying let him die peacefully. They should know that even though a patient is dying, there is a way that the patient can die peacefully, at least to ease the agony of death for the patient and let help the patient die peacefully, is part of our definition isn't it?" (Case 3 – N)

The findings from the study show an expression of mixed feelings about the care, in which the majority of the patients and their family carers expressed negative emotions, while others felt that the nurses could do better if the hospital management provided an enabling environment for the nurses to put in their best. The negative feelings expressed by both family carers and patients were related to lack of provision of institutional end-of-life care pathways by the hospital management. Therefore, the nurses were left to deliver care in an undefined form.

6.3 Chapter summary

This chapter highlights the experiences and feelings of nurses and family carers about the care delivered to patients at the end of life in a general ward. Where the nurse: patient ratio was 1:10-15, this shows the extent of workload and stress faced by the nurses. The nurses in the study said they experienced distress when providing care, especially when a patient's condition was deteriorating and requiring more attention. They described patient care at the end of life as highly demanding, involving working round the clock. The next finding chapter (Chapter Seven) describes communication among nurses, patients, and family carers, their educational needs, and support needs.

CHAPTER SEVEN: COMMUNICATION AMONG PARTICIPANTS, THEIR EDUCATIONAL NEEDS, AND SUPPORT NEEDS

7.0 Introduction

This chapter is comprised of three sections; the first section describes communication among nurses, patients, and family carers as a vital component to the provision of end-of-life care. Patients and family carers described their relationships with the nurses as cordial. Although nurses were not obtaining consent for care, they were praised by some of the patients and family carers for the care they delivered, while others were not happy with the nurses' attitudes toward them. Some of the patients and family carers complained about healthcare professionals withholding information from them. The second section focuses on the educational needs of the participants, creating awareness in family carers and patients, and family carers' ignorance about care. The third section emphasises patients' and family carers' support needs, balancing family carers' jobs and caring, and reassurance of patients and their family carers.

7.1 Communication

This section describes communication among nurses, patients, and family carers, obtaining consent for care, praise the nurses received from the patients and family carers, nurses' attitudes toward family carers, teamwork, and how healthcare professionals withhold information from patients and their family carers.

Excellent communication is central to nursing care, especially when dealing with patients and family carers at the end of life. It is part of the nurses' responsibility to ensure that patients and family carers receive adequate information regarding patient care. Communication among nurses, patients, and family carers was said to be effective according to one of the nurses (Case 6 - N). Who described how she convinced patients' relatives to provide a drug prescribed to their patient, which they initially refused to go and buy the drug saying that plasil is a drug

meant for the treatment of vomiting, while the patient had hiccoughs. However, the nurse explained to them that it could be used for hiccoughs. So that explanation by the nurse persuaded the family carers to provide the drug for the patient which helped to stop the hiccoughs thus relieving the patient from suffering:

> *"I talk to them prepare their mind and tell them about the prognosis. We interact with family carers in the language they understand, explain the condition, the prognosis as I said earlier, and then encourage them. For example, a doctor wrote plasil injection for a patient, and the relatives said the patient doesn't need it. I explained to them that he needs it for the hiccough, they went to the pharmacy and bought it." (Case 6 – N)*

> *"I found some of them are friendly and appropriate; you know human beings are not the same. They may all be nurses, but I guess they go with their temperament and personalities, I am very conscious of that, I can't say all nurses are like this or all nurses are like that." (Case 2 – FC)*

The importance of education and factual information regarding patient care helps patients and family carers to solve their problems, clarifies issues, and relieves them of stress. Professional nursing practice demands that patients are treated with moral worth, and they should be central in making decisions. Most of the nurses and the family carers said that they related well to each other.

On the other hand, there were some negative comments about how the nurses communicated with some of the family carers. Some felt that some of the nurses were rude to them and found it difficult to communicate with them:

> *"Sometimes there are some that are very rude. But some of them are very good, whatever you complain they will listen to you. Some of them is total negligence, if you complain they will ask why you are talking like that." (Case 10 – FC)*

> *"Mhmm… Sometimes I feel like I am disturbing them.*

Like yesterday the oxygen stopped working, I think it has a problem when it stops bubbling you go there and said, nurse, it has stopped. I think it's my responsibility to communicate anything I observed because they are not sitting here with me. I have that reservation that maybe some of them may feel offended when you call for their attention to certain things." (Case 12 – FC)

"There is lack of orientation to the family carers, and whenever a patient or the relation made any mistake, the nurses shout at him." (Case 11 – FC)

Some of the family carers were not happy with the way the nurses treated them. For example, Case 10 – FC, Case 11 – FC and Case 12 – FC did not receive a full explanation of the disease process and treatment modalities of their family members, which could have relieved them from anxiety.

7.1.1 Relationships among nurses, patients, and family carers

Nurses interact with many individuals who have different values and experiences such as patients, family carers, other healthcare professionals, and even among themselves. It is essential for nurses to establish rapport with patients and their families. However, this was not the case in most of the situations in this study. Typical examples were presented in section 5.1.12 (See field notes 1a and 1b). There were mixed feelings regarding the relationships between family carers and nurses. Family carers described their relationships with some of the nurses as hostile:

"You know how life is, different people with different character. Sometimes if he is in need of something from them we do go and inform the nurses. Especially when his condition changes, some of them answer us while others shout at us that we are disturbing them too much. I usually tell them if I didn't tell you whom should I tell?" (Case 7 – FC)

"I was trying to inform the nurses and those doing houseman-ship, but they were throwing some bad words to me. She even missed some of her medication because they couldn't get a vein." (Case 10 – FC)

However, some of the nurses indicated that their relationships with the family carers were cordial, they related well to them without any

problems. This can be seen from the statements below:

> *"Well, as for me in person, I relate with my patients' relatives, I crack jokes with them. So that I can break that barrier that makes them feel that as if they are communicating with visitors, I try to be friendly with them, I pull them so that they could feel free with us and respond to me when in need of assistance and get things done to my patient. From the period of admission, if you create that rapport and you build on the rapport till the time the patient becomes seriously ill, it will not be difficult as such for you to control the patient's relation's attitude towards their dying patient." (Case 3 – N)*

> *"We relate with them gently because it is not easy to lose somebody. We easily relate with the family carers because we nurses also have relatives and we know how it feels for someone who lost his relative. Even though some may prove to be difficult." (Case 10 –N)*

Relationships among nurses, patients, and family carers were cordial most of the time. It only turned sour when the nurses were under stress, and the patients or family carers proved to be difficult. However, the nurses always showed some level of professionalism in such situations.

7.1.2 Obtaining consent for care

Before carrying out a nursing task on a patient, it is expected that nurses should inform the patient about the procedure. Following the provision of adequate information, the nurse should then obtain consent from the patient. However, some of the family carers said that most of the nurses carried out their tasks without prior information or obtaining consent from the patients. The family carers were asked whether nurses informed them before carrying out their procedures, they answered as follows:

> *"No, they don't inform you, but I trust they are doing the right thing. Although, there was a time when some of the drugs were cancelled, by chance I heard them discussing. Because of that, one of them came asking for a drug this morning, so I was able to let her know it has been discontinued. But she looked at the paper, and it has been cancelled. That communication helped her. But many times, they don't explain to you what they are doing." (Case 12 – FC)*

"They don't explain to us, they only ask us to bring the thermometer, and they come with BP apparatus." (Case 7 – FC)

"No, they don't. When they come to administer a drug, they will ask me to bring the drug and give it." (Case 8 – FC)

Similarly, during one of the observations a nurse observed the patient's vital signs without prior information or obtaining consent from the patients.

The nurse came with the BP apparatus asked the FC for a thermometer and observe patient's vital signs. There was no explanation before and after the procedure, and she left. (Case 2 – O)

It is the responsibility of nurses to explain to a patient and seek his/her consent for whatever they want to do, at the same time it is the patient's right to know what is going to be done to him/her. But that was not the case with those nurses identified by some of the family carers (Case 7 – FC and Case 8 - FC) who didn't explain procedures to them or patients when they are carrying them out. This was confirmed during my observations (Case 2 - O).

7.1.3 Nurses' attitudes toward family carers

One of the family carers described the attitudes of some of the nurses toward them as positive, although some are better than the others:

"The nurses are trying their best, but some of them are better than the others. There are some that don't allow me to touch the mess up from my mother, they do the necessary cleaning, and I assist them to hold her. There are some that are caring." (Case 10 – FC)

However, most of the family carers talked about the negative attitudes of the nurses towards them. For example:

"I don't think I utter bad words to any of them, but they are always eager to talk back at you whenever you asked them." (Case 3 – FC)

"There was a time I went to call a nurse, but he told me it is not the time of his work." (Case 4 – FC)

> *"You see the look from the face that I am disturbing them, but I have to do that communication." (Case 12 – FC)*

One of the family carers (Case 13 - FC) described how the nurses were eager to answer them with a negative response because most often the nurses were tense and stressed due to their workload. This was what usually resulted in conflicts between the nurses and the family carers.

However, some of the nurses said that their attitudes toward family carers depended upon the situation and the level of their stress. They said the family carers are not their primary concern, and sometimes they proved to be difficult by refusing simple instructions given to them by the nurses:

> *"It is the patient that is the first point of call, and sometimes relatives add extra stress to you. You are managing the patient you are managing them. As a nurse, you are all-around you don't expect to smile after much stress. What provokes hostility is where patient's relation is not ready to agree with you or to even follow simple rules of the hospital, you keep talking over and over because the relatives don't see the way you see things." (Case 8 – N)*

> *"At times many visitors want to see their patient at odd hours which affects patients' wellbeing especially those with high BP or stroke. The patient may not have enough time to rest, but the relations will not see it that way, so they misinterpreted your action for hostility." (Case 8 – N)*

> *"The relations have their grievances with the nurses, and I remember the time when I was on night duty a relation came to me and said he wasn't happy with the way my colleague talks about his brother's sickness." (Case 9 – N)*

The nurse is expected to handle both patients and their relatives with compassion, although one of the nurses (Case 8 - N) said relations are not their priority which ideally is not supposed to be the case. Relatives form an integral part of patients' care because they contribute immensely to patients' wellbeing. Therefore, nurses need to acknowledge this contribution and support relatives.

7.1.4 Withholding information

The provision of adequate information to both patients and their family carers during end-of-life care reduces anxiety and distress. Withholding information is a common phenomenon among healthcare professionals. Some of the nurses indicated that they didn't discuss patients' conditions with them or with their relatives, most often they referred the case to the doctors. While some of the nurses assumed that family carers noticed changes in their patients, so they only require reassurance:

> *"Some patient's relatives come and ask, but I use to tell them it is their doctor that is responsible for that, some will say that their doctor did not inform them anything. So, if I discussed with the nurse-in-charge and I have the go-ahead I tell them." (Case 10 –N)*

> *"You know a patient's diagnosis is confidential, and we don't normally tell them unless otherwise." (Case 12 – N)*

> *"We leave that for the doctors to do. Because they are the one licensed to tell the patient their diagnosis and the prognosis. But sometimes if the patient's condition goes out of the way, the relations still come to us as nurses to ask. There is that fear I may lose the patient, but we try not to show the fear on our face, so we smile and give hope to both patient and relations." (Case 8 – N)*

Most of the family carers confirmed that they were not informed about the condition of their patients, some of the family carers got to know their patient's problems only by overhearing doctors' discussions or from the drugs prescribed. While others were based on their observations of patients' physical condition:

> *"We only know that he has a stroke because it is a physical illness and he has diabetes, they usually give us prescriptions to buy this and that." (Case 4 – FC)*

> *"I heard a bit of what the doctors were discussing." (Case 12 – FC)*

> *"Yes, we were told by the doctor that he has a liver disease." (Case 7 – FC)*

> *"She undergoes dialysis 38 times, none of them explain to me about her condition. They are telling me to keep on praying, God will see her through." (Case 10 – FC)*
>
> *"I was not told about my diagnosis up till now." (Case 10 – P)*

One of my observations confirmed that even the doctors withhold information from their patients and family carers unless they seek explanations of the patient's condition from the doctors. Patients and their family carers at times are uncertain about the care or the procedure carried out on the patients, and this could be distressing. This inadequate information generates tension and anxiety for both patients and their family carers because there is that fear of unknown circumstances. Therefore, a simple explanation for someone who is ignorant about a situation especially when it involves caring for a loved one at the end of life could relieve tension and anxiety:

> *A doctor from the oncology team visited the patient to find out about the review by the neurosurgeons, the doctor went through the patient's case notes, jotted some things down and left without any explanation to the patient and the family carer. I asked the family carer, and she said that is how they are working unless they seek for an explanation, otherwise they will not tell them what they intend doing, or when it involves spending money that is when they involve them. (Case 3 – O)*

7.2 Nurses, patients, and family carers educational needs

This section describes the situations of nurses, patients, and family carers regarding educational needs, family carers' lack of knowledge about care, and the nurses' effort to educate the family carers. All the family carers showed an interest in educational needs especially about the management of their patients' conditions and preventive measures:

> *"For instance, they started by telling my mother she has diabetes and she needs a special diet. So I need education about this, many times they watch us." (Case 12 – FC)*

> *"They came and told me that I should not be giving her some food especially much of carbohydrates, I should not allow her to get hungry, and I should be exercising her limbs, but they didn't tell me the reasons." (Case 8 – FC)*

On the other hand, nurses expressed their concern about the needs to update their knowledge and skills through regular seminars, workshops, and conferences. Some of the junior nurses blamed the senior ones for not allowing them to attend seminars and workshops. They said it was quite difficult for them to go back to school because of the bureaucratic processes in the hospital. Some of the nurses attributed their inability to further their education or update their knowledge to a shortage of nurses. However, they all agreed on the importance of knowledge updates:

> *"Education is critical, in some institutions because of the shortage of staff they don't send nurses to school. This affects both nurses and the patients." (Case 13 – N)*

> *"We need to be doing seminars and workshop to improve our knowledge to take care of the patient. You know our seniors don't allow us to go for seminars, they are the one going." (Case 5 – N)*

> *"If we could be sponsored for palliative and end-of-life care courses, even workshops or seminars on palliative care will be helpful, since we care for these patients daily. Training in that aspect will surely benefit both the nurses and the patients." (Case 8 – N)*

7.2.1 Family carers' ignorance about care

Some of the family carers were not aware that bathing patients was one of the nurses' responsibilities, so they took it upon themselves and made patients' physical care part of their routine. Therefore, they didn't even wait for or contact the nurses about that. This was confirmed by the statement made by some of the family carers and a patient below:

> *"When I came, I met my younger sister doing it, and I asked her do we call the nurses to do these she said no we are the one to clean her. So I never ask the nurses to come and clean. Okay, but it is good to know that is their work. All of them knew her condition but none of them ever come to say I will clean her, and I say no I will do it. I never make any move because my sister told me is our responsibility. But I am happy to do it because*

she is my mother." (Case 12 – FC)

"Maybe they are playing on our ignorance because we thought it was our responsibility. Maybe if we were told it was the nurses' responsibility to do this, it wouldn't have happened." (Case 13 – FC)

"I don't know why, maybe is because there is someone around me doing what they are supposed to do, I believe if I am alone they will do it." (Case 13 – P)

7.2.2 Creating awareness

The nurses try their best to explain to the family carers the general rules and regulations regarding living on the ward from time to time usually during ward meetings:

"The nurses on most occasions have been calling us for a meeting in the morning. The matter remains the same because we the relatives have not been obeying, especially when using the toilets. Some of us are frustrating the system." (Case 13 – FC)

The family carer was called to join other family carers for a health talk by the nurses on some of the issues relating to ward sanitation, visitation, payment of hospital bills and other issues related to patients' wellbeing. (Case 6 – O)

The nurses described how they educated patients and their family carers, but they expressed concern over the difficulties they faced when explaining certain issues to family carers.

"So you have to take another time to educate them. But you now divert the time talking to patients' relatives trying to convince them over something that they are not well clear about it. They need health education so that they will not see patient on oxygen and conclude that the patient is going." (Case 3 – N)

"I have a patient in the side room the BP kept elevating because he doesn't take his drugs as prescribed. I told him that was the reason the BP was not coming down. I explained to him the benefit of taking all the drugs and encouraged him." (Case 6 – N)

It is the nurses' responsibility to ensure that patients take their drugs when they are administered, but most often the nurses give the drugs to family carers to give to the patients.

7.3 Patients and family carers support needs

This section describes patients' and family carers' support needs regarding physical, emotional, financial, and spiritual needs. It also explains what some of the patients were expecting regarding care, and issues relating to patient privacy. Further concerns addressed by the section include family carers' disappointment about care support, pondering between hope and despair, balancing family carers' jobs and caring, and reassurance.

7.3.1 Patient and family carers' needs

Patients' and family carers' needs include physical, emotional, financial and spiritual needs. For financial needs, the nurses did almost nothing but refer them to the social welfare department, because some patients' conditions are financially demanding. Spiritually sometimes an Imam or a priest was invited to come and talk to the patients and the relations. They needed much more of nurses' attention at that time.

> *"The need of the patient is to receive appropriate treatment and care. We make sure they have their drugs, they are well fed and make sure that their personal hygiene is duly cared for, like oral care, bed bath, etc." (Case 11 – N)*

> *"If a patient comes into the ward and is not able to provide some of the needs, we have the welfare unit in the hospital we can contact them if they can provide one or two things that the patient needs." (Case 13 – N)*

> *"My father is unconscious cannot even raise his hand, cannot wipe his mouth, he is fed with the aid of NG tube, and his position is to be changed every 3 hours." (Case 1 – FC)*

Some of the family carers described the severity of the patients' conditions and how their needs were not met. Apart from the routine nursing care that is common for every patient, the severity of patients' conditions determined the kind of fundamental nursing care they received.

7.3.1.1 Patient expectation

It is part of the nursing task to ensure that patients are comfortable all the time and it is expected that nurses should be able to assess the condition of their patients. However, one of the patients expressed concern that nurses were not meeting their expectations while they were on duty:

> *"What I expect is that the nurses should not wait until the patient need their attention before they come to see him, especially the one in pains or the new patients. They should always go round and ask the patients if there is any problem because some may feel reluctant, may be afraid to call them or may be far from where they can hear their voice. So, I expect them to move around like an examiner supervising a student." (Case 13 – P)*

The patient observed that the nurses were always at their station instead of moving around to check the patients' condition. There were several instances where patients were in a serious need of assistance the family carers were not around, and the nurses were there sitting at their station. The nurses were reluctant to check on the patients because of the presence of the family carers by the patients' bedsides, forgetting that sometimes the family carers also have their individual needs or they may have gone out to get some drugs or food for the patients.

7.3.1.2 Patients' privacy

Providing privacy is essential when caring for patients and is regarded as an aspect of dignity in the care of patients at the end of life. Unfortunately, the wards have only one or two screens that are not really in good condition. Therefore, patients had to wait for others to finish using the screen before they were able to use it. I observed that none of the wards had more than two screens, and none of the screens were in good condition. One of the wards (Male medical ward A) had only one screen.

Family carers waited their turn to get the screen for their patients which made it difficult to provide privacy for patients. It was also observed that a family carer (Case 6 - O) delayed physical care to her loved one due

to lack of enough screens to provide privacy for the patient. The family carer needed both screens to provide adequate privacy for the patient. Therefore, she had to queue up and wait for others to finish using the screens.

Sometimes even healthcare professionals had to wait for the screen to carry out their procedures. It was also observed that there was lack of sufficient bed linen in the wards, patients could spend two or more days without having the bed sheet changed.

> *"There was a time in this ward where a patient is in need of attention that requires the use of screen; the patient has to wait in a queue because what we had was just one screen that would have to go round all the beds when there is a need for use." (Case 14 – P)*

> *"A patient who cannot move from one place to another, like moving from here to the restroom who needed a screen to do whatever he wants to do, or even in a situation where a patient needs to be seen urgently, when he requires a kind of emergency, and a screen is needed a patient will have to wait." (Case 14 – P)*

> *"The screens are not in good condition, and there are only few it is quite difficult to provide privacy for the patient." (Case 11 – FC)*

> *"The family carer went to look for a screen but could not get one because there are only two screens in the ward and they are in use for other patients. The patient could not be cleaned up until one hour thirty minutes later because the family carer had to queue up for the screen." (Case 6 – O)*

7.3.2 Family carers' disappointment with care support

Most of the family carers expressed dismay about some issues regarding the care of the patients. Some of them attributed it to nurses, others to the doctors:

> *"More emphasis is given to their procedures even during exams when they are asked they mention everything, but they don't put it into practice." (Case 3 – FC)*

> *"I think there is tribalism in their work sometimes you can see them concentrating on one patient, but I don't know maybe it depends on the illness only God knows." (Case 5 - FC)*

“There was a time I was angry, and I told them if I had known I would have left her at home instead of bringing her here wasting a lot of money. There isn’t any attention from morning to night only for the nurses to be giving her tablet.” (Case 10 – FC)

The nurses were very much aware of the situation because one of the nurses described the reaction of family carers, saying that sadness could be seen in their faces especially when their loved one was dying. The same situation was apparent during an observation when a family carer expressed his sadness:

“If you look at their faces they are disturbed you don’t know the position of that patient in the family, maybe the breadwinner. By the time they see the condition is changing they will not be happy.” (Case 7 – N)

“The patient supposed to be fed at 10:00 am but could not have his meal until 11:00 am when the nurse came and asked the family carer to prepare the food. I asked the family carer about the patient’s feeding, and he expressed dismay especially the nurses’ delay in feeding the patient which keeps on changing the feeding time.” (Case 1- O)

One of the patients (Case 7 - P) also showed his disappointment with the nurses’ competencies, that some of the nurses only came to ask if the patients had had their medications. The patient said that nurses were not allowed to set up a line for intravenous fluids but had to wait for a doctor even if the patient was in critical condition. This restriction is only present in teaching hospitals and contradicts national guidelines that advocate that nurses are trained and licensed to do this. However, nurses in primary and secondary care hospitals can set up a line for intravenous fluids:

“Nurses? Do they know how to put intravenous line? They only ask if you have had your medication.” (Case 7 – P)

7.3.2.1 Hope

The nurses were full of hope when caring for the patients, and they always tried to encourage the family carers not to lose faith because the

patient may still recover.

> *"I normally tell them not to lose hope, because at time miracles do happen they still come back to life." (Case 4- N)*

> *"We tell them that we nurses only provide care and only God that heals, and death is on everybody is just that our days are different." (Case 10 –N)*

One of the family carers (Case 1 - FC) was hopeful that if the problems they mentioned were addressed, the quality of care their patients were receiving would be improved. Some of the family carers were seen to remain hopeful despite the condition of their patients:

> *"If all these problems could be addressed certainly patients' quality of care will be improved." (Case 1 – FC)*

> *Met the FC sitting down on a chair with his palms on the cheek and elbows on the bed staring at the patient and thinking deeply. I asked him about the patient's condition he said: "We thank God, but the condition remains the same." (Case 3 – O)*

It was a typical response from both the patients and their family carers, whenever they were asked about the patient's condition to say "we thank God." Even if a patient was dying after which other explanations could follow as in Case 3- O. Positive religious coping shows a dependence on faith and finding meaning in illness, while negative religious coping views illness as punishment. Religious beliefs continue to be essential aspects of end-of-life care, forming part of the structural support when death is near.

7.3.2.2 Despair

Despite being hopeful at times, there is a stage at which the patient's condition becomes hopeless for both nurses and family carers. When nurses and family carers noticed that the patient's condition continued to deteriorate without any sign of improvement they began to lose hope. The family carers seem to have lost hope in the following statements:

“But since we came here I have not seen any change, every day the condition is getting worse.” (Case 10– FC)

“Her case seems to be a little bit hopeless, as they (doctors) declared that day.” (Case 12– FC)

“I greeted the family carer and asked about the patient’s condition, and he said the condition remains the same that he begins to lose hope.” (Case 1- O)

One of the major concerns was that most often patients were brought to the hospital in a debilitated condition due to economic hardship, ignorance, and poor health seeking behaviour. Most of them came to the hospital as the last option when they had tried all other means of treatment and failed, and they were expecting a miracle to happen. In some fortunate cases, patients may have recovered. Death is a natural and inevitable phenomenon, so illness, distress, and dying are life processes, and Muslims face them with patience, meditation, and prayer. In Islam, death is to be accepted as the will of Allah and should not be fought against or resisted. It was revealed in the Holy Quran (Q3: 139) “It is not possible for a soul to die except with Allah’s permission at a term set down on record.”

7.3.3 Balancing family carers’ job and caring

Family sustainability depends mostly on the income of its members, and this means of earning is usually affected by hospital admission of a loved one. The challenges of being a family carer are quite enormous as some of the family carers (Case 10 – FC and Case 13 - FC) had to leave their jobs to take care of their loved ones in the hospital. Case 8 – FC was a student who had to leave school and suspend all her activities to be able to look after her mother. In this situation, there are combinations of difficulties, including leaving one’s job, anxiety over caring for the loved one, as well the other challenges arising from the hospital.

“I just abandoned my job for more than three months.” (Case 10 – FC)

“I need to leave my job, and the possibility of me getting it back is very low because I work for an individual. The children are in school, and those that are not in the boarding school are in the care of another person.” (Case 13 – FC)

“I am a student, I left my school, and I also had to suspend other issues.” (Case 8 – FC)

7.3.4 Reassurance

The nurses identified support, coordination, and education as their roles at the end-of-life. Any care provided should be of great benefit to the patient. When advanced care or aggressive treatment was no longer beneficial to the patient, and the nurses perceived that the patient was suffering, then the focus of care was shifted to a comfortable death. Both patients and family carers need to be reassured especially at this critical period:

“Both patients and family carers need to be courageous and more toward their God because nobody knows the end. They should be focused and not to be distracted because of the sickness.” (Case 1 N)

“You have to console them, encourage them, stand by them and reassure them by talking to them and encouraging them.” (Case 4- N)

“So you keep on reassuring them that we are all from God and one day everyone will die. You try to prepare their mind and reassure them for it so that it will not be a shock in case it suddenly happens.” (Case 7 – N)

During one of my observations, I found a patient who had a sleepless night due to severe abdominal pain with a nasogastric tube in situ. He wanted the tube to be removed, but the nurse came and explained to him the need for having the tube in place and reassured him that as soon as his condition improved, she would remove it:

Met patient sitting on the bed said to have had a sleepless night due to severe abdominal pain and wants the NG-tube removed, the nurse explains to him the importance of leaving it in situ. She reassured him and told him it would be removed as soon as his condition improves and the patient was calm. (Case 5 –

O)

7.3 Chapter Summary

This chapter was described in three sections: the first section explained communication among nurses, patients, and family carers, how the nurses performed care without obtaining consent for the care, nurses' attitudes toward family carers, and how healthcare professionals withheld information from patients and their family carers. The second section described the situations of nurses, patients, and family carers regarding educational needs, family carers' ignorance about care, and the nurses' effort to educate the family carers. The third section described patients and family carers support needs regarding physical, emotional, financial, and spiritual needs. It also explained what some of the patients were expecting regarding care, and issues relating to patient privacy. Further concerns addressed by the section included family carers' disappointment about care support, pondering between hope and despair, balancing family carers' jobs and caring, and reassurance. The next finding chapter highlights factors that hinder or facilitate effective end-of-life care.

CHAPTER EIGHT: BARRIERS AND FACILITATORS TO END-OF-LIFE CARE

8.0 Introduction

This chapter illuminates participants' views regarding factors that hinder or facilitate effective end-of-life care. The chapter is comprised of two major sections: the first section explores the barriers to end-of-life care. Throughout the study, the participants highlighted several factors that affected the provision of quality end-of-life care such as problems from the hospital management which included a shortage of nurses, logistical problems, and poor conditions of service, decayed infrastructure, security laxity, and language barriers. While the second section highlights the factors that provided the nurses with additional strength to continue to deliver their care and the perceived factors that can promote end-of-life care such as improvement of drug supply, improvement of staffing level, provision of rewards/incentives and staff training.

8.1 Barriers to end of life care

The nurses said some family carers hinder the delivery of care because they sometimes prove to be difficult. All the participants considered economic factors as contributors to poor end-of-life care. The bureaucratic managerial processes in the hospital, language barrier, and ward challenges were also highlighted as barriers to the provision of good end-of-life care.

The impact of these barriers on the daily lives of the participants was evident not only in the interviews but also during the period of my observations. The second section highlights those factors that strengthen the nurses to continue to deliver care to patients despite the challenges. Most of the nurses described a feeling of fulfilment about care as a factor that motivated them to continue with the care. Finally, the section also focuses on those factors perceived to promote end-of-life care which include: improvement of drug supply, improvement of staffing levels, staff training, and rewards or incentives.

8.1.1 Family Carers

Some of the nurses described family carers as one of the barriers to the provision of good quality end-of-life care. They said that some of the family carers became very aggressive, used offensive words and could even go to the extent of raising a hand to a nurse.

> *"Some patient relatives can even go to the extent of raising a hand to a nurse at work some will just be talking to you somehow because they are losing their loved ones. We do count some of these challenges as happening out of the pain of losing loved ones." (Case 10 –N)*

> *"You put in your best, and the relatives feel that you haven't done anything since they see that their loved one is dying. Sometimes non-cooperation you ask them to buy this and buy that some feel reluctant to go and buy, so you find it difficult in handling the situation." (Case 3 – N)*

> *"Sometimes the relatives become very aggressive they may even want to beat the nurse as if she is the one responsible for patient's condition. But the relatives sometimes you are trying to suction or pass an NG-tube or administer oxygen they may refuse to allow you to do that thinking that, that will even make the patient die." (Case 5 – N)*

8.1.1.1 Economic factors

Due to the low level of earnings by most of the family carers, the cost of drugs and other hospital bills becomes a barrier to the provision of end-of-life care. Financial problems were a major concern among patients and their family carers because healthcare expenses are paid 'out-of-pocket.' All the family carers expressed concern over the high cost of hospital bills even though the government owns the hospital. They said that they spent a lot, but most of the time their expectations were not met.

> *"The money charged per oxygen cylinder is ₦1, 800 (£3.60) and they still brought other bills for two cylinders to us, sometimes you don't have the money on the ground you must go and look for it, at the end you may not get what you want." (Case 4 – FC)*

> *"We are buying drugs almost every day and you know the situation we are in this country, if you don't have*

money in this hospital, you will not be able to stay here. If you want to buy a drug now, you will start hearing thousands unlike before." (Case 5 – FC)

"When they come, they write drugs for us to go and buy, you can see it (pointing to a box containing drugs) that is nine thousand naira (₦9000=£18.00). Well, once you come to the hospital, you only pray for the patient to get well. Yesterday we spent ₦7000 (£14.00) and today ₦9000 (£18.00), two days ago ₦6000 (£12.00). We spent two weeks, and it was only once we bought a drug of ₦700 (£1.20), is just from ₦5000 (£10.00) and above." (Case 6 – FC)

Nurses also confirmed the statements made by family carers regarding the difficulty in dealing with healthcare expenses. Nurses also perceived it as a barrier that affected the quality of care they provided for the patients. Sometimes nurses wanted to administer drugs to patients, but the drugs were not available, or the nurse wanted to carry out a task that required the use of a surgical glove and the patient didn't have one.

"Sometimes lack of finance from the relatives to buy some things to take care of the patient become an obstacle in taking care of the patient." (Case 3 – N)

"At times they exhaust all the money they have, you have to keep encouraging them. There was a time they had no money even to buy a surgical glove was a problem. We used to solicit for them or tell them to write to the social welfare department to help them financially which they normally do." (Case 4- N)

"They pay like N1, 800/cylinder and they can have like 3-4 cylinders a day depending on the severity of the condition. We have patients with end-stage renal failure, and some of them are on dialysis like three times a week. How many of them can afford it except those that are rich." (Case 9 – N)

During one of the observations (Case 1- O), an accounting clerk brought a paper with some amount of money written on it and asked the family carer to go and pay. The accounting clerk told the family carer that they had no money left in their ledger and that they were in debt to the hospital. Therefore, they needed to settle their debt and at the same time top-up for further management. In another observation (Case 5 –

O) a nurse brought a paper and asked the family carer to go and buy a nasogastric tube for his patient.

> *I was sitting with the family carer an account clerk asked the family carer to go and pay some amount of money that they owe the hospital. The FC said that he has no money, he needs to call his people at home. (Case 1- O)*

> *The nurse came with a piece of paper with NG-tube written on it and gave the FC to go and buy. (Case 5 – O)*

8.1.2 Hospital management

Provision of state-of-the-art equipment in any hospital is the sole responsibility of the management and is essential for the quality of care. All the nurses interviewed complained about the inability of the hospital management to provide the required equipment for quality of care. They expressed concern especially when they were caring for a patient at the end of life when most patients need oxygen. One of the nurses (Case 9 - N) said that there was a time when they went around the whole hospital but could not find a cylinder of oxygen. Sometimes a patient had to travel for up to 200km to another hospital for services such as CT scan or dialysis due to a failure of the machines. Another nurse (Case 12 - N) said they had a problem with their allowances, but the hospital management was not doing anything about it.

> *"But the problem we have majorly is lack of resuscitative equipment like oxygen apparatus, for example, four patients were in a terrible situation, but we have only two cylinders the other patients have to be on oxygen concentrator which administer only 21% the patients suffer. Sometimes you have to go round the hospital looking for an oxygen cylinder, or even the gas room where they supply the oxygen you find out that there is no oxygen in the hospital." (Case 9 – N)*

> *"Another issue is allowances for the staff are not being paid." (Case 12 – N)*

> *"Sometimes you will be working, and there is no light, so you have to strain your eyes and to put the patient at risk especially when serving drugs. At times even scan, a patient had to be sent out of the hospital, consider the risk on the roads patient travel more than 200km to do*

CT scan or even dialysis, so all of these has to do with management." (Case 8 – N)

Patients and family carers expressed dismay with regards to how the hospital management handled the affairs of the hospital. They said that there was a failure in the hospital administration due to their incompetence and laid-back attitude. They added that there was nothing in the hospital that is moving as it should, as such the quality of care in the entire hospital had deteriorated.

> *"The hospital management is so compromised and is in a mess, and I am sorry if the Chief Medical Director (CMD) and the director of administration will hear this let them know that people are watching, is only that some of them are keeping quiet. For me is the type that doesn't keep quiet, I feel, I voice out what should be done." (Case 14 – P)*
>
> *"In the area of managing the hospital, honestly speaking if I have to score the management, I will score them below 50. So, it is gross incompetence, and you know, the competence and ability to deliver to take the hospital to the next level is lacking. I am telling you this before God and man all that is left in this hospital is just that name, the glory is gone, because there is nothing to show." (Case 14 – P)*
>
> *"This man, this my friend (CMD) is killing the hospital, no nurses, doctors are not serious, nurses are not serious, nothing is serious because he is not serious too. Whenever you are serious in your house, everyone will be serious. He supposed to be dropped out and get somebody who is interested in the job because he is lazy, he cannot push." (Case 11 - P)*

The above statements were made by two of the patients (Case 14 – P and Case 11 - P) who had a similar diagnosis (Guillain-Barré syndrome), these patients were physically dependent but mentally and intellectually sound. Therefore, they were able to observe and give their views on the situations in the hospital. For example, Case 14 – P observed the ineffectiveness on the side of the management and inability to move the hospital forward because the managerial processes in the hospital were compromised. Case 11 – P accused the CMD who he said was his friend as the person responsible for the infrastructural decay in the hospital and described him as not serious

and lazy and couldn't push things forward, and should have been replaced with someone interested in the job.

8.1.2.1 Doctors

Family carers showed that doctors were part of the problem with ensuring the quality of care, at times their response may even have led to a loss of patients. Some of the family carers said, sometimes you can hardly find doctors on call at night and weekends. Consultants were only seen occasionally or when they came with students. On many occasions, patients were left in the hands of junior ones causing more harm than good:

> *"Another problem is about doctors on call especially at night when their attention is needed, and you hardly find them because they will tell you they cannot reach them, and this can lead to loss of a patient." (Case 1 – FC)*

> *"They left her in the hands of these young ones that are using her for their practice damaging some of her veins as you can see all over her hands. For the doctors to come and examine her, they won't be able to come but send the junior ones." (Case 10 – FC)*

> *"No doctor came to see us since Friday up to today Monday, for the consultant you only see them occasionally, and we need special care at all times. There was a doctor who came for a particular test, and he set for everything on his computer, the computer shut down because of low battery, and he left up till now he never comes back this is the fifth day." (Case 4 – FC)*

A nurse confirmed the statements made by the family carers about the challenges faced as a result of an absence of doctors during end-of-life care, where a nurse looks for doctors, but they could not be found.

> *"Although they run calls, sometimes a patient is dying, and there is no doctor on the ground, at that point you will write a call note and send the attendant to A&E or around the hospital looking for the doctors, so we need a doctor stationed right inside the ward to look after the patients." (Case 9 – N)*

8.1.2.2 Shortage of staff

Adequate personnel is the key to the provision of quality of care especially at the end of life. Lack of or inadequate staffing results in

poor quality of care and eventual loss of lives. Nurses are the healthcare professionals most affected by this shortage, where you find two nurses in a ward caring for 30 patients or more. However, the number of other healthcare professionals was perceived to be inadequate by staff:

> *"There is lack of enough staff to cover the shifts. One or two patients are enough for a nurse to spend many hours giving total care, but two nurses are covering 30 patients or more, and there are seriously ill patients." (Case 11 – N)*
>
> *"Number of staff is less we have only one attendant to take samples to laboratories." (Case 12 – N)*
>
> *"There was a situation just a nurse, a single nurse on morning duty in this ward a 33-bedded ward and you find two in the afternoon, two at night, so tell me how do you explain that? You see where a staff nurse runs from pillar to post to ensure all the patients get the necessary care. These are the problems; I don't know if I am answering your questions"? (Case 14 – P)*

When there is inadequate staffing, the whole system suffers, for example, one of the nurses reported that when the number of nurses was insufficient, the nurses were overworked which results in increased stress and burnout causing absenteeism from work due to sick leave as discussed in section 6.1.1.1. This further decreases the number of nurses working on the wards. When there is a shortage of nurses, patients are at the receiving end because of lack of attention, poor quality of care and hostility from the nurses. This increases tension and anxiety for both patients and their family carers. The nurse-patient ratio in the ward was on average 1:15, which is far from the international standard ratios of 1:5 on the adult units for community hospitals, and 1:4 for teaching hospitals (Welton, 2007). The supporting staff who ran errands (attendants/domestic staff) were also inadequate for example only one during a shift and sometimes none. In such cases, the nurses were left with dual responsibilities as nurses and attendants as well.

8.1.2.3 Logistical problems

All the nurses mentioned one or two problems regarding the availability of working materials such as bed tables to write on, lockers to keep patients' items, consumables, and thermometers in wards. One of the nurses (Case 12 - N) said patients had to buy ordinary cotton wool and spirit for injections. For stationery, nurses had to find paper and draw lines on it; the time wasted in drawing those lines was enough to administer medication to a patient. Some nurses said they sometimes used their money to buy stationery for documentation:

> *"Certain things are supposed to be available by a patient bedside, even the bed table that we use to write is not there, talk less of the locker to keep patient's items. Patients' files are kept under the mattress." (Case 11 – N)*

> *"The hospital is no longer providing consumables, and now even thermometer patients provide for themselves, ordinary cotton wool and spirit for injection patients have to buy. Stationery, you have to find a paper and draw lines, the time you waste in drawing those lines is enough to administer medication to a patient. You may need oxygen in the ward you can't get it, common pulse-oximeter you don't have. There was a time we bought glucometer for the ward from the staff welfare that we contributed." (Case 12 – N)*

> *"Patient is dying no cannula to put normal saline, and relatives have to go to the pharmacy and buy. They supposed to supply all these for emergency use, and later the relative could go and buy for replacement." (Case 4- N)*

Some of the nurses complained of lack of consumables, and stationery to document care in the wards which made it difficult to provide quality care to the patients especially in cases of emergency.

Some of the patients too expressed their concerns about how the logistics problem affected the care they received. Lack of adequate equipment like dialysis machines contributed to patients suffering in the hospital.

> *"As big as this hospital they only have four dialysis machines. Do they have life-support machines in this hospital? If they have, it can't be more than one. When*

three to four patients are demanding their lives to be saved using that machine, what will happen?" (Case 14 – P)

In most cases, the management received feedback from the staff, patients, and family carers that there were problems in the hospital and knew these problems fully existed not only in the adult medical unit but also in other units because they went around the entire hospital every week. They were unable to offer a solution to these problems leaving the whole system in a mess.

8.1.2.3.1 Delayed patient discharge

One of the nurses mentioned that sometimes patients were left on the ward without being discharged despite an improvement in their condition.

> *"They also delay patient discharge for no reason. If the patient doesn't want to go home, they allow the patient to stay, forgetting about re-infection." (Case 9 – N)*

A patient's discharge may be delayed if he/she owed money to the hospital and such patients were retained on the ward until they settled their bills. Although one of the nurses said, a patient discharge could be delayed without any obvious reason which could lead to nosocomial infection.

8.1.2.3.2 Delay in releasing test results

Some family carers expressed concerns about how results from investigations were delayed, at times patients could be discharged without their results being released.

> *"There was a time we did a test (CT scan) we waited till they discharged us without releasing the result. The recent one was a test we paid for, but they could not provide the result." (Case 4 – FC)*

> *"This patient has been coughing for the past two weeks we were asked to do an x-ray, and we did five days ago, but up till now they did not tell us the result, and he is still coughing." (Case 7 – FC)*

Another delay described by family carers was the inability of patients to obtain their results for investigations within the appropriate time. There were inadequate funds for management in the hospital, which could be

observed from the decayed infrastructure. The hospital is a tertiary one financed by the government and receives monthly subvention but could not provide the environment to enable quality care.

8.1.2.5 Decayed infrastructure

Some of the family carers reported cases of total blackout where nurses used the flashlight from their phones to attend to patients and provide nursing care because the hospital failed to provide an alternative power supply. One of the family carers (Case 1 - FC) complained of a toilet blockage in one of the wards where it took the management up to a month to fix it. Another family carer (Case 5 - FC) cried about the presence of cockroaches in their storage boxes within the wards, and the management did nothing about it. A patient (Case 14 - P) said the hospital could not provide sustainable dialysis for patients with renal problems, and sometimes they referred the patients to the nearest teaching hospital or even to a private hospital. They said that the causes of the setback were that the management employed people who were not interested or didn't have the zeal to do the job.

> *"Another problem in the hospital is a poor electricity supply." (Case 12 – FC)*
>
> *"There was a time when there was a blockage in the toilet it took one month for them to repair the toilet. Another thing is that at times they take off the light at night and they do not start the generator on time or not at all." (Case 1 – FC)*
>
> *"We have a problem with some stubborn insects that resist all forms of treatment and the hospital is not doing anything about it." (Case 5 – FC)*
>
> *"Just a dialysis machine they will tell you is faulty, you go to specialist private hospitals in this country they have about 16 – 17 dialysis machines, they even have that of HIV patients separately." (Case 14 – P)*

8.1.2.5.1 Conditions of service

Most of the nurses especially the junior ones felt that the superior officers were suppressing them and preventing them from progressing career-wise. The condition in which the staff found themselves in the

hospital was thought to be discouraging by most of the nurses interviewed. One of the nurses (Case 3 - N) said the junior nurses are oppressed by the senior ones making the atmosphere unconducive for them and hindering their progress. Likewise, another nurse (Case 12 – N) said they spent many years without going on a course, or even attending a seminar or workshop outside the hospital because the more senior nurses were the ones who always went. A family carer (Case 13 - FC) said the cleaners told him that they were not paid for several months and that affected their output, causing the general ward sanitation to be bad especially the toilet as mentioned in Section 8.1.4. One of the patients also said a security man asked patients whether they had food left because they had not been paid for over three months.

> *"There should be that rapport between the superior and the subordinate so that the atmosphere can be conducive, and the younger nurses should not feel oppressed all the time." (Case 3 – N)*
>
> *"You spent so many years without going for a course or even seminar as a nurse. Since I started working here, I have never gone to a seminar or workshop outside this hospital." (Case 12 – N)*
>
> *"The people cleaning this place came here around 4:00 am and before 6:00 am they finished. But two to three days now nobody cleans it, they said the cleaners were not paid for several months." (Case 13 – FC)*
>
> *"The security men came to the patients and asked for leftover food because they were not paid for over three months. Such security men have wives and children at home. Now tell me how you want them to work effectively." (Case 14 - P)*

8.1.2.5.2 Security laxity

The security system in the hospital was porous as described by one of the family carers and unidentified persons could enter patient areas at any time. A patient also mentioned that visitors could abuse nurses and may even threaten to beat them.

> *"People can come and stay with a patient without any identification this may pose a security threat." (Case 11 - FC)*
>
> "*Security allow people to come all the time without restrictions." (CASE 1 – FC)*
>
> *"We have seen cases where some of the visitors want to beat the matron in charge." (Case 14 - P)*
>
> *"They were abusing the matron because they were told that it is not a visiting time in an early morning like this. In such cases, this may be out of the jurisdiction of the nurse/matron in charge to control such. Because it will take the intervention of the hospital management as a whole to make sure that every security man is stationed at the entry of every ward." (Case 14 - P)*

The issue of security laxity in the hospital may be attributed to the poor conditions of service of these security men as mentioned in Section 8.1.2.5.1 above. Although the security men were always present at each of the ward entrances, visitors came in any time they wished without being restricted to the visiting hours (1600-1800) by the security men. The reason for this lack of attention by the security men was due to the benefit (leftover foods) they derived from the patients and their family carers as described by one of the patients (Case 14 - P). Most often the nurses were left with the burden of controlling the visitors which sometimes caused conflict between the nurses and the family carers.

8.1.3 Language barrier

The hospital is in the northern part of the country where Hausa is the major language, although patients are referred from all over the country. Due to the nature of the hospital being a referral centre it accommodates both patients and personnel from all over the country. Therefore, it is possible to experience a language barrier because there are over 500 languages in the country. Some of the nurses from other parts of the country who could not speak Hausa described language as a barrier to the provision of end-of-life care because they often depended on the information provided by the family carers. In some situations where both patient and family carer did not understand

English and the nurse did not understand Hausa, the nurse had to use an interpreter. In rare cases, some patients and family carers didn't understand either English or Hausa, on such occasions, the nurses had to find someone who understood their language to interpret for them.

> *"Sometimes there is a language barrier; anyway, we are trying to learn the language. Initially, when I came, I had to use an interpreter." (Case 10 -N)*
>
> *"We have a language barrier, where patients cannot understand the nurse that cannot speak Hausa if he doesn't understand English." (Case 13 – N)*
>
> *"Where there is language barrier patient and nurse don't understand each other. For instance, if a patient can only understand Hausa and the nurse understands only English, there must be barrier especially when administering medication." (Case 7 – N)*
>
> *"If the patient doesn't understand Hausa, we are in Hausa environment and cannot understand English so how can you communicate effectively? Sometimes we depend largely on information given by family careers." (Case 9 – N)*

8.1.4 Ward challenges

It was also observed (Case 1 - O) that there was a lack of bed linen in the wards, so patients could spend two or more days without having the bed sheet changed. Most of the family carers complained of one thing or the other regarding their stay in the ward. They lamented the situation of the toilets and some of them said they didn't use them because of their poor condition. One of the family carers (Case 4 - FC) whose patient's bed was close to the toilets said whenever the door to the toilet was left opened a terrible smell came from the toilets. He added that there was a time when he went to throw away his patient's urine that he ended up vomiting due to the dilapidated condition of the toilets simply because the nurses have their toilets that are kept clean and locked all the time. Another family carer (Case 1 – FC) said his problem with the ward apart from the toilets was with the nurses admitting patients with infectious diseases close to his relative. The reason why the family carer made this allegation was that the nurses

admitted a patient who was coughing to their cubicle whose diagnosis was yet to be confirmed:

> *"Some people pour the urine anyhow in the toilets, so they messed up the place and is always smelling. Sometimes there is no water." (Case 8 – FC)*
>
> *"We that are very close to the toilet, sometimes the door is left open and the smell coming out is terrible. Sincerely speaking I am not using the toilet, there was a time I entered I almost vomited because of the odour. I entered it yesterday to throw away the urine of my patient, and this caused me to vomit." (Case 4 – FC)*
>
> *"One of the major problems with this ward is admitting patients with communicable diseases. Another problem is the toilet the medical personnel has theirs different from the patient own which is clean and locked for their use." (Case 1 – FC)*
>
> *"After the handover, the family carer asked the nurse to change his patient's bed sheet because it was dirty, the nurse told him that they don't have enough to go round for all the patients." (Case 1- O)*

The nurses described family carers among the barriers to providing care to patients at the end of life. The findings show that some of the nurses were hostile to family carers, and family carers responded aggressively. Thus compounding the challenges they faced, making the ward environment unhealthy for them and their patients. The patients and family carers paid considerable amounts of money in anticipation of good quality care services. Apart from the hospital charges paid, patients provided drugs and other consumables for their care, because patients felt that they had paid for the services and provided the necessary materials for the care, they expected optimum care from the nurses. Therefore, the inability of the nurses to deliver the necessary care to the patients generated tension and anxiety for patients and family carers. In addition to these problems, the language barrier was also found to be a challenge for some nurses, patients, and family carers because the Hausa language was predominantly spoken in the study setting.

On the other hand, the hospital management failed to provide the necessary equipment for quality care. For example, there was a time when the nurses could not find oxygen to administer to a patient in the entire hospital. The hospital also sent patients to another hospital about 200km away for services such as CT scans and dialysis due to the failure of their machines.

However, some patients were unable to pay hospital bills, buy drugs or consumables due to financial problems. The nurses found it difficult to provide care for these patients, and they ended up referring them to the social welfare department for help. This situation also exposed the nurses to anxiety and moral distress. Some of the family carers had to leave their jobs to be with their loved ones, and this placed further stress on the few resources they had. Some of them sold their properties such as land, farms, and houses to pay hospital bills, buy drugs and feed themselves.

Another challenge was the absence of doctors on call at night and weekends, and consultants only came around with students for ward teaching. Also, there were only two nurses per shift at night and weekends, and this meant that the whole system suffered inadequate staffing. Therefore, patients were at the receiving end because of lack of attention, poor quality of care and hostility from the nurses. Staff welfare was compromised causing poor environmental hygiene and security laxity, in general, the entire hospital management was in disarray.

8.2 Facilitators to end-of-life care

This section highlights the nurses' drive (fulfilment of care) to continue to deliver their care and the perceived factors that can promote end-of-life care such as improvement of drug supply, improvement of staffing levels, provision of rewards/incentives and continuing professional development.

8.2.1 Fulfilment of care

Despite all the challenges faced by the nurses during end-of-life care

they still found solace in the care they provided to the patients. One of the nurses (Case 10 - N) said although they sympathised with patients and their family carers there was that feeling of joy whenever she delivered her care effectively, even if the patient died after the care. Another nurse (Case 3 - N) expressed a feeling of satisfaction after the relatives took the patient's body away and realised that she had done all that was supposed to be done.

> *"There is joy in it although there is sympathy. The joy is that at least you were able to render the last help to the patient before he passed away. We care, but only God has the power to heal." (Case 10 –N)*

> *"I feel satisfied at the end of the day when the patient has been packed and the body released to the patient's relatives or taken to the mortuary. Then I seat back and ask myself what I have done to this patient. If I was able to give myself the answer that I have done this, I have done that, and I feel yes I have actually done, and yet the patient died I feel satisfied. But if I ask myself did you do this or that? I found that I have forgotten to do this or that, the whole day will not be nice for me." (Case 3 – N)*

> *"When I nurse my patient, and they get well at the end of the day I feel overwhelmed, I feel joy, the whole of my day is filled with joy." (Case 8 - N)*

Some of the nurses expressed satisfaction and a feeling of fulfilment about the care they delivered to patients. They said that there was a feeling of joy whenever they cared for a patient to his last breath, especially when they knew that they had actually put in their best and yet they could not save the patient's life. This feeling of fulfilment for the nurses is directly connected with the Islamic perspective on caring which is regarded as a divine duty. Nursing care is linked with righteousness, and good work, and attracts reward from the Almighty Allah. Islam emphasises the importance of reward from God for nursing care and advises nurses not to complain or be dissatisfied. Also, good behaviour and conduct, relieving problems for others, and supporting patients and their relatives are considered as actions making the nurse deserving of entering heaven.

8.2.2 Factors that can promote end-of-life care

The findings show that some factors were perceived to promote end-of-life care such as improvement of drug supplies, improvement of staffing levels, provision of rewards/incentives and continuing professional education. The participants felt that if the hospital management could emphasise these factors, a lot of problems would be solved.

8.2.2.1 Improvement in drug supplies

There were a lot of issues regarding drug supply in the hospital as described by some of the nurses and the family carers in the statements below. A family carer narrated how they travelled for about 20km to buy insulin due to its unavailability in the hospital.

> *"There was a time her insulin finished my dad had to go to the market to buy it, and he was afraid of buying a fake one." (Case 8 – FC)*

> *"The pharmacy in the ward closes by 6:00 pm after that one has to go to the emergency unit or G.O.P.D for payments even if it is in the night." (Case 1 – FC)*

> *"Some drugs that are supposed to be available for example the one to stimulate the heart will not be available at that time." (Case 1 N)*

> *"There should be an improvement in drugs supply to avert unforeseen circumstances." (Case 7 – N)*

Drug supply has been a problem in the hospital. One of the family carers (Case 8 - FC) complained about the risk of purchasing drugs outside the hospital, apart from the stress of going to buy the drug there is the possibility of buying drugs that are not genuine. The implication of buying a fake drug is quite detrimental to the patient because it is the same as administering poison to a patient. Another family carer (Case 1 - FC) said they had have found it very difficult to obtain drugs from the pharmacy shop within the hospital after 6:00 pm because the pharmacists on the wards closed at 6:00 pm. Therefore, they had to go to the emergency unit or General Out-Patient Department (GOPD) to get the drugs which were far from the wards. Some nurses (Case 1 – N and Case 7 - N) complained of the lack of adequate drug supplies to the hospital and advised the management to improve the supply. Both

patients and family carers believed that improving the drug supply in the hospital could ease their difficulties in accessing the drugs and reduce the risk of purchasing fake drugs from outside the hospital.

8.2.2.2 Improvement in staffing levels

Similarly, the nurses said if the hospital management or the government could employ more nurses it would improve the staffing levels in the hospital, thus improving the quality of care.

> *"We need manpower we have able hands the only thing is to plead with the government to employ more staff." (Case 7 – N)*
>
> *"The management needs to employ more nurses if we have more hands the quality of care will be improved. Now we have one nurse managing 12 patients or more, if there are is seriously ill patients your attention will be much divided you know." (Case 8 – N)*
>
> *"We need experienced nurses and doctors with palliative and end-of-life care training, trained critical care nurses, and intensive care nurses. We also need resuscitation equipment." (Case 9 – N)*

All the nurses wanted the hospital management to employ more nurses because they considered it as part of the solution to solve the problem of staffing, thereby improving the quality of care. One of the nurses (Case 9 - N) emphasised the need for specialist nurses especially in the area of palliative and end-of-life care and critical care.

8.2.2.3 Provision of rewards/incentives

Staff welfare is a significant factor that improves the performance of staff and their wellbeing. This could be in the form of support, motivation, rewards, and incentives. One of the nurses said irregular payment of wages hindered their performance. The nurses complained of lack of encouragement and motivation from the management. Most of the nurses lived at a distance from the hospital because of lack of accommodation within the hospital and found it difficult to reach the hospital because there were no standard means of transportation. They either used their private cars for those that had them or used public transport. One of the nurses (Case 11 - N) said they spent a lot on transportation and sometimes their salaries were delayed which

hindered their performance. Therefore, they wanted the government to pay their wages and allowances on time as a form of motivation to enhance their performance (Case 12 - N).

> *"Considering the hardship we are passing through, most of us are staying far away from the hospital, and we spend money daily to come here, at times if the payment is inadequate it hinders performance." (Case 11 – N)*

> *"The government has to do everything possible to motivate their staff, pay their salaries on time, and pay their allowances. When you are hungry, you can't concentrate." (Case 12 – N)*

> *"When a nurse is giving quality care, putting in her best and made a mistake she should be called, explain to her how she goes wrong and corrects her politely." (Case 3 – N)*

One of the nurses (Case 3 - N) said sometimes they would be delivering care to patients diligently and putting in their best instead of receiving words of encouragement they end up being bullied by their superiors over a small mistake and this demoralised the junior nurses.

8.2.2.4 Staff training

A major responsibility of the management is to send their staff for training to provide them with new knowledge. One of the nurses (Case 12 - N) mentioned in the statement below that the management did not recognise a certificate from a member of staff who went for training without approval.

> *"Staff training on courses like palliative nursing, disaster nursing, accident and emergency nursing will help the nurses to be able to perform well." (Case 1- N)*

> *"We should imbibe the habit of re-education or be updating the knowledge of our nurses through conferences, seminars, presentations and back to school." (Case 3 – N)*

> *"There is a protocol; you have to write your name for nomination. If you go to school without the approval of the management you are on your own, they will not recognise the certificate." (Case 12 – N)*

> *"We need constant continuing education because some nurses if you ask them to assess an unconscious patient, they will tell you that they cannot do it because they did it last in school." (Case 9 – N)*

Staff training has been a major problem for the nurses in the hospital. All the nurses emphasised the need for nurse training, for example, one of the nurses (Case 1 - N) wanted nurses to be sent on courses on palliative and end of life care, disaster nursing, and accident and emergency care to strengthen their knowledge and skills for better patient care. Apart from attending courses some of the nurses said updating their knowledge through conferences, seminars, and workshops would be of great benefit for both patients and nurses. One of the nurses (Case 9 - N) said most of the nurses had forgotten about many procedures learned in school, for example, some of the nurses were asked to assess an unconscious patient but were unable to do that.

8.2.3 Chapter summary

This chapter highlights barriers and facilitators to end-of-life care, where economic factors were found to be a significant barrier to delivering effective end-of-life care. Other barriers discussed were problems from the hospital management which included a shortage of nurses, logistical problems, and poor conditions of service, decayed infrastructure, and security laxity. The language barrier was also found to affect patients' care significantly. The chapter further highlights the factors that provided the nurses with additional strength to continue to deliver their care despite the challenges. Finally, some factors were perceived to promote end-of-life care such as improvement in drug supplies, improvement in staffing levels, provision of rewards/incentives and staff training. The next chapter discusses the key findings from the study in conjunction with the relevant literature.

CHAPTER NINE: DISCUSSION AND CONCLUSIONS

9.0 Introduction

The previous chapters illustrated how the phenomena relating to the findings were uncovered. Although four major themes were presented as distinct chapters, however, there were several sub-themes which further supported the development of the themes. Findings showed that nurses described their caring roles at the end of life in the form of assisting patients by providing both fundamental and routine care. Family carers were fully involved in the care of patients, and they carried out various activities to ensure the wellbeing of their loved ones especially fundamental physical care. Apart from nurses, other healthcare professionals played a significant role in the care of patients at the end of life. These included doctors from various specialities, social workers and physiotherapists. Both nurses and family carers had varying experiences when caring for patients at the end of life. These ranged from a feeling of fulfilment, some degrees of discomfort, to emotional distress. It was clear from the findings that most patients had their needs unmet at the end of life. They expressed their negative feelings about the care they received and attributed the problems to hospital policies and poor managerial processes in the hospital. Nurses and family carers recognised that high workload due to a shortage of nurses contributed significantly to their stress and burnout.

Nurses also felt that it was part of their responsibility to make sure that patients and family carers received sufficient information regarding patient care. Some of the nurses indicated that they didn't discuss patients' conditions with them or with their relatives, most times they referred the case to the doctors. Although some family carers described their relationships with some of the nurses as unfriendly, some of the nurses indicated that their relationships with the family carers were cordial. All family carers showed interest in educational needs and support especially about the management of their relatives' conditions and preventive measures. Financial problems were a major concern among patients and their family carers because healthcare expenses

are paid out-of-pocket. All family carers expressed concern over the high cost of hospital bills even though the government owns the hospital. All nurses interviewed complained about the inability of the hospital management to provide the required equipment for quality of care. Finally, some nurses expressed satisfaction and a feeling of fulfilment about the care they delivered to patients.

As mentioned earlier in Section 1.5, palliative and end-of-life care has been established in most of the tertiary hospitals in the country for over a decade, through the Hospice and Palliative Care Association of Nigeria (HPCAN). However, there are no national policies or programmes on palliative and end-of-life care in the country, and it is yet to be integrated into the country's health system.

This chapter discusses the key findings from the study in conjunction with the relevant literature that addressed the research question: How is nursing care delivered to patients in the hospital at the end of life from the perspective of nurses, patients, and family carers? The first theme, caring role (both fundamental and routine care), included nurses, other healthcare professionals and family carers' roles in delivering care. The second theme, experiences and feelings about care from the participants, covered feelings about dying patients, workload, stress and burnout. The third theme, communication, educational needs, and support needs included relationships among participants, nurses' attitudes toward family carers, teamwork, and withholding information. Other aspects include creating awareness, family carers' lack of knowledge about care, patient and family carers' needs, patient expectations and reassurance. Lastly, the fourth theme, barriers and facilitators to end-of-life care, covered economic factors, problems with hospital management, lack of human resources, logistical problems, poor conditions of service, and language barrier.

9.1 Caring roles

As highlighted in the previous section, caring roles entail both fundamental and routine care delivered to patients. These caring roles

are carried out by both nurses and family carers, and by other healthcare professionals. In this section, participants' roles are discussed in relation to existing literature.

9.1.1 Nurses' caring role

The care nurses delivered to patients in the form of fundamental and routine care was highlighted in section 5.1, where all the nurses described their roles in the form of total nursing care for patients. This includes bed bathing, oral care, treatment of pressure areas, changing of linen when dirty, changing of position, monitoring of I.V. fluids, maintaining of intake and output, monitoring of vital signs. Feeding of the patient via NG-tube for those that can't tolerate oral feeding, psychological and spiritual support to patient and relatives. This finding is supported by the work of Zheng et al. (2015), Amendolair (2011) and Grbich et al. (2001), where they described nursing care as overall care of patients from administering medication, observing vital signs, to carrying out procedures and treatments as well as promoting patients' physical and psychological comfort. They also highlighted listening, providing information to patients and carrying the families along when giving care as part of the nurse's caring role. Beckstrand et al. (2006), added that caring roles also involve communicating with other healthcare professionals, and patients' and family carers' education.

Nurses caring for the patients at the end of life closely monitor patients to adequately meet both the patient's and the family's needs (Thompson et al., 2006), they are confronted with the challenge of spending a great deal of time with the individual patient and their relatives in a situation of fear, despair, and anxiety (Paulsen et al., 2018). Wallerstedt and Andershed (2007) describe care at the end of life as everyday encounters with patients, families, and staff. The nursing role is aimed at emotional and spiritual support for patient and family; this means nurses care for the whole person (Royak-Schaler et al., 2006, Noome et al., 2016). A major aspect of physical care is to improve patients' personal hygiene and wellbeing, and a core nursing role is bed bathing. However, it was found in the current study that the

nurses were not carrying out such a role. When asked the last time they bathed a patient, most of them mentioned two weeks or more. It was confirmed throughout my observations; there were no bed baths performed by the nurses. This is in contrast of the studies by Royak-Schaler et al. (2006) and Grbich et al. (2001), that physical aspect of care encompassed personal hygiene needs and nurses play an important role in managing patients' physical care and facilitating other care services at the end of life. However, all the patients and the family carers confirmed that the nurses tried their best to ensure that they carried out all the routine nursing care (see Chapter Three) because routine tasks could not be carried out by the family carers. This was also confirmed by several observations (Case 1- O, Case 2 – O, Case 3 – O).

The current findings show that there is no clear pathway for delivering care at the end of life, or a developed palliative and end-of-life care model in the study setting. This may be due to the absence of policies and guidelines on palliative and end-of-life care in the country's healthcare system. Nurses and family carers deliver their care in different dimensions as described in the model shown in Fig. 9. Combining the two aspects of care into collaborative care would provide effective end-of-life care. In situations where nurses and family carers worked together, the communication gap is closed, anxiety is reduced, the patients received the best care, and both patient and family carers showed positive feelings. While nurses, on the other hand, experienced less burden of care. Therefore, nurses should involve family carers in their plan of care and decision making.

As presented in section 5.5, the nurses-Family carers care model comprised of three parts: care by nurses, care by family carers, and care by both nurses and family carers (collaborative care). The model provides a simplified means by which the patients' needs are fulfilled. These needs include physical, psychological, social, and spiritual needs. The model was developed from the observations of how the nurses and the family carers delivered care to patients at the end of life

in a general medical ward. The nurses and the family carers recommended that a separate ward for patients with end of life care needs should be provided. Having a separate ward would provide a suitable setting for the implementation of the model because it is part of the hospital tradition to allow family carers to stay with the patients all the time. Based on my observations, the nurses and the family carers delivered care in parallel. The nurses concentrated on the routine and fundamental care, while the family carers performed the physical, psychological, and spiritual care. Because of the religious and cultural dimensions of care in the context, the family carers were happy to carry out such tasks, especially when it involves one's parent or spouse. Their major concern was the hospital bills paid and not getting the expected care from the nurses and other healthcare professionals. Therefore, if this model is adopted and implemented, and family carers are formally recognised to deliver care to patients hand in hand with the nurses at the end of life, the quality of care would be improved, and patients' needs would be met. The collaborative care would however address the economic burden faced by the patients and the family carers when the hospital agrees with the recommendation of 50% reduction of the hospital bills for patients admitted into the end of life care ward. Because family carers contribute significantly to patients care, and such contributions if translated in monetary terms yield a significant amount of money.

The nurses would also welcome the idea of implementing the model because they had already relinquished the physical aspect of care to the family carers informally. So when this is formalised, both nurses and patients will benefit from it. It will also improve the interaction among nurses, patients, and family carers, at the same time bridge the communication gaps. Because many of the healthcare professionals find it difficult to support the family carers. Therefore, there is a need to recognise the family carers formally the healthcare system Hudson (2013). This may be of great benefit to the nurses and other healthcare professionals, especially in resources allocation and time to offer

pertinent interventions. Hudson (2013) suggested that additional support for family carers would result in improved patient wellbeing, enhanced bereavement outcomes, and less burden on the healthcare system.

However, those patients that may lack a member of the family for caregiving due to time constraints, work or other issues; an arrangement would be made for them through an agency to provide a trained caregiver to complement the effort of those family carers whom in one way or the other are unable to stay with the patients and are able to pay. Involving formal caregivers through agencies would provide job opportunities to those teaming youth interested in caregiving without interfering with the nurses' technical roles.

Palliative and end of life care in South Africa and Uganda have gained a foothold already in their national healthcare system. Among African countries, only South Africa and Uganda were at position 34 and 35 respectively based on the recent ranking of quality of death index by the Economic intelligence unit. Uganda has made palliative and end of life care for patients with AIDS and cancer a priority in its National Health Plan. Patients with HIV/AIDS and cancer receive either community-based care or home-based care. The care is designed to meet the cultural and practical needs of the people in Uganda, which is less expensive because of the family and community support at the end of life. It also lessens the burden of already overcrowded hospital wards (Spence, 2004).

Accurate record keeping is another vital role of nurses for effective communication and future reference. Nurses were observed to document activities after their procedures. However, some of the nurses were not trustworthy, as they were found documenting certain activities they did not carry out as reported by Case 11 – P in Section 5.1.2.2, or documenting activities carried out by others which was confirmed by several observations discussed in Section 5.1.2.2. This issue is a form of deception and quite harmful to the patients and the entire healthcare

system. Although I am a researcher, it is my duty as a nurse to protect patients from harm. Therefore, the incidents were reported to the ward manager to prevent future occurrence.

Another nurse's role in end-of-life care is a prompt response to patients' and family carers' requests which was expressed in two different responses. For example, Case 12 – P and Case 10 – FC said the nurses responded promptly whenever they called their attention. However, some patients and family carers (Case 11 – P, Case 7 – FC, Case 5 – FC and Case 2 – FC) experienced a delayed response from the nurses. This is in contrast with a statement by Efstathiou and Clifford (2011) on the fundamental roles of nurses in providing emotional support to patients and families at the end of life by being present at the bedside, having a listening ear and providing comfort. The delay in responding to calls was attributed to the nurse-patient ratio discussed in Chapter Eight, where two nurses or sometimes a single nurse cared for 30 or more patients. In addition to the delay in responding to calls, the majority of patients and their family carers reported that most nurses refrained from carrying out their responsibilities especially fundamental nursing care that involves the care of the patient's personal hygiene, changing position and treatment of pressure areas which was shifted to the family carers.

Several observations during this current study confirmed a task shift as discussed in Section 5.1.6.1. Apart from nurses, other healthcare professionals such as doctors especially the senior ones were found to have shifted their responsibilities to the junior doctors. Case 14 – P said he had noticed this situation when house officers were unable to make the right decision for his condition. He said there was a time his catheter got blocked at 11:00 pm, but he couldn't get the doctors' attention until 4:00 am (see Section 6.1.2). Furthermore, the current study confirmed previous work by Beckstrand et al. (2006), which found that lack of consistency existed in the way patients were cared for at the end of life, and patients' and family carers' needs were not adequately met.

9.1.2 Other healthcare professionals' role

Other healthcare professionals such as doctors from various specialities, social workers, and physiotherapists contribute immensely to end of life care. Nurses are at the forefront concerning care delivery and always in touch with the patients at the end of life (White and Coyne, 2011, Efstathiou and Clifford, 2011), in contrast with other team members who only visit them (Valiee et al., 2012). Although family carers seem not to appreciate the fact that care at the end of life in the hospital is handled with a team approach rather than a single speciality (Ferry et al., 2002), and healthcare professionals are expected to care for both the dying patients and their relatives (Paulsen et al., 2018). Nurses, as members of the multidisciplinary care team, play a central role in providing care to patients at the end-of-life and their families (Valiee et al., 2012). Nurses coordinate patient care and work with doctors, pharmacists, physiotherapists, social workers, chaplains, and volunteers to support patients and their families (Royak-Schaler et al., 2006). In the current study, doctors from various specialities, social workers, and physiotherapists were found to play their part in ensuring effective end-of-life care. Palliative and end-of-life care is a multidisciplinary task, but it was not the case in the current study. It was observed during the study that healthcare professionals were carrying out their roles in isolation. The majority of them were not performing their prescribed roles as witnessed during observations.

9.1.3 Family carers' role

Family carers played a significant role in the care of patients at the end of life, although they required attention and care similar to that of patients. This is in line with a study by Thompson et al. (2008) where family members were described as recipients of care who needed all the support and information from healthcare professionals. Most family carers stated that they carried out most of the fundamental nursing care described in Section 5.1.1. The findings of the current study show that many of them (Case 1 – FC, Case 3 – FC, Case 10 – FC and Case 13 – FC) reported emptying urine bags, bathing patients, changing the

patient's position, washing patients' clothes and meeting several other patients' needs which were confirmed during the period of observation. All family carers in the current study were willing to take up considerable duties for the wellbeing of their loved ones. This finding substantiates previous work (Spichiger, 2009) where most family members are actively involved in the fundamental care of the patients, largely by supporting their activities of daily living for better outcomes. Some occasionally assisted when needed, while others assisted regularly. In another study, contrary to the current findings (Noome et al., 2016), family members were not aware of the possibility of taking part in the care of their loved ones at the end of life, and they did not think of it.

However, it was noted that nurses in the current study explained the reason why family carers were allowed to be with their loved ones all the time. Some of the nurses (Case 8 – N and Case 9 – N) stated that it was because they didn't have enough staff and the relatives wanted to be with the patients to support them. Therefore, hospital management allowed one family carer per patient, although most of the time there were two or more family carers to a patient. In a previous study (Andershed, 2006), relatives expressed their need to be with the patient especially when approaching the end of life to say goodbye and also being present when the patient died. In a recent study (Noome et al., 2016) that supported the current findings, family members expressed their wish to stay with the patient at the bedside and perform their rituals during the dying process. Nurses affirmed the importance of having family members being together with the dying, which was a beneficial interaction, not only for the dying but also for the families. Sometimes even the patients wanted to see their people there. As discussed in Section 5.4.2, a family carer (Case 13 – FC) said allowing family carers to be with the patients prevented the potential risk of harm to the patients, since the nurses were not there all the time. He narrated an incident when he went to buy some drugs outside the hospital when his

wife went into hypoglycaemic shock without the knowledge of the nurses.

9.2 Experiences and feelings about care

In this section experiences and feelings about care amongst nurses, patients, and their family carers were discussed. It further discussed the nurses' and family carers' feelings about dying patients, nurses' workload, stress, and burnout as well as how nurses recognise a dying patient, and dignity in dying.

9.2.1 Nurses' caring experiences

Throughout this study, nurses described their varying experiences which ranged from feelings of fulfilment to some degree of discomfort and emotional distress. When a patient's condition was deteriorating, nurses experienced distress and felt that they required more support to care for such patients. Care of patients and their families in the hospital at the end of life may be a poor experience. This finding supports the work of (Amendolair, 2011, Efstathiou and Clifford, 2011) were nurses, other healthcare professionals, and families became frustrated when patients did not respond to treatment as expected.

Some nurses in this study described patient care at the end of life as highly demanding both physically and mentally and involved working round the clock. They also described being faced with conflicting situations especially when the plan of care had been shifted to preparation for dying. Beckstrand et al. (2006) reported that to meet both the patient's and family's needs adequately when death was predictably imminent, the nurse caring for the dying patient has to be closer to that patient. A study by Dunn et al. (2005) reveals that nurses with more caring experience for dying patients have more positive care experiences at the end of life. Although nurses use their experience and skills to find the appropriate intervention for dying patients, when they are unable to do the necessary role regarding symptom management, the nurses experience feelings of helplessness. However, the current study found that when nurses were powerless, they showed a variety of

emotions such as anger, frustration, guilt, resentment or sorrow. Ong et al. (2018) state that nurses experience profound positive and negative psychosocial effects when providing end of life care, with the negative being more prominent. The nurses in this study described their experiences of delivering care to patients at the end of life as devastating despite prioritising the care. This finding is supported by the work of (Valiee et al., 2012) which found that nurses suffered a moral conflict when they witnessed a patient suffering and were uncertain about the best measures for the patient and the family.

9.2.2 Patients' experiences of receiving care

The majority of patients in the current study described negative experiences, although a few of them had a positive experience and commended the nurses for that. Among those patients said to have experienced good care from the nurses was a younger brother to a senior nurse in the hospital (Case 14 - P). He appreciated the efforts of nurses towards ensuring that he got all the necessary nursing care at any given time. Those patients with the negative experiences said they were not happy with the quality of care they received and expressed frustration with healthcare professionals who failed to carry out their tasks. According to some of the patients, some of the nurses were only charting during their shifts. This means that they paid less attention to the patients' needs but wrote pages about the patients. This is in contrast to a qualitative study on nurse-patient relationships in palliative care by Mok and Chiu (2004) where ten hospice nurses and ten terminally ill patients were interviewed. The nurses were found to have a holistic approach in caring for the patients, attending to their physical, psychosocial and spiritual needs, and responding to the patients' voiced and unvoiced needs. They ensured patients' comfort without being asked, and were reliable, available, and listened to patients' deeper feelings. According to Ferry et al. (2002) patients at the end of life have special emotional, physical and spiritual needs. Therefore, ignoring such needs only exacerbates patients' problems, making it more difficult to deliver effective care. Evidence has shown that patients who died

after stroke have psychosocial concerns, high levels of symptom burden and unmet needs (Payne et al., 2010). The current study supports these findings, three of the patients studied had a stroke (Case 2 – P, Case 3 – P and Case 6 - P) and most of their care needs were shifted to their loved ones (see Section 5.1.6.1).

The role of the family in the care of patients at the end of life is essential (Gustafson and Lazenby, 2018). All the patients reported a positive experience regarding the care they received from their family carers. They commended the role played by their family carers, and highly valued and appreciated the care they received from their respective family carers. For example, Case 13 – P described how her husband bathed her, fed her, washed her clothes and provided all her needs. Similarly, Case 5 – P and Case 10 – P explained how their children cared for them and provided all their needs. The hospital stay has been found to be more bearable for family carers when patients have positive experiences with care (Spichiger, 2009).

9.2.3 Family carers' experiences

In this study caring for patients at the end of life was found to be a huge burden by most of the family carers. Some described their caring experiences as a mixture of feelings, while others considered caring for their loved ones as an obligation. They said although the care requires a lot of sacrifices, they were happy to do it. This might be connected with the religious teachings in which caring for the sick is considered to be rewarding, especially for children who care for their parent. While caring for a patient at the end of life, family carers expressed their experience of watching their loved ones in pain and suffering and perceived they lacked control (Grbich et al., 2001). This was evidenced in the current study, where some family carers (Case 12 – FC, Case 11 - FC and Case 10 – FC) narrated how they watched their loved ones crying and suffering in pain throughout the night and imagined what those patients went through**.** In addition to suffering, many of the family carers (Case 5 – FC, Case 8 – FC, Case 10 – FC and Case 13 – FC) found caring for patients at the end of life frustrating, challenging, and

highly demanding. The current study confirmed previous work of (Spichiger, 2009, Woodman et al., 2016) which found that being with and caring for patients especially at the end of life imposes a significant burden on families, in spite of families always wanting to be with, care for and advocate for their patients. Some of the family carers they had provided occasional assistance as needed; others said they had assisted on a regular basis. Spichiger (2009) added that accompanying a patient at the end of life especially for a long period was exhausting and family carers became fatigued. In another study on family perspectives on end-of-life care experiences in nursing homes (Wetle et al., 2005), family carers reported that healthcare professionals did not sufficiently address the needs of patients at the end of life. Many family carers said they had become patients' advocates due to the poor care they experienced. The current findings also show healthcare professionals did not engage with family carers in making decisions about the care of their loved one, which also increases tension and anxiety. Al Mutair et al. (2018) confirmed that family carers maintained closeness with their loved ones at the end of life to ensure participation in the caring process and also witness the care provided by healthcare professionals**.** Despite the challenges encountered by family carers during the hospital stay, some family carers reported that providing care at home has its own emotional and physical burdens which result to hospital admission (Woodman et al., 2016).

9.2.4 Patients' feelings about care

As reported in section 6.2.1 there were expressions of negative feelings about care from most of the patients. Several factors were found to have contributed to that, such as the bureaucratic nature of hospital policies and poor managerial processes in the hospital. The hospital policies restricted nurses from carrying out certain procedures such as establishing an intravenous line even if a patient was in dire need, and nurses have to wait for a doctor. Even though they were trained and licenced to do this, which contributed to the lack of an enabling environment in which nurses were able to put in their best. This issue

brought about the idea of having nurse-specialists especially in the area of palliative and end-of-life care so that they can practice independently, and also as multidisciplinary team members. Because patients feel unsafe in the hands of staff who lack the knowledge and expertise to provide effective end-of-life care (Robinson et al., 2015). Some patients (Case 11 - P and Case 14 – P) felt that lack of determination from the management, nurses and other healthcare professionals resulted in the poor quality of care delivery. If the Chief Medical Director (CMD) was determined everyone in the hospital would be determined in carrying out their responsibilities. One of the patients (Case 14 - P) cited an example where only the nurses and the house officers were left to care for the patients on the ward, even though the house officers are still in the process of learning, while the senior doctors were only seen occasionally on the wards.

9.2.5 Family carers' feelings about care

Most family carers in this study expressed negative feelings about the care received by their loved ones. They felt that nurses and other healthcare professionals were not providing the care needed by patients. One of the family carers (Case 10 – FC) said since they admitted his mother the senior doctors had not seen her, they only left her in the hands of the junior ones who used her for practice damaging some of her veins. Another family carer (Case 11 – FC) reported that the nurses hardly spent two minutes with the patients but could write pages about the patient. Doctors and nurses were too busy to advocate for patients, so family carers did that and watched over their loved ones (Royak-Schaler et al., 2006)**.** These were some of the reasons that pushed the family carers to be actively involved in the care of their loved ones when they realised that the hospital environment was no longer supportive. The current study is in line with the work of Andershed (2006) who described some family carers' dissatisfaction with the care of patients' personal hygiene, unmet patient needs, inadequate supportive environment, and rigid hospital routines. Some studies (Noome et al., 2016, Royak-Schaler et al., 2006, Andershed,

2006) described feelings of satisfaction, thankfulness, and pleasure among family carers as valuable experiences especially when they noticed the respect nurses showed to their patients. However, these studies contradict the current study since the majority of the family carers expressed negative feelings about the care delivered by the nurses and other healthcare professionals.

9.2.6 Workload, stress, and burnout

The nurses in the study complained of too much workload and regarded end-of-life care as time and energy consuming. Some of them said they were quite aware that the patient would not recover unless a miracle happened, but they still put in their best to care for dying patients, and this further stressed them leading to subsequent burnout. For example, one of the nurses (Case 9 – N) narrated an incident where they lost three patients during a night shift simply because they didn't have enough hands and lacked the equipment and the technology to assess their patients. Even the family carers acknowledged that the nurses were stressed due to the workload as reported in section 6.2.4. The level of the workload on the wards put pressure on the nurses which significantly affected the quality of care delivered to patients. One of the family carers (Case 3- FC) said some of the nurses appeared disconsolate when delivering care, which may have been due to stress, or unhappiness with the working conditions. Workload, stress, and burnout were directly connected with the availability of nurses as shown in the above example. Patients and family carers expressed concern about the inability of the nurses to be with the patients all the time even though they were always at their station, but didn't usually go to patients unless they were called or when they were administering drugs.

Some nurses and the majority of family carers supported the idea of caring for patients at the end of life in a separate ward since they always required close monitoring and the presence of loved ones. This idea is in line with a study by Wallerstedt and Andershed (2007) where nurses described difficulties in caring for patients with palliative and end-of-life care needs at the same time as patients in a curative phase.

However, some nurses were opposed to separating patients at the end of life from other patients. Because it is difficult sometimes to recognise the dying process, they said the patient's condition can change very quickly and might warrant transfer to the end-of-life care ward, and so could divide the nurses' attention. Diagnoses of dying were often late sometimes within hours (Reid et al., 2015), and healthcare professionals do not adjust caring approaches accordingly (Wetle et al., 2005).

Recognising the dying patient could be difficult sometimes; however, most of the nurses in the current study laid more emphasis on a low Glasgow Coma Scale (GCS) score and low oxygen saturation. The nurses mentioned these clinical manifestations based on their experiences (see Section 6). These findings are supported by the work of (van der Werff et al., 2012), where the participants mentioned that respiratory function declined in most cases with low oxygen saturation and death rattle. There is increased anxiety and restlessness with decreased ability to eat or drink when patients are approaching the end of life. Notwithstanding, the nurses have a common view that even if a patient is going to die there should be some level of comfort so that he/she dies a peaceful death. Nurses emphasised that dignity maintenance is a positive aspect of ensuring a good death. Greater attention is paid to maintain patients' dignity during end-of-life care even when managing unconscious patients (Zheng et al., 2015).

9.3 Communication among participants, and their educational needs and support

In this section, communication among nurses, patients, and family carers as a key component of the provision of end-of-life care was discussed. Patients' and family carers' relationships with the nurses were also discussed. Further issues discussed in the section include withholding of information by healthcare professionals, educational needs and support of the participants, creating awareness, family carers' lack of knowledge about care, patients' and family carers' needs, and balancing family carers' jobs and caring.

9.3.1 Communication among participants

It is part of the nurses' responsibility to ensure that patients and family carers receive adequate information regarding patient care. This helps to clarify issues for patients and family carers and relieve them of distress. In a study by (Zheng et al., 2015), findings show that effective communication reduces psychological distress among patients at the end of life**.** Good quality end-of-life care from the perspective of nurses, patients, and family carers is characterised as being friendly, approachable, welcoming and being able to develop a rapport (Attree, 2001). According to some nurses in the current study, communication was said to be effective among the nurses, patients, and the family carers as reported in Section 7.1. However, some of the family carers felt that some of the nurses were rude to them and found it difficult to communicate with them. When communication from healthcare professionals is ineffective, and information dissemination to patients and family carers is inadequate, anxiety and distress are increased. This statement is in line with a recent study (Gustafson and Lazenby, 2018), that communication difficulties affect patients' care and have a negative impact on family carers, impair their coping strategies and prolong the grieving process.

Moreover, poor communication among nurses, patients, and family carers during end-of-life care could be a source of stress for the nurses (Zheng et al., 2015). Therefore nurses and other healthcare professionals require excellent communication skills, especially when communicating with dying patients and their loved ones**.** Beckstrand et al. (2006) suggest that improved communication among healthcare professionals and also between patients and their family carers would eventually facilitate a good death.

Excellent communication is central to nursing care, especially when dealing with patients and family carers at the end of life. Several studies support this finding (Zheng et al., 2015, Payne et al., 2010, Thompson et al., 2008, Dunn et al., 2005, Andershed, 2006, Attree, 2001, Grbich et al., 2001). Communication and information sharing between patients

and family carers and healthcare professionals influence both patients' and family carers' satisfaction with end-of-life care. The majority of nurses stressed the importance of interacting with patients and their families during end-of-life care (Dunn et al., 2005), family carers always express satisfaction about care whenever healthcare professionals act in the best interests of their loved ones (Andershed, 2006). However, it is in contrast with the current study where communication among nurses, patients, and family carers was poor.

It is essential for nurses to establish a rapport with patients and their families. Working together with the patients and their family carers is considered an essential tool for quality care at the end of life and a good death. In the current study, nurses were found to distance themselves from the patients and family carers, and they only engaged with them when carrying out procedures. In a similar study about the experiences of nurses caring for dying patients outside palliative care settings, (Wallerstedt and Andershed, 2007) described factors such as organisational setting, poor communication, relational difficulties, and insufficient cooperation within the multidisciplinary team as significant sources of stress in end-of-life care.

Withholding information is a common phenomenon among healthcare professionals. In the current study, as reported in Section 7.1.4, some nurses (Case 12 – N, Case 10 –N and Case 8 – N) indicated that they didn't discuss patients' conditions with them or with their relatives, most often they referred the case to the doctors. This finding is in line with the studies of Royak-Schaler et al. (2006) that doctors and nurses find it difficult to discuss end-of-life care issues or believe it is not their responsibility, and Grbich et al. (2001) said healthcare professionals argue about how much, who and when information should be provided to patients and their family carers.

Family carers are always inquisitive for more information about their loved ones (McNamara and Rosenwax, 2010), however, most of the family carers in the current study confirmed that they were not informed

about the condition of their relatives, some of them got to know their relatives' problems only by overhearing doctors' discussions or from the drugs prescribed. While others said, their knowledge was based on their observations of patients' physical condition. These statements were also confirmed by my observation (Case 3 – O) (see Section 7.1.4). These findings are also supported by previous studies (Ong et al., 2018, Efstathiou and Clifford, 2011, Spichiger, 2009), where some family carers said they were excluded or disregarded by healthcare professionals when giving care. While others said they had received information superficially, with nurses distancing themselves from families and dying patients at the end of life owing to the difficulty of recognising the exact time to shift from cure to comfort care (Al Mutair et al., 2018).

9.3.2 Nurses, patients, and family carers educational needs

Findings from the current study show that none of the nurses had palliative or end-of-life care education or had even attended a seminar, workshop, or conference in areas related to palliative or end-of-life care. This finding was consistent with the findings of previous studies (Kell and Walley, 2009, Machira et al., 2013, Fadare et al., 2014, Kassa et al., 2014, Woodman et al., 2016) where nurses were reported to not know about palliative and end-of-life care. Similarly, Dekker et al. (2012) report that 9 of the 11 nurses in their study had no palliative care training and were unable to articulate what palliative care was; rather they referred only to care of patients diagnosed with cancer. In another study of nurses' perceptions of quality end-of-life care on an acute medical ward (Thompson et al., 2006), the nurses identified a lack of palliative and end-of-life care education and experience among physicians as barriers to quality end of life care. As discussed in Section 7.2, nurses expressed their concern about the need to update their knowledge and skills through regular seminars, workshops, and conferences. Given these findings, palliative and end-of-life care education become the necessary tool for transforming palliative and end-of-life care in Nigeria in particular, and in sub-Saharan Africa in

general. The majority of the nurses in the studies had no prior palliative care education because it is not in their curriculum, indicating a lack of emphasis on palliative care at pre-registration level and within clinical practice. This is congruent with the current study in which the majority of nurses do not have a degree in nursing. Even in some places where progress has been made in palliative and end-of-life care education and practice, the amount and quality of palliative and end-of-life care education are inadequate (White and Coyne, 2011)**.**

This study also demonstrated a lack of support from hospital management for nurses who have the desire to further their education. Nurses said it was quite difficult for them to go back to school because of the bureaucratic processes in the hospital, they followed a long protocol where they first put down their names for nomination. If they went to school without approval from the management they were on their own, their certificate would not be recognised. In this case, the government needs to intervene and call for hospital management to do everything possible to motivate their staff to further their education, attend seminars, and workshops, definitely a nurse needs to have a continuous education. Some of the junior nurses blamed the senior ones for not allowing them to attend seminars and workshops, while some of the nurses attributed their inability to further their education or update their knowledge to a shortage of human resources in the hospital.

Family carers showed an interest in educational needs especially about the management of their patients' conditions and preventive measures (see Section 7.2). As discussed in Section 9.1.3, since family carers cannot be prevented from caring for their loved ones due to the shortage of nurses, it is necessary to educate them in order to improve the quality of care at the end of life. In research conducted by Amendolair (2011), participants demonstrated the need for patients and their family carers to have education about the illness, medications and how best to take care of themselves. Nurses in the current study described how they educated patients and their family carers,

explaining the general rules and regulations regarding living on the ward usually during ward meetings. However, they expressed concern over the difficulties they faced when explaining certain issues to family carers.

Additionally, the findings from the current study show that the majority of family carers were ignorant about nurses' responsibilities in the care of their loved ones. Some family carers took it upon themselves to make patients' physical care part of their routine. They didn't even wait for or contact the nurses about that. Most family carers expressed dismay on certain issues relating to the care of patients, some of them regretted coming to the hospital and wished they were at home. This was confirmed by the statements made by some family carers during the interviews and also during observations. Nurses were very much aware of the situation because one of them (Case 7 – N) described the reaction of family carers, saying that sadness could be seen in their faces especially when their loved one was dying. Family carers at the end of life are considered in a special group at risk of compromised health or with lack of coping ability and require support (McNamara and Rosenwax, 2010).

As discussed in section 7.3.2.1, the findings of the current study show that some nurses were full of hope when caring for patients and encouraged family carers not to lose hope because their relative may still recover. Some family carers were seen to remain hopeful despite the condition of their relatives. Although there is a stage at which the patient's condition becomes hopeless for both the nurses and family carers. When nurses and family carers noticed that the patient's condition continued to deteriorate without any sign of improvement they began to lose hope. However, nurses said they continued to care for patients at the same time encouraging family carers. Most often patients were brought to the hospital in a debilitated condition due to economic hardship, ignorance, and poor health seeking behaviour. They came to the hospital as the last option after they had tried all other

means of treatment and failed, and they were expecting a miracle to happen.

9. 3.3 Patients and family carers' support needs

Patients and family carers have varying needs during end-of-life care, and nurses are expected to ensure these needs are met. These needs include physical, emotional, financial, and spiritual needs. Nurses in this study carried out routine nursing care which is more the technical aspect of care as described in Chapter Three. Fundamental care which mainly involves physical care was left in the hands of family carers. Spiritually sometimes an Imam or a priest was invited to come and talk to the patients and the relations depending on their religious faith. For financial needs, nurses referred patients to the social welfare department. Both patients and family carers expressed concern over their unmet needs, and the inability of nurses to meet their expectations. This is in contrast with a study conducted in a developed country by Robinson et al. (2015), where patients admitted in the hospital had their palliative and end-of-life care needs and expectations met. As a result of the inability of the nurses in the current study to meet up with the patients' needs, family carers tried their best to safeguard patients by protecting them from any harm and advocating for them. They performed their roles as family carers diligently, at times they went the extra mile to carry out some aspect of the nurse's role.

Patients and family carers also complained about lack of privacy. As a result, family carers often needed to compete for the one or two available screens that were not really in good condition to provide privacy. Providing privacy is essential when caring for patients and is regarded as an aspect of dignity in the care of patients especially at the end of life. Family carers waited their turn to get the screen for their relatives which made it difficult to provide privacy for them. It was also observed that family carers delayed physical care to their loved ones due to lack of sufficient screens to provide privacy.

9.4 Barriers and Facilitators to end-of-life care

This section discusses the participants' views regarding factors that hinder or enable effective end-of-life care. Throughout the study, participants highlighted several factors that affected the provision of quality end-of-life care. All participants considered economic factors as a contributor to poor end-of-life care. Also included for discussion in this section were bureaucratic managerial processes in the hospital, language barrier, feelings of fulfilment about care, perceived factors that can promote end-of-life care included improving drug supplies and improved workforce, training, and rewards or incentives.

9.4.1 Barriers to end-of-life care

Family carers were described as barriers to the provision of quality end-of-life care by the nurses. It was noted that some of the family carers became very aggressive when interacting with the nurses, some even threatened to beat the nurses. These kinds of behaviours put the nurses off which may invariably affect the quality of care delivered to patients. Sometimes family carers prevented nurses from carrying out certain procedures such as suctioning, passing an NG-tube or administering oxygen thinking that the patient would die. The nurses contributed to this because it was observed during the study that the nurses did not explain procedures neither did they seek consent from patients and their family carers when carrying out procedures. Therefore, it is imperative for nurses to educate patients and their family carers regarding any procedure to be carried out for a patient. At the same time, nurses need education in communication skills in addition to palliative and end-of-life care education. In a similar finding by (Royak-Schaler et al., 2006, Dunn et al., 2005), nurses reported family as a barrier to the provision of good end-of-life care due to their hostile behaviours, ignorance about life support, and refusal to accept the patient's poor prognosis.

As discussed in Section 8.1.1.1, patients and their family carers expressed concern about hospital bills and other healthcare expenses. Even in a public hospital owned by the government, patients buy their

drugs and pay for feeding, laboratory investigations, and other hospital services. Patients and family carers considered the high cost of healthcare to be a major barrier due to their economic situation. Some of them said friends and family members had been donating generously toward the care of their loved ones. Others said to have sold or leased their farmlands, and other resources to care for their loved ones. This finding is similar to that of Gardiner et al. (2014) where family carers sold their properties or collect loans to handle care expenses. Nurses were also affected by this financial constraint, thus affecting the quality of care they provided for patients. Findings from this study show that some patients could not afford to pay for hospital services or buy their drugs; therefore, nurses referred them to the social workers for assistance.

There were instances when nurses wanted to administer drugs to patients, but the drugs were not available, even a surgical glove some patients found it difficult to buy, which sometimes affected the care delivered by the nurses. It was also confirmed during some of the observations that family carers were asked to go to the pharmacy to buy drugs, and others to go to the accounts department and settle their bills, but had no money. In a nutshell, lack of finance is a significant burden to patients and their family carers especially when end-of-life care is prolonged. In the work of Grbich et al. (2001), the cost of medications was commonly mentioned as a barrier to effective end-of-life care, especially when drugs were unavailable from an inpatient facility. To reduce the economic burden of care at the end of life, and to fulfil the wishes of some patients to die at home, Robinson et al. (2015) suggest the idea of reducing hospitalisation at the end of life. Although some patients with palliative care need benefit from the hospitalisation. However, in the current study family carers were allowed to care for their loved ones in the hospital and the same time pay for the services, which they could equally do the same at home. This means that if they could get the necessary support home-based care would have been the

best for them by reducing the economic burden and allow patients to die at home.

The current study also found that the hospital management was unable to provide the required equipment for quality of care at the end-of-life. Equipment like suction machines and oxygen apparatus were inadequate, and the few available ones were faulty, while pulse-oximeters were unavailable in the whole medical unit of the hospital. Reducing admission at the end of life, and allowing patients to die at home saves hospital's cost (Gardiner et al., 2014), and this could have helped the hospital to provide the necessary equipment. However, contrary to this idea, in the current study, the benefit is from the perspective of the patients. All the nurses interviewed expressed concern especially when they were caring for a patient at the end of life, when most patients require suctioning and oxygen administration. It was also noticed that patients had to travel for up to 200km to another hospital for services such as CT scanning or dialysis due to a failure of the machines. In a previous study on family perspectives on end-of-life care experiences in nursing homes (Wetle et al., 2005), inadequate supplies and poor equipment maintenance were also highlighted as barriers to good end-of-life care.

Generally, problems related to logistics such as availability of working materials like bed tables to write on, lockers to keep patient's items in, screens to provide privacy, and consumables were found to be a major setback in this study. For example, patients provided for themselves cotton wool and spirit for injection; nurses sometimes used their own money to buy stationery for documentation because the hospital failed to provide those items. Even in cases of emergency family carers were asked to go and buy items like syringes, cannulae, and catheters for their patients. There were emergency trays in all the wards in the medical unit, however, during observations, all the trays were almost empty only a few items were available (adrenalin injection, vitamin K Injection, endotracheal tube, nasogastric tube, pairs of gloves and xylocaine injection). In addition to small numbers of nurses per shift due

to the shortage of staff, nurses wasted a lot of time drawing lines on sheets of paper to record their activities which invariably affected patient care. The amount of time spent in drawing lines was enough to carry out some procedures on one or more patients.

Beckstrand et al. (2006), also found that the shortage of nurses contributes to poor nursing care delivery at the end of life thus preventing a good death. The current study demonstrated that nurses were the healthcare professionals most affected by this shortage, where two nurses, or sometimes one nurse, was caring for more than 30 patients or more. Shortage of nurses causes the patients to suffer lack of attention, poor quality of care and unfriendliness from the nurses, and thus increases pressure and anxiety.

Apart from the shortage of staff, infrastructural decay (see Section 8.1.2.5) was also found to have hindered good quality end-of-life care in the hospital. For instance, some of the family carers reported cases of power failure resulting in total blackout and nurses used the flashlight from their phones to provide nursing care to patients. Also, cockroaches were sighted in the storage boxes within the wards, and the management did nothing about that. These findings were in line with the previous work of (Thompson et al., 2008), where nurses identified poor physical features of an environment as an impediment to providing good end-of-life care. According to Wallerstedt and Andershed (2007), lack of support, poor leadership and inadequate resources are sources of stress among nurses. The conditions of service in the hospital were discouraging, nurses reported having spent many years without attending a course, seminar or workshop outside the hospital, and allowances were not paid for several years. The security system in the hospital was poor, visitors came in and out of the ward whenever they liked, and visitors could abuse nurses and may even threaten to beat them.

Additionally, language difficulties have also been found to be a barrier to good quality end-of-life care (Andershed, 2006), which is in line with

the current study. The hospital is in the northern part of the country where the Hausa language is dominant. It was possible to experience a language barrier as discussed in Section 8.1.3.

9.4.2 Facilitators to end of life care

Although nurses were faced with several challenges when providing care to patients at the end of life, there was still that sense of accomplishment. In the current study, nurses were reported to have expressed satisfaction and a feeling of fulfilment even if the patient eventually died after they provided their care effectively. Nurses said there was a feeling of joy whenever they were able to provide care at the end-of-life to the patient, and the patient died with dignity. Caring for patients at the end of life provides a sense of accomplishment and a feeling of self-worth (Amendolair, 2011), also satisfying the patients' and their family's wishes remained the driving force for nurses (Wallerstedt and Andershed, 2007), and influenced a positive outlook on nurses' life (Zheng et al., 2015). However, some of the nurses in the current study expressed a feeling of dullness throughout the day whenever they realised that something was missing in the care delivered to patients, thus preventing them from fulfilling the wishes of the patients and their families. This finding is supported by previous work by Zheng et al. (2015) where nurses tended to criticise themselves for their inability to provide the desired care to the patients and their families.

9.4.3 Factors that can promote end-of-life care

The current study suggests that some factors, when put in place, could promote care at the end of life. These factors were directly related to the poor managerial processes and hospital's policies. If the management could improve drug supplies, improve workforce, provide rewards or incentives to staff, and encourage staff training and development, certainly the quality of care at the end of life could be improved.

9.4.3.1 Improvement of drug supply

Patients and family carers complained about inadequate drug supplies in the hospital, they said sometimes, family carers travelled for a distance of up to 20km or more to buy drugs. Apart from the stress of going to buy the drug, there is the possibility of buying drugs that are not genuine which is very detrimental to the patient.

9.4.3.2 Improvement of staffing levels

Similarly, nurses required the hospital management to employ more nurses because they considered it as part of the solution to the manpower problem thereby improving the quality of care. They emphasised the need for specialist nurses especially in the area of palliative and end-of-life care, and critical care.

9.4.3.3 Provision of rewards or incentives

The hospital management seems to have neglected the issue of staff welfare, sometimes their wages were delayed which hindered their performance. Most of the nurses lived at a distance from the hospital because of lack of accommodation within the hospital and found it difficult to reach the hospital because there were no standard means of transportation. They either used their private cars for those that had them or used public transport. Moreover, nurses reported delivering care to the patients diligently and putting in their best without any encouragement from their ward heads, or the management, even their allowances were not paid for several months.

9.4.3.4 Staff training

All the nurses in this study complained of a lack of opportunities to further their education and attend training, workshops, and seminars. Most nurses said they had forgotten about many procedures learned in school, for example, some of them were asked to assess an unconscious patient but were unable to do so. There is a need for the hospital management to strengthen their knowledge and skills for better patient care. Updating nurses' knowledge through conferences, seminars, and workshops would be of great benefit for both patients and nurses, thus improving the quality of care at the end of life.

9.5 Study implications

In this study, the needs and problems of participants during end-of-life care were identified. The implications of the study could help to influence practice, education, research, and policy.

9.5.1 Implications for practice

The results of this study have provided valuable insights that further our understanding of how nursing care is delivered at the end of life. To the best of my knowledge, this study is the first to explore the process and experiences of nursing care of patients at the end of life in a Nigerian hospitals from the perspective of nurses, patients, and family carers. The findings show that there is no clear pathway to approach end-of-life care in the setting. Nurses and family carers deliver care independently and parallel to each other. Therefore, the model of care developed from the current study (nurses-family carers care model) when adapted would provide a new approach to good end-of-life care that is ethically and culturally acceptable. This could be achieved when nurses incorporate family carers when making decisions, and also in the care of their loved ones. This bridges the communication gaps, reduces anxiety and hostility, and establishes rapport among nurses, patients, and family carers, thus making the ward environment conducive for care delivery.

The findings suggest that nurses need to engage actively in the care of patients, especially in fundamental care, this provides the nurses with an opportunity to carry out their physical assessment during fundamental care thus reducing the risk of pressure ulcers and other conditions related to immobility. Nurses in this study also felt that it was part of their responsibility to make sure that the patients and family carers received sufficient information regarding patient care and to ensure accurate record keeping. Throughout this study, family carers and patients felt that nurses and other healthcare professionals were not providing either adequate information or the care needed by patients. Therefore, the study suggests training in communication skills is needed for nurses to improve interaction with patients, family carers

and other healthcare professionals. Nurses should also collaborate with other healthcare professionals to provide quality care for their patients. Patients should be encouraged to voice their problems, ask questions about their care plan, and to take part in decision-making about their care. The hospital management and other stakeholders should also consider the following:

-Creating a separate ward for end of life care patients.

- Collaborative care between nurses and family carers.

- A 50% reduction of hospital bills to all patients admitted to an end of life care ward to compliment the effort of the family carers because hospital bills are paid out of pocket.

- Setting up a formal caregiving agency to serve as a pool for families in need of caregivers. This is because of a cultural shift in the family structures in which the extended family is gradually declining, and the nuclear family is becoming more popular among the younger generation. Therefore, caregiving in the near future may move from the family members to care agencies.

9.5.2 Implications for education

There is a fundamental gap affecting the approach to palliative and end-of-life care in our hospitals when caring for patients. This study indicated that nurses have no prior education about palliative and end-of-life care, and many of them were not willing to accept the challenges of staying up-to-date with education and developing new skills in their practice. Therefore, it becomes necessary for nurses to seek palliative and end-of-life care education, and at the same time improve their knowledge through continuing education programmes post-registration. According to Gysels et al. (2011) nurses trained and working in palliative care settings demonstrate a more positive approach and have a better awareness of patients' needs at the end of life compared to nurses with no palliative and end-of-life care training**.** In Nigeria there is an absence of palliative and end-of-life care modules in the curriculum of medical and nursing training institutions, there is also a lack of proper

understanding of the need for palliative care by health care professionals and a lack of public awareness. These challenges could be overcome through sensitising policymakers, stakeholders, and educational institutions to the need to include palliative and end-of-life care in both the undergraduate and postgraduate medical and nursing curriculum through:

- Curriculum development on palliative and end of life care education and practice for both undergraduate and postgraduate nursing and medical education

- Training of registered nurses on palliative and end of life care

- Continuing professional development on issues related to palliative and end of life care through seminars, workshops, and conferences.

9.5.3 Implications for research

There is a dearth of literature relating to palliative and end-of-life care in Nigeria; only a few sources were found (Onyeka et al., 2013). It is suggested that similar studies to this one should be conducted across the country and other sub-Saharan countries. Studies of patient and family perceptions of what is considered to be a good death should also be conducted. Both nurses and family carers recommend that patients at the end of life should be separated from other patients in the general medical units to an end of life care ward in order to have proper care and attention, thus improving the quality of care received by the patients. When such is implemented, research needs to be conducted to determine the impact of the separation on the quality care received by the patient.

- When nurses are trained on palliative and end of life care, a research should be conducted to determine the impact of the training on the quality of care provided.

9.5.4 Implications for policy

The results of this study highlighted some of the barriers faced when providing end-of-life care. Hospital management needs to consider

rewards and incentives to motivate staff, and also ways of addressing logistical problems. Palliative and end-of-life care is not integrated into the mainstream health system in Nigeria which is a major challenge. Policy makers and professional bodies need to consider the possibility of the implementation of the following recommendations:

- Development of policies on palliative and end of life care education and practice

- Integration of palliative and end of life care into the mainstream of the Nigerian healthcare system.

- Engaging with policy makers, especially members of the national assembly (members of the parliament) and stakeholders on policies regarding palliative and end of life care in Nigeria.

- Development of guidelines and care pathways that are culturally congruent with the Nigerian healthcare system.

9.6 Study Strengths and limitations

9.6.1 Study strengths

To my knowledge, this is the only study that has explored the process and experiences of nursing care of patients at the end of life from the perspectives of nurses, patients, and family carers. The study occurred in a real-life setting; therefore findings go beyond what is known already and contribute significantly to our understanding of the current palliative and end-of-life care practice. This study used a qualitative research approach combining participant observation and semi-structured interviews to enhance the credibility of the findings. Adopting this research approach allowed me to develop a direct account of how end-of-life care was practiced. Participant observation explored an in-depth understanding of the study phenomenon, while the interviews allowed the participants to share their experiences of delivering and receiving care at the end of life.

The study was conducted in one of the university teaching hospitals in northern Nigeria. The hospital serves as referral centre most especially

for cancer cases from all over the federation; is referred to as the centre of excellence for oncology. It is anticipated that there is a greater likelihood of transferability of results from this study to other settings because of its diverse nature in terms of patients and personnel.

9.6.2 Study limitations

Research studies usually have limitations including the current study. There were limitations to the data collection and analysis, during the observation periods there may have been changes in nurses' behaviour due to my presence at the bedside and being observed. Another limitation is the inability to provide a detailed account of the activities because sometimes field notes could not be recorded during periods of observation in order to limit the tension that may arise in the nurses. However, a detailed account of my data collection and analysis methods has been provided, and I also remained neutral during data collection by constantly reminding myself and the participants of my researcher's role. Most of the nurses said they had never participated in a qualitative study. They were very anxious about having their voices recorded during the interviews, despite the assurance of anonymity, some even asked if they could be given the interview guide to answer in the form of a questionnaire. Two patients were unable to participate in the interview due to unconsciousness, and they could have provided different perspectives, which were not represented in the study. Some participants have also contributed more than others due to their experiences, interests, and nature of their illness.

9.7 Conclusion

This study explored in-depth experiences and understanding of the nursing care of patients at the end of life from the perspective of nurses, patients, and family carers. To the best of the researcher's knowledge, this study is the first to explore the process and experiences of the nursing care of patients at the end of life in hospital. A qualitative ethnographic case study research design was employed to gain an in-depth and detailed description, understanding and explanation of

ordinary occurrences as experienced by those in the field. My philosophical viewpoint (interpretive paradigm) and the research question governed the selection of the approach. Participant observations and semi-structured interviews were used as the tools for data collection. Four major themes were presented as distinct chapters with several sub-themes that further explained the major themes. Findings from this study show that patient care was in three-fold: care by nurses, care by family carers, and care by both nurses and family carers (collaborative care). The nurses delivered care to patients at the end of life without a clear pathway or a definitive approach, due to the absence of policies and guidelines. Palliative and end-of-life care is not included in either undergraduate or postgraduate medical and nursing curriculum and is not integrated in the mainstream healthcare system in Nigeria. Family carers were fully involved in the care of the patients to ensure the wellbeing of their loved ones. Both nurses and family carers had varying experiences ranging from a feeling of fulfilment, to some degree of discomfort to emotional distress. It was clear from the findings that most of the patients did not have their needs met. The financial burden was a significant barrier to delivering care because patients and their family carers pay for their healthcare services. While patients and their family carers expressed dissatisfaction with the care they received, nurses attributed the poor quality of care to inadequate staffing levels, decayed infrastructure, logistical problems and poor conditions of service. Healthcare professionals, policymakers, and all stakeholders need to collaborate on how best to help patients and their family carers and how to strengthen healthcare institutions. This could be achieved by introducing palliative and end-of-life care to both the undergraduate and postgraduate medical and nursing curriculum, by developing policies and guidelines, and by integrating palliative and end-of-life care into the mainstream healthcare system of the country.

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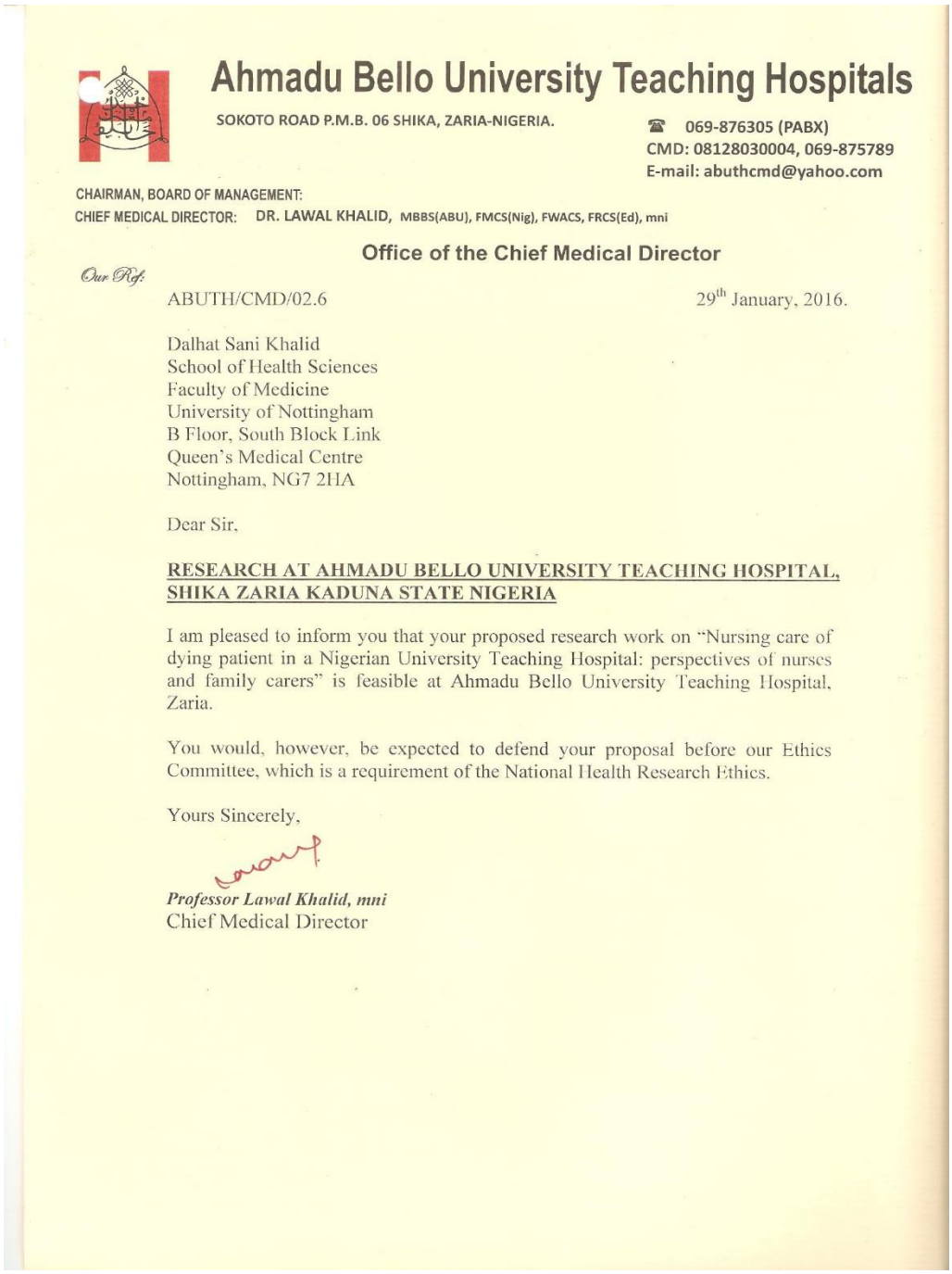
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Appendices

Appendix One: Feasibility letter



Ahmadu Bello University Teaching Hospitals

SOKOTO ROAD P.M.B. 06 SHIKA, ZARIA-NIGERIA.

☎ 069-876305 (PABX)
CMD: 08128030004, 069-875789
E-mail: abuthcmd@yahoo.com

CHAIRMAN, BOARD OF MANAGEMENT:
CHIEF MEDICAL DIRECTOR: DR. LAWAL KHALID, MBBS(ABU), FMCS(Nig), FWACS, FRCS(Ed), mni

Office of the Chief Medical Director

Our Ref: ABUTH/CMD/02.6

29th January, 2016.

Dalhat Sani Khalid
School of Health Sciences
Faculty of Medicine
University of Nottingham
B Floor, South Block Link
Queen's Medical Centre
Nottingham, NG7 2HA

Dear Sir,

RESEARCH AT AHMADU BELLO UNIVERSITY TEACHING HOSPITAL, SHIKA ZARIA KADUNA STATE NIGERIA

I am pleased to inform you that your proposed research work on "Nursing care of dying patient in a Nigerian University Teaching Hospital: perspectives of nurses and family carers" is feasible at Ahmadu Bello University Teaching Hospital, Zaria.

You would, however, be expected to defend your proposal before our Ethics Committee, which is a requirement of the National Health Research Ethics.

Yours Sincerely,

Professor Lawal Khalid, mni
Chief Medical Director

Appendix Two: Approval letter from University of Nottingham Ethics Committee

The University of Nottingham

Direct line/e-mail
+44 (0) 115 8232561
Louise.Sabir@nottingham.ac.uk

Faculty of Medicine and Health Sciences

Research Ethics Committee
C/o Faculty PVC Office
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

24th October 2016

Dalhat Sani Khalid
PhD Student
Nottingham Centre for Advancement of Research into Supportive, Palliative and End of Life Care (NCARE)
School of Health Sciences
Room B33, B Floor
QMC Campus
Nottingham University Hospitals
NG7 2UH

Dear Dalhat

Ethics Reference No: OVS12092016 – **please always quote** **ABUTH Feasibility ref no:** ABUTH/CMD/02.6	
Study Title: Exploring the processes and experiences of the nursing care of patients who are dying in a Nigerian University Teaching Hospital: healthcare professionals, patients, and family carers perspectives. **Short Title:** Nursing Care of patients who are dying.	
Chief Investigator/Supervisors: Professor Gina Higginbottom, Mary Seacole Professor of Ethnicity and Community Health, School of Health Sciences, Professor Karen Cox, Professor of Cancer and Palliative Care, Nottingham Centre for Advancement of Research into Supportive, Palliative and End of Life Care (NCARE), School of Health Sciences.	
Lead Investigators/student: Dalhat Sani Khalid, PhD Student, Nottingham Centre for Advancement of Research into Supportive, Palliative and End of Life Care (NCARE), School of Health Sciences.	
Type of Study: PhD, overseas, Zaria-Nigeria	
Proposed Start Date: 09/2016	**Proposed End Date: 31/05/2017** 9mths
No of Subjects: 30-45	**Age:** 18+years
School: SoHS	

Thank you for submitting the above application which was considered by the Committee and the following documents were received:

Short Title: Nursing care of patients who are dying:

- Application form version 1.0 date 23/08/2016
- Letter from Chief Medical Director confirming Feasibility at Ahmadu Bello University Teaching Hospital Zaria, Nigeria dated 29th January 2016
- Protocol Final Version 1.0 date 23/08/2016
- Recruitment poster version 1.0 date 23/08/2016
- Participant information Sheet (Nurses) version 1.0 date 23/08/2016
- Consent Forms x 2 (Nurses) Final version 1.0: 23/08/16
- Interview Topic Guide (Nurses) version 1.0: 23/08/2016
- Participant Information Sheet (Family Carers) Final version 1.1 23/08/16
- Consent Forms x2 (Family Carers) Final version 1.0: 23/08/16
- Interview Topic Guide (Family Carers) version 1.0: 23/08/16
- Participant Information Sheet (Patients) version 1.0: 23/08/2016
- Consent Forms x 2 (patients) version 1.0: 23/08/2016
- Interview Topic Guide (patients)

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

The University of Nottingham

A Favourable opinion is given on the understanding that all appropriate ethical and regulatory permissions are respected and followed in accordance with all local laws of the country in which the study is being conducted and those required by the host organisation/s involved.

A favourable opinion is given on the understanding that the conditions set out below are followed:

1. Please submit copies of letters of permission/approval from the Ahmadu Bello University Teaching Hospitals Health Research Ethics Board when these are available for our records.
2. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).
3. You must notify the Chair of any serious or unexpected event.
4. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.
5. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

pp Lamiegatsi

Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix Three: Approval letter from ABUTH Ethics Committee

HEALTH RESEARCH ETHICS COMMITTEE

AHMADU BELLO UNIVERSITY TEACHING HOSPITAL

SHIKA - ZARIA, NIGERIA.

E-mail: abuthshika@yahoo.com website: www.abuth.org

Chairman of Board: Chief. Shuaib Oyedokun Afolabi *Fnil*
Chief Medical Director: Prof. Lawal Khalid, *MBBS, FMCS, FWACS, FRCS(ED) mni*
Chairman, Medical Advisory Committee: Prof. Abdullahi Mohammed, *MBBS, FWACP, FICS*
Director of Administration: Barr. Ishak Bello, *LL.B, BL., LL.M, PGDM, AHAN, FCAI*

Our Ref: ABUTH/HREC/CL/05 Date: 25th January, 2017

Your Ref: _____

ABUTH HREC FULL ETHICAL CLEARANCE CERTIFICATE

Exploring the Process and Experiences of Nursing Care of Patients who are Dying in Ahmadu Bello University Teaching Hospital, Zaria-Nigeria: Nurses, Patients, and Family Carers Perspectives.

ABUTH Ethics Committee assigned number:	-	ABUTHZ/HREC/Y4/2016
National Health Research Ethics Comm. NO.	-	**NHREC/10/12/2015**
Name of the principal Investigator:	-	**Mr. Dalhat Sani Khalid**
Address of the Principal Investigator:	-	School of Health Sciences, University of Nottingham, UK.
Date of receipt of valid application:	-	14th November, 2016
Date of meeting when final determination On ethical approval was made:	-	24th January, 2017

This is to inform you that the research described in the submitted protocol, the consent forms and other participant information materials have been reviewed and ***given full approval by the Health Research Ethics Committee.***

Please note: this approval dates from **25th January, 2017 - 25th January, 2018**

No participant recruitment into this research may be conducted outside these dates.

All informed consent forms in this study must carry the ABUTH HREC number assigned to this research and the duration of ABUTH HREC approval of the study.

This HREC expects that you submit your application as well as an annual report for ethical clearance renewal 3 months prior to expiration of study dates. This is to enable you obtain renewal of your approval and avoid interruption of your research.

If there is delay in starting the research, please inform the ABUTH HREC so that starting dates can be adjusted accordingly.

No changes are permitted in the research without prior approval by ABUTH HREC, except in circumstances outlined in national code for Health Research Ethics: http://www.nhrec.net.

ABUTH HREC reserves the right to conduct compliance assessment visits to your research site without prior notification.

Prof. Aisha. I. Mamman *MBBS, FMCPath*
Chairperson, ABUTH HREC

Appendix Four: Study poster

Ahmadu Bello University
Zaria - Nigeria

The University of Nottingham
UNITED KINGDOM • CHINA • MALAYSIA

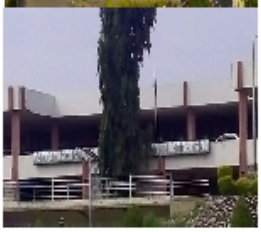
EXPLORING THE PROCESS AND EXPERIENCES OF NURSING CARE OF PATIENTS WHO ARE SERIOUSLY ILL IN AHMADU BELLO UNIVERSITY TEACHING HOSPITAL, ZARIA-NIGERIA: NURSES, PATIENTS, AND FAMILY CARERS PERSPECTIVES

Dalhat Khalid, Prof Gina Higginbottom and Prof Karen Cox
School of Health Sciences, University of Nottingham

What is this study about?

Palliative and end of life care is an international issue but is receiving very little formal attention in Sub-Saharan Africa, research to inform adequate palliative and end of life care in Africa is at an early stage and many research areas need to be explored. Previous studies were carried out in western countries, but the information is culturally incongruent and not transferrable to poor resource context like Nigeria. This means that the information exists will not necessarily be helpful because of the cultural sensitivity, values and beliefs attached to end of life care in Nigeria. The proposed research aims to address this gap in current knowledge and identify implications for practice. By exploring the process and experiences of nursing care of patients who are seriously ill, there is also the potential to subsequently provide a better understanding to nurses, patients, and family carers.





Ahmadu Bello University Teaching Hospital, Zaria-Nigeria .

What is involved?

At least a week of participant observation, and

An average of 60 minutes interview





- If you are interested and need further information or queries please contact:
- Dalhat Sani Khalid
- Tel: +2348026509010
- Email: ntxds6@nottingham.ac.uk

Appendix Five: Karnofsky performance status

Score	Status
100%	Normal, no complaints, no signs of disease
90%	Capable of normal activity, few symptoms or signs of disease
80%	Normal activity with some difficulty, some symptoms or signs
70%	Caring for self, not capable of normal activity or work
60%	Requiring some help, can take care of most personal requirements
50%	Requires help often, requires frequent medical care
40%	Disabled, requires special care and help
30%	Severely disabled, hospital admission indicated but no risk of death
20%	Very ill, urgently requiring admission, requires supportive measures or treatment
10%	Moribund, rapidly progressive fatal disease processes
0%	Death

Adopted from www.npcrc.org

Appendix Six: Case profiles

CASE 1

Age of the patient	70 years
Occupation	Retiree
Ward	MMWA
Date of Admission	15/12/16
Duration of Admission	2 Months
Diagnosis	Type II DM
Problems	Was admitted fully conscious, after a month of admission he becomes totally dependent due to a state of unconsciousness, developed pressure sores on the hips due bedridden.
Nursing Actions	- Monitoring blood glucose 6 hourly - Changing position 3 hourly - N.G – tube feeding 4 hourly - Monitoring input and output - Daily dressing
Family carer	Son – 31-year-old, hold a national diploma and a government employee.
Interactions and observations	The family carer prepared pap and milk in a cup and informed the nurse which she responded promptly. She fed the patient with about 300 – 400mis via the N.G tube. After the feeding, the nurse wheeled a dressing trolley to the patient's bedside and said that she wants to dress the patient's wound (pressure sore) which was developed as a result of hospitalisation. She asked the family carer to bring out the dressing materials. She did the dressing, changed the patient's position and left. The nurse came and asked the FC to prepare the food for the patient (milk and pap) while taking over. The FC prepared the food and informed the nurse. At 2:50 pm the nurse came and fed the patient via nasogastric tube. The accounting clerk asked the patient to go and pay some amount of money that they owe to the hospital. The FC said that he has no money, he needs to call his people at home. When he was asked about the patient's condition during an observation, the family carer said to Allah be the glory. He said the nurses were always there for them despite some challenges which were common in this type of situation. He said the nurses were trying when you compare their number with that of the patients, there must be challenges of taking longer times during medication coupled with the coordination of the patients. The family carer said that their main problem was that they combined seriously ill patients and other patients. Patient like my father needs total care but get less attention. The nurse said in an interview that feeling that a patient is dying is really a pathetic situation, so as a nurse I try to do my possible best and make sure patient is kept alive and once he is going to die let him die a peaceful death,
Interviews	Nurse and family carer only.

Case 2

Age of the patient	**52 years**
Occupation	Driver
Ward	MMWB
Date of Admission	06/02/17
Duration of admission	3 Weeks
Diagnosis	Repeated Stroke/ D.M
Problems	The patient had a previous admission five months ago due to a similar condition. The patient was readmitted to the hospital following another episode of stroke and difficulty of breathing. He is conscious and alert but on frequent oxygen therapy.
Nursing Actions	- Monitoring blood glucose 6 hourly - Changing position 4 hourly - Oxygen therapy PRN - Monitoring input and output
Family carer	Son -20-year-old secondary school Student
Interactions and observations	The FC changed the patient's position; he also applies sudocream on his earlobe to prevent pressure sore. The family carer called the nurse to check the fluid of oxygen which she did. The family carer observed that the patient was exerting pressure on the ankle joint, the attention of the nurse was drawn in which she asked the FC to blow air into two surgical gloves which she put between the two legs at the ankle joints. The patient had his blood glucose tested which was within normal range. The nurse told the FC to prepare the food, and the nurse serves the food via an NG-tube. The patient is on oxygen and I.V fluid. The nurse came and observed the patient's vital signs but no explanation was given before and after the procedure. The patient complained about the food the hospital serves and the hospital bills, and he said the management should reduce the medical fee because it was too high and the food they provided was too small.
Interviews	Nurse, patient and family carer

Case 3

Age of the patient	**53 years**
Occupation	House Wife
Ward	FMWA
Date of Admission	13/01/17
Duration of Admission	41 Days
Diagnosis	Ischemic stroke
Problems	Had developed a pressure sore on the sacrum, the patient is in an unconscious state and dependent upon the nurses and family carers.
Nursing Actions	- Changing position 3 hourly - N.G – tube feeding 4 hourly - Monitoring input and output - Drug administration
Family carer	Daughter – 24-year-old Banker, Hold a Master degree in Accounting and Auditing
Interactions and observations	A doctor from the oncology team visited the patient to find out about the review by the neuro-surgeons, the doctor went through the patient's case notes. The nurse asked the FC to prepare food (pap + milk); she prepared the food for the patient waiting for the nurse to come and serve. The nurse used a mortar and a pestle to crush drugs (locovid 100mg and cognitol 5m) which she administered via NG – tube after the feeding. The family carer said she feels good to care for her mother. She said: 'I pray Allah heals her, because I love to see her work on her feet again, but never the less I am happy to be here. That I have the opportunity to care for my mum financially, morally and everything'. When she was asked concerning the nurses, she said: Some of them let me use this word because some of them have been nice, although it is their job, let me say they have been doing what they are supposed to do, it may not be all, there are some that they don't do it. But the basic things they do like serving medication, attending to you when you need them may be when her breathing is not normal we call them they bring whatever like oxygen, this and that as in the basic thing they do some of them do it'.
Interviews	Nurse and Family carer only

Case 4

Age of the patient	**75 years**
Occupation	Farmer
Ward	MMWB
Date of Admission	01/03/17
Duration of Admission	1 Week
Diagnosis	Sepsis with DM
Problems	Developed septicaemia and was confused. Fever and chills were present, had difficulty in respiration, dysuria, nausea, and vomiting and severe muscle cramp.
Nursing Actions	- Changing position 3 hourly - N.G – tube feeding 4 hourly - Monitoring input and output - Drug administration - Tepid sponging PRN
Family carer	Son – 33-year-old civil servant, hold a master's degree in sociology
Interactions and observations	The nurse asked the FC to bring out the drugs he bought from the pharmacy, and the nurse served the patient intravenous ceftriaxone and left, she returned after 15 minutes and recorded it. While recording the injection the FC was asked about what the patient took in the morning, and he said pap, she then asked about the amount he showed a cup of 300mls to her, and she recorded it. This patient is on strict input and output, but the nurse is not paying the required attention to it. FC and his brother screened the patient's bed cleaned him up, changed his clothing and started making the bed. As they were doing that the unit head came around, she called the nurses to take over from the Family carers. The FCs made the bed and put the patient in a comfortable position. The nurse said her experience of care was not easy, especially when turning heavy patients and cleaning them. She said sometimes, the patients mess up the place after cleaning, and you start cleaning all over which was not really easy. She gave an example of patient on bed three, when he was given a bed bath, and having his dress on, the patient will still defecate. Doctors came to see the patient reviewed his laboratory results and study the X-ray disc in their computer and said that the chest was clear.
Interviews	Nurse, patient and family carer

Case 5

Age of the patient	**45 years**
Occupation	Trader
Ward	MMWA
Date of Admission	29/02/17
Duration of Admission	2 Weeks
Diagnosis	CLD
Problems	The patient's abdomen was distended due to ascites which is an accumulation of fluid in the abdomen. There was constipation due to a decrease in intestinal motility. Poor appetite, anorexia, and difficulty in swallowing. Vomiting of blood and jaundice.
Nursing Actions	- Monitoring input and output - Drug administration - Parenteral nutrition
Family carer	Brother – a 30-year-old teacher
Interactions and observations	The patient had difficulty in swallowing, and the nurse informs the doctor about the patient's condition. The Patient vomited blood in the night, and his doctors were informed. The doctors suggested that an NG-tube should be passed to the patient. The nurse came with a piece of paper with NG-tube written on it and gave the FC to go and buy. The FC went and bought the NG-tube, and informed the nurse. The nurse brought a tray containing the requirement for the insertion of NG-tube and inform the patient that he wants to put the NG-tube to him which he successfully did. The issues of patient's education on what an NG-tube is, why the insertion and also an informed consent were compromised. The nurse came to serve drugs, and he asked the FC to bring out the patient drugs, then checked for the ones that were due for serving, he crushed the drugs using mortar and pestle and served the patient via the NG-tube. The patient asked the nurse for how long will he stay with the NG-tube, the nurse reassured the patient and told him it would be removed as soon as his condition improves. The family carer said the nurses were trying their best because they were always there to serve the patient his medication. The family carer narrated some of the problems they were facing especially with the doctors, that if they complained to them they will not take any action.
Interviews	Nurse, patient and family carer

Case 6

Age of the patient	**65 years**
Occupation	Trader
Ward	FMWB
Date of Admission	28/02/17
Duration of Admission	1 Month
Diagnosis	Right Hemispheric stroke
Problems	A weakness of the left side of the face, arm, and leg, inability to walk, swallowing problems. The patient developed pressure ulcers due to decreased mobility.
Nursing Actions	- Changing position 3 hourly - N.G – tube feeding 4 hourly - Monitoring input and output - Drug administration
Family carer	Daughter - 24-year-old Housewife with no formal education
Interactions and observations	The FC gave the patient a bed bath and changed the bed sheet which was given by the nurse. The FC used wide polythene at the middle of the bed to cover the bed sheet to prevent it from soiling, and she also placed a wrapper on the polythene. The patient was then placed comfortably on her right lateral position. The FC took the soiled clothes out to wash, the nurse came and asked about the FC I told her she has gone out to wash the soiled clothes. The nurse looked for the patient's drugs and served via the NG-tube, observes the vital signs and recorded. The nurse came and observed the patient's vital signs and recorded. She noticed a rise in temperature (38.8^{oc}) so she exposed the patient and tepid sponged. The nurse came and served the patient's drugs via the NG-tube. While serving the drugs, she asked the FC to prepare the food for the patient after which she served and documented. Physiotherapy team came and exercised the patient's limbs, applied some powder and changed her position. The nurse said to me in an interview that they manage two types of stroke; the ischaemic and the haemorrhagic stroke. She added that the ischaemic stroke has a better prognosis than the haemorrhagic stroke. Likewise she said patients with cardiological conditions especially with stage IV New York heart disease don't do well because they have to be constantly on oxygen. Once there is cut off of the supply of oxygen, such patients suffered a lot.
Interviews	Nurse, patient and family carer

Case 7

Age of the patient	**38 years**
Occupation	Driver
Ward	MMWA
Date of Admission	30/12/16
Duration of admission	4 Months
Diagnosis	Tuberculosis/Retroviral disease
Problems	Fever, leaking fluid from the catheter site, shortness of breath, Chest pain
Nursing Actions	-Daily wound dressing - Tepid sponging PRN - Care of the chest-tube
Family carer	Businessman Aide – 32-year-old
Interactions and observations	The patient told me that the doctors don't care about him, and students will come and be asking him silly questions. He pointed at his chest tube and said he spent 12 days with it. He said they don't care about him, and they only do their practice with him. He questioned the nurses and said: "where are the nurses when I am taking the drugs?" The family carer said sometimes if he needs something from them, we do go and inform the nurses. Especially when his condition changes, some of them answer us while others shout at us that we were disturbing them too much. The family carer said to me, you know how life is, different people with a different character. He said he usually tells the nurses that if he didn't tell them whom should he tell? Also in an interview, the nurse explains her role in the care of this patient, and she said it involves total nursing care which includes bed bath, oral care, treatment of pressure area changing of linens when dirty, changing of position, monitoring of I.V fluid, maintaining of intake and output, and monitoring of vital signs. Feeding of the patients via NG-tube for those that can't tolerate oral feeding, psychological and spiritual support to patient and relatives.
Interviews	Nurse, patient and family carer

Case 8

Age of the patient	**60 years**
Occupation	Hose wife
Ward	FMWA
Date of Admission	31/03/17
Duration of Admission	10 Weeks
Diagnosis	Sepsis/ Diabetes Mellitus
Problems	A case of diabetes mellitus with septicaemia. There was a presence of hyperthermia, breathlessness, dysuria, nausea, and vomiting. The patient was also having a chronic wound on his foot (Diabetic foot)
Nursing Actions	- wound dressing - Tepid sponging PRN - strict monitoring of input and output - Drug administration - Oxygen administration PRN
Family carer	Daughter – 25-year-old advanced level student
Interactions and observations	During an observation, the family carer bathed her mother, fed her and made comfortable. The nurse came and administered the drugs to the patient including an injection. The patient had a fever, and the nurse asked the family carer to do tepid sponging for the patient. The nurse told the daughter that she should not give her food much of carbohydrates, and should not allow her to get hungry. The family carer narrated her situation and she said "I am a student. I left my school, I also had to suspend other issues. I haven't taken my bath for the past two days. You will not eat well, you will not sleep well because in the middle of the night they will get up, you have to follow them gradually, and they will say they need this, and they need that. It has not been funny; someone impatient will not be able to tolerate these."
Interviews	Nurse, patient and family carer

Case 9

Age of the patient	**58 years**
Occupation	Trader
Ward	FMWB
Date of Admission	26/03/17
Duration of Admission	5 Weeks
Diagnosis	End Stage Renal disease
Problems	Inability to urinate, fatigue, drowsiness, dry and itchy skin. Breathlessness and oedema.
Nursing Actions	- Changing position 4 hourly - Oxygen therapy PRN - Monitoring input and output - Renal dialysis three times a week - Drug administration
Family carer	Daughter – 30-year-old Businesswoman
Interactions and observations	The patient pays ₦1, 800/cylinder (£3.60) and they can have 3-4 cylinders of oxygen in a day, depending on the severity of the condition. Patient with end-stage renal failure have a very poor prognosis because of the environment, and some of them have to be on dialysis two to three times a week. Only a few of them can afford it. Some of them have an accumulation of fluid, and they die because they cannot afford dialysis or renal transplant. The nurse said that the patient was not getting the best because the hospital is constrained and the patient lacks enough finance, so there were mixed feelings. She said in an interview: "well is not encouraging because we don't have the facilities to care adequately for those patients; actually I am not happy about it. Sometimes it can be stressful, the burnout, there was a time I was on night duty we lost three patients because our hands are tied down we don't have the equipment and the technology to asses our patients."
Interviews	Nurse, patient and family carer

Case 10

Age of the patient	**57 years**
Occupation	Librarian
Ward	FMWB
Date of Admission	03/04/17
Duration of Admission	3 Weeks
Diagnosis	Acute kidney injury
Problems	Inability to urinate, fatigue, drowsiness, dry and itchy skin. Breathlessness and oedema.
Nursing Actions	- Changing position 3 hourly - Renal dialysis two times a week - Monitoring input and output - Drug administration
Family carer	Son – A 28-year-old civil engineer and self-employed
Interactions and observations	The family carer commended that some of the nurses were trying their best, but some of them are better than the others. He said: "There were some that don't allow me to touch the mess up, I allowed them to do the necessary clean up, and I assisted them to her, lift her or turn her to the necessary position. They needed to clean the stool and her private part after removing the diaper they put it inside a bag, and they give me to go and discard it." He said he was doing his possible best in caring for her, because she is his mother. That a healthy person supposed to look after the sick ones. And he was looking into God to know what to do, so he ensured all the necessary support for her to come back to normal life. He lamented on the inability of the senior doctors to see his mother every day. He said they left her in the hands of the young ones that were using her for their practice and damaging some of her veins all over her hands. He wished that she was separated from other people because of her critical condition, to a special place with advanced nurses and doctors to look after her. The nurse said some of the family carers proved difficult, but they called them and spoke to them one on one, they gave them health talk to take necessary precautions during their period of stay. She said they informed them about the does and don'ts. Some of the patients with financial difficulties we them referred to the social welfare department. During the interview the nurse narrated some of the challenges that they faced. But she said the work had been already signed, so any challenge that comes their way they face it. Some patient relatives can even go to the extent of raising a hand to a nurse at work; some will just be talking to you somehow because they are losing their loved ones.
Interviews	Nurse, patient, and Family carer only

Case 11

Age of the patient	**55 years**
Occupation	Businessman
Ward	MMWB
Date of Admission	17/02/17
Duration of Admission	17 Weeks
Diagnosis	Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
Problems	Patient cannot walk, cannot move even his finger. Completely dependent and confined to bed.
Nursing Actions	- Changing position 3 hourly - Monitoring input and output - Drug administration
Family carer	Wife – 47 years old Diploma
Interactions and observations	The patient accused the nurses of being harsh when delivering care. He said most of the nurses were only sitting down and documenting every day that they slept well, they ate, they drank water, and that was all. He asked me to check his file to see what was written. He added that sometimes, the nurse would not come and see them but can tell that or report that they slept well, the nurses might not even greet you, but they can say you slept well. But it's not true because they don't even know your condition. The observation of the patient was not there. The patient also said that another funny thing was that nurses cannot put a cannula to you, nurses cannot give an injection to you, and then what is their work? It means if there is no doctor and the patient needs drip (I.V Fluid) it means he/she cannot have it? An incident happened during one of the observation where the nurse underserved the patient his drug. The patient said: "Look at it in front of you the nurse just gave me four tablets, if I don't know what I am doing I am taking only the four tablets he gave me. But because I know how many drugs I am taking I told him I am taking eight to nine tablets why can't he give me all? So this is a very good experience in front of you happened." The family carer said their priority in the hospital was to make a payment, even if the patient is dying. For example, a patient that requires oxygen, the relative is asked to go and pay, bring the receipt and then have the oxygen in situ. Most of the death in this hospital is out of negligence. Oxygen has been absent in the hospital for the past two days. There was a patient that died; the nurses only stopped the oxygen and left the corpse on the hand of the relations. On the other hand, the nurse described the challenges they were facing in two folds, one from the management, and the other from the patients and their relatives. He said, from the management side, there was a lack of enough facilities and lack of enough staff to cover the shift or the ward itself. For example, a large ward with many patients but only one or two nurses cared for them. One or two patients are enough for a nurse to spend many hours to give total care.
Interviews	Nurse, patient and Family carer

Case 12

Age of the patient	**47 years**
Occupation	Teacher
Ward	FMWB
Date of Admission	11/05/17
Duration of Admission	3 weeks
Diagnosis	Chronic myeloma
Problems	Weakness, fatigue, dizziness, shortness of breath, total dependence
Nursing Actions	- Changing position 4 hourly - Oxygen therapy PRN - Monitoring input and output - Drug administration
Family carer	Daughter – 26 years old teacher B.A (Ed)
Interactions and observations	The family carer said that she was doing her best to make sure that her mother was clean and tidy because she cannot do anything for herself, she changes her diapers, adjusts her position especially now that she is on oxygen to ensure that it flows well. Also when the nurses come on ground to do their work, she assists them with what they need; like gloves, syringes whatever they want to use. The family carer asked her younger sister who was there before her whether to call the nurses to do the cleaning? The younger sister said no they were the one to clean her. All the nurses knew her condition but none of them have ever come to say I will clean her and we said no. The family carer said she never made any move to ask the nurses to clean their mother because her sister told her out of ignorance that it was their responsibility. But she said she was happy to do it because she is her mother. The family carer said to have experienced anxiety and fear, and it was a painful moment for her seeing her mother in that condition, and could not do anything, and the people she thought they could help were not of any use. And the doctors were nowhere to be found; they did not leave any phone number. When she had a discussion with doctors, they told her that her case seems to be a little bit hopeless, which was a sad moment and had to go after the doctors, asking if there is any hope for her mother. She said they were objective to her, and they said they should hope for the best. But she said she doesn't want to give up on her mother, so she was praying hard and hope for the best. The family carer said that one of the nurses surprised her for being vigilant and observant by noticing that she had not been eating well. It means she was caring for both patients and their relatives.
Interviews	Nurse, patient and Family carer

Case 13

Age of the patient	**45 years**
Occupation	Housewife
Ward	FMWA
Date of Admission	28/04/17
Duration of Admission	6 weeks
Diagnosis	Diabetic ketoacidosis
Problems	Patient said before her hand was operated, it uses to hurt her a lot; she would be doing mhm, mhm, mhm or be shouting. She said she was always thinking of her family at home, her kids are all boys, and they cannot cook for themselves. Intermittent hypoglycaemic coma.
Nursing Actions	- Daily dressing - Changing position 2 hourly - Monitoring input and output - Drug administration
Family carer	Husband – a 53-year-old driver
Interactions and observations	The family carer explained to me about the care of his loved one; he said whatever he will do with regards to her health was his responsibility and was more or less out of love. So he had to do everything that could bring her sound health. He said it was not easy especially in the hospital because where they stayed was not comfortable, but they put all those aside and took the challenge because the focus was the sound health. He put away the stress and sees everything as an easy thing to do. On a lay man's aspect, he said he had no grudges with what the nurses were doing. But he narrated his concern on the risk of leaving the patient because there was a time he went to buy drugs in the town when he returned he met the wife in hypoglycaemia. He met her sweating, and quickly brought out her glucometer and tested her sugar level, then he discovered it was below the normal level, based on his little experience he was able to overcome that without drawing the attention of any of the nurses or doctors. The patient said she expected that the nurses should be cleaning the patients, but she didn't see them doing it for anybody, and the husband was willing to do it, so they didn't bother to call them. The nurse talked about meeting the patients' needs, and she said all fingers are not equal, for instance, if a patient comes into the ward and is not buoyant enough to provide some of the needs they refer the patient to the welfare unit in the hospital, sometimes they involved the place of worship that such a patient needs help. If they can be able to provide one or two things that the patient needs.
Interviews	Nurse, patient and Family carer

Case 14

Age of the patient	**46 years**
Occupation	Civil servant
Ward	MMWB
Date of Admission	05/02/17
Diagnosis	Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
Problems	The patient had two previous admissions prior to the current admission. He said to have been on Catheter since April 2016. His condition was called Gullian Barry Syndrome (CIDP), so there was numbness that set from the lower limbs unto the upper limbs. Patient also developed bed sore.
Nursing Actions	- Changing position 3 hourly - Monitoring input and output - Drug administration
Family carer	Brother - 35 Adv. Diploma Self-employed
Interactions and observations	The patient described his situation as someone having a condition called Gullian Barry Syndrome, CIDP. The patient lost sensation from the lower limbs unto the upper limbs. The only way he experienced full bladder was when he began to sweat profusely even when the fan was on. The patient needs help all the time, because he uses diapers, so he always calls for help. He said there was a time when the ward gave him money for personal use, to get some drinks because of hypoglycemia. In most cases as a result of when sugar level drops or something like that. The patient described his concerns, he said "Another thing is this, now look around, you don't see any of the senior doctors, all you can find is the house officers who are not if you ask me going by the profession called medicine a house officer is he who hasn't hatched yet. In the area of managing the hospital, honestly speaking if I have to score the management I will score them below 50. It is written everywhere, incompetence and you know nonchalant attitude. Honestly speaking I appreciate you coming around. This is going to serve as a medium, as a window for me to express all that I have been nursing all the feelings and the anger that I have always had about the way things are turned around. One other thing is, I don't know if it is associated or as a result of the environment.
Interviews	Nurse, patient and Family carer

Appendix Seven: Example of field notes

CASE 1-MMWA	Unit No	Age – 70 years	Occupation – Retiree
Tribe – Hausa	Date of Admission – 15/12/16	Diagnosis – Type II DM	Religion – Islam

Nursing Actions	Daily dressing	Monitoring blood glucose 6 hourly	Changing position 3 hourly
	N.G – tube feeding 4 hourly	Monitoring input and output	

Date& Time	Observation	Reflection
13/02/17 8:30am 10:06am 10:20am 11:30am	Two nurses came and ask the family carer (FC) whether he bath the patient, the family carer said he did. The nurses went ahead and made the bed. The head of nursing department visited the ward and met the nurse observing the patient's vital signs, she asked the nurse if there is any problem, the nurse complained that the sphygmomanometer is faulty. The nurse was asked to submit a request for a new one. The nurse told the family carer that is time for feeding and she left to the next patient. The family carer prepared pap and milk in a cup and informed the nurse which she responded promptly. She fed the patient with about 300 – 400mis via the N.G tube. The nurse wheeled a dressing trolley to the patient's bed side and said that she wants to dress the patient's wound (pressure sore) which was developed as a result of hospitalization. She asked the family carer to bring out the dressing materials. She did the dressing, changed patient's position and left.	The nurses relinquished part of their responsibility to the family carers. Bathing of the patients is one of the fundamental nursing task and the nurses left it in the hand of the family carers. The head of nursing department is carrying out a supervisory role that will bridge the gap between the management and the staff. It has become a tradition for the nurses to engage the family carers in their fundamental and routine care. I felt that the nurse should have informed the patient and the family carer and obtained consent prior to the procedure. There was no any interaction during the procedure and no documentation after the procedure.
14/02/17 2:00pm 2:30pm	Met the patient lying down on a dorsal position while the family carer sitting on a chair with his head on the patient's bed. I greeted the family carer and asked about the patient's condition, he said the condition remain the same, that he begins to lose hope.	There is feeling of hopelessness by the family carer because he is not witnessing any improvement from his father.

3:30pm 4:00pm 6:00pm	The nurse came and asked the FC to prepare the food for patient (milk and pap) while taking over. The FC prepared the food and inform the nurse. At 2:50pm the nurse came and fed the patient via naso-gastric tube. After the feeding the nurse left and the FC parked the feeding utensils and washed them. When the FC returned from washing the utensils, he cleaned the patient's sweat from his face and changed his position. I asked the FC about the patient's feeding, he expressed dismay especially nurses delay in feeding the patient which keeps on changing the feeding time. Five of the patient's relations came for visitation. The nurse came and tested the blood glucose and then served the patient's drugs via the naso-gastric tube after crushing the drug using mortar and pestle. The nurse recorded the drug given on the patient's chart and moved to the next patient.	
16/02/17 8:30am 10:00am 11:00am	During the handover patient was calm lying on the left lateral position. After the handover the family carer asked the nurse to change his patient's bed sheet because is dirty, the nurse told him that they don't have enough to go round for all the patients. The FC removed the one on the bed and used his own bed sheet for the patient, he went and wash the bed sheet himself. The FC prepared the food for the patient and inform the nurse. Doctors came for the ward round, they reviewed the patient's condition and added a drug to his treatment. They inspect the pressure sore and said that is healing after which the nurse dressed the wound. The account clerk asked the patient to go and pay some amount of money that they owe the hospital. The FC said that he has no money, he needs to call his people at home.	In a situation like this there is need to prioritize patients' care and needs. Patient and the family carer are seriously facing financial problems.

Appendix Eight: Participant information sheet for nurses

Participant information sheet (Nurses)

Exploring the Process and Experiences of Nursing Care of Seriously ill Patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

Name of Researcher(s): Dalhat Sani Khalid, Professor Gina Higginbottom and Professor Karen Cox

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team members will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Please do ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of the study is to explore the process and experiences of nursing care of seriously ill patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria. We are interested in finding out how is nursing care delivered to seriously ill patients in the hospital. It is also essential to generate evidence of clinical and health services data, to ensure that end-of-life care service provision is effective, appropriate, acceptable, ethical and culturally competent.

Why have I been invited?

You have been invited to take part in this study because you are delivering care to the patient who is receiving care during the end of life and as someone who might be interested in taking part in the study.

Do I have to take part?

No. It is up to you to decide whether to take part or not. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form to say that you have agreed to take part in the study and understand what this involves. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

If you decide you would like to take part, you will be observed while delivering care to patients during the end of life. After the period of observation, you will be invited to participate in an interview. This can take place in your office, or any other private location of your choice. With your permission, the interviews will be recorded using a digital audio recorder. The

interview will be about the process and your experiences of delivering care to seriously ill patients.

What are the possible disadvantages and risks of taking part?

We realised that the topic we are studying is emotive. We ask you to consider very carefully how you would feel about sharing your experience with the researcher. It is possible that you may feel upset at some time during the interview. However, you will never be under any pressure to answer questions or talk about topics that you prefer not to discuss. The interviews will focus on your experience and what was important to you. You can stop or take a break at any time.

What are the possible benefits to taking part in the study?

We cannot promise the study will help you but the information we gather may help provide a better understanding about the process and experiences of delivering care to seriously ill patients. It may also help to identify the support needs and improve the care.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence, in accordance with the Data Protection Act, 1998.

All interview data (audio recordings and interview transcripts) will be anonymised and kept strictly confidential, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the university will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data will be kept for 3 – 6 months after the end of the study so that we are able to contact you about the findings of the study if you have told us that you would like to receive these. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

The only circumstances under which confidentiality would be broken would arise if the researchers were made aware of actions or situations resulting in serious risk of harm to yourself or others. The researchers would discuss this with you and consider the need to raise the matter with an appropriate person.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected.

What will happen to the results of the research study?

This project will form part of a thesis for a higher degree and will be reported in publications in nursing/medical journals/presented at various conferences. None of the participants will be identified by name in any reporting of the findings.

The results of the study will also be fed back to the service to ensure professionals are aware of the process and experiences of delivering care to seriously ill patients. All participants will be sent a summary of the findings and recommendations at the end of the study if they would like to receive this.

Who has reviewed the study?

All research in Ahmadu Bello University Teaching Hospital is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given approval by the ABUTH Research Ethics Committee.

What do I have to do?

Please let the researchers know if you are interested in taking part or would like to find out more about the study. They will contact you directly to discuss this. You do not have to respond if you do not want to take part. However, it would be very helpful if you could indicate your position. You may also contact the researchers directly by phone or email using the contact details given below.

Further information and contact details: If you decide you would like to take part or want further information please contact us using the details below if you have any questions

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Appendix Nine: Consent form for nurses

CONSENT FORM (Nurses)
Final version 1.0: 28/06/16

Title of Study: Exploring the Process and Experiences of Nursing Care of Seriously ill patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

REC ref:

Name of Researcher: Dalhat Sani Khalid, Professor Gina Higginbottom and Professor Karen Cox

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number ……dated..... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the study involves participant observation and I agree to take part. ☐
5. I understand that the interview will be audio recorded using an audio recorder and those anonymous direct quotes from the interview may be used in the study reports. ☐
6. I understand that all data will be anonymous and confidential with the exception of information being revealed during the interview which is of concern and may need reporting i.e. potential risks to another person or to myself. ☐
7. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed. ☐
8. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

Appendix Ten: Research topic guide for nurses

Exploring the Process and Experiences of Nursing Care of Seriously ill Patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

Research topic guide for nurses

Background

• Welcome and thank participant
• Introduce interview topics/ researcher
• Confirm the completion of consent form
• Personal details: relationship with patient, age, education, address, employment...etc.

Core interview

- Can you describe your roles as a nurse in the care for patients who are dying?
- Tell me about your experiences in caring for patients who are dying.
- What are your thoughts and feelings about caring for patients who are dying?

- How do you relate with the family carers when delivering care to dying patients?
- How do you meet the needs of both the patients who are dying and their relatives?
- What advice would you give a family carer with regards to end-of-life care experiences?

- What are the challenges of caring for patients who are dying?
- What are the barriers to care of patients who are dying in the hospital?
- What are the facilitators to care of patients who are dying in the hospital?
- What are the educational and support needs in caring for patients who are dying?

Conclusion

• Summary of what has been discussed.
• Any further concerns?
• Thank participants.

Appendix Eleven: Participant information sheet for Family carers

Participant information sheet (Family carers)

Exploring the Processes and Experiences of Nursing Care of Seriously ill Patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

Name of Researcher(s): Dalhat Sani Khalid, Professor Gina Higginbottom and Professor Karen Cox

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team members will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Please do ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of the study is to explore the processes and experiences of nursing care of seriously ill patients in in Ahmadu Bello University Teaching Hospital Zaria-Nigeria. We are interested in finding out how is nursing care delivered to seriously ill patients in the hospital. It is also essential to generate evidence of clinical and health services data, to ensure that end-of-life care service provision is effective, appropriate, acceptable, ethical and culturally competent.

Why have I been invited?

You have been invited to take part in this study because you are a family member looking after your loved one who is receiving care during the end of life and as someone who might be interested in taking part in the study.

Do I have to take part?

No. It is up to you to decide whether to take part or not. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form to say that you have agreed to take part in the study and understand what this involves. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect the medical care given to your loved one.

What will happen to me if I take part?

If you decide you would like to take part, you will be observed on the care delivered to your family member during the end of life. After the period of observation, you will be invited to participate in an interview. This can take place in one of the private rooms in the ward, or any other private location of

your choice. With your permission, the interviews will be recorded using a digital audio recorder.

The interview will be about the process and your experiences of delivering care to your loved one. It will also cover how you relate with the healthcare professionals when delivering care to your family member and find out the barriers and facilitators to the care in the hospital.

What are the possible disadvantages and risks of taking part?

We realised that the topic we are studying is emotive. We ask you to consider very carefully how you would feel about sharing your experience with the researcher. It is possible that you may feel upset at some time during the interview. However, you will never be under any pressure to answer questions or talk about topics that you prefer not to discuss. The interviews will focus on your experience and what was important to you. You can stop or take a break at any time. If you feel this would be helpful, the researcher can give you information about how to access local sources of support.

What are the possible benefits to taking part in the study?

We cannot promise the study will help you but the information we gather may help provide a better understanding about the process and experiences of delivering care to seriously ill patients. It may also help to identify the support needs and improve the care.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence, in accordance with the Data Protection Act, 1998.

All interview data (audio recordings and interview transcripts) will be anonymised and kept strictly confidential, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the university will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data will be kept for 3 – 6 months after the end of the study so that we are able to contact you about the findings of the study if you have told us that you would like to receive these. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain

your confidentiality, only members of the research team will have access to your personal data.

The only circumstances under which confidentiality would be broken would arise if the researchers were made aware of actions or situations resulting in serious risk of harm to yourself or others. The researchers would discuss this with you and consider the need to raise the matter with an appropriate person.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected.

What will happen to the results of the research study?

This project will form part of a thesis for a higher degree and will be reported in publications in nursing/medical journals/presented at various conferences. None of the participants will be identified by name in any reporting of the findings. The results of the study will also be fed back to the service to ensure professionals are aware of the process and experiences of delivering care to seriously ill patients among nurses and family. All participants will be sent a summary of the findings and recommendations at the end of the study if they would like to receive this.

Who has reviewed the study?

All research in Ahmadu Bello University Teaching Hospital is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given approval by the ABUTH Research Ethics Committee.

What do I have to do?

Please let the researchers know if you are interested in taking part or would like to find out more about the study. They will contact you directly to discuss this. You do not have to respond if you do not want to take part. However, it would be very helpful if you could indicate your position. You may also contact the researchers directly by phone or email using the contact details given below.

Further information and contact details: If you decide you would like to take part or want further information please contact us using the details below if you have any questions.

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Appendix Twelve: Consent form for family carers

CONSENT FORM (Family carers)
Final version 1.0: 28/06/16

Title of Study: Exploring the Processes and Experiences of Nursing Care of Seriously ill Patients in a Nigerian University Teaching Hospital

REC ref:

Name of Researcher: Dalhat Sani Khalid, Professor Gina Higginbottom and Professor Karen Cox

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number ……dated..... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the study involves participant observation and I agree to take part. ☐
5. I understand that the interview will be audio recorded using an audio recorder and those anonymous direct quotes from the interview may be used in the study reports. ☐
6. I understand that all data will be anonymous and confidential with the exception of information being revealed during the interview which is of concern and may need reporting i.e. potential risks to another person or to myself. ☐
7. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed. ☐
8. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix Thirteen: Research topic guide for family carers

Exploring the Processes and Experiences of Nursing Care of Seriously ill Patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

Research topic guide for family carers

Background

• Welcome and thank participant
• Introduce interview topics/ researchers/
• Confirm the completion of consent form
• Personal details: relationship with patient, age, education, address, employment...etc.

Core interview

- Can you describe your roles as a family carer?
- Tell me about your experiences in caring for your loved one.
- What are your thoughts and feelings about caring for your loved one?

- How do you feel about communicating / interacting with the nurses?
- Do you have problem regarding interaction with them? Tell me more, give me an example
- Are they available when you need them? Tell me more

- Do you feel satisfy with what they are doing to your loved one? Discuss more
- Any suggestions to improve this?
- What are your educational and support needs when caring for your loved one?

Conclusion

• Summary of what has been discussed.
• Any further concerns?
• Thank participants.

Appendix Fourteen: Participant information sheet for Patients

Participant information sheet (Patients)

Exploring the Processes and Experiences of Nursing Care of Seriously ill Patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

Name of Researcher(s): Dalhat Sani Khalid, Professor Gina Higginbottom and Professor Karen Cox

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team members will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Please do ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of the study is to explore the processes and experiences of nursing care of seriously ill patients in in Ahmadu Bello University Teaching Hospital Zaria-Nigeria. We are interested in finding out how is nursing care delivered to seriously ill patients in the hospital. It is also essential to generate evidence of clinical and health services data, to ensure that end-of-life care service provision is effective, appropriate, acceptable, ethical and culturally competent.

Why have I been invited?

You have been invited to take part in this study because you are classified as one of the patients receiving care as seriously ill patient and as someone who might be interested in taking part in the study.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form to say that you have agreed to take part in the study and understand what this involves. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your medical care or legal rights.

What will happen to me if I take part?

If you decide you would like to take part, you will be observed on the care you are receiving. After the period of observation, you will be invited to participate in an interview. With your permission, the interviews will be recorded using a digital audio recorder.

The interview will be about the process and your experiences of receiving care. It will also cover how you relate with the healthcare professionals when

delivering care to you and find out the barriers and facilitators to the care in the hospital.

What are the possible disadvantages and risks of taking part?

We realised that the topic we are studying is emotive. We ask you to consider very carefully how you would feel about sharing your experience with the researcher. It is possible that you may feel upset at some time during the interview. However, you will never be under any pressure to answer questions or talk about topics that you prefer not to discuss. The interviews will focus on your experience and what is important to you. You can stop or take a break at any time. If you feel this would be helpful, the researcher can give you information about how to access local sources of support.

What are the possible benefits to taking part in the study?

We cannot promise the study will help you but the information we gather may help provide a better understanding about the process and experiences of delivering care to seriously ill patients. It may also help to identify the support needs and improve the care.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence, in accordance with the Data Protection Act, 1998.

All interview data (audio recordings and interview transcripts) will be anonymised and kept strictly confidential, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the university will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data will be kept for 3 – 6 months after the end of the study so that we are able to contact you about the findings of the study if you have told us that you would like to receive these. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

The only circumstances under which confidentiality would be broken would arise if the researchers were made aware of actions or situations resulting in

serious risk of harm to yourself or others. The researchers would discuss this with you and consider the need to raise the matter with an appropriate person.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected.

What will happen to the results of the research study?

This project will form part of a thesis for a higher degree and will be reported in publications in nursing/medical journals/presented at various conferences. None of the participants will be identified by name in any reporting of the findings.

The results of the study will also be fed back to the service to ensure professionals are aware of the process and experiences of delivering care to seriously ill patients among nurses and family. All participants will be sent a summary of the findings and recommendations at the end of the study if they would like to receive this.

Who has reviewed the study?

All research in Ahmadu Bello University Teaching Hospital is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given approval by the ABUTH Research Ethics Committee.

What do I have to do?

Please let the researchers know if you are interested in taking part or would like to find out more about the study. They will contact you directly to discuss this. You do not have to respond if you do not want to take part. However, it would be very helpful if you could indicate your position. You may also contact the researchers directly by phone or email using the contact details given below.

Further information and contact details: If you decide you would like to take part or want further information please contact us using the details below if you have any questions.

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Appendix Fifteen: Consent form for patients

CONSENT FORM (Patients)
Final version 1.0: 28/06/16

Title of Study: Exploring the Process and Experiences of Nursing Care of Seriously ill patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

REC ref:

Name of Researcher: Dalhat Sani Khalid, Professor Gina Higginbottom and Professor Karen Cox

Name of Participant: **Please initial box**

1. I confirm that I have read and understand the information sheet version number ……dated..... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the study involves participant observation and I agree to take part. ☐
5. I understand that the interview will be audio recorded using an audio recorder and those anonymous direct quotes from the interview may be used in the study reports. ☐
6. I understand that all data will be anonymous and confidential with the exception of information being revealed during the interview which is of concern and may need reporting i.e. potential risks to another person or to myself. ☐
7. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred is will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed. ☐
8. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix Sixteen: Research topic guide for patients

Exploring the Processes and Experiences of Nursing Care of Seriously ill Patients in Ahmadu Bello University Teaching Hospital Zaria-Nigeria: perspectives of nurses, patients and family carers

Research topic guide for patients

Background
• Welcome and thank participant
• Introduce interview topics/ researcher
• Confirm the completion of consent form
• Personal details: age, education, address, diagnosis...etc.

Core interview

- Tell me about your experiences of receiving care from the nurses.
- Tell me about your experiences of receiving care from your family member.
- What are your thoughts and feelings about the care you are receiving?
- How do you feel about communicating / interacting with the nurses?
- Do you have problem regarding interaction with them? Tell me more, give me an example
- Are they available when you need them? Tell me more

Conclusion
• Summary of what has been discussed.
• Any further concerns?
• Thank participants.

Appendix Seventeen: Floor plan of the male medical wards

