

**A NURSE-LED PALLIATIVE CARE PROGRAMME FOR WOMEN RECEIVING  
PALLIATIVE CHEMOTHERAPY FOR BREAST CANCER IN GHANA**

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**A thesis submitted to the Faculty of Health Sciences,  
University of the Witwatersrand,  
in fulfilment of the requirements for the degree of  
Doctor of Philosophy.**

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## DECLARATION

I, Gbande Sulleh, declare that this thesis is my own work. It is submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted for any degree or examination at this or any other University.

Signature: 

Date 31/07/2024

Student Identification Number **2536535**, Protocol Number **M220540**

## **DEDICATION**

The entire project is dedicated to all women receiving palliative chemotherapy for breast cancer. It is my hope and prayer that this work would contribute to evidence that would be used to design a global intervention that can support women incapacitated by cancer and empower them to enjoy life by adding life to their days, since their days are numbered.

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# ABSTRACT

**Introduction:** Breast cancer is the most common cancer among women worldwide. In Ghana, the majority of the breast cancer patients present with advanced disease qualifying for palliative treatment only. Palliative chemotherapy is the first line of treatment for women diagnosed with breast cancer. The use of palliative chemotherapy drugs brings about unpleasant life experiences. Yet, there seems to exist no evidence-based nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer in Ghana.

**Purpose of the study:** The study developed, validated and pilot tested a nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer in Ghana.

**Research design and methods:** The study adopted a sequential multi-method design in four phases. Phase 1 consisted of a scoping review; Phase 2 was a qualitative descriptive design with a semi-structured interview guide as a data collection instrument. Based on the results of Phases 1 and 2, Phase 3 developed the palliative nursing care programme that was pilot tested in Phase 4 using an intervention approach and a pre-test post-test method to collect the data. The primary outcome was symptoms' distress reduction while the secondary outcomes were pain reduction, improve quality of life and meet their spiritual needs.

**Results:** The scoping review in Phase 1 resulted in the identification of 110 articles, with 6 of them meeting the inclusion criteria after screening. Fourteen (14) themes were generated and discussed. In Phase 2, three themes and twelve sub-themes were identified from interviewing the patients. Among the palliative care needs recognized were professional information support needs, symptom management needs, psychosocial needs, socio-economic needs, and spiritual needs. In Phase 3, the palliative nursing care programme was developed, building upon the outcomes of Phases 1 and 2, along with the Fitch model. The programme was subsequently validated by experts. In Phase 4, the Wilcoxon rank signed-rank test showed that before the intervention severity of pain among patients was high with a mean score  $m=9.34$  ( $SD\pm 1.04$ ). However, after the intervention the severity of pain among breast cancer patients reduced, with a low mean score  $m=2.75$  ( $SD\pm 0.00$ ), with a significance of  $p\text{-value} \leq 0.05$ .

**Conclusion:**

This study developed a nurse-led palliative care programme based on literature and the needs of women receiving palliative chemotherapy for breast cancer. The programme was validated by experts, and the outcomes have been met as the women experienced reduce pain, improved quality of life, and fulfilment of their spiritual needs.

**Keywords:** Breast Cancer, Palliative Chemotherapy, Palliative care, Nurse-led palliative care programme, Women, Experience, Supportive, Educative and Advocacy programme, Palliative care Needs

## PRESENTATIONS ARISING FROM THIS STUDY

- a. Gbande, S. Obiora, O.L., & Maree, J.E. 2023. Palliative care needs of women diagnosed with advanced breast cancer: International Conference on Cancer Nursing, Glasgow, UK. September 29 – October 2, 2023. Abstract no. 855
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## **ACRONYMS AND ABBREVIATIONS**

<b>ACS:</b>	American Cancer Society
<b>APCA:</b>	Palliative Care Association
<b>BPI:</b>	Brief Pain Inventory
<b>CDC:</b>	Centers for Disease Control and Prevention
<b>ECOG:</b>	Eastern Cooperative Oncology Group
<b>EORTC:</b>	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire
<b>HREC:</b>	Human Research Ethics Committee
<b>HTH:</b>	Teaching Hospital in the Volta Region
<b>IRB:</b>	Institutional Review Board
<b>NCDs:</b>	Non-communicable diseases
<b>NCI:</b>	National Cancer Institute
<b>PC:</b>	Palliative Care
<b>PNC</b>	Palliative nursing care
<b>PROF.:</b>	Professor
<b>QoL:</b>	Quality of life
<b>RCT:</b>	Randomized Control Trial
<b>REC:</b>	Research Ethics Committee
<b>SDG:</b>	Sustainable Development Goals
<b>SDS:</b>	Symptoms Distress Scale
<b>SEA:</b>	Supportive, Educative and Advocacy Programme
<b>SpNQ:</b>	Spiritual Need Questionnaire
<b>U.S.A:</b>	United States of America
<b>U.K:</b>	United Kingdom
<b>WHO:</b>	World Health Organisation

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# CHAPTER ONE OVERVIEW OF THE STUDY

## 1.1 Introduction

This chapter presents an overview of the study, the background, the problem statement, the study aims, the research questions and objectives, the significance of the study, research design and the clarification of concepts used in the study are discussed. An outline of the overall study concludes the chapter.

## 1.2 Background to the Study

Cancer is a major public health concern across the world and has attracted the attention of policymakers and various health care professionals (Allemani et al., 2018). According to the World Health Organisation (WHO), breast cancer is the most common cancer among women worldwide, accounting for 30% of all new cancer diagnoses among women in 2020 (World Health Organisation, 2021). Thus, approximately 19.3 million women were recently diagnosed with breast cancer globally with an estimated 10 million cancer deaths in 2020 (Sung et al., 2021).

In Africa, breast cancer is the most prevalent cancer among women, representing 27.7% of the total number of people diagnosed with cancer. (Bahnassy et al., 2020). Based on the 2020 GLOBOCAN statistics, Africa recorded 186,598 morbidities of breast cancer, and 85,787 mortalities. In addition, statistics on breast cancer vary by region and country within the continent, highlighting the diversity of healthcare challenges and disparities faced by African women in relation to breast cancer (World Health Organisation, 2020a). For instance, Sub-Saharan Africa faces some of the highest breast cancer mortality rates in the world with 20.1 per 100,000 women per year (Anyigba et al., 2021, Adewale, 2023).

In Ghana, breast cancer is the most prevalent cancer among women, mirroring the global and African trends (Ssentongo et al., 2022). In 2020, Ghana reported approximately 4,500 women newly diagnosed with cancer, with 2,200 deaths attributed to the disease during the same year (World Health Organisation, 2020b).

Despite efforts to enhance breast cancer screening and diagnosis in Ghana, it remains concerning that most Ghanaian women present with advanced disease (Bonsu et al., 2014a). According to Agyemang et al. (2021), approximately 60% of Ghanaian women have Stages III and IV cancer when diagnosed. Brinton et al. (2017) and Edmund et al. (2013), suggest several factors contributing to this delayed presentation and advanced breast cancer

diagnoses. These factors include a lack of knowledge about the disease, inadequate recognition and assessment of breast cancer symptoms, deep-seated fears and denial rooted in sociocultural beliefs, geographical location, impediments within the health system, and, in some instances, the aggressive biological characteristics of the tumour (Bonsu et al., 2014a, Agbokey et al., 2019).

Patients with metastatic (Stage IV) breast cancer are treated with palliative intent as the disease cannot be cured (Drageset et al., 2021). Palliative treatment consists of chemotherapy, radiation therapy, hormonal therapy and surgery which are aimed at relieving patients and their families of distressing physical, psychological, social and spiritual symptoms to improve quality of life (World Health Organisation., 2020). Palliative care is delivered by an array of professionals that all have equally important roles to play including nurses, physicians, paramedics, support workers, physiotherapists, pharmacists, and volunteers (World Health Organisation, 2020d). Nurses depend on impeccable assessment of pain and other distressing symptoms to be able to render efficient care.

**Nurse-led** palliative care programmes have gained international recognition for their effectiveness in managing chronic and terminal illnesses. These programmes, led by specialized nurses, are crucial in providing holistic care that addresses not only the physical symptoms but also the psychological, social, and spiritual needs of patients (Grant et al., 2017). The Australian College of Nursing (2020) emphasizes the critical role of nurses in delivering palliative care, highlighting their unique position to offer continuous, compassionate, and patient-centered care.

Globally, nurse-led palliative care programmes have shown significant benefits in improving the quality of life for patients with terminal illnesses (Australian Colloge of Nursing, 2020, Grant et al., 2017). For instance, in high-income countries such as Australia, Canada, and the UK, these programmes are well-integrated into the healthcare system, ensuring that patients receive comprehensive care across different settings, including hospitals, hospices, and at home (Grant et al., 2017). These programmes are characterized by well-structured training for nurses, interdisciplinary collaboration, and robust support systems for both patients and families.

In contrast, the African context presents a different picture. Many African countries face numerous challenges in implementing effective palliative care services, including limited resources, insufficient training for healthcare providers, and a lack of awareness about palliative care among the public and healthcare professionals (Knaul et al., 2018). Despite these challenges, there have been notable efforts to establish nurse-led palliative care programmes in some African countries. For example, in Uganda, nurse-led initiatives have

been pivotal in providing home-based palliative care, significantly improving access to these vital services in rural areas (Kikule, 2003).

### **1.3 Problem Statement**

The incidence of late-stage breast cancer presentation is a significant global health issue, profoundly affecting treatment outcomes (Wilkinson & Gathani, 2022; Arnold et al., 2022a). Globally, many women continue to present with advanced stages of breast cancer, which complicates treatment and reduces the likelihood of successful outcomes. This trend is particularly pronounced in developing regions. In Africa, the situation is even more critical, with a considerable number of women diagnosed at late stages due to factors such as limited access to healthcare, lack of awareness, and socio-economic barriers (Bray et al., 2018). Specifically, in Ghana, a stark example is observed in the Volta Region, where most patients seeking treatment at the academic hospital present with advanced stages of the disease, making curative treatment unfeasible. This local scenario mirrors the broader continental challenges but is exacerbated by region-specific issues such as inadequate medical infrastructure and cultural beliefs about cancer (Anim et al., 2019).

Thus, while late presentation of breast cancer is a global issue, the severity and underlying causes can vary significantly between regions, with Ghana exemplifying some of the most acute challenges seen across Africa. Late presentation of breast cancer necessitates palliative chemotherapy, raising concerns about the financial burden of this treatment and who bears the cost (Carrera et al., 2018; Adanu et al., 2022; Omotoso et al., 2023).

Chemotherapy drugs often cause unpleasant adverse effects that are difficult for patients to cope with and negatively impact their quality of life (Butow et al., 2015a; Gallagher, 2016). These side effects and the harsh experiences associated with the medications frequently lead to treatment attrition (Zhang et al., 2018; Macharia, 2019). Patients who continue with chemotherapy often experience fatigue, nausea, vomiting, hair loss, dysphagia, and pain, without access to a structured palliative care programme (Angelou, 2021).

If this problem remains unaddressed, women with advanced breast cancer will continue to suffer from debilitating disease and treatment related side effects without adequate support, leading to decreased quality of life, higher rates of treatment discontinuation, and potentially earlier mortality. The financial burden on patients and their families will remain unmitigated, exacerbating economic hardships. Moreover, the lack of structured palliative care programmes will result in suboptimal management of symptoms and psychosocial distress, further diminishing the well-being of these patients.

In response to this critical issue, the researcher sought to develop, validate, and pilot test a nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer in Ghana. This study wished to address the identified gaps by providing structured holistic palliative care to improve the outcomes for women with advanced breast cancer in the Volta Region.

#### **1.4 Purpose of the study**

Research purposes are the pivot of a research study, with emphasis on what needs to be accomplished within the scope of a study, thus by the end of the research process (LoBiondo-Wood and Haber, 2021). Purposes are abstract in nature and broad in scope while the objectives of a study are the specific tangibles and achievable goals (LoBiondo-Wood and Haber, 2021). Consequently, this study aimed at identifying the palliative care needs of women who were receiving palliative chemotherapy for breast cancer, and the development of a nurse-led palliative care programme for these women.

#### **1.5 Research Questions**

To address the research problem, this research questions was formulated:

Would a nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer based on the literature and their needs, meet their palliative care needs, reduce pain, improve their quality of life and meet their spiritual needs?

#### **1.6 Research Objectives**

The objectives of the study were to:

1. Describe literature on interventions employed to support women receiving palliative chemotherapy for breast cancer (Phase 1 of the study)
2. Describe the palliative care needs of women receiving palliative chemotherapy in an academic hospital in at the Volta Region of Ghana (Phase 2 of the study)
3. Develop, validate and pilot-test a nurse-led palliative care programme for women receiving palliative chemotherapy. The primary outcome was unmet palliative care needs and the

secondary outcomes were reduction in pain, improve quality of life and meet their spiritual needs (Phases 3 and 4 of the study)

## **1.7 Significance of the Study**

Nurses play a crucial and multi-faceted role in the delivery of palliative care. As integral members of interdisciplinary healthcare teams, nurses provide compassionate and palliative care, addressing not only physical symptoms but also attending to the psychosocial and spiritual needs of patients. Their expert assessment and monitoring skills enable them to manage complex symptoms effectively, mitigating pain and discomfort. Furthermore, nurses act as skilled communicators, facilitating open dialogues with patients and their families to establish care goals and preferences, ensuring a patient's dignity and autonomy are respected throughout their journey. As educators, they provide invaluable support, equipping both patients and their families with the knowledge and skills necessary to make informed decisions about their care. Additionally, nurses offer invaluable emotional support, fostering a therapeutic environment that nurtures trust and a sense of comfort for patients and their loved ones (Coyle and Kirk, 2019, Moran et al., 2021). Their unwavering commitment and advocacy for palliative care promote the provision of compassionate end-of-life care, making an indelible impact on the lives of those they serve (Coyle and Kirk, 2019).

Consequently, the nurse-led palliative care programme has the potential to empower women diagnosed with breast cancer by providing them with essential knowledge, symptom management strategies, and an enhanced quality of life while undergoing palliative chemotherapy (Luo et al., 2021; Faessler et al., 2023). This programme will hopefully contribute to the existing body of knowledge about patient needs, nurse-led palliative care programmes and could serve as a model for other cancer care settings.

## **1.8 Research Design and Methods**

To answer the research questions, a sequential multi-method design was used; the study consisted of four phases. Multi-method is the use of more than one research approach, each undertaken thoroughly and complete in itself (Leedy and Ormond, 2010, Leedy et al., 2019). The results are triangulated to form a comprehensive whole (Leedy and Ormond, 2010). The study was conducted in four phases. Phase 1 answered the first research objective using a scoping review. Phase 2 responded to the second research objective using a qualitative descriptive design with a semi-structured interview guide as a data collection instrument. Based on the results of Phases 1 and 2, Phase 3 developed a palliative nursing care programme that was pilot tested in Phase 4 using an intervention approach and a pre-test

post-test method to collect the data constituting objective three of the study. Table 1.1 illustrates the sequential multi-methods.

**Table 1.1: Illustration of the Sequential Multi-Methods Used**

<b>Phases of the study</b>	<b>Approach</b>	<b>Population and Sampling</b>	<b>Data Collection process</b>	<b>Data Analyses</b>
1. To describe literature on interventions employed to support women receiving palliative chemotherapy for breast cancer.	Scoping review	Qualitative and Quantitative articles (n=6)	Search Engines - Cumulative Index to Nursing and Allied Health Literature (CINAHL) complete, PubMed, MEDLINE Complete, SCOPUS, and ProQuest. Arksey and O'Malley scoping methodology- PRISMA-ScR	Descriptive statistics and content analysis
2. Describe the palliative care needs of women receiving palliative chemotherapy in an academic hospital in the Volta Region of Ghana	Qualitative descriptive	All women receiving palliative chemotherapy for breast cancer at an academic hospital.  Purposive sampling (n=24)	Qualitative interviews as per the semi-structured interview guide	Content analysis

Phases of the study	Approach	Population and Sampling	Data Collection process	Data Analyses
3. Develop and validate a nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer	Develop a nurse-led palliative care programme	Quantitative and Qualitative data triangulation  Experts (n=7)		
4. Pilot-test the nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer	One-group pre-test-post -test intervention	All women attending the nurse-led palliative care programme (n=24)	<p><b>Primary outcome:</b> Unmet palliative care needs: This was measured using a researcher administered questionnaire (Symptom Distress Scale)</p> <p>Secondary outcomes:</p> <p>As identified in Phase 2 of the study using the following researcher questionnaires BPI, SpNQ and EORTC-QLQ BR45</p>	Descriptive statistics  (SPSS)

## 1.9 Underpinning Philosophical Assumption of the Study

According to Burns and Grove (2010), assumptions are statements that are regarded as true even when they have not undergone scientific testing. Similarly, Polit and Beck (2020b) explain assumptions to be fundamental ideas that are believed to be true without evidence or verification. Assumptions are the basis of the theoretical framework or conceptual model of a study, and they guide the selection of research questions, variables, and hypotheses (Polit and Beck, 2020b). Researchers make assumptions about the nature of the phenomenon they are studying, the relationships among variables, the possible outcomes of the study, and the limitations and implications of the findings. It is essential for researchers to be aware of their assumptions and to evaluate them critically to ensure that they are justified and valid. Failing to do so can lead to biased or inaccurate conclusions, which can undermine the credibility and usefulness of the research (Polit and Beck, 2020b). As such, the researcher based his philosophical assumption on Virginia Henderson's basic human needs assumptions.

According to Henderson (1966), the specific role of a nurse is to help patients, whether they are ill or healthy and perform the tasks that promote their health, recovery, or a peaceful death if they had the requisite strength, will, or knowledge to do so on their own. And, to assist the patient in becoming independent as soon as feasible. Nurses help individuals meet their basic needs, including physical, psychosocial and spiritual, and strive to achieve independence in the nurses' care. Henderson (1966) theory emphasises basic human needs and how these needs can be met by nurses. All patients have a fundamental desire for comfort, which can be enhanced with good pain and symptoms management (Henderson, 1966, Henderson, 1991). Henderson (1966) premised her basic human needs theory on four basic concepts termed the metaparadigm.

The nursing metaparadigm involves four key concepts, which are person, health, environment, and nursing. This concept forms the foundation for nursing practice and provides direction to nursing care delivery. Also, the nursing metaparadigm provides a framework for understanding the essential concepts that are relevant to nursing practice (Registered Nurses All Guides about Registered Nursing Schools and Programmes, 2023). It is evident from the above that palliative care is an essential aspect of nursing care for individuals diagnosed with cancer, including women diagnosed with breast cancer who are receiving palliative chemotherapy.

The concept of the person is central to nursing care and involves an individual receiving care. In the context of palliative care for women diagnosed with breast cancer, the person is a woman who has received a diagnosis of breast cancer and is receiving palliative chemotherapy. The person is unique and has her values, beliefs, and preferences, which can influence her response to the diagnosis and treatment. According to Acquaye et al. (2022), a

woman's personal and cultural beliefs about illness, treatment, and death affect the way she copes with the diagnosis of breast cancer and her ability to adhere to the palliative chemotherapy regimen.

The concept of health refers to the state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (World Health Organisation, 1948). In the context of palliative care for women diagnosed with breast cancer, the goal is to improve the quality of life, manage symptoms, and provide emotional and spiritual support. Palliative chemotherapy is used to control symptoms and improve the quality of life in women with advanced breast cancer. According to Shao and Varamini (2022) palliative chemotherapy provides a significant benefit to women with advanced breast cancer by reducing symptoms, improving functional status, and enhancing the quality of life.

The environment concept refers to the physical, social, and cultural context in which the person exists. In the context of palliative care for women diagnosed with breast cancer, the environment includes the hospital or hospice setting, the community, home and the family. According to Zadeh et al. (2018), the environment is essential in the delivery of palliative care as it influences a woman's physical, psychological, and spiritual well-being. The environment should provide a conducive atmosphere that enhances a woman's comfort, security, and emotional support. In this study the environment was the chemotherapy unit of the Teaching Hospital.

The nursing concept is central to the nursing metaparadigm and involves the provision of care to a person in need. In the context of palliative care for women diagnosed with breast cancer, nursing involves providing physical, emotional, psychosocial and spiritual support to women receiving palliative chemotherapy. The nursing role involves managing symptoms, providing pain relief, supporting a woman's emotional and psychosocial well-being, and enhancing a woman's quality of life (Warth et al., 2020). According to Young et al. (2020), nursing care is essential in the delivery of palliative care as it involves close monitoring of a woman's symptoms, provision of supportive care, and education on self-care management.

It is obvious that breast cancer patients undergoing palliative care have complex physical and emotional needs that require comprehensive care. Virginia Henderson's basic need theory (Henderson et al., 1978) provides a framework for understanding the needs of these patients and developing an holistic care plan that addresses all their needs. For example, the physiological needs of breast cancer patients may include pain management, nutrition, and symptom control. The psychological needs of these patients may include counselling, emotional support, and stress management (Henderson et al., 1978). The spiritual needs of these patients may include finding meaning and purpose in life, addressing existential

concerns, and connecting with a higher power. The social needs of breast cancer patients may include social support, family communication, and community involvement (Henderson, 1978, Hinzey et al., 2016).

Palliative care providers can use Henderson's basic need theory to assess and address the complex needs of breast cancer patients (Ndiok and Ncama, 2018). By addressing all a patient's needs, including physical, psychosocial, spiritual needs, palliative care can improve a patient's quality of life, reduce symptoms, and increase her sense of well-being (Henderson, 1964, Ndiok and Ncama, 2018). In summary, Virginia Henderson's basic need theory provides a valuable framework for understanding and addressing the needs of breast cancer patients undergoing palliative chemotherapy.

## **1.10 Theoretical Framework for the Study**

The theoretical framework for this study is the Model for Developing Complex Interventions in Nursing, designed by Margarita Corry and colleagues (Corry et al., 2013). This model consists of several stages: defining the problem (symptom management, psychosocial support), drawing on existing evidence and expertise, designing a tailored intervention, testing it in a clinical setting, implementing and monitoring, evaluating its outcome, integrating it into practice, and ensuring long-term sustainability. This structured approach can enhance the quality of care and support for patients including breast cancer patients, and ultimately improve their quality of life. See section 2.6 of chapter two for details on the theoretical framework.

In addition, the study adapted the Fitch framework for developing the palliative nursing care programme as it holistically addresses the multifaceted needs of women undergoing palliative chemotherapy for breast cancer. Details of the framework and its applications are described in Chapter 7

## **1.11 Clarification of Concepts**

Clarification of concepts refers to the process of making a particular idea, topic, or subject matter clearer and more easily understandable in context. It involves breaking down complex or vague concepts into simpler, more precise terms, so that individuals can grasp the underlying meaning with greater clarity. This process is commonly used in education, communication, problem-solving, and research (Dunn, 2021). Table 1.2 below defines the concepts.

**Table 1.2: Clarification of Concepts**

<b>Concept</b>	<b>Definition</b>
Breast Cancer	Breast cancer is a type of cancer that starts in the cells of the breast. It occurs when the cells in the breast tissue grow abnormally and uncontrollably, forming a tumour. The tumour can either be non-cancerous (benign) or cancerous (malignant). Breast cancer is the most common cancer among women worldwide; it can also occur in men ( National Cancer Institute, 2021a, American Cancer Society, 2022a).
Palliative chemotherapy	Palliative chemotherapy is chemotherapy administered to patients with advanced or metastatic cancer, aimed at managing symptoms, improving comfort, and extending life without curative intent (American Cancer Society, 2022b, Healthline Media LLC, 2023).
Palliative care	According to the World Health Organisation (2020), Palliative care is a multifaceted approach to caregiving with the goal of enhancing quality of life and alleviating distressing symptoms among individuals with severe and complicated illnesses and management of pain and other problems, psychosocial, spiritual and physical (World Health Organisation, 2020d).
Nurse-led palliative care programme	For this study's purpose, a nurse-led programme is when a nurse is responsible for the overall development, implementation, management and continuity of care for a programme.

<b>Concept</b>	<b>Definition</b>
Experiences	The manner and ways the participants in a study underwent chemotherapy and how it made them feel. The feelings may be physical, emotional, cultural, spiritual, or social. It is a process that influences the entire life of an individual or group and might lead to a change of behaviour and way of thinking about life (National Cancer Institute, 2021b).
Women	Females aged 18 years and above in this study.
Support	Support in this study means the researcher provided encouragement and emotional help to breast cancer patients who were receiving palliative chemotherapy for breast cancer (Hui et al., 2013, Fitch et al., 2008).
Education	Education is a process in which and by which the knowledge, characters and behaviours of human beings are shaped and moulded (Banks and Banks, 2019). In this study the educational material will help to impart knowledge, develop the powers of reasoning and judgment, and generally prepare women with the knowledge they need to help identify and seek early treatment for breast cancer for curative rather than palliative care.
Advocacy	Advocacy is an activity by an individual or group that aims to influence decisions within health, political, economic, and social institutions. Advocacy includes activities and publications to influence public policy, laws and budgets by using facts, their relationships, the media, and messaging to

Concept	Definition
	educate government officials and the public (Berghmans et al., 2020). In this study advocacy includes various activities such as media campaigns (both print and social media), public speaking, commissioning, and publishing research findings to make a case for women receiving palliative chemotherapy for breast cancer

This study report is structured as outlined in Table 1.3 below.

**Table 1.3: Layout of the study**

CHAPTER	OBJECTIVE
Chapter One	This chapter presents an overview of the study: the background, the problem statement, the study aims, the research questions and objectives, the significance of the study, research design, clarification of concepts used in the study, overview of the underpinning philosophical assumption of the study and theoretical framework for the study are discussed.
Chapter Two	Literature review and conceptual framework for the study.
Chapter Three:	This chapter discusses the philosophical assumptions in research, design and methods and the development and validation of the palliative nursing care programme.
Chapter Four:	Phase 1: Scoping literature review.
Chapter Five	Phase 2: In-depth interviews of women with breast cancer and receiving palliative chemotherapy.
Chapter Six	Discussion phases 1 and 2.
Chapter Seven	PHASE 3 - Development/adaptation and validation of the palliative nursing care programme

CHAPTER	OBJECTIVE
Chapter Eight	PHASE 4: Pilot testing of the programme.
Chapter Nine:	Implications for practice and recommendations for future research and conclusion.

## 1.12 Summary of Chapter One

Chapter one presented an overview to the study, including the background to the study, study purpose, problem statement, research objectives and questions and significance of the study. Also, definition of concepts used in this study, philosophical assumptions and synopsis of the conceptual framework for the study were described in this chapter.

The next chapter provides an in-depth literature review process and the conceptual framework for the study.

# CHAPTER TWO LITERATURE REVIEW

## 2.1 Introduction

The preceding chapter presented an overview of the study, which comprised of the background to the study, the problem statement, significance, objectives, aim, research questions and operational definition of some concepts used in the study. A brief overview of the research methodology was also outlined. This chapter presents cancer as a global health problem followed by breast cancer and the need for palliative care as presented in the literature. It also explains in detail the conceptual framework for palliative chemotherapy. Literature was reviewed using the following data bases: Cumulative Index to Nursing and Allied Health Literature (CINAHL) complete, PubMed, MEDLINE Complete, SCOPUS, and ProQuest. Key words such as women, palliative, palliative chemotherapy, supportive care, nurse-led, breast cancer and breast cancer treatment and statistics on breast cancer were used in the search process.

## 2.2 Cancer as Global Health Problem

Cancer poses a significant global health challenge, affecting individuals of all ages and backgrounds (World Health Organisation, 2022). In 2021, the global cancer burden was estimated at 18.1 million morbidities, resulting in 9.6 million cancer-related deaths (Sung et al., 2021). Furthermore, approximately one out of every five men and one out of every six women worldwide are expected to experience cancer during their lifetime, and among them, one out of every eight men and one out of every eleven women will die of the disease (Nelson, 2018).

According to the WHO, in 2018, an estimated 43.8 million people were alive who had been diagnosed with cancer in the previous five years (2013-2018). This represents 36 different types of cancer across 185 countries, and includes people who were diagnosed in previous years and are still alive in 2018 (World Health Organization, 2018). However, concerning future trends, it is projected that the number of newly diagnosed cancer patients will increase by approximately 70% over the next two decades (World Health Organization, 2007, Torre et al., 2015). This escalation can be attributed to various factors, including the growing and aging population, changes in lifestyle due to improved social and financial conditions, and alterations in the prevalence of specific causes of cancer (Smetana et al., 2016). Notably, rapidly rising economies have witnessed a shift from cancers linked to poverty and infections to those associated with a more developed way of life (World Health Organization, 2018, Maree et al., 2012).

In the past, the majority (85%) of recently diagnosed cancer patients were concentrated in developed countries, with only a small percentage (15%) occurring in countries with low Human Development Index score (HDI) (Azubuike et al., 2018, Fitzmaurice et al., 2015). However, the scenario is expected to change drastically by 2030, with developing countries bearing about 70% of the global cancer burden (World Health Organisation, 2010, American Cancer Society, 2023). This shift can be attributed to the emergence of different risk factors in developing and newly developed countries, such as improved standards of living, aging populations, adoption of Western diets, increased tobacco and unhealthy food consumption, and decreased physical activity (World Health Organisation, 2020c).

### **2.3 Breast Cancer Statistics in Africa**

In Africa, breast cancer has become a major public health concern for the continent's rapidly growing population, changing lifestyle habits, and increased life expectancy (PennState Health, 2023). In addition, breast cancer incidence in Africa is projected to double by 2040, highlighting the urgent need for effective breast cancer control and prevention measures (The Cancer Atlas, 2023, PennState Health, 2023, Arnold et al., 2022b).

In Ghana, like many other African countries, breast cancer poses a substantial threat to public health (Osei-Afriyie et al., 2021). According to the International Agency for Research on Cancer (IARC) in 2020, Ghana reported an age-standardized breast cancer incidence rate of approximately 46.3 per 100,000 women, and the mortality rate was around 17.4 per 100,000 women (International Agency for Research on Cancer, 2020). In addition, based on the 2020 GLOBOCAN report, Ghana is projected to experience a significant increase in breast cancer cases, with an estimated 4,645 (20.4%) new incidences (Breast Care International, 2023). This number is more than twice the 2,062 new incidences reported in 2012, and unfortunately, approximately 50% of those diagnosed may die due to the disease (Breast Care International, 2023). The main contributing factor to this high mortality rate is primarily late-stage diagnosis and presentation (Breast Care International, 2023).

Furthermore, challenges faced in addressing the breast cancer burden in Africa and Ghana are multifaceted (Blackwell, 2020). Limited resources and infrastructure for cancer screening, diagnosis, and treatment create barriers to early detection and intervention (Blackwell, 2020). Additionally, inadequate awareness and knowledge about breast cancer among the general population contribute to delays in seeking medical attention, resulting in diagnoses at later stages when treatment options may be limited (Blackwell, 2020, Roberts et al., 2022).

Moreover, the lack of sufficient funding for breast cancer research and prevention programmes hampers efforts to develop tailored interventions and improve healthcare services (Aziato and

Clegg-Lampzey, 2015, Asoogo and Duma, 2015). The high cost of breast cancer treatments and the scarcity of oncology specialists further exacerbate the problem, making it difficult for many patients to access timely and quality care (Aziato and Clegg-Lampzey, 2015).

## **2.4 Breast Cancer Diagnosis**

To understand breast cancer survival, it is essential to understand the process of breast cancer diagnosis, grading, staging, and treatment. The initial step in establishing a breast cancer diagnosis involves conducting a comprehensive history-taking and physical examination. Subsequently, a series of diagnostic tests are employed (Rosenzweig et al., 2014, Dollinger, 2002). These investigations encompass a range of assessments and tests to confirm the presence of the illness and identify the specific tumour type, extent, location, and stage (Levesque et al., 2015).

Diverse tests, including physical examinations and investigative procedures like blood tests, x-rays, Computer Tomography (CT) scans, Magnetic Resonance Imaging (MRI), and Positron Emission Tomography scans (PET) can be utilized for diagnosing breast cancer. However, a histopathological examination holds critical importance as it serves to definitively confirm the diagnosis and provides crucial guidance for the treatment and management of patients (Wait et al., 2017, Gordon et al., 2018).

### **2.4.1 Cancer grading system for breast cancer**

A breast cancer grading system, presented in Table 2.1, has been developed to accurately characterize the malignancy of individual tumour diagnoses in humans (Martins-Filho et al., 2017, American Cancer Society, 2022b). This grading system evaluates the extent of malignancy based on cellular anaplasia, diversity, and mitotic activity (Mendoza et al., 2015). By comparing cancer cells to their normal counterparts in terms of appearance and cellular behaviour (Webster et al., 2017), the grading system distinguishes between low-grade tumours, which closely resemble normal cells in appearance and function, and high-grade tumours that exhibit increased aggressiveness and resistance to treatment (Galli et al., 2017). The significance of the breast cancer grading system lies in its vital role in treatment planning and predicting potential outcomes (Xie et al., 2021). By providing valuable insights into the tumour's aggressiveness and potential response to therapies, this system helps medical professionals make informed decisions regarding treatment strategies for patients (Xie et al., 2021, Marta et al., 2014, 2019, Lambin et al., 2013).

**Table 2.1: Grading System for Breast Cancer Malignancy**

<b>Grade</b>	<b>Definition</b>
GX	Grade cannot be determined.
G1	Cells are highly differentiated, resembling cells from their origin, indicating a "low-grade tumour."
G2	Cells are moderately differentiated, resembling normal cells, but exhibiting some malignant traits.
G3	Cells are poorly differentiated, showing few typical cellular features, but the source of cells can still be identified.
G4	Cells are poorly differentiated, with markedly abnormal cellular appearance, making it challenging to determine the source of cells.

Source: American Joint Committee on Cancer (2016).

To choose the most suitable treatment for a particular tumour, it is essential to determine the cancer stage. Tumour staging involves identifying the tumour's extent, location, and the level of its spread, which is done through a step-by-step process (Thomas and Gould, 2020, Galli et al., 2017, America Cancer Society, 2023). The earlier the tumour is detected with minimal spread, the better the chances for successful treatment or disease control.

American Joint Committee on Cancer (2016) employs the "Tumour, Node, Metastasis (TNM) staging system," as presented in Table 2.2, to stage malignancies and define prognostic factors, such as their growth pattern and spread. The TNM system employs T for tumour size or extent, N for the presence or absence of lymph node involvement, and M for the presence or absence of distant metastasis. The assigned numbers (e.g., T3, N2, M1) indicate the degree of tumour size, nodal involvement, and metastasis spread (Galli et al., 2017). Once the TNM staging is determined, it is combined to establish the overall stage of the cancer.

**The TNM classification system serves several important purposes:**

- To stage the tumour at the time of diagnosis,
- To monitor the disease's progression in relation to the typical course of cancer,
- To provide standardized data on which to base treatment options, and
- To specify the prognosis (Galli et al., 2017, American Joint Committee on Cancer, 2016)

**Table 2.2: Tumours, Node and Metastasis Classifications of Breast Cancer**

Classification	Definition
TX	"Primary tumour cannot be evaluated."
T0	"No evidence of primary tumour."
Tis	"Carcinoma in situ (early cancer that has not spread to neighbouring tissue)."
T1-T4	"Size and/or extent of the primary tumour."
NX	"Assessment of local lymph nodes cannot be done."
N0	"No regional lymph node involvement (no cancer found in the lymph nodes)."
N1-N3	"Involvement of regional lymph nodes (number and/or extent of spread)."
M0	"No distant metastasis (cancer has not spread to other parts of the body)."
M1	"Distant metastasis (cancer has spread to distant parts of the body)."

Source: American Joint Committee on Cancer (2016).

Tumours are typically categorized into four stages, namely Stages 1 to 4. Stage 1 represents the mildest form of the disease, while Stage 4 indicates disseminated and advanced cancer. Some cancers may even be classified as Stage 0, denoting non-invasive cancer found only in breast ducts and lobules tissue, with no spread to adjacent tissues (Galli et al., 2017, Webster et al., 2017, Lambin et al., 2013).

The stage of breast cancer at the time of diagnosis plays a crucial role in determining available treatment options and prognosis. It significantly influences the length of survival (Rivera-Franco and Leon-Rodriguez, 2018). Early detection at Stage 1 results in a more favourable prognosis, whereas detection at Stage 4, where the breast cancer has metastasized to other

parts of the body, leads to lower chances of survival (Akram et al., 2017). Therefore, the earlier breast cancer is screened and diagnosed, the better the chances of survival for at least five years after diagnosis (Giaquinto et al., 2022, Siegel et al., 2023).

Unfortunately, many breast cancer patients often seek medical attention when the disease has already progressed to late stages (Stage 3 or 4), making them terminally ill and requiring aggressive treatment with limited chances of survival (Ghandourh, 2016, Clegg-Lamprey, 2017).

## 2.5 Breast Cancer Treatments

As of 2015, the American Cancer Society and Matthews and Choi (2016) have highlighted a variety of treatment modalities available for cancer patients including patients with breast cancer. The choice of treatment modalities depends on factors such as the cancer's location, tumour grade, and stage, as well as the patient's performance status (Kelly and Shahrokni, 2016). The performance status is a measure of a patient's overall well-being and ability to carry out daily activities, and it helps determine their capacity to tolerate therapies like chemotherapy and radiotherapy (Kelly and Shahrokni, 2016, Young et al., 2015). The widely utilized scoring system for this purpose is the "Eastern Cooperative Oncology Group (ECOG)" as presented in Table 2.3.

**Table 2.3: Eastern Cooperative Oncology Group (ECOG)**

<b>Grade</b>	<b>ECOG Description</b>
0	Fully active, able to perform all pre-disease activities without restriction.
1	Restricted in physically strenuous activity but still ambulatory, capable of light or sedentary work, light housework, and office work.
2	Ambulatory and capable of all self-care, but unable to engage in work activities. Up and about more than 50% of waking hours.
3	Capable of only limited self-care, spending more than 50% of waking hours confined to bed or chair.
4	Completely disabled, unable to perform any self-care, and entirely confined to bed or chair.

Grade	ECOG Description
5	Deceased.

Source: The Eastern Cooperative Oncology Group (ECOG) (Oken et al., 1982).

Cancer treatment, including breast cancer, can be approached through various methods, including surgery, radiotherapy, chemotherapy, immunotherapy, targeted therapy hormonal therapy, or a combination of different treatments, which are determined based on the cancer's stage (Jelovac and Armstrong, 2011, Zhou and Li, 2022, National Cancer Institute, 2023). The primary objectives of breast cancer treatment are to either cure the disease or significantly extend the life of the patients while ensuring the best possible quality of life (QoL) for survivors (World Health Organisation, 2018). For individuals with advanced breast cancer and a favourable prognosis, curative treatments should be made available. Simultaneously, palliative anticancer treatments should be administered to prolong survival and maintain the optimal QoL for both patient and family (Akhlaghi et al., 2020a, Laryionava et al., 2018, Heckel et al., 2015).

### 2.5.1 Cancer surgery

Cancer surgery serves various purposes, including diagnosis, tumour staging, cure, palliation, and even prevention in cases of genetic predisposition to certain cancers (Oncology Nursing Society, 2013). This treatment approach can be combined with chemotherapy, radiation, and immunotherapy as part of a comprehensive, multidisciplinary treatment plan.

Curative surgery is the primary treatment used when cancerous tumour cells are confined to a specific body part (Bacchetti et al., 2014). It aims to completely remove the localized tumour and potentially cure the patient of the breast cancer.

Palliative surgery addresses breast cancer in its advanced stages and aims to alleviate distress and discomfort or manage complications related to the disease (Stanford Medicine Health Care, 2023, Bacchetti et al., 2014). While it may not cure the cancer, it helps improve the patient's quality of life.

### 2.5.2 Radiotherapy

Radiotherapy plays a significant and indispensable role in cancer management, especially breast cancer as it often improves survival rates (Lutz et al., 2014). This treatment method

involves focusing a "high-energy" beam of ionizing radiation precisely on cancerous breast tissue, causing damage to the cancer cells (Symonds et al., 2019). By targeting the genetic makeup of the cells, radiotherapy prevents them from growing and dividing, effectively shrinking tumour size, and destroying cancerous cells. Administered as either external beam radiotherapy or brachytherapy, radiotherapy aims to eliminate as many cancer cells as possible while minimizing harm to neighbouring healthy cells (Symonds et al., 2019, Taleghani et al., 2018). To achieve this objective, fractionation is utilized, allowing healthy tissues to recover between treatment sessions (Symonds et al., 2019, Bamps et al., 2018). It's important to note that the effects of radiotherapy remain localized to the treatment area, and the destruction of breast cancer cells occurs gradually over several days, with the DNA damage leading to the death of cancer tissue even after the radiation therapy has ceased, continuing for weeks or more (Symonds et al., 2019).

Radiotherapy can also be used as palliative radiotherapy for breast cancer patients (Jacobson et al., 2021). One of the key benefits of palliative radiotherapy for breast cancer patients is the effective relief of pain. Pain is a common symptom in advanced stages of cancer, and palliative radiotherapy can target painful lesions, bone metastases, or other localized sources of discomfort. A study by Chow et al. (2017) demonstrated the significant pain reduction achieved with palliative radiotherapy in breast cancer patients with bone metastases, highlighting its positive impact on patient well-being. Additionally, palliative radiotherapy contributes to the improvement of overall quality of life for breast cancer patients. By managing symptoms and enhancing physical comfort, patients may experience increased mobility, reduced dependency on pain medications, and a better ability to engage in daily activities. The study by (Gaze et al., 2019) emphasizes the positive impact of palliative radiotherapy on the quality of life in patients with advanced breast cancer, indicating its role in comprehensive palliative care.

### **2.5.3 Breast cancer immunotherapy, targeted therapy, and hormonal therapy**

In recent times, significant advancements have been made in the field of cancer research. This includes the ability to identify specific gene mutations present in various cancers including breast cancer, as well as a deeper understanding of cellular actions and the processes driving carcinogenesis. These developments have led to the emergence of targeted agents and immunotherapeutics (Brant et al., 2019). These innovative therapies offer substantial benefits by inhibiting or destroying breast cancer cells in a more precise and cell-specific manner (Brant et al., 2019, Velcheti and Punekar, 2021).

Immunotherapy for breast cancer involves the use of natural or artificial substances to activate the immune system, enabling it to recognize and combat breast cancer cells (Dine et al., 2017). This treatment approach can either boost the immune system's ability to attack the breast cancer cells or introduce "man-made" immune system proteins to enhance the patient's immune response (Fukumura et al., 2018, Masoudiyekta et al., 2018). Since its inception in 1985, immunotherapy has become a crucial and contemporary option in oncology (National Cancer Institute, 2022, Zacharakis et al., 2022).

Immunotherapeutic methods utilize components of a cancer patient's own immune system to selectively target cancer cells, thereby minimizing side effects associated with conventional treatments (Fukumura et al., 2018, Koury et al., 2018, Zacharakis et al., 2022).

Targeted therapy focuses on specific changes found in breast cancer cells that contribute to their growth, division, and spread. It targets genes or proteins present in breast cancer cells or cells related to cancer growth, such as breast cancer vascular cells (Webster et al., 2017). The development of targeted therapies for various types of cancer is progressing rapidly (Stanford Medicine Health Care, 2023). This approach is pushing the boundaries to significantly improve palliative patient health outcomes and overall quality of life (Chan and Hughes, 2015).

Hormonal treatment, a form of systemic therapy, is prescribed for breast cancer patients whose cancer is influenced by hormones to inhibit tumour growth (Webster et al., 2017, Palumbo et al., 2013). This treatment lowers hormone levels in the body, which helps prevent cancer progression and plays a vital role in the treatment of breast and prostate cancer (Garay and Park, 2012). Hormonal therapy has notably improved disease survival rates in breast cancer patients over a ten-year period (Dowsett et al., 2010), and it has shown positive responses in patients with advanced or metastatic disease (Sweeney et al., 2015).

#### **2.5.4 Chemotherapy, and palliative chemotherapy**

Chemotherapy, which forms part of Systemic Anticancer Therapies (SACT) is a form of tumour therapy that uses cytotoxic treatments to inflict damage on the breast cancer cells (Palumbo et al., 2013, Burstein, 2022). This treatment can target breast cancer cells that have spread to other parts of the body, not just the primary tumour. However, it also affects other rapidly growing cells, as it lacks specificity. While breast cancer cells cannot repair the DNA damage caused by chemotherapy, normal cells have the ability to do so (Pegg, 2011, Behranvand et al., 2022). Consequently, healthy tissues with high replacement rates, such as those in the mouth and intestinal lining, may be harmed by chemotherapy (Pegg, 2011).

In many cases, chemotherapy is combined with surgery or radiation treatment, however, for patients diagnosed with advanced breast cancer, palliative chemotherapy is administered, aimed at managing symptoms, improving comfort, and extending life without curative intent (American Cancer Society, 2023). Symptom management is a critical aspect of palliative care, and studies have highlighted the importance of integrating palliative care interventions alongside palliative chemotherapy regimens (Jaime, 2021)..

Despite the advancements in palliative chemotherapy, several challenges remain. One significant issue is the development of drug resistance, which can limit the effectiveness of palliative chemotherapy over time (Haider et al., 2020). Researchers are actively investigating strategies to overcome drug resistance, such as combining chemotherapy with targeted agents or immunotherapies (Haider et al., 2020).

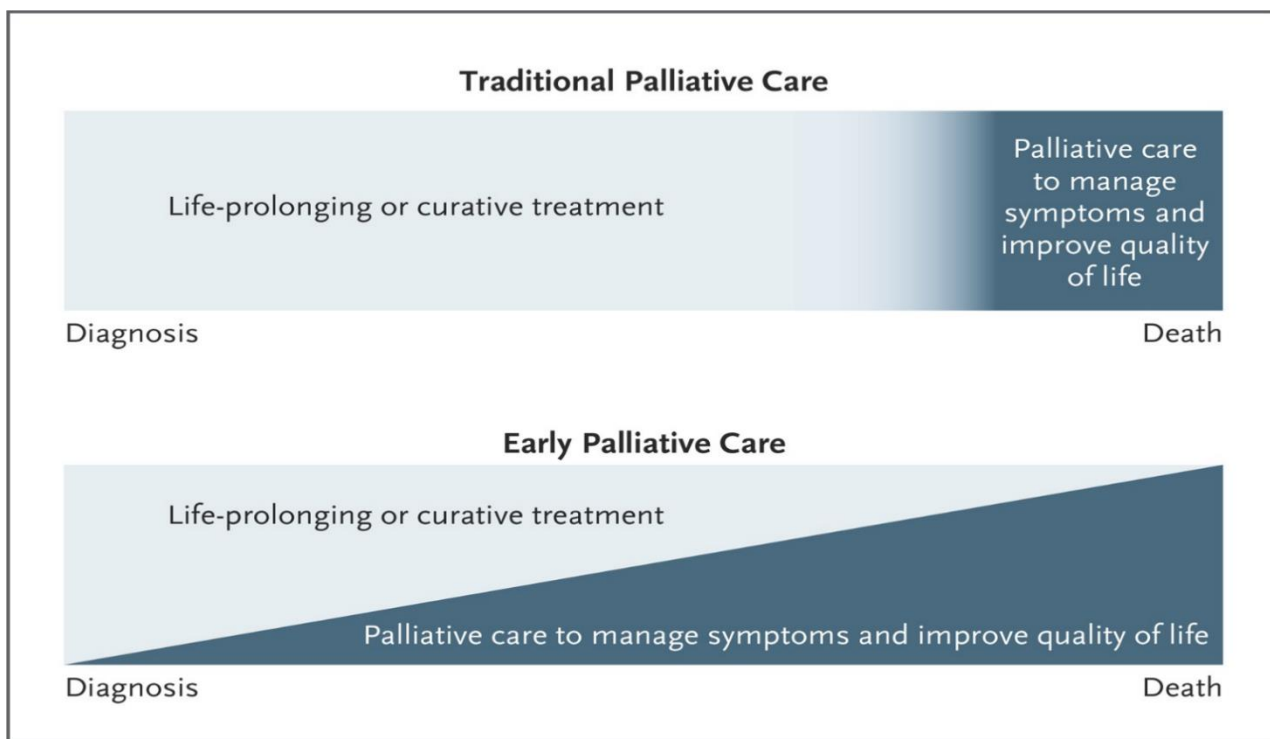
### **2.5.5 Immune checkpoint inhibitors:**

Immunotherapy has revolutionized cancer treatment, and its role in palliative care is also being explored. Immune checkpoint inhibitors (ICIs) are a class of drugs that enhance the body's immune response against cancer cells. Recent studies have investigated the potential of combining palliative chemotherapy with ICIs to achieve better treatment outcomes in certain cancer types (Chhabra and Kennedy, 2021). Preliminary results suggest that this combination may lead to improved response rates and prolonged survival in some patients (Chhabra and Kennedy, 2021).

## **2.6 Palliative Care**

### **2.6.1 History and evolution of palliative care in breast cancer**

Palliative care in breast cancer has evolved significantly over the years (Hallenbeck, 2022). In the past, cancer care focused primarily on curative treatments, with limited attention given to symptom management and psychosocial support (Hallenbeck, 2022). However, the hospice movement in the 1960s and 1970s brought about a paradigm shift in cancer care, emphasizing the importance of palliative care as an integral part of cancer management (Metzger, 2023). The recognition that patients with advanced cancer required comprehensive support led to the development of specialized palliative care services for cancer patients (Kayastha and LeBlanc, 2020). Figure 2.1 below shows the Traditional versus Early Palliative Care model.



**Figure 2.1: Traditional Versus Early Palliative Care Model**

(Source: Foley and Gelband, 2001)

## 2.6.2 Principles and Goals of Palliative Care in Breast Cancer

The principles of palliative care in breast cancer are centred on providing comprehensive care that addresses the physical, emotional, psychosocial, and spiritual needs of patients and their families (World Health Organisation, 2020c, America Cancer Society, 2023). The primary goal is to improve the quality of life for patients by managing pain and other distressing symptoms, enhancing functional status, and promoting dignity and autonomy (World Health Organisation, 2020e). Palliative care also aims to facilitate open communication between patients, families, and healthcare providers, fostering shared decision-making and personalized care plans (World Health Organisation, 2022). Palliative care affirms life and regards dying as a normal process; and intends neither to hasten nor postpone death (World Health Organisation, 2020c).

## 2.6.3 World Health Organization's policy position on palliative care

The World Health Organisation (WHO) recognizes palliative care as an essential component of cancer control and management (World Health Organisation, 2020c). The WHO has defined palliative care as an approach that improves the quality of life of patients and their families facing life-threatening illnesses, including breast cancer (World Health Organisation, 2020c).

In its 2014 resolution on palliative care, the WHO urged member states to integrate palliative care into their healthcare systems and ensure equitable access to these services for all patients in need. The policy position emphasizes the importance of early integration of palliative care alongside curative treatments, promoting a holistic approach to breast cancer management (World Health Organisation, 2020c).

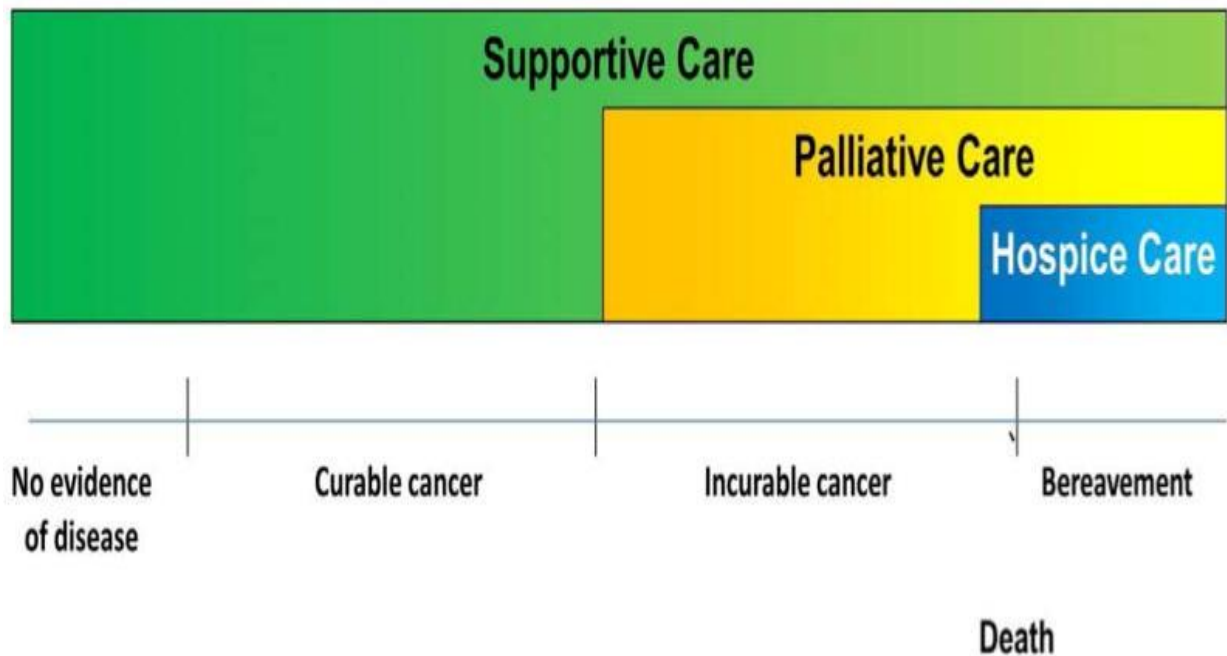
#### **2.6.4 Role of palliative care in improving quality of life, symptom management, and psychosocial support:**

Palliative care plays a vital role in improving the quality of life for breast cancer patients (Kaur, 2013). By providing comprehensive symptom management, such as pain control, fatigue management, and nausea relief, palliative care helps patients maintain their functional independence and overall well-being (Kaur, 2013). Moreover, palliative care teams offer psychosocial support, including counselling and emotional assistance, to address the psychological and emotional distress commonly experienced by breast cancer patients and their families (Kaur, 2013, Kayastha and LeBlanc, 2020).

Furthermore, palliative care fosters communication and shared decision-making between patients and healthcare providers, ensuring that patient preferences and values are considered throughout the treatment journey (Kaur, 2013). This approach not only improves patient satisfaction but also enhances treatment adherence and clinical outcomes (Bacchetti et al., 2014).

#### **2.6.5 Benefits of Early Palliative Care Involvement in Cancer Treatment**

Multiple studies have demonstrated the advantages of early palliative care involvement in cancer treatment, especially in breast cancer patients undergoing chemotherapy. Notably, a seminal study by Temel et al. (2010) found that patients with metastatic non-small cell lung cancer who received early palliative care alongside standard oncologic treatment experienced improvements in quality of life, mood, and symptom management compared to those receiving standard care alone. Building upon this evidence, a study by Cherny et al. (2018c) focused specifically on breast cancer patients receiving palliative chemotherapy. They revealed that early palliative care involvement led to reduced symptom burden, improved patient satisfaction, and a higher likelihood of end-of-life care discussions, ultimately positively influencing patient palliative health outcomes. See Figure 2.2 for illustration of the implementation of palliative and support care.



**Figure 2.2: Illustrates the Implementation of Palliative and Support Care Throughout the Cancer Journey**

(Source: Hui and Bruera, 2016)

As already mentioned, palliative chemotherapy is often used to manage symptoms and improve quality of life for patients with advanced cancer including breast cancer patients whose conditions are no longer curable (Cheng et al., 2015). However, palliative chemotherapy can also cause significant side effects that can negatively impact a patient's quality of life. This is where the need for palliative care becomes critical.

Consequently, a systematic review by Fitch and Maamoun (2016) found that women receiving palliative chemotherapy for breast cancer had a range of palliative care needs, including physical, emotional, and practical needs. Physical needs included management of treatment-related symptoms such as fatigue, pain, and nausea. Emotional needs included addressing anxiety, depression, and fear of death. Practical needs included information and support for financial and work-related issues, as well as support for family members.

Similarly, another study by Aboshaiqah et al. (2016) found that women with advanced breast cancer who were receiving palliative chemotherapy had a high symptom burden, including pain, fatigue, and psychological distress. They also reported concerns about the impact of the disease and treatment on their family and relationships. The study highlighted the need for a holistic approach to palliative care that addresses physical, emotional, and practical needs.

In another vein, a study by Cherny et al. (2018c) investigated the palliative care needs of women with advanced breast cancer receiving palliative chemotherapy. They found that

women had a range of supportive care needs, including symptom management, emotional support, information and education, practical support, and support for family. The study emphasized the importance of a multidisciplinary approach to palliative care that involves healthcare professionals, patients, and families.

Furthermore, in a study by Cherny et al. (2018c), women receiving palliative chemotherapy for breast cancer reported that their healthcare providers did not always address their supportive care needs adequately. Patients reported a lack of information about treatment options, side effects, and self-management strategies. The study highlighted the importance of effective communication between patients and healthcare providers to address the supportive care needs of women with breast cancer receiving palliative chemotherapy.

That notwithstanding, literature have shown the benefits of integrating palliative care into the management of breast cancer patients receiving palliative chemotherapy. For example, a randomized controlled trial by Schulman-Green et al. (2023) showed that early palliative care intervention alongside standard oncology care for patients with breast cancer improved symptom burden, quality of life, and psychological well-being. This study served as a landmark for the integration of palliative care in the management of patients with advanced cancer.

Another study by Pornrattanakavee et al. (2022) evaluated the impact of a palliative care intervention for patients with advanced cancer receiving chemotherapy. The study found that the intervention improved patient-reported outcomes, including quality of life and symptom burden, and reduced depression and anxiety.

A nurse-led programme refers to a healthcare initiative or intervention that is primarily designed, implemented, and overseen by nurses. In such programmes, nurses take a central role in planning, coordinating, and delivering care or services to individuals or communities. These programmes leverage the expertise, skills, and knowledge of nurses to address specific health issues, promote wellness, or improve healthcare outcomes (Corner, 2003, Lamb et al., 2015, Khair and Chaplin, 2017).

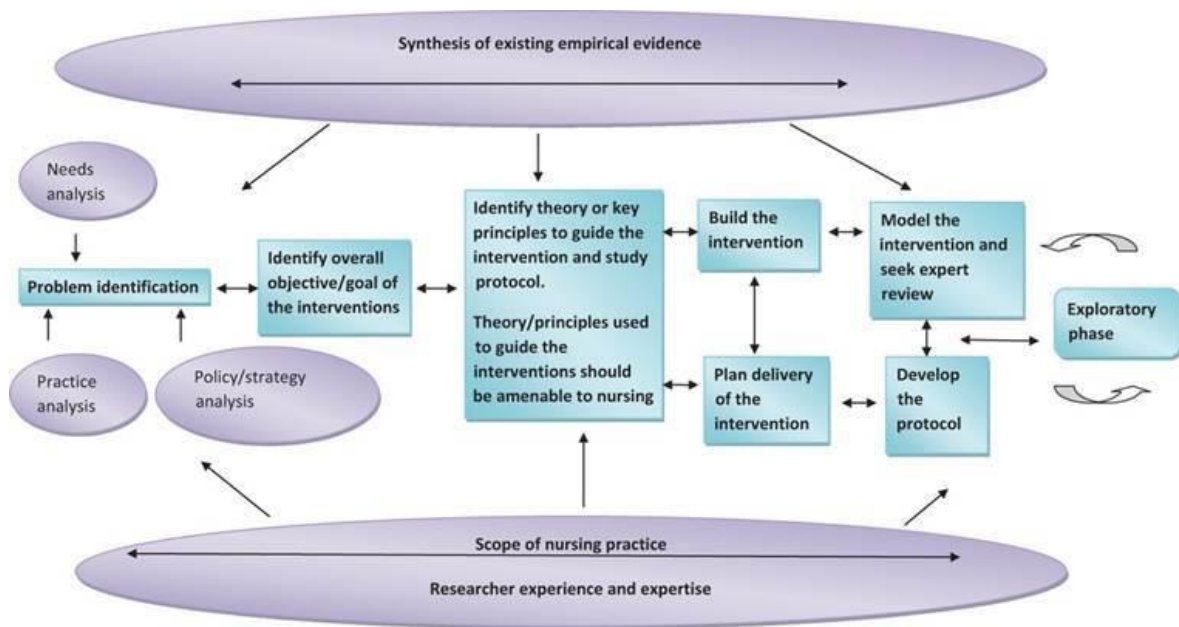
Nurse-led programmes can cover a wide range of areas, including preventive care, chronic disease management, health education, and community outreach. The goal is often to enhance patient care, optimize healthcare resources, and improve overall health outcomes (Khair and Chaplin, 2017). For instance, the studies by Sigler et al. (2022) and Liddicoat (Liddicoat Yamarik et al., 2023) both explore nurse-led palliative care programmes for patients with advanced cancer but focus on different aspects and outcomes of these programmes. Both studies highlight the effectiveness of nurse-led palliative care programmes in managing advanced cancer patients' care. Sigler et al. show that in-person interventions can significantly improve patients' understanding of their illness, while Liddicoat Yamarik et al. demonstrate

that telephonic interventions can enhance engagement and end-of-life planning. These findings suggest that incorporating both in-person and telephonic nurse-led programmes with different approaches may provide comprehensive and flexible care tailored to patient needs and circumstances (Liddicoat Yamarik et al., 2023, Sigler et al., 2022)

## **2.7 Conceptual Framework for the Study**

The conceptual framework adapted for this study is the Model for Developing Complex Interventions in Nursing propounded by Margarita Corry and colleagues in 2013 (Corry et al., 2013). The model offers a comprehensive and structured framework for the creation and assessment of intricate healthcare interventions in the field of nursing (Corry et al., 2013). This model serves as an invaluable guide, enabling healthcare professionals to systematically develop, implement, and evaluate complex interventions, ultimately enhancing the quality and effectiveness of nursing care and contributing to evidence-based healthcare practices (Corry et al., 2013, Saal et al., 2018).

In addition to providing a structured approach to developing and evaluating complex healthcare interventions, the model also offers a comprehensive context for addressing the unique needs of women receiving palliative chemotherapy for breast cancer (Corry et al., 2013). This model consists of several interconnected stages, where each stage plays a vital role in crafting effective interventions that can significantly impact the quality of care and support for patients (Corry et al., 2013). Moreover, a number of studies align with the principles outlined in this model, supporting its validity and relevance in the field of nursing and healthcare (Gale et al., 2013, Robb et al., 2018, Bleijenberg et al., 2018, Östlund et al., 2019, Behrens and Langer, 2022, Connell et al., 2015). Figure 2.3 illustrates the Model for Developing Complex Interventions in Nursing.



**Figure 2.3: Model for Developing Complex Interventions in Nursing Framework**

(Source: Corry et al., 2013)

At the inception of the intervention development process, the first stage involves defining the problem or issue. For women undergoing palliative chemotherapy for breast cancer, this could encompass managing symptoms, enhancing their quality of life, and addressing their psychosocial needs (Devarakonda et al., 2023). In support of this stage, research by Teo et al. (2019) highlights that effective palliative care interventions in oncology often begin with a clear understanding of the challenges patients face, emphasizing the importance of symptom management and psychosocial support (Teo et al., 2019).

Furthermore, theoretical underpinning is a crucial aspect of this stage, which involves drawing on relevant theories and existing evidence to inform the intervention development. In this study, Virginia Henderson's theory of basic human needs underpins the significance of integrating existing evidence into the intervention design (Ahtisham and Jacoline, 2015, Khan, 2023). Consequently, this reinforces the value of theoretical underpinning in the model's first stage.

The next phase, "Identifying Evidence and Expertise," emphasizes the importance of gathering existing evidence and consulting with experts in the field. Research by Pornrattanakavee et al. (2022) advocates for a multidisciplinary approach in oncology interventions, involving input from oncologists, palliative care specialists, and experienced nurses. This study emphasizes the need for collaboration with experts when designing interventions for palliative chemotherapy patients (Pornrattanakavee et al., 2022).

Subsequently, the "Development and Design of the Intervention" stage comes into play, where the actual intervention is crafted based on gathered evidence and expert input. In the context of breast cancer palliative care, this aligns with the findings of Kennedy Bashan et al. (2022), who emphasize the importance of designing patient-centred interventions that incorporate symptom management, psychosocial support, and family communication (Kennedy Bashan et al., 2022).

Furthermore, the "Model Testing" stage, which encourages pilot studies or feasibility studies, is supported by the work of Klaic et al. (2022), who stress the value of practicality and acceptability assessments in ensuring the feasibility of healthcare interventions (Klaic et al., 2022).

As the intervention progresses through the stages, including implementation, monitoring, evaluation, integration into practice, and dissemination, the model remains consistent with the current body of research in the field of nursing and healthcare (Corry et al., 2013). By systematically applying the model's principles and drawing from relevant studies, nurses and healthcare providers can develop comprehensive palliative care programmes for women receiving palliative chemotherapy for breast cancer that effectively address their unique needs (Corry et al., 2013, Saal et al., 2018).

In conclusion, the Model for Developing Complex Interventions in Nursing, is a structured framework that offers a comprehensive approach to addressing the unique needs of women undergoing palliative chemotherapy for breast cancer. This model encompasses multiple interconnected stages, each playing a crucial role in crafting effective interventions aimed at improving the quality of care and support for patients. Supported by various studies, the model emphasizes the importance of defining the problem, incorporating theoretical underpinning, gathering evidence and expertise, designing the intervention, and conducting practicality assessments. As the intervention progresses through stages such as implementation, monitoring, evaluation, integration into practice, and dissemination, it remains consistent with the evolving body of research in nursing and healthcare. Ultimately, this model provides a systematic and evidence-based approach for developing comprehensive palliative care programmes that cater to the unique needs of these patients, thereby enhancing their quality of life and well-being.

## **2.8 Summary**

In this chapter, a brief history of cancer as a disease, breast cancer symptoms, diagnosis and treatment were presented as well as the role of palliative care in breast cancer care. In addition, the conceptual framework for the study was explained in detail.

The next chapter describes the philosophical assumptions in research, design and methods and the development and validation of the palliative nursing care programme.

# **CHAPTER THREE PHILOSOPHICAL ASSUMPTIONS, DESIGN AND METHODS**

## **3.1 Introduction**

The preceding chapter presented literature relating to the study topic. This chapter explains the philosophical assumptions in research, and this research's design and methods.

## **3.2 Philosophical Assumptions in Research**

Research in various academic disciplines is guided by a set of philosophical assumptions that underpin the way research is conceived, conducted, and interpreted (Singh, 2019). These assumptions are essential for understanding the foundations and methodologies of academic inquiry (Singh, 2019, Vveinhardt, 2018).

Philosophical assumptions are, therefore, the fundamental beliefs and perspectives that researchers hold about the nature of reality, knowledge, and the relationship between the researcher and the subject of study (Vveinhardt, 2018, Davies and Fisher, 2018). These assumptions serve as the theoretical underpinnings of research and influence research design, data collection, analysis, and interpretation (Vveinhardt, 2018, Davies and Fisher, 2018). They include; post-positivism, constructivism, participatory worldview/ transformative worldview, pragmatism, ontology and epistemology (Mackenzie and Knipe, 2006).

### **3.2.1 Post-positivism**

A post-positivist approach in research represents a philosophical perspective that challenges the fundamental assumptions of positivism, a school of thought that emphasizes empirical observation, objectivity, and the search for universal laws (Panhwar et al., 2017, Ryan, 2006, Phillips and Burbules, 2000). Post-positivism acknowledges the limitations and shortcomings of positivism and offers an alternative framework for conducting research, often with a more detailed and interpretive approach (Panhwar et al., 2017, Ariail Reed, 2023, Miller, 2005) . Researchers adopting this approach use qualitative methods and may draw upon analytical theory to examine power dynamics critically (Ariail Reed, 2023). This perspective allows for a comprehensive understanding of complex, context-dependent research phenomena (Ariail Reed, 2023).

### 3.2.2 Constructivism

Constructivism is a philosophical and methodological framework that plays a significant role in contemporary research (Vygotsky and Cole, 1978). It highlights the subjective nature of knowledge and emphasizes the role of human subjectivity and social interaction in the construction of knowledge and meaning (Vygotsky and Cole, 1978, Fosnot, 2013, Richards et al., 2018). This approach posits that reality is not objective and external, but rather shaped by an individual's interpretation, context, and experiences (Vygotsky and Cole, 1978).

The key characteristics of constructivism in research include the subjective nature of knowledge, the recognition of multiple realities, the importance of social interaction, the use of qualitative methods, reflexivity, contextual understanding, and the dynamic and emergent nature of knowledge and meaning (Vygotsky and Cole, 1978, Richards et al., 2018, Guba and Lincoln, 1994).

- Subjective Nature of Knowledge

At the core of the constructivist approach lies the belief that knowledge is subjective and is constructed by individuals through their experiences, interactions, and cognitive processes (Creswell, 2013). Researchers acknowledge that their own perspectives and biases can influence the research process (Creswell and Poth, 2016, Creswell, 2013). In the constructivist paradigm, subjectivity is not something to be eliminated but rather embraced as an integral part of the knowledge construction process. This stance encourages researchers to recognize their own positionality and the potential impact of their worldview on research outcomes (Lincoln and Guba, 1989).

- Multiple Realities

Constructivism challenges the notion of a single, objective reality and instead recognizes that there can be multiple, valid interpretations of reality (Gergen, 2018). Researchers do not assume a universal truth, but rather explore how different individuals or groups construct their own versions of reality (Gergen, 2020). This recognition of multiple realities underscores the importance of cultural and contextual diversity in understanding the world around us (Lincoln et al., 2011, Lincoln and Guba, 2016, Lee, 2011, Denzin and Lincoln, 2008).

- Social Interaction

Social interaction is a central tenet of constructivist research (Schwandt, 2007). Researchers often study how individuals and groups negotiate and share their interpretations of reality in social contexts (Lincoln et al., 2011, Schwandt, 2007). It is through these interactions that

knowledge is co-constructed and meaning is negotiated. Social constructivism, in particular, emphasizes the social nature of knowledge creation, highlighting the interplay between individuals and their sociocultural environments (Vygotsky and Cole, 1978). This perspective underscores the significance of context and relationships in shaping our understanding of the world.

- Qualitative Methods

Qualitative research methods, such as interviews, observations, and content analysis, are commonly used in constructivist research to explore the depth and complexity of individuals' constructions of reality (Tomaszewski et al., 2020, Merriam and Tisdell, 2015). These methods are well-suited for capturing the rich narratives and diverse interpretations that align with a constructivist perspective (Lincoln and Guba, 1985, Tomaszewski et al., 2020). Qualitative research allows researchers to delve into the intricacies of human experiences and the multifaceted nature of knowledge construction (Merriam and Tisdell, 2015).

- Reflexivity

Researchers adopting a constructivist approach engage in reflexivity, acknowledging their own subjectivity and biases and how these may influence the research process (Guba and Lincoln, 1994, Denzin and Lincoln, 1994). This self-awareness is essential for maintaining the integrity of the research (Denzin and Lincoln, 1994, Hatch, 2023). Researchers reflect on their assumptions, values, and preconceptions, which may impact the data collection, analysis, and interpretation (Hatch, 2023, Charmaz, 2017). Reflexivity ensures transparency and rigor in constructivist research (Hatch, 2023).

- Contextual Understanding

Constructivist research emphasizes the importance of understanding the social, cultural, and historical contexts in which knowledge is constructed (Lincoln and Guba, 1985). Researchers seek to grasp the significance of these contextual factors, recognizing that knowledge is situated within specific sociocultural settings (Lincoln and Guba, 1985). Contextual understanding adds depth to the interpretation of data and provides a more holistic view of knowledge construction (Lincoln and Guba, 1985).

- Emergent and Dynamic

Knowledge and meaning are viewed as emergent and dynamic, evolving over time and in response to changing circumstances (Crotty, 1998a). Constructivists appreciate that knowledge is not static; it is in a constant state of flux as individuals interact, learn, and adapt

to new experiences and information (Crotty, 1998a, Trần, 2013). This dynamic perspective is particularly relevant in fields where rapid changes and developments are the norm, such as technology, culture, nursing and education (Crotty, 1998a, Trần, 2013).

### **3.2.3 Participatory Worldview/ Transformative Worldview**

The Participatory Worldview is grounded in the idea that individuals and communities are actively engaged in shaping their own realities. It emphasizes the interconnectedness of all life forms and the inherent value of each being (Smith, 2021, Tuhiwai, 2022). A Participatory Worldview promotes a deep sense of responsibility towards the natural world and encourages ethical and sustainable living (Tuhiwai, 2022). This perspective sees humans as co-creators of their environment, stressing the importance of active participation in decision-making processes that affect the environment and society (Flader, 1971, Leopold, 1949).

In the Participatory Worldview, concepts like sustainability, social justice, and holistic well-being are central (Anderson, 1992, Orr, 1992). The worldview has been linked to indigenous and traditional knowledge systems, which often embody a deep respect for nature and intergenerational wisdom (Cajete, 2000). It encourages individuals to reevaluate their relationship with the environment and advocate for policies and practices that preserve ecological balance (Denevan, 2002).

- Transformative Worldview

The Transformative Worldview goes beyond the Participatory Worldview by emphasizing personal and societal transformation as a means to address pressing global issues. It recognizes that the complexity of modern challenges necessitate not only active participation but also a fundamental shift in values, beliefs, and attitudes (Eisler, 2008, Kivunja and Kuyini, 2017). This worldview holds that our current societal structures are often rooted in unsustainable and inequitable paradigms that must be dismantled and replaced with more just and sustainable alternatives (Korten, 2006, Kivunja and Kuyini, 2017).

Transformation in the Transformative Worldview is deeply rooted in personal growth and development. It requires individuals to critically assess their beliefs and values and to engage in practices that foster self-awareness and empathy (Kivunja and Kuyini, 2017, Wilber, 2000). From this inner transformation, it is believed that collective change can be achieved, leading to a more just and sustainable world (Boetto, 2016, Bhattacharjee, 2019). This worldview is often associated with movements like deep ecology, eco-spirituality, and social justice advocacy (Boetto, 2016, Bhattacharjee, 2019)

- Interplay between Participatory and Transformative Worldviews

These two worldviews are not mutually exclusive, and in fact, they often complement each other. The Participatory Worldview provides the foundational principles for engaging with the world and recognizing our interconnectedness (Sheppard, 2021, Callicott, 2011). It promotes active participation and ethical responsibility. However, it can sometimes be insufficient in addressing the deep-seated systemic issues that require transformative change (Mertens, 2017, Savin-Baden and Major, 2023). The Transformative Worldview, on the other hand, focuses on the need for profound shifts in values and beliefs to address complex global problems (Grant and Osanloo, 2014, Mertens, 2017). While it emphasizes the inner transformation of individuals, it relies on the Participatory Worldview's principles for actualizing change in the external world (Mackenzie and Knipe, 2006, Hiebert, 2008, Mertens, 2017).

In practice, individuals and communities often adopt a hybrid approach, recognizing the need for both participation and transformation (Macy and Brown, 1998, Hurtado, 2015). They may engage in participatory activities, such as sustainable living and community involvement, while also pursuing transformative practices, like self-reflection and social activism (Macy and Brown, 1998, Luitel and Taylor, 2019). This integrated approach acknowledges the intertwined relationship between personal growth and societal change (Luitel and Taylor, 2019).

A participatory worldview encourages active involvement of patients in decision-making about their treatment and care (Luitel and Taylor, 2019). It recognizes the importance of empowering patients and involving them in the research process, ensuring their voices are heard (Luitel and Taylor, 2019).

### **3.2.4 Pragmatism**

Pragmatism, as a philosophical approach, places a strong emphasis on practicality and the uses of knowledge (Thayer, 2017, Dixon, 2020, Kaushik and Walsh, 2019). In the context of research, pragmatism offers a valuable perspective that prioritizes real-world applicability and problem-solving over abstract truth (Dixon, 2020, Kaushik and Walsh, 2019). This approach recognizes that the value of knowledge is not solely determined by its theoretical accuracy, but also by its ability to address concrete problems and make a positive impact (Thayer, 2017). According to Dewey (1930), there are some key aspects of pragmatism in research for instance.

- Problem-Centred Approach:

One of the central tenets of pragmatism in research is its problem-centred nature. Pragmatist researchers begin their inquiries with a specific problem or question that requires resolution (Thayer, 2017, Dewey, 1930). Their primary focus is on addressing real-world issues and finding practical solutions (Thayer, 2017). Unlike some other philosophical perspectives that may prioritize the pursuit of knowledge for its own sake, pragmatists seek to generate knowledge that is immediately applicable and beneficial to society (Thayer, 2017, Dewey, 1930).

In the pragmatic view, the value of research lies in its ability to solve problems and improve people's lives (Shook, 2022, Dewey, 1930). This practical orientation ensures that research is not divorced from the concerns and needs of the real world (Thayer, 2017).

### **3.2.5 Ontology**

Ontology, a fundamental concept in the philosophy of research, plays a pivotal role in shaping the research approach of any study (Moon and Blackman, 2014, Moon and Blackman, 2017). This philosophical perspective deals with questions about what exists, what can be known, and how knowledge is acquired (Moon and Blackman, 2014, Fam et al., 2018). It is one of the three primary components of research philosophy, alongside epistemology and axiology (Moon and Blackman, 2017, Al-Ababneh, 2020). Researchers' ontological stances significantly influence various aspects of the research process (Creswell and Creswell, 2017) for instance:

- Ontology and the Perception of Reality:

The ontological perspective held by a researcher directly influences his/her perception of reality and existence (Guba and Lincoln, 1994, Creswell and Creswell, 2017). It helps him/her define and understand what is real within the context of their research (Guba and Lincoln, 1994). For instance, if a researcher adheres to a realist ontology, he/she considers that objective and observable phenomena are real, and this belief informs the research design and the methods used (Creswell and Creswell, 2017).

- Influence on Research Questions and Objectives:

A researcher's ontological stance shapes the formulation of research questions and objectives (Scotland, 2012, Crotty, 1998b). Depending on their ontology, researchers may focus on exploring the nature of physical entities, social constructs, human experiences, or abstract concepts (Crotty, 1998b). This choice guides the direction of the research and the type of data collected (Scotland, 2012, Crotty, 1998b).

- Methodology Selection:

Ontology also plays a significant role in methodological choices. Researchers who embrace a positivist ontology, aligned with realist perspectives, are more likely to employ quantitative methods such as experiments and surveys, emphasizing objective, measurable entities. Conversely, those adhering to constructivist or interpretivist ontologies might favour qualitative methods like interviews, content analysis, or participant observation to explore the subjective experiences and meanings of participants (Fusch et al., 2018, Denzin et al., 2023, Stainton, 2021)

- Data Collection and Analysis:

The ontological perspective influences how data is collected and analysed (Denzin et al., 2023). Researchers with a realist ontology seek to capture objective, verifiable data, emphasizing the importance of reliability and replicability. On the other hand, researchers with constructivist or interpretivist ontologies focus on understanding the multiple, subjective realities of participants, often prioritizing rich, context-specific data (Denzin et al., 2023, Merriam and Tisdell, 2015, Merriam, 2009). This impacts the choice of data sources, data collection instruments, and data analysis techniques (Merriam, 2009).

- Interpretation of Findings:

A researcher's ontological stance significantly affects how findings are interpreted and presented (Creswell and Creswell, 2018, Merriam, 2009). Different ontological perspectives may lead to varying interpretations of the same data, which underscores the importance of acknowledging and discussing these differences in the research approach and discussions (Creswell and Creswell, 2018).

- Paradigms in Research

As indicated earlier, different ontological perspectives are often associated with specific research paradigms (Scotland, 2012). For example, positivism aligns with a realist ontology and is often linked to quantitative research, while interpretivism aligns with constructivist or subjectivist ontologies and is commonly associated with qualitative research (Creswell and Creswell, 2018). Understanding these paradigms helps researchers position their work within a broader philosophical context (Creswell and Creswell, 2018).

### 3.2.6 Epistemology

Epistemology, a branch of philosophy that explores the nature of knowledge, its acquisition, and its justification, is a fundamental cornerstone in the realm of research (Moon and Blackman, 2017, Keong et al., 2023, May and Perry, 2022). Epistemological perspectives guide the methods, assumptions, and approaches researchers employ to generate knowledge (Moon and Blackman, 2017, Keong et al., 2023). Within this domain, three prominent epistemological approaches exist and they are; empiricism, rationalism, and constructivism (Moon and Blackman, 2017, May and Perry, 2022).

Empiricism, the first of these approaches, underscores the significance of sensory experience and empirical evidence in the process of acquiring knowledge. Empiricists contend that knowledge is primarily derived from direct observation, experimentation, and sensory perception. Researchers who align with an empiricist perspective place a premium on collecting data from the physical world to substantiate their claims. This approach finds a natural home in the scientific method, where hypotheses are formulated, rigorously tested, and refined through the accumulation of empirical evidence (Smith, 2020, O’Gorman and MacIntosh, 2015, Gray, 2021).

In contrast, rationalism asserts that knowledge can be gleaned through reason, logic, and introspection. Rationalists believe that certain truths and principles can be known a priori, without the need for sensory experience. Researchers who adhere to a rationalist approach may prioritize deductive reasoning, mathematics, and philosophical analysis to develop their knowledge and construct arguments (Sangeetha, 2021, Jones, 2019).

The third major epistemological approach, constructivism, posits that knowledge is actively constructed by individuals, often within a social or cultural context (Kamal, 2019, Romaioli and McNamee, 2021, Rannikmäe et al., 2020, Bogna et al., 2020). Researchers who embrace a constructivist stance recognize that knowledge is not an objective, fixed reality, but is instead shaped by the perspectives, experiences, and interpretations of individuals (Kamal, 2019, Rannikmäe et al., 2020). Qualitative research methods, such as interviews and ethnography, are commonly associated with constructivist research (Kamal, 2019, Romaioli and McNamee, 2021, Bogna et al., 2020). For instance, Garcia’s study on cultural identity adopted a constructivist epistemological approach, acknowledging that identity is a socially constructed concept influenced by personal experiences and cultural context (Garcia, 2018).

### 3.2.7 Researcher's Philosophical Stance

The researcher's philosophical assumption is both constructivist with a participatory/transformational worldview. These philosophical approaches offer valuable perspectives for research design and implementation, as well as for the development of educational intervention programmes that are tailored to the specific needs and experiences of the target population (Brooks and Brooks, 1999). Thus, constructivism is a philosophical stance that suggests that knowledge is actively constructed by individuals based on their experiences, interactions, and interpretations (Amineh and Asl, 2015, Brooks and Brooks, 1999). In the context of palliative care research, this perspective is highly relevant as it recognizes that people's perceptions and experiences of palliative care needs can vary significantly (McIlpatrick, 2007, Hannon et al., 2017). By embracing a constructivist approach, researchers can delve into the subjective experiences and perspectives of women receiving palliative chemotherapy (Brooks and Brooks, 1999). This approach aligns with the idea that reality is not something objective and external but is, in fact, a product of our cognitive processes and interactions with the world (Brooks and Brooks, 1999, Von Glasersfeld, 2013, Burns et al., 2022).

Incorporating constructivism into the research process allows for a deeper description of the unique needs and challenges faced by women in palliative care (Fearon et al., 2021). By actively engaging with the experiences and interpretations of the individuals involved, researchers can gain a more detailed understanding of their needs (Fearon et al., 2021). This knowledge is essential for tailoring an educational intervention programme that is meaningful and effective for this specific population (Fearon et al., 2021, Prado et al., 2022, O'Callaghan and McDermott, 2004). In essence, constructivism provides a foundation for recognizing the subjectivity of human experience and the importance of considering these perspectives in the design and implementation of research and intervention programmes (Prado et al., 2022, Burns et al., 2022).

As outlined by Guba and Lincoln (1994), constructivism is closely linked to qualitative research methodologies, where the researcher is considered an integral part of the research process. In this approach, data collection and analysis are not separated but are intertwined, emphasizing the researcher's role in actively constructing meaning alongside the participants. Thus, constructivism supports the idea that understanding the palliative care needs of women goes beyond statistical data and should include the complex, personal, and subjective dimensions of their experiences (Guba and Lincoln, 1994, Burns et al., 2022).

On the other hand, the participatory/transformational worldview emphasizes the active involvement of the women receiving palliative chemotherapy in shaping the research process

and educational intervention (Kandel and Wagley, 2022). This approach recognizes the importance of including their input, perspectives, and agency in all stages of the research (Kandel and Wagley, 2022, Asaba and Suarez-Balcazar, 2018). By involving the target population in the research process, it ensures that the resulting intervention is not only relevant but also genuinely effective in addressing their specific needs (Kandel and Wagley, 2022, Asaba and Suarez-Balcazar, 2018).

A participatory approach is rooted in the belief that those who will benefit from a programme or intervention should have a say in its design and implementation (Asaba and Suarez-Balcazar, 2018). By empowering the participants to contribute to the development of the educational intervention programme, researchers acknowledge their expertise in their own experiences and challenges (Asaba and Suarez-Balcazar, 2018). This approach can lead to more meaningful, culturally sensitive, and contextually relevant programmes (Asaba and Suarez-Balcazar, 2018, Hall, 1992).

Freire (2020) introduced the concept of a transformative worldview in his work on critical pedagogy. It emphasizes the importance of collective action, empowerment, and social change. In the context of palliative care, the transformative worldview can be seen as a way to not only meet the immediate palliative educational needs of women but also to empower them to advocate for improved palliative care services and policies, leading to better long-term outcomes (Freire, 2020, Campbell and Brysiewicz, 2017, Hole and Selman, 2020).

In summary, from the discussion above, it is clear that philosophical perspectives and assumptions of researchers inform how individuals understand and approach various aspects of knowledge, reality, and research. These philosophical perspectives included pragmatism, constructivism, post-positivism, participatory worldview/transformative world view, reflexivity and the evolution of multimethod sequential research. The researcher concluded that the philosophical perspectives of constructivism and the participatory/transformative worldview offer a robust foundation for understanding and addressing the palliative care needs of women. The constructivist approach highlights the subjective nature of knowledge and experience, while the participatory/transformative worldview emphasizes active involvement and empowerment of the target population. Together, these perspectives can guide researchers and educators in developing programmes that are both sensitive to the individual experiences of women in palliative care and effective in addressing their unique needs.

### **3.3 Research design**

This was a multi-method study and consisted of four phases thus, a scoping literature review, qualitative descriptive inquiries, development of a nurse-led palliative care programme and

pilot-testing of the programme. Multi-method research is the use of more than one research approach, each undertaken thoroughly and complete in itself (Leedy et al., 2019). The results are then triangulated to form a comprehensive whole (Leedy et al., 2019). This was the method of choice as the first two phases were used to inform the palliative nursing care programme. Phase one answered the first research question by means of a scoping review. Phase two responded to the second research question through a qualitative descriptive design with a semi-structured interview guide. The third and fourth phases answered the last research question thus, the development and validation of the palliative care programme (Phase three) and pilot testing of the programme (Phase four)

### **3.3.1 Phase 1: Scoping Review Approach**

The research approach for this phase of the study was a scoping review. Scoping reviews have gained widespread support as the most standard methodology for synthesising research evidence (Arksey and O'Malley, 2005, Levac et al., 2010, Munn et al., 2018). Scoping studies serve as an expedient and efficient approach for gathering foundational ideas and predominant perceptions upon which research relies, while also capturing the spectrum of available evidence. Scoping can be undertaken as independent research, especially when exploring complex domains or exploring into complicated studies (Arksey and O'Malley, 2005, Daudt et al., 2013). The scoping review also endeavours to provide an overview of a potentially vast and diverse body of literature encompassing a comprehensive subject area (Arksey and O'Malley, 2005, Peters et al., 2021, Anderson et al., 2020, Armstrong et al., 2011).

Scoping reviews serve as a valuable tool for describing research findings, identifying gaps in knowledge within a research field, establishing research priorities, unveiling insights for decision-making, identifying literature that aligns with scoping review methodologies, and offering guidelines and quality standards for the presentation of scoping review studies (Buchberger et al., 2016, Peters et al., 2021)

The researcher opted to employ the "five-stage framework" proposed by Arksey and O'Malley in 2005 (Arksey and O'Malley, 2005) to guide the scoping review. This framework facilitates a meticulous and clear methodological approach, enabling the replication of the search strategy and ensuring the consistency of results in the scoping review. Arksey and O'Malley's objective was to stimulate discourse on the value of scoping reviews while providing a foundational blueprint for a practical model. Following the inception of their scoping review framework, subsequent researchers have drawn upon their experiences with scoping reviews, describing and enhancing the core methodology (Peters et al., 2021, Pham et al., 2014, Brien et al., 2010).

## **3.3.2 Phase 2: Qualitative Design/Approach**

### **3.3.2.1 Research Approach**

A qualitative descriptive approach was used to generate data. Thorogood and Green (2018) note that researchers conducting qualitative descriptive studies aim to gather as much data as they can to enable them to capture all the elements of an event what combine to make it the event that it is. Furthermore, a qualitative descriptive design provides a detailed and straightforward description of a specific phenomenon or topic. It aims to answer questions like "What is happening?" (Sandelowski, 2000). It is against this background that the researcher adopted to describe the palliative care needs of women diagnosed with breast cancer and are receiving palliative chemotherapy.

### **3.3.2.2 Setting**

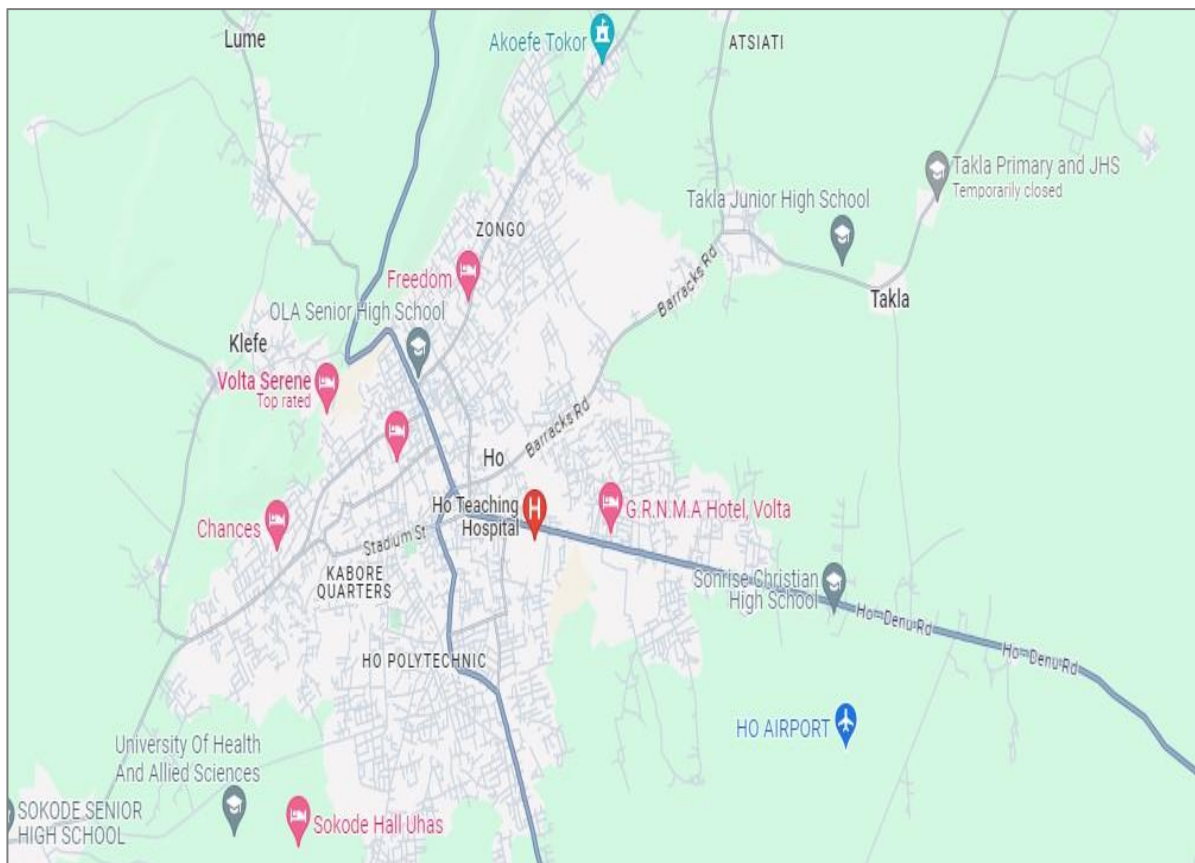
Creswell and Creswell (2018) define the research setting as the "physical, social, cultural, and temporal context in which the research is conducted" (p. 201). The authors emphasize that the setting includes not only the physical location where the data is collected, but also the broader social and cultural context that shapes the research process and the interpretation of the findings. The research setting can have an important influence on the validity and generalizability of research results, as it can influence the behaviour of study participants, the availability of resources, and the social and cultural norms that shape the research context (Creswell and Creswell, 2018).

This study was conducted in a Teaching Hospital located in the Ho Municipality of the Volta Region, Ghana. The hospital, the main referral facility in the region until its upgrade to a teaching hospital in 2019, now serves the University of Health and Allied Sciences. It was commissioned on 29 April 2019 after obtaining approval from the Health Professional Regulatory Bodies and the Health Facilities Regulatory Authority of Ghana.

The facility was chosen because it is the exclusive provider of palliative chemotherapy and radiotherapy services in the Volta Region. Its services are vital for improving the quality of life for cancer patients by offering symptom relief and extended survival. The hospital's integration with the University of Health and Allied Sciences enhances its capabilities by fostering a robust academic and clinical environment suitable for rendering palliative care services. This dual role elevates the standard of healthcare in the region and contributes to the education and training of palliative care specialists.

The hospital offers services in oncology, internal medicine, surgery, obstetrics and gynecology, child health, and public health. The oncology unit, which has 20 beds and a separate daycare unit for out-patient treatment, is staffed by one oncology nurse specialist, eight registered general nurses, two consultant surgeons, and four house officers. This unit operates 24/7 with a daily average attendance of five patients and provides adjuvant, neoadjuvant, and palliative care services (Tampuori., 2019).

Between 1 January 2020 and 31st December 2020, 1,800 patients were seen in the oncology unit of the Ho Teaching Hospital according to the hospital's admissions record. According to the admission records, there were 330 (18.3%) patients with histologically proven breast cancer. The mean age was 48.1 years. The majority (44%; n=799) of the women presented with Stage IV breast cancer. Oestrogen and progesterone receptors were positive in 700 and 500 of the patients respectively and 600 were Human Epidermal Growth Factor Receptor 2 (Her2) positive. The average duration of symptoms was nine months at the time of the first consultation at the hospital and the average tumour size was 6cm x 7cm (Ho Teaching Hospital Admission Records, 2020). Figure 3.1 below shows the map of the study setting.



**Figure 3.1: Map Showing Ho Township, Ghana**

Source: Google map data (2023)

### **3.3.2.3 Study population**

In research, the study population refers to the entire group of individuals or instances that meet the criteria for inclusion in a research project. It is the larger group from which researchers draw a sample for their study (Hu, 2014).

The population of the study consisted of all women 18 years and above living in Ho, Ghana. The target population was all women diagnosed with breast cancer treated with palliative chemotherapy at the study setting. To be included in the study, women had to be 18 years or older, diagnosed with Stage IV breast cancer, receiving, or having received palliative chemotherapy within the month prior to data collection and live in Ho, Ghana. The exclusion criteria included women who were receiving palliative chemotherapy but were less than 18 years and women who could not speak English.

### **3.3.2.4 Sampling and Recruitment**

Sampling in research refers to the process of selecting a subset of individuals or units from a larger population to participate in a study. This process is used to reduce the cost, time, and effort required to collect data while still allowing researchers to make inferences about the larger population (Rubin and Babbie, 2010, Creswell and Creswell, 2017, McCombes, 2022). Similarly, McCombes (2022), indicated that, sampling is a portion of the population that is used in a study to describe the characteristics of interest in a whole population. In this study, a purposive sampling technique was used to recruit 24 women diagnosed with breast cancer and receiving palliative chemotherapy. Purposeful choosing of participants permits the researchers to investigate both the collective and distinctive expressions a desire phenomenon through a wide-range of demographically diverse population (Thorogood and Green, 2018). It gives room for eliciting data from people that are deemed information-rich or make a sample of expectations (Creswell and Creswell, 2018, Lune and Berg, 2017). The final sample sizes were determined by data saturation. Data saturation in qualitative descriptive design is when themes and sub-themes in the data become repetitive or redundant thus, further data collection no longer gives any new information (Creswell and Creswell, 2018, Lune and Berg, 2017, Fusch and Ness, 2015).

### **3.3.2.5 Procedure for Data Collection**

The procedure for data collection entailed the following:

- The University of the Witwatersrand's Research Ethics Committee granted the researcher ethical clearance to conduct this study (See Appendix A for Wits ethical clearance).

- In order to enter the academic hospital and recruit eligible participants and gather data, permission was also acquired from the hospital management and ethical clearance obtained from the Research Ethics Committee of the Ho Teaching Hospital (See Appendix B for HTH ethical clearance).
- The study information leaflet (See Appendix E) was handed over to the women that met the inclusion criteria for them to read, understand and consent a week before the interview was conducted. During the discussion of the information leaflet, the women were informed about the possible duration (45-90 minutes), nature and topic of the interview. They were informed that the interview would be audio taped with their permission and that their names and other personal identities would not be recorded due to confidentiality and anonymity of the study. They were verbally requested to consent for the interview to be audio recorded before beginning the recording
- Having been informed, they were allowed to voluntarily consent (See Appendix F) to participate in the study. They were also informed that they could withdraw at any time or stage of the study and that would not affect the services they were receiving or would be receiving in the future at the hospital.
- After obtaining informed consent, an appointment was made for the interviews at a time and venue appropriate to each participant.
- The researcher told the participants that even though he was a nurse conducting a postgraduate study, they, as the participants, were the experts of their own experiences in order to increase their trust and confidence. They could therefore express their experiences however they considered proper.
- To ask insightful questions that came up during data analysis and to bolster the validity of the findings and interpretation, follow-up interviews were conducted. During these interviews, additional information from the participants' experiences that may not have been shared in the first interview were obtained and where clarification was needed, that was also sought.
- Data saturation was achieved at 24th interview and an additional three interviews were done to clarify issues, then, recruitment was discontinued.
- Data collection and analysis occurred concurrently. Recordings were numbered with codes with P1 for participant one, P5 for participant 5 etc. to ensure anonymity of participants.
- Four participants expressed signs of emotional distress—during the interviews and were referred by the researcher in consultation with the medical superintendent, to see a counsellor (clinical psychologist) in the same facility, thus the academic hospital.

### **3.3.2.6 Data Collection and Instrument**

When using a qualitative descriptive design, data collection is a systematic process of gathering information and rich, detailed descriptions about a particular phenomenon or topic of interest (Polit and Beck, 2020b, Elliott and Timulak, 2021). The data serve as evidence for the experience under investigation and the basis on which conclusions are built (Pinnegar et al., 2007, Merriam and Tisdell, 2015). In qualitative research, a variety of approaches are employed to collect data, including focused group discussions, textual analysis, fieldwork, interviews, and visual analysis. However, in-depth, interviews were conducted guided by an interview guide due to the sensitive nature of the subject under research.

Each participant was interviewed using a face-to-face approach. A face-to-face interview enables participants to describe experiences in detail and allows the researcher to probe participants when necessary (Creswell and Creswell, 2018). The interview guide consisted of sections A and B. Section A contained the demographic information of the participant thus, age, tribe and religion. Age of participants was included in the biographic data collection sheet because, age distribution of participants helps in identifying the predominant age groups affected by breast cancer in the Volta region as different age groups may have varying palliative care needs. Additionally, data on tribe was also collected because, tribal affiliations often come with specific social structures and support systems. Thus, some tribes in the Volta region of Ghana required that, women seek permission from their husbands before seeking medical care. Therefore, understanding the women's tribal background could help the researcher to structure the nurse-led palliative care programme in a manner that engaged with these support systems effectively for the woman's benefits.

Section B comprised open-ended questions that were developed based on a literature review (Kvale and Brinkmann, 2009, Creswell and Creswell, 2017), expert opinions from the researcher's supervisors, and the objectives two of the study. The questions included were as follows:

- a. please can you tell me your experience following palliative chemotherapy treatment for breast cancer.
- b. can you please explain how this experience has affected or influenced your life.
- c. please describe the most difficult time for you during your treatment, with probes asking why that particular time was the most difficult?
- d. can you please tell me what it is like to live with advanced breast cancer.
- e. please what did you do independently to maintain your well-being during palliative chemotherapy treatment? Probes include questions about confidence, inner strength, hope, and prayer.

- f. can you please tell me your palliative care needs at this stage. Probes include why is this, the most difficult need? How can we care for you to make your cancer journey easier?

Finally, the interviewee were given an opportunity to share any additional information that has not been covered by the previous questions (See Appendix G). According to Creswell and Creswell (2018) the researcher should ask broad questions and participants should be allowed to tell their stories freely in a naturalistic setting. An in-depth interview is the method of choice in this study as it affords participants room to elaborate their experiences following palliative chemotherapy treatment.

The interview guide was pre-tested on two women with similar characteristics to that of the women in this study before the final data collection. The data collected during pretesting were excluded from the main study due to modifications made to the phrasing of certain probing questions (“what makes it difficult” was changed to “why is that the most difficult” and “any difficult need” was changed to “Why is this, the most difficult need”). These adjustments were necessary to ensure participants' expected understanding, leading to the decision not to incorporate the pretested data in the final analysis.

The researcher conducted the interviews in English language since the women could speak English fluently and were audio recorded with the participants' explicit permission. The necessary field notes were taken as the interview progressed. The duration of each interview ranged from 45 to 60 minutes. Probes and prompting questions were done during the interviews to facilitate an in-depth discussion (Gray and Grove, 2021).

Transcribed scripts were presented to participants for further input and clarifications where necessary. All the interviews were conducted by the researcher and the demographic information was gathered from the participants before the beginning of the main interview.

During the interviews, some (4) participants experienced emotional distress as a result of the nature of the in-depth interview. They were referred to the counsellor who agreed and offered free counselling services as agreed before the study.

### ***3.3.2.7 Data Management and Analyses***

General information of participants was entered into an Excel spreadsheet after pseudonyms were assigned to them. The voice recordings were transcribed word for word. An inductive qualitative content analysis method was used to analyse the data (Vears and Gillam, 2022). According to Thorogood and Green (2018), inductive qualitative content data analysis is a vigorous form of exploration of spoken and visual data that is leaning toward summarizing the

informational contents of that data. Inductive qualitative content analysis is data- derived. Content is grouped into similar themes and subthemes and codes are applied systematically from the data generated as the study progresses.

The utilization of inductive qualitative content analysis is justified in this study focused on the palliative care needs of women with breast cancer. By employing inductive qualitative content analysis, the researcher can systematically analyse and interpret the textual data collected from interviews that shed light on the most pertinent issues surrounding palliative care for these patients (Elo and Kyngäs, 2008). This method also allows for flexibility in exploring unexpected aspects and emergent themes, ensuring that the study remains sensitive to the individuality of each participant's journey (Elo and Kyngäs, 2008, Polit and Beck, 2020a).

Data collection and analysis of this phase of the study occurred concurrently thereby enabling the researcher to modify the data management in order to accommodate new data and perspectives (Thorogood and Green, 2018). For the participants' demographic data, tables were used to present analysis (See Table 5.1). Korstjens and Moser (2018) qualitative content analysis approach was used. The data were analysed as follows:

- i. The transcripts were read and re-read to get a sense of the whole and allow the researcher to know who is telling and when, where, what and how the incidents happened.
- ii. Notes and headings were written in the text while reading it. The written in-text material was read through again and headings were jotted down in the margins.
- iii. The headings were then collected from the margins and transferred onto coding sheets.
- iv. The headings were grouped into codes, sub-themes and then themes in that order.
- v. The researcher put together events and incidents with similar codes as sub-themes. And sub-themes were grouped into main themes. See (Appendix S) for details.

### **3.4 Trustworthiness to Enhancing the Rigour of phase 2.**

Shenton (2004) and Korstjens and Moser (2018) explain how researchers can meet Guba's four criteria for ensuring trustworthiness of research namely: credibility, dependability, confirmability, and transferability.

#### **3.4.1 Credibility**

Credibility is achieved through ensuring that the data findings accurately reflect reality and are deemed believable (Korstjens and Moser, 2018, Shenton, 2004). To achieve credibility, the

researcher purposefully recruited participants who met the inclusion criteria and could describe about their palliative care needs and experiences during cancer treatment. Member checks were employed to review and validate findings or participants' responses, engaging them in discussions about the identified themes for accuracy and resonance with their experiences. Triangulation, a rigorous method advocated by several authors (Lincoln and Guba, 1985, Shenton, 2004, Johnson et al., 2020), further enhanced credibility in this study. Data were collected through various methods and diverse participants were included at different stages of the research. Additionally, an independent coder coded some transcripts, enabling comparisons to be made.

To reinforce the study's credibility, prolonged engagement with the participants was ensured. This involved establishing rapport and building trust to foster open and honest communication. The interview recordings were frequently reviewed, and transcripts were carefully examined to ensure accurate reporting.

### **3.4.2 Transferability**

Transferability refers to the extent to which the findings of a study can be successfully reproduced in different contexts or settings (Shenton, 2004). To enhance transferability, the researcher provided a comprehensive account of the research setting, participant backgrounds, and the methodology used, allowing other researchers to apply the study's conclusions to similar settings. Additionally, for an audit trail, there was a systematic and organized record-keeping process. All transcribed data and field notes were meticulously stored in various locations, including a computer folder, email, and a physical cabinet.

Direct quotations from the participants were included in the study to offer readers a deeper understanding of the context in which the research was conducted. Reflexivity was also maintained throughout the study.

### **3.4.3 Reflexivity of the researcher**

Reflexivity in research refers to awareness and critical examination by the researcher of their own biases, assumptions, and subjective influences on the research process (Lazard and McAvoy, 2020). In a study involving women receiving palliative chemotherapy for breast cancer, maintaining reflexivity, the researcher acknowledged and addressed potential preconceptions about gender roles, medical treatments, and cultural perspectives related to illness (Whitaker and Atkinson, 2021). The researcher in this study actively engaged in self-reflection throughout the study, considering how personal experiences, gender differences

and beliefs may shape the interpretation of data and interactions with participants. By adopting a reflexive approach, the researcher enhanced the credibility and validity of the study by minimizing the impact of his own biases on the research findings (Lazard and McAvoy, 2020, Subramani, 2019, Whitaker and Atkinson, 2021).

#### **3.4.4 Dependability**

Dependability refers to the extent to which research findings are consistent, reliable, and can be replicated. The measure of dependability lies in how the research is conducted, analysed, and presented. For the purpose of enabling external researchers to replicate the study and obtain similar results, each step of the research process should be meticulously reported (Gioia et al., 2013, Shenton, 2004).

To achieve dependability, the researcher provided a comprehensive description of the research setting, the methodology employed, and background information about the study participants. Furthermore, to enhance consistency all participants were interviewed using the same interview guide, and their transcripts were subjected to the same method of identifying themes and sub-themes. Throughout the research process, all relevant documents were preserved for an audit trail. This was done to adhere to and enhance the dependability of the study and bolster the credibility of the findings.

#### **3.4.5 Confirmability**

Confirmability represents the ability of the researcher to demonstrate that the research findings and interpretations are clearly the reflections of the participants and not the preferences of the researcher (Shenton, 2004, Thorogood and Green, 2018). To enhance confirmability of the research findings the demographics of the participants were described along with their palliative care needs and chemotherapy experiences. This allows readers to comprehend to whom the findings of the research are relevant. Also, all audio recordings were transcribed by the researcher shortly after the interview. This was done to avoid any difficulties in identifying and interpreting interviews and that the researcher accurately portrayed the meanings participants were attempting to express. To do this, each interview was replayed and checked against the corresponding transcript for accuracy of the findings by the researcher. See 0for details.

### **3.5 Phases 3: Development/Adaptation and Validation of the Palliative Nursing Care Programme**

This phase describes the process involved in the development/adaptation and validation of the palliative nursing care programme for women receiving palliative chemotherapy for breast cancer. A draft of the palliative nursing care programme developed based on Phases 1 and 2, Fitch module, and the opinions of the expert panel in Phase 3. The palliative nursing care programme was presented to the expert panel for validation using a scoring sheet with a 5-point Likert scale and necessary changes were made to some statements. They were allowed to make comments, which informed the changes to be made to the programme content. Details are presented in Chapter Seven of the study.

### **3.6 Phase 4: Programme Implementation and Pilot-Testing**

Phase 4 deals with programme implementation and pilot-testing of the palliative nursing care programme. The proposed and validated palliative nursing care programme underwent a pilot test, and its outcomes were assessed through interventions and pre-test post-tests. The assessment focused on the primary outcome, which was symptoms distress, and secondary outcomes, including pain and/or quality of life/or spiritual needs. Each phase, along with its corresponding research design, was thoroughly discussed in the methodology chapter of this study. Further details can be found in Chapter Eight.

### **3.7 Summary**

Philosophical assumptions, design and methods of the study were presented. The next chapter details phase 1 findings.

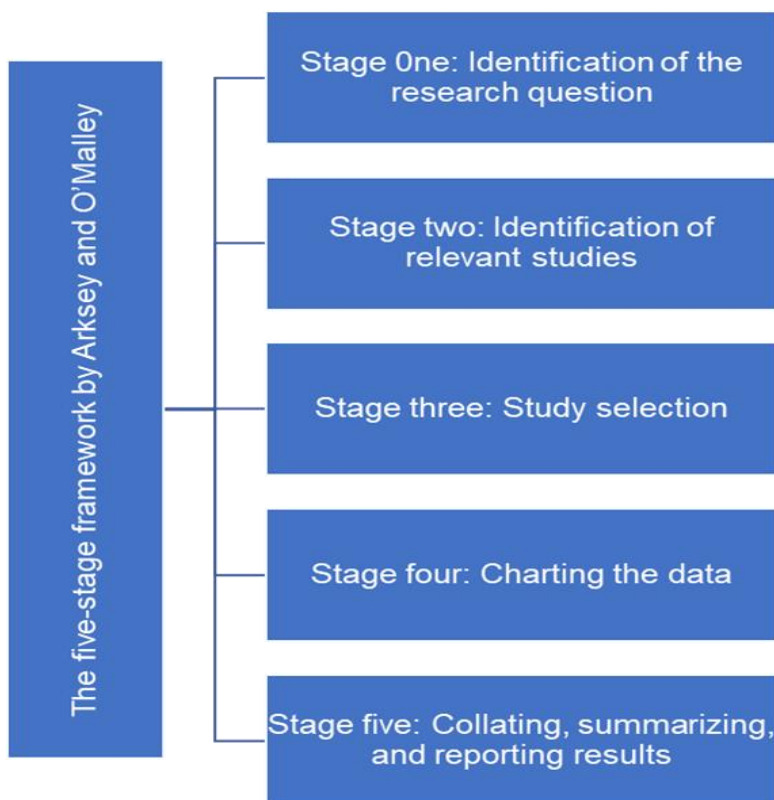
# CHAPTER FOUR PHASE 1: SCOPING REVIEW

## 4.1 Introduction

Philosophical assumptions, design and methods of the study were presented in the preceding chapter. This chapter presents the process and results derived from the scoping review. The results from the review contributed to the development of the palliative nursing care programme.

## 4.2 Framework and Study Selection

The scoping review followed the PRISMA-ScR extension for scoping reviews and the five-stage framework by Arksey and O'Malley (Arksey and O'Malley, 2005, Levac et al., 2010, Munn et al., 2018) as described in Chapter Three of this study. This framework ensured a thorough and replicable search strategy for the scoping review results (Peters et al., 2021, Arksey and O'Malley, 2005). Scoping reviews serve to describe research findings, both qualitative and quantitative, pinpoint gaps in knowledge, set research priorities, brighten decision-making implications, and offer guidelines for reporting scoping review investigations (Peters et al., 2021, Munn et al., 2018). See Figure 4.1 below for the overview of the five-stage framework of Arksey and O'Malley (2005) that guided the scoping review.



**Figure 4.1: Overview of the five-stage framework of Arksey and O'Malley (2005)**

### **4.2.1 Stage One: Identification of the Research Question**

The research questions that guided this section of the study were:

- i. What are the interventions employed to support women receiving palliative chemotherapy for breast cancer within the 10-year period thus, 1 January 2012 to 31 December 2021?
- ii. What are the gaps and trends in these programmes?
- iii. What is the guide for future research into nurse-led programmes to support women receiving palliative chemotherapy for breast cancer?

### **4.2.2 Stage Two: Identifying Relevant Studies**

To perform the literature search, relevant peer-reviewed journal articles published between January 1st, 2012, and December 31st, 2021, were sought from electronic databases as described in Table 4.1. A ten-year period was chosen for the scoping review because it strikes a balance between comprehensiveness and manageability, captures relevant trends and advancements, and adheres to academic publishing practices, and considers practical data availability. This makes it an optimal timeframe for conducting a thorough and relevant scoping

review (Arksey & O'Malley, 2005). The process of identifying relevant data commenced in July 2021 and concluded in December 2021. Regular and systematic searches were conducted to ensure comprehensive coverage of available literature. The search characteristics led to the identification of 107 articles, while 3 studies came from reference lists, totalling 110 (n=110) studies.

**Table 4.1: Databases Searched, Search Strings and Results**

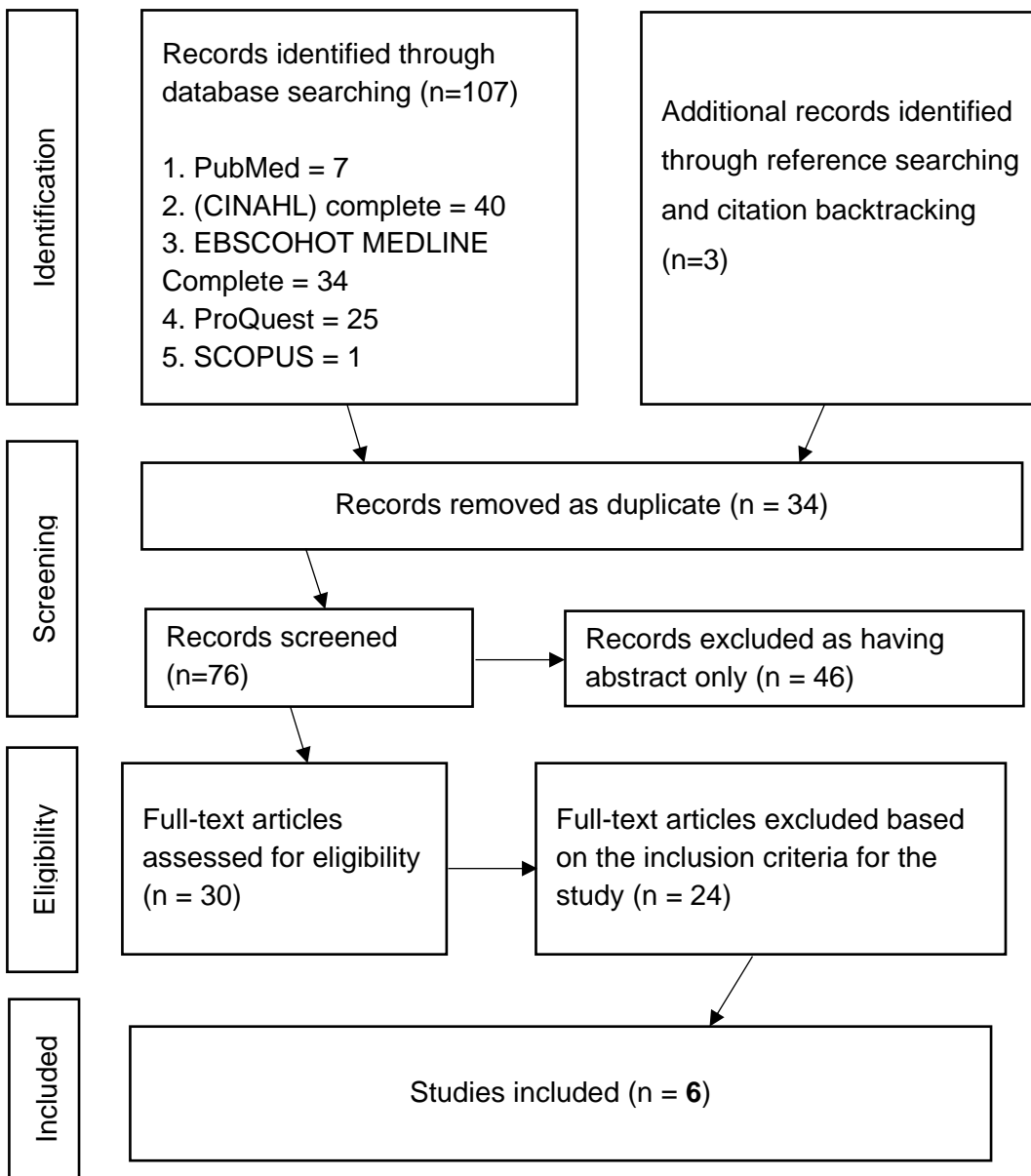
Database	String	Number of results (n=110)
PubMed	Nurs*-led OR nurse participated “palliative care” OR “supportive care intervention” OR program* AND wom?n OR female NOT “male with breast cancer” OR “advanced breast cancer” OR breast neoplasm AND “receiving palliative chemotherapy”  Filters: English language, women, 1 January 2012 to 31 December 2021	7
CINAHL Complete	(((nurse-led) AND (palliative care programme)) OR (supportive care intervention)) AND (for breast cancer women)) AND (receiving palliative chemotherapy) between 1 January 2012 to 31 December 2021	40
MEDLINE Complete	(((nurse-led) AND (palliative care programme)) OR (supportive care intervention)) AND (for breast cancer women)) AND (receiving palliative chemotherapy) between  1 January 2012 to 31 December 2021	34
ProQuest	(((nurse-led) AND (palliative care programme)) OR (supportive care intervention)) AND (for breast cancer women)) AND (receiving palliative chemotherapy)  Between 1 January 2012 to 31 December 2021	25
Scopus	Nurs*-led OR nurse participated “palliative care” OR “supportive care intervention” OR program* AND wom?n	1

Database	String	Number of results (n=110)
	OR female NOT "male with breast cancer" OR "advanced breast cancer" OR breast neoplasm AND "receiving palliative chemotherapy"  Between 1 January 2012 to 31 December 2021	
Additional records identified through reference searching and citation backtracking	-	(n=3)

### 4.2.3 Stage Three: Study Selection

For study selection, the researcher focused exclusively on empirical studies, requiring them to have been published in English between 1 January 2012 to 31 December 2021 and, within peer-reviewed journals. The reason for this inclusion criteria was because, a ten-year period strikes a balance between comprehensiveness and manageability, captures relevant trends and advancements, and adheres to academic publishing practices, and considers practical data availability. This makes it an optimal timeframe for conducting a thorough and relevant scoping review (Hiebl, 2021). In addition, while grey literature can offer valuable insights, especially for emerging or less-studied topics, relying primarily on empirical data ensures a more robust, reliable, and comprehensive scoping review. Excluded were literature reviews, editorials, letters to the editor, dissertations, discussion papers, case reports, conference proceedings, and grey literature. Title and abstract screening of retrieved literature were carried out by the researcher and a university librarian. and the researcher. Literature sorted based on titles underwent abstract screening to examine their applicability to the review. After the completion of this process, a consensus meeting took place between the researcher and his supervisors. As indicated earlier, the search characteristics led to the identification of 107 articles, while 3 studies came from reference lists, totalling 110 (n=110) studies. Thirty-four (n=34) duplicate articles were removed.

Records excluded as having abstracts only were forty-six (n=46). Full-text articles excluded based on the inclusion criteria were twenty-two (n=24) leaving six articles for the review. See Figure 4.2 PRISMA-ScR Flow chart.



**Figure 4.2: PRISMA-ScR Flow chart of the scoping review search process**

(Source: Tricco et al., 2018)

#### 4.2.4 Stage Four: Charting the Data

During Stage Four, a data extraction sheet was crafted by the researcher for organizing the data (Table 4.2). The data extraction sheet, following the guidelines of Arksey and O'Malley (2005), facilitated a consistent summarization and effective integration of results. The data were systematically recorded based on author(s), publication year, country of origin, name of

journal, purpose of the study design, population and sampling, and data collection methods and analysis is and major finding. The data was extracted by the researcher and reviewed by the research supervisors.

**Table 4.2: The palliative care programmes available for women with breast cancer (2012-2021, general characteristics (n=6))**

Author (year) and country where the study was conducted	Name of Journal	Purpose of the study	Study Design	Sampling method and sample size	Data collection method and analysis	Major Findings
1. Komatsu et al. (2020b)  Japan	European Journal of Oncology Nursing	To evaluate the effects of a patient-centred medication self-management support programme in patients with metastatic breast cancer undergoing oral anticancer treatment.	Randomized Controlled Trial (RCT)	Purposive and stratified sampling  (n= 155)	<ul style="list-style-type: none"> <li>• Resea rcher-Admini stered Questi onnair e</li> <li>• Descri ptive statisti cs and conten t analysi s</li> </ul>	A significant effect of the programme was not found in the programme because the adherence rate was low.
2. Reiser et al. (2019a)	American Journal of	To describe the effect of a quality	A prospective pre- and post-	Convenience sampling	<ul style="list-style-type: none"> <li>• Self-admini</li> </ul>	Purposeful nurse-led assessment for social

Author (year) and country where the study was conducted	Name of Journal	Purpose of the study	Study Design	Sampling method and sample size	Data collection method and analysis	Major Findings
USA	Hospice and Palliative Medicine	improvement project for coordination of supportive care in metastatic breast cancer	experimental cohort design	(n=118)	<p>stered questionnaire and data extraction sheet</p> <ul style="list-style-type: none"> <li>• Descriptive statistics data analysis</li> </ul>	service and palliative care needs increases referrals with improvement in patient-reported outcomes.
(Yee et al., 2019)	Journal of Pain and Symptoms Management	To determine the safety and feasibility of a physical activity programme for women	Randomized Controlled Trial (RCT)	Stratified sampling (n=14)	<ul style="list-style-type: none"> <li>• Researched-administered</li> </ul>	A partially supervised home-based physical activity programme for women with metastatic

Author (year) and country where the study was conducted	Name of Journal	Purpose of the study	Study Design	Sampling method and sample size	Data collection method and analysis	Major Findings
		with metastatic breast cancer and explore the efficacy of the programme			<p>questionnaire</p> <ul style="list-style-type: none"> <li>• Descriptive statistics data analysis</li> </ul>	breast cancer is feasible and safe. The dose of the resistance training component was well tolerated and achievable in this population
4.Ye et al. (2017b) China	Breast cancer Treatment and Research	'Be Resilient to Breast Cancer' (BRBC) was designed to help Chinese women with metastatic breast cancer to enhance their resilience levels, biopsychosocial functions, and	Randomized Controlled Trial (RCT)	Stratified and randomized sampling (n=226)	<ul style="list-style-type: none"> <li>• Researched-administered questionnaire and focus group</li> </ul>	Be Resilient to Breast Cancer did not significantly prolong 3- or 5-year survival (median survival, 36.7 months in IG and 31.5 months in CG).

Author (year) and country where the study was conducted	Name of Journal	Purpose of the study	Study Design	Sampling method and sample size	Data collection method and analysis	Major Findings
		potentially extend their life span.			<ul style="list-style-type: none"> <li>interview guide</li> <li>• Descriptive statistics and content analysis</li> </ul>	
5. Lee et al. (2017a) South Korea	Holistic Nursing Practice	To describe the effects of a Mindfulness-Based Stress Reduction Programme on the physical and psychological status and QOL of patients with metastatic breast	Non-equivalent group Experimental design.	Not specified (n=18)	<ul style="list-style-type: none"> <li>• Self-administered questionnaires</li> <li>• Descriptive</li> </ul>	The mindfulness-based stress reduction programme had an effect on improving average pain and alleviating distress

Author (year) and country where the study was conducted	Name of Journal	Purpose of the study	Study Design	Sampling method and sample size	Data collection method and analysis	Major Findings
		cancer receiving anticancerous treatment			statistics data analysis	
6. Yee et al. (2014c), (Ye et al., 2017a)  Australia	Journal of Cancer Survivorship	To explore differences in physical activity and fitness between women with metastatic breast cancer compared to healthy controls and factors associated with their physical activity levels	Not specific	Not specified (n=71)	<ul style="list-style-type: none"> <li>• Self-administered</li> <li>• Descriptive statistics data analysis</li> </ul>	Women with metastases were significantly less aerobically fit than the control group, as evidenced by a lower mL•kg <sup>-1</sup> •min <sup>-1</sup> value (25.3 vs. 31.9; P<0.001).

## **4.2.5 Stage Five: Collating, Summarizing, and Reporting Results**

This stage involves the synthesis of the gathered information to provide a comprehensive overview of the literature (Levac et al., 2010, Sucharew and Macaluso, 2019, Arksey and O'Malley, 2005). During this stage, researchers organized and analysed the data collected from the selected studies, identifying key themes, patterns, and trends within the literature (Arksey and O'Malley, 2005). The goal was to condense the wealth of information into a coherent summary that highlights the main findings, research gaps, and areas of consensus or disagreement (Arksey and O'Malley, 2005). This stage requires a critical evaluation of the literature and the ability to present a clear narrative that effectively communicates the current state of knowledge on the chosen topic (Arksey and O'Malley, 2005, Levac et al., 2010).

Researchers may use various methods, such as thematic analysis or content analysis, to extract and present the relevant information in a way that contributes to the overall understanding of the subject under investigation (Arksey and O'Malley, 2005). Additionally, this stage sets the foundation for the subsequent interpretation and discussion of the findings, guiding the formulation of recommendations and implications for future research or practice (Arksey and O'Malley, 2005, Sucharew and Macaluso, 2019). This review used descriptive statistics and content analysis.

## **RESULTS**

### **4.3 General Characteristics of the Articles**

Different research designs were included in the reviewed studies and work was primarily quantitative (n=4, 66.66%). Two (n=2, 33.33%) were mixed methods. Out of the total number of studies (n=6), 3 (n=3, 50%) used a randomized control trial study design and 1 (n=1, 16.66%) each used prospective pre-test post-test experimental cohort design, and non-equivalent control group experimental design. One (n=1, 16.66%) did not specifically mention the design.

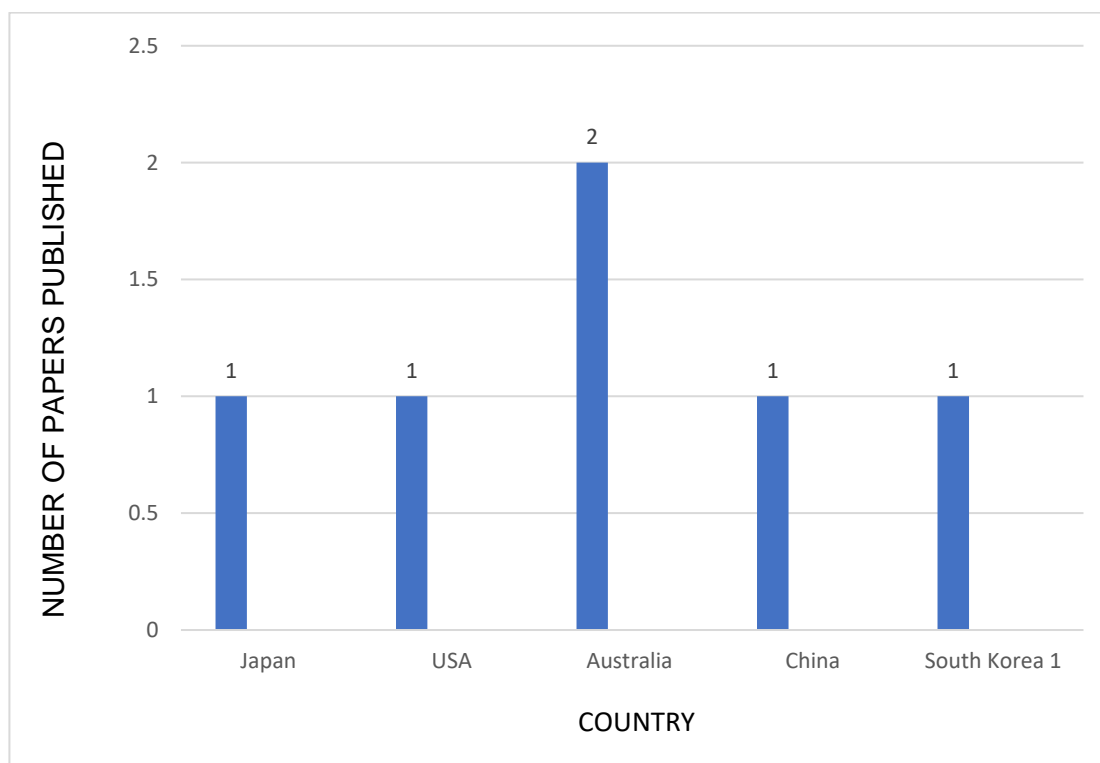
In total, four sampling methods were employed across the studies. Two studies utilized two sampling methods each: the first study employed stratified and simple randomized sampling, while the second study used purposive and stratified sampling. Additionally, one study each utilized purposive and convenience sampling methods (n=1, 16.66%) individually. Notably, two studies (n=2, 33.33%) did not provide specific details regarding their sampling methods.

The sample sizes of the studies ranged from 14 to 226 participants with a median of 94.5. Studies that adopted randomized controlled trial designs had its lowest sample size of 14 and highest of 226 participants. Those with experimental design had their sample sizes range between 18 to 118.

Four studies were quantitative (n=4, 66.66%) and two (n=2, 33.33%) were mixed methods. Three (n=3, 50%) of the studies each used researcher-administered questionnaires self-administered questionnaires. Only two (n=2, 33.33%) of studies used both descriptive statistics and content analysis, the rest of the studies (n=4, 66.66%) used descriptive statistics data analysis only. Refer to **Error! Reference source not found.** for details, including articles i ncluded in the study.

#### 4.4 Countries of Origin, Years, and Journals of Publication

The articles included in the review originated from five (n=5) countries with none found in Africa. The highest percentage of the articles (n=2, 33.33%) came from Australia, followed by USA, Japan, and China who each published 1(n=1, 16.7%) article during the review period. Refer to Figure 4.3,



**Figure 4.3: Shows countries contributing to the data collection and their percentage yield**

Sixty-seven percent (67%) of the work was published in 2017 and 2019 while there were no publications in 2012, 2013, 2015, 2016 and 2020. The papers were published in six (6) different journals (n=6), thus, an article per journal. The details are provided in Table 4.3.

**Table 4.3: Year and journal of publication of the Studies Included in the Review (n=6)**

<b>Year</b>	<b>Number (n)</b>	<b>%</b>
2021	1	16.66
2020	0	0
2019	2	33.33
2018	0	0
2017	2	33.33
2016	0	0
2015	0	0
2014	1	16.66
2013	0	0
2012	0	0
<b>Journal</b>	<b>Quantity of data (n=6)</b>	<b>Percentage (%)</b>
American Journal of Hospice and Palliative Medicine	1	16.66
Breast Cancer Treatment and Research	1	16.66
European Journal of Oncology Nursing	1	16.66
Holistic Nursing Practice	1	16.66
Journal of Cancer Survivorship	1	16.66
Journal of Pain and Symptom Management	1	16.66

Data collection tools also varied across the studies. In all 22 different instruments were used for data collection. The most commonly used instruments were, Patient-reported outcomes questionnaire, Hospital anxiety and depression scale, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30), Wisconsin brief pain inventory, Distress Thermometer, Japanese version of the 36-item Functional Assessment of Cancer Therapy-Breast (FACT-B) scale, and Back-leg dynamometer and hand dynamometry. Refer to Table 4.4 for the instruments in the reviewed studies.

**Table 4.4: Instruments used in the scoping review (n=22)**

Instruments	Reiser et al. (2019a)	Lee et al. (2017a)	Yee et al. (2019)	Komatsu et al. (2020b)	Yee et al. (2014b)	(Ye et al., 2017a)	Total number of articles	Percentage (%)
Generalized Anxiety Disorder Scale (GAD-7)	YES							
Patient-reported outcomes questionnaire	YES				YES		2	33.33
Wisconsin Brief Pain Inventory		YES				YES	1	16.66
Breathing Frequency Match (BFM 5000 equipment)		YES					1	16.66
Hospital Anxiety and Depression Scale		YES				YES	2	33.33
Distress Thermometer		YES				YES	1	16.66
Functional Assessment of Cancer Therapy Scales for Breast (FACT-B)		YES					1	16.66
Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F) questionnaire			YES				1	16.66

Instruments	Reiser et al. (2019a)	Lee et al. (2017a)	Yee et al. (2019)	Komatsu et al. (2020b)	Yee et al. (2014b)	(Ye et al., 2017a)	Total number of articles	Percentage (%)
European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-30)			YES			YES	2	33.33
International Physical Activity Questionnaire (IPAQ)			YES				1	16.66
ActiHeart device			YES				1	16.66
Back-leg dynamometer and hand dynamometry			YES		YES		2	33.33
Japanese version of the 10-item General Self-Efficacy (GSE) Scale.				YES			1	16.66
Japanese version of the 36-item Functional Assessment of Cancer Therapy-Breast (FACT-B) scale.				YES		YES	1	16.66
Japanese version of the 6-item Kessler 6 (K6) scale for psychological distress.				YES			1	16.66

Instruments	Reiser et al. (2019a)	Lee et al. (2017a)	Yee et al. (2019)	Komatsu et al. (2020b)	Yee et al. (2014b)	(Ye et al., 2017a)	Total number of articles	Percentage (%)
Japanese version of the 13-item M.D. Anderson Symptom Inventory for symptom severity and interference.				YES			1	16.66
A self-designed patient satisfaction scale				YES			1	16.88
Quality of life questionnaire							1	16.66
Godin Leisure-Time Exercise Questionnaire (GLTEQ)					YES		1	16.66
SenseWear physical activity monitor					YES		1	16.66
10-item Conner-Davidson Resilience Scale (CD-RISC-10)						YES	1	16.66
Overall well-being Visual Analog Scale	YES						1	16.66

## 4.5 Focus of the Study

The focus of the studies was diverse; as such they were group into two categories: specific focuses (Table 4.5) and synthesized focuses Table 4.6.

**Table 4.5: Specific study focus**

Author	Specific focuses
1. Reiser et al. (2019)	<ul style="list-style-type: none"> <li>a. Focused on providing structured support and coordination of care for patients with metastatic breast cancer through a nurse navigator-led approach.</li> <li>b. Assessing changes in patient-reported outcomes related to generalized anxiety, overall symptom distress, and overall well-being before and after the implementation of the SEA programme.</li> <li>c. Evaluating the influence of the SEA Programme of Care on referrals to palliative care, social services, and clinical trials.</li> </ul>
2. Lee et al. (2017b)	<ul style="list-style-type: none"> <li>a. Focused on the physical and psychological status and well-being of patients with metastatic breast cancer. The study also had the following outcome measures:</li> <li>b. Pain levels and its interference with daily activities.</li> <li>c. Heart rate variability (HRV) to assess autonomic nervous system function.</li> <li>d. Anxiety and depression using the Hospital Anxiety and Depression Scale.</li> <li>e. Distress levels using the Distress Thermometer.</li> <li>f. Quality of life using the Functional Assessment of Cancer Therapy Scales for Breast (FACT-B).</li> </ul>
3. Yee et al. (2019)	<ul style="list-style-type: none"> <li>a. Focused on supervised exercise sessions conducted either at the participant's home or a local park. The sessions included brisk walking and resistance training. Additionally, participants were prescribed an unsupervised walking programme.</li> </ul>

Author	Specific focuses
	<ul style="list-style-type: none"> <li>b. Feasibility was assessed through recruitment and retention rates, adherence to the intervention, and safety measures.</li> <li>c. Safety was evaluated based on any adverse events related to the intervention.</li> </ul>
4. Komatsu et al. (2020a)	<ul style="list-style-type: none"> <li>a. The primary focus was adherence to medication after three months, assessed using the medication possession ratio (MPR).</li> <li>b. Secondary outcomes included measures of self-efficacy, quality of life, psychological distress, symptom severity, symptom interference, and patient satisfaction.</li> </ul>
5. Yee et al. (2014a)	<ul style="list-style-type: none"> <li>a. Focused on physical activity, fitness levels, and quality of life of women with metastatic breast cancer</li> </ul>
6. Ye et al. (2017a)	<ul style="list-style-type: none"> <li>a. Focused on evaluating the effectiveness of a mentor-based and supportive-expressive programme named "Be Resilient to Breast Cancer" (BRBC) on Chinese women with metastatic breast cancer</li> </ul>

**Table 4.6: Themes/focus of the studies**

Theme/focus	Number (n)	Percentage (%)
Informational support	2	33.33
Quality of life	3	50
Financial support	3	50
Pain	5	83.33
Fatigue	4	66.66

<b>Theme/focus</b>	<b>Number (n)</b>	<b>Percentage (%)</b>
Nausea/vomiting	4	66.66
Sleep disturbance	1	16.66
Shortness of breath	1	16.66
Appetite changes	3	50
Dry mouth	1	16.66
Social work needs	1	16.66
Social needs	5	83.33
Anxiety,	3	50
Depression	2	33.33

## 4.6 Summary

This chapter presented the results of Phase 1 of the study. The study explored nurse-led palliative care programmes specifically designed for women undergoing palliative chemotherapy for breast cancer. The review period spanned from January 1, 2012, to December 31, 2021. The objectives were to; a. scope for implemented nurse-led programmes for women undergoing palliative chemotherapy for breast cancer, b. identify gaps and trends in existing programmes, and c. provide guidance for future nurse-led programmes.

The research followed a five-stage framework established by Arksey and O'Malley (2005), using the PRISMA Extension for Scoping Reviews (PRISMA-ScR). The literature search was conducted from July 2021 to December 2021, resulting in the identification of 110 relevant studies from various databases. After screening and removal of duplicates, six studies were selected for inclusion in the scoping review. A systematic data extraction process was employed, adhering to Arksey and O'Malley's framework. Extracted details encompassed author information, publication year, country of origin, study aim, design, population, sampling, data collection methods, and instruments used.

Results: a. Study Origins: The studies originated from five countries, with Australia contributing the highest proportion (33.33%). b. Publication Years: The majority of publications occurred in 2017 and 2019, accounting for 67% of the selected studies. c. Journals: Six different journals published these studies, each contributing one article. d. Focus Areas: The studies addressed diverse topics, including information support needs and symptom management (i.e. pain, nausea and vomiting, and fatigue).

Characteristics of Reviewed Studies: a. Research Designs: Different research designs were employed, primarily quantitative (66.66%) and mixed methods (33.33%). b. Sampling Methods: Various sampling methods were utilized, with sample sizes ranging from 14 to 226 participants. c. Data Analysis: The studies employed various data analysis approaches, including descriptive statistics and content analysis in two studies, while others used descriptive statistics only.

The next chapter provides the results of Phase 2.

# **CHAPTER FIVE RESULTS OF PHASE 2: QUALITATIVE STUDY**

## **5.1 Introduction**

The preceding chapter presented the scoping literature review, which was the first objective of the study. This chapter focuses on the second objective of the study, thus, to describe the palliative care needs of women receiving palliative chemotherapy in an academic hospital in the Volta Region of Ghana. The findings from this phase formed part of the evidence for the development of a palliative nursing care programme for women receiving palliative chemotherapy for breast cancer.

## **5.2 General Characteristics of the Participants**

The participants consisted of 24 (n=24) women receiving palliative chemotherapy for breast cancer. Their ages ranged between 39 to 79 years with a median age: 54.5. A majority (n=22, 91.66%) of the women were married. All (n=24, 100%) participants conceived once in their life. More than half (n=13, 54.20%) of the participants had a university education. With religion, the majority (n=16, 66.66%) were Christians and Ewe by tribe (n=20, 83.33%). Details of the general characteristics of the participants are presented in Table 5.1.

**Table 5.1: General Characteristics of the Participants**

<b>Code</b>	<b>Age</b>	<b>Marital status</b>	<b>No. of pregnancies</b>	<b>Level of Education</b>	<b>Religion</b>	<b>Tribe</b>
P1	39	Married	3	Technical University	Christian	Ewe
P2	58	Married	2	University	Christian	Ewe
P3	39	Married	4	University	Christian	Ewe
P4	62	Married	4	University	Christian	Ewe
P5	39	Married	2	Technical University	Christian	Ewe
P6	39	Married	2	Secondary school	Christian	Ewe
P7	50	Married	2	Technical University	Muslim	Ewe
P8	50	Married	3	University	Christian	Ashanti
P9	51	Married	4	University	Muslim	Hausa
P10	53	Married	2	University	Christian	Ewe
p11	53	Married	5	University	Muslim	Hausa
P12	53	Married	2	Technical University	Christian	Ashanti

Code	Age	Marital status	No. of pregnancies	Level of Education	Religion	Tribe
P13	54	Married	3	Technical University	Christian	Ewe
P14	54	Widow	5	University	Traditional	Ewe
p15	54	Married	4	University	Christian	Ewe
P16	55	Married	1	University	Christian	Ewe
P17	39	Widow	2	Secondary school	Traditional	Ewe
P18	58	Married	2	University	Christian	Ewe
P19	58	Married	3	University	Christian	Ewe
P20	59	Widow	5	Technical University	Muslim	Ewe
P21	39	Married	1	Secondary school	Christian	Ewe
P22	62	Married	1	Technical University	Christian	Ewe
P23	78	Married	2	University	Muslim	Ewe
P24	79	Married	1	Technical University	Muslim	Ewe

### 5.3 Themes and Sub-Themes

Three themes and twelve sub-themes were identified from the data. The themes were: 1. Experiencing the side effects of treatment; 2. Coping with breast cancer and treatment 3. Needs of women diagnosed with breast cancer. Find Table 5.2 below for a summary of the themes and sub-themes identified from the data.

**Table 5.2: Themes and Sub-Themes Identified from the Data**

THEMES	SUB-THEMES
Theme 1: Experiencing the side effects of palliative chemotherapy	<ul style="list-style-type: none"> <li>• Experiencing the physical side effects</li> <li>• Experiencing the psychosocial consequences of the disease and treatment</li> <li>• Living with the economic burden of the treatment</li> </ul>
Theme 2: Coping with breast cancer and its treatment	<ul style="list-style-type: none"> <li>• Adapting to the new normal way of life</li> <li>• Being hopeful and optimistic</li> <li>• Coping by means of religion</li> <li>• Social support aids coping</li> </ul>
Theme 3: The needs of women diagnosed with breast cancer	<ul style="list-style-type: none"> <li>• Socio-economic needs</li> <li>• Psychosocial needs</li> <li>• The need for spiritual support</li> <li>• The need for symptom management</li> <li>• The need for professional informational support</li> </ul>

## 5.4 Theme 1. Experiencing the Side Effects of Palliative Chemotherapy

The subthemes of experiencing the side effects of palliative chemotherapy were, experiencing the side effects of treatment, experiencing the psychosocial consequences of the disease and treatment and living with the economic burden of the treatment.

### 5.4.1 Subtheme 1: Experiencing the Physical Side Effects

The participants experienced various side-effects such as nausea and vomiting, loss of hair, skin colour changes, fatigue, and loss of taste that negatively influenced their daily activities. Nausea and vomiting made talking, cooking and personal hygiene difficult. The participants explained:

*"The whole day, I have been feeling like vomiting, I can't take anything by mouth, my mouth is full with saliva you see that I can't even talk well because of saliva in my mouth" (P19)*

*"I have been vomiting since yesterday...this mostly happens immediately I take my infusion and the whole day; I will not be able to cook, wash, and even speak" (P1)*

*"...Yesterday I felt like regurgitating everything I swallowed...at this time, the anti-nausea medication is rubbish, so I spent my time with my head in the chamber pot like a baby" (P11)*

The nausea and vomiting were so severe, that some participants wondered if they would be able to continue treatment. A participant said:

*"Eii!! my brother, the whole day, I have been in the washroom as if am a housefly hovering over the water closer because of vomiting...This thing is like hell for me, I may not be able to complete my treatment because of how I am feeling especially with the vomiting" (P24)*

The participants also experienced hair loss which reminded them of the seriousness of having to be treated with chemotherapy, the graveness of a cancer diagnosis and shame.

*"See my hair, my son... I lose everything on my head, when I comb my hair in the morning then my hair will start dropping like no one's business. Let me say, three months after my first chemotherapy, I see my hair dropping on my bed each morning that I wake up and that is how serious chemotherapy is" (P23)*

*“Am wearing a wig as we speak, I lost almost all my hair too because of breast cancer pause” (P2),*

Participants also reported that they felt odd noticing a change in colour of their palms and feet.

The participants said:

*“My fingers, palm, and foot colour began changing, it became dark, completely dark (clinch fist and eyes) ... this is what chemotherapy does to us hmmmmm”, (P4)*

*“When I commenced chemo, I least expected my body to undergo these massive changes because we were told about nausea and vomiting not change in palm colour, see my hands, feet, see my body (pause)...My nails, palm, skin, and face became dark, am losing it” (P7)*

*“...My body is changing and it is amazing how fast it is really changing, see my palm and foot, the colour has completely changed...Now I am shy, I hide my hands in my clothes when someone is knocking on my door. Cancer is deadly and is so shameful how your body can change for the worse” (P20).*

They often experienced fatigue and that affected their ability to carry out daily activities. It also decreased their physical mobility due to continuous exhaustion,

*“This chemo thing is a whole lot my brother, you will feel weak and fatigued, your whole body becomes like there are no bones in them...you can't even stand for a long time, so, now I sit on a stool to bath” (P3)*

*“...Simply attempting to recuperate constantly is tiring and it's continuous. Genuinely you put your body through some serious hardship. A few issues come and go but others such as extreme tiredness stay on for months” (P12).*

*“I am often exhausted and become powerless, sometimes I am unable to do simple house chores that I used to do with ease because I feel fatigued and exhausted each time, I take chemo” (P22)*

Experiencing taste alterations prevented them from eating their favourite and staple foods.

*“Like there would be days where I really wanted light soup and fufu. I wanted light soup, all that I would need to eat would be fufu and light soup. but when this food is brought, I can't eat...it is tasteless, I mean totally tasteless and am like wow am I dying or what, so annoying” (P5)*

*"...inside mouth just tasted like I was eating graphic paper whenever I dropped food, I mean nothing, no taste. all of my taste buds are dying off, and just rotting in my mouth. That's literally what it tasted like, all my taste buds were gone, inside my mouth taste like a child, and what is more irritating is that I can't even enjoy my favourite food pizza" (18).*

Owing to the chemotherapy, participants experienced menstrual changes, changes that influenced vaginal health and sexual functioning. Some did not understand what the cause of these symptoms were. The participant said:

*"Let's say about a month following my chemotherapy I felt a change in my vagina, it became dry which wasn't usual for me and when I informed the nurse, she said it's due to the side effect of my treatment...I mean my chemo" (P14)*

*"I have been having irregular menses for about two months now. It used to come every 28 days but the last two months, it came when I didn't expect it and this month it has delayed which is not normal for me" (P17)*

*"Maybe you can help me out of this, I even shy as we talk about this but I need help, my period has stopped which is not usual..." (P21)*

#### **5.4.2 Subtheme 2: Experiencing the Psychosocial Consequences of the Disease and Treatment**

Participants reported that they experienced shock and depression when they heard of the cancer diagnosis. Some participants also had suicidal thoughts due to their unexpected cancer reports. They explained:

*"Immediately I heard of my diagnosis, I was shocked and depressed... since I was told I had breast cancer up to date, I am not myself" (P21).*

*"... I am surprised and still shocked about this whole thing...how and when this thing called cancer started (pause), it is not in our family...so where did I get it from. In fact, am depressed" (P2)*

*"... most of the time I was depressed, I had some major life-changing events, and (hmmmm) that gave me little hope at the beginning of the treatment" (P12)*

*"I cannot forget my initial thought after my diagnosis, I felt sad when the Dr told me I had breast cancer according to the lab result. Knowing what I knew about cancer, then, it is better I commit suicide, I said to myself" (P6)*

Having to undergo chemotherapy added to participants emotional distress and led to sadness and anxiety. The participants expressed it as follows:

*"Having chemo going through my blood constantly made me more restless than the disease itself. Since we were told the medication will kill all the fast-growing cells in our body, I been anxious since then...I am just thinking in case that it was a medical procedure I am not sure it would be like these experiences " (11)*

*"...Everything started like fine with me until after I started my third dose of chemotherapy then I started experiencing forgetfulness...I can put my mobile phone on the table and start looking for it the whole day, this made me very sad (shaking of the head), when you add this to many other problems of life (pause), I feel like committing suicide" (P20)*

The participants lived in fear and uncertainty. They feared disease progression and what the outcome of the treatment could be. They became scared of any swelling like boils on their body as they think that could be another cancer.

*"for me the future is blink...I am not certain at all what my tomorrow will be like, each passing day my condition gets worse, I am afraid tomorrow will not meet me" (P15)*

*"The toughest part for me as we speak now my brother, is for me not knowing the future...how will all this end me, what again will the doctors say to me about my condition and how bad it is going, will I die...I mean, what is this? cancer is giving me psychological toucher" (P18)*

*"... Each time I had even a little growth on my chest or hand I became frightened regardless of whether it's cancer or not. My brain is busy with this sort of thinking", (P9).*

Also, participants reported that their breast cancer diagnosis and the chemotherapy they received adversely affected their social lives. Many of the participants pulled out from social functions and events due to the fact that they did not want to disturb family members and friends with their health issues. Some participants reported that they could not enjoy their annual leaves, due to an altered body image.

*"I'm one kind of individual who keeps things to myself simply because I don't want people to worry about me and so I couldn't enjoy my annual leave with the people I often does... I don't also disturb them or say border them with my personal stuff" (P7)*

*"... would rather not stress others with my private matters" (P3)*

*"I'm a fun person, yes...I love chilling out and hugging up with friends during my annual leave periods or weekends however when I started chemo, things started changing...my entire body system was affected by the chemo drug and because of these changes in my health status, I couldn't enjoy my leaves. I'm either in the room or the house, I mean indoors", (P24).*

Some participants added that they experienced strain on their personal relationships due to the physical changes on their bodies:

*"Hair loss, weight loss, and fatigue impacted my self-esteem and confidence and that made me feel less attractive or desirable I became isolated and hopeless" (P16)*

*"...at a point, my partner and I felt I am no longer the same person like before the cancer, and that thinking was difficult for him to understand and adjust thereby resulting in series of challenges in our relationship (P14)*

### **5.4.3 Subtheme 3: Living with the Economic Burden of the Treatment**

Financial crises were identified from the data as one of the costs of living with advanced breast cancer. The participants indicated that the additional financial burden resulting from treatment, transport for medical appointment, investigations, food and new body wears all contributed to their financial crises. Again, not being able to work full time due to fatigue and long waiting hours in the hospital also affected them financially.

*"I never expected the cost of my breast cancer treatment to be so high. Even with insurance, the bills for chemotherapy and other procedures have been overwhelming."(P10)*

*"It's hard enough dealing with the physical and emotional toll of breast cancer, but the financial burden of treatment is adding even more stress to my life. The National Health Insurance doesn't cover the chemotherapy treatment " (P19)*

*"Financially, I lost a lot. You can imagine, I was always wasting my working hours at the clinic for appointments? and due to delays at the hospital," (P8).*

Some participants indicated that in addition to the high cost of the medication, they have to spend money on essential accessories like wigs to improve their appearance.

*"I have to buy wigs every now and then to keep my head up because I lost all my hair and it came with costs you know! " (P13).*

*"My nails are all dead, my hair is gone, what should I do? I have to buy nail cover and wigs so as to help maintain my outfit. I had to demand more money for that to be fixed," (P14).*

Some participants could not afford the transport costs for their medical appointments. While others had to rely on loans from family and friends to settle their medical bills: The participants explained:

*"The stress of figuring out how to pay for transportation on top of my medical bills has made my breast cancer diagnosis even more overwhelming and I had to postpone some cycle because I couldn't transport myself." (P2)*

*"I've had to rely on friends and family to help me get to my appointments in most cases because I can't afford the cost of treatment, let alone the transport fare or bus fare." (P23)*

*"There is a stage in life when everything seems to collapse...collapse so much that, I could not even afford the fare and it was necessary (P 16)"*

*I reversed my chemo date (long break). Aside from the six hundred and seventy Ghana I have to pay for each cycle, I needed to do other things including transportation. For me, it is very difficult with no money and the economy is hard (tears)...I want to die and be free... " (P6)*

Some participants sold their properties and used the proceeds for payment for laboratory investigations, specific prescribed food and new clothes.

*"... I had land at (XXX name of town mentioned), I had to sell it to add to my amounts of money to pay for my laboratory investigations. Because at some point I realized that without money this cancer may take my life" (P13)*

*"Loss of appetite, and nausea and vomiting made it difficult to maintain a healthy diet. And most of the new diets I shifted to for health wise were not easily available and also a little expensive compare to my staple and favourite foods in the past" (P5)*

*"My hair loss was a significant concern to me, so I sold most of my new clothing that I have not used before to help purchase wigs, gloves, long-sleeves and other body wears". (P2)*

In summary, the participants experienced a range of physical side effects such as weakness and fatigue, loss of hair, and nausea and vomiting. Some experiences were so severe, that some wondered if they would be able to continue treatment. Participants also experienced psychosocial consequences of the disease and treatment. These included anxiety, sadness and depression and isolation. Participants reported that the economic burden of treatment significantly contributed to their financial crises. The costs of treatment, transportation for medical appointments, investigations, food, and new clothing all added to their financial strain. Due to this overwhelming burden, some participants were brought to tears during the interview, feeling that they had lost everything, including their life savings.

## **5.5 Theme 2: Coping With Breast Cancer and its Treatment**

The subthemes of coping with breast cancer and its treatment were adapting to the new normal way of life, hope/optimism, religion and social support.

### **5.5.1 Subtheme 1: Adapting to the New Normal Way of Life**

Participants reported adapting to a new normal way of life; they began wearing gloves to cover their hands due to chemotherapy effects while others *wore a scarf to cover their hair following alopecia*. Below are some narrations.

*"During my chemotherapy journey, my hands went through so many changes. The sensitivity and discoloration were hard to hide. I started wearing gloves not just for protection but also to shield my hands from prying eyes. It became my silent armour, allowing me to face the world with confidence (P 1)."*

*"Chemotherapy affected every part of my body, but the changes in my hands were the most visible. They became so sensitive and discoloured. Wearing gloves was my way of maintaining a sense of normalcy and privacy, shielding the world from the raw realities of my treatment (P17)."*

One participant added:

*"As the effects of chemotherapy became evident on my hands, I felt the need to cover them up. The gloves I wore weren't just a fashion statement; they were a shield, a protective barrier between me and the world. They allowed me to navigate through my days with dignity, concealing the visible signs of my battle with breast cancer (P 22)."*

Other participants reported that they used scarves to cover their hair following hair loss to chemotherapy.

*"Initially, I was hiding when my body started changing but one day, I told myself, I must be strong...so I started seeing things as the new normal and that include wearing of scarf (P8)*

*"I never wore a scarf in my life before, but here is the case my hair is gone, how do I go for programmes with a head without hair...guess what, one day I went into the room and wore a scarf and when I checked in the mirror it wasn't bad. So, I have to adjust that way" (P10)*

Another participant had this to say:

*Initially it wasn't easy wearing scarf but as times went on, it became the other of the day. I wore scarf because I lost all my hair and so, I needed something to cover my head (P24).*

## **5.5.2 Subtheme 2: Being hopeful and optimistic**

Participants had a sense hope and the possibility that things can improve, and a belief that one's efforts can make a difference. As such, they developed the tendencies to expect good things to happen, and to look for the positive aspects of situations, even in the face of adversity.

*"Every day is a struggle, but I choose to hold onto hope that I will beat this and see my children grow up." (P4)*

*"Optimism is what keeps me going. I know that the road ahead won't be easy, but I believe that I can overcome the challenges and come out stronger." (P7)*

*"There are days when I feel like giving up, but then I remind myself that I am still alive and that every moment is precious. I hold onto hope that I will make the most of the time I have left." (P15)*

Another participant added:

*"I never imagined that I would be in this situation, but I am determined to stay positive. I believe that my attitude can make a difference in how I experience this cancer journey." (P8)*

One participant further stated:

*“I am also optimistic in life because of my past experience...I have learned to be positive and cheerful no matter the situation and that kept me going” (P14)*

### **5.5.3 Subtheme 3: Coping by means of religion**

Participants reported that, they relied on religious coping strategies to adopt to cancer diagnoses and treatment burden. To these women, prayer and faith can provide comfort, a sense of hope, and a way to connect with something larger than themselves.

*“I pray a lot, cancer didn’t stop me from praying, in fact it helps increase my faith in God...because, I don’t know where this disease is from, and the best I could do is to increase my prayer time, and that gave me hope and a sense of connection to the Almighty God that it will end well” (P4)*

*“What enabled me to continue my treatment was prayers. After my first cycle, I lost hope, because I could not bear with the problems (hmmm)! My heart was beating faster; I couldn’t breathe well... my whole body was like I was dying. I couldn’t come out of the room and my child picked up a phone and called our church pastor and told him that mommy is dying after returning from the hospital. Whatever happened to me I can’t remember until the following day. A prayer team was formed and we both prayed two times a day. If not for those prayers, I can’t tell where I would have been by now” (P6)*

One participant added:

*“...Somewhere in the bible, I remember it was said, cast all your burden upon Jesus and He will give you rest...I never forget that bible verse. Me and prayer we are one, I never stop praying for God’s help because of what the chemo will do you (errh)! is like you are going to die but prayer increases my faith in God” (P22)*

Another participant reported:

*“A disease that they say they don’t know the cause of, what medicine can cure it? Tell me what medicine can cure it? is only God...personally, I am a Pentecostal, we pray a lot...sometimes I pray in tongues, another time, all I do is to cry to God prayerfully because He is a prayer answering God, He is my hope and all in this situation” (P5)*

#### **5.5.4 Subtheme 4: Social support aids coping**

Participants reported that, social connections such as families, friends, and organizations also assisted them to cope with the cancer burden and chemotherapy effects.

*“My husband was very supportive during my treatment; I remember one day I was sitting down sad because of what I was experiencing due to chemotherapy. That day he dressed up and was about to go to work, and when he turns to see the way, I was seating on the sofa, he drew closer and said, “B” (Name of wife) doesn’t worry too much, this is not your fault, unlike STI’S where we will be wondering who cheated on the other...cancers are no one’s fault...easy “B” that gesture alone was enough for me to fight for my life. I needed to live for him (Name of husband mentioned)” (P1)*

Another participant added:

*“When I first arrived at the church, the mother of my son’s closest playmate was already seated and when she saw me, she walked to me and asked, “You got two more cycles to end your chemo right?” Certainly, I answered her. I had not really spoken to her about my treatment but clearly, my son had told his friend and she popped her boot and had like two envelopes. She said, “I’ve heard what is going on, and please take this to support yourself.” It was just a random act of kindness and impacted me because I thought if something were to happen to me, there were people in this world who would look after my kids that kindness kept me moving on” (P24)*

One participant also had this to say:

*“I received support from family members (name mentioned) ... she always cooked for me, I also received some donations from friends and church members and that was really helpful without that, I tell you, I couldn’t have coped with this thing call cancer my son” (P19)*

This theme described the coping mechanisms women receiving palliative chemotherapy for breast cancer adopted. The women coped through hope and optimism, prayer and faith, and a sense of being connected to something greater than themselves.

### **5.6 Theme 3: Needs of Women Diagnosed with Breast Cancer**

Five sub-themes emerged from the theme the needs of women diagnosed with breast cancer: socio-economic need, psychosocial need, need for spiritual support, need for symptoms management and need for professional information support.

## 5.6.1 Subtheme 1: Socio-Economic Needs

Most of the participants experienced a shortage of money and could not afford the treatment. As a result, some had to postpone their treatment. The participants explained:

*“I’m a retiree, so my monthly salary is not even enough...I say it is too small for me let alone to pay for my chemo. right now, my headache is how to get money to complete my treatment, it is too expensive” (P21).*

*“...I postponed my treatment about two times because my money was insufficient for both lorry fare and that of treatment. My major need as we speak is money” (P23).*

*“I’ m short of money and I need to complete my chemotherapy. It means I have to look for more money” (P4)*

Likewise, some participants wished they could get assistance from churches to support them to pay for their hospital bills:

*“In my neighbourhood once, someone is sick; their fellowship members donate to support...so at a point I felt like I wish I was in a certain fellowship (XXX name mentioned) because I needed money but help was coming from nowhere” (P13).*

*“...thanks to the women's ministry fellowship initially they gave me 100 dollars as an assistant to enable me to pay for my chemo not long after and that money got finished because one cycle of chemo alone is 700 dollars, now I have not completed my treatment but there is no money either. I wish they could come to my aid again because that is my biggest need for now as am in debt” (P17)*

One participant reported that she registered her mother for a life insurance scheme at her workplace and that assisted her when her mother had an accident a year ago without difficulty. Unfortunately, she did not ensure herself.

*“I least expected that I would be in this situation. I registered for sickness/death insurance for only my mother because of her age and that did help me in taking care of her medical bill... but here I am today, struggling for money to care for myself, I should have known better and ensure for myself but I took it for granted because I was well and now, there is nothing left for me to take care of myself and I need to complete my treatment also...I need money my dear (P6)*

## 5.6.2 Subtheme 2: Need for Psychosocial Support

The participants experienced various psychosocial support needs including the need for counselling, support groups, orientation to the hospital and its environs, and reassurance. Those who received counselling felt it was a lifeline and assisted them manage their fear and anxiety.

*“Counselling has been a lifeline for me ever since you introduced the clinical psychologist to us. It’s given me a safe space to process my emotions during difficult time and cope with the challenges of my illness but what happens when you are gone?” (P6)*

*“I didn’t realize how much I needed counselling until I started going for it. It’s helped me manage my anxiety and fear about the future, and given me tools to cope with the physical side effects of chemotherapy however, he is only one person, we need more of them to help us.” (P17)*

With the need for support groups participant had this to say:

*“Navigating this journey feels overwhelming at times. I wish there were support groups where I could connect with others who understand and share their experiences (P19).”*

*“It’s not just about the physical challenges of treatment. I often feel isolated and could benefit from a support group where I can talk openly about my fears and hopes (P13).”*

One participant added the need for support from her husband:

*“I am surviving because of the quality of support I receive from my family but I think I need more especially from my husband” (P10).*

The need for orientation to the hospital and its environs were report as follows:

*“I was traumatized on my first day of chemo. No one oriented us to the place...I didn’t know where the chemo office is located, at the OPD I was told I should go to the surgical ward so I started walking on the corridors, moving from one place to another without finding the place” (P2)*

*“...I was moving from one place to another just to locate G2 or G1 because at the consulting room I was told to go there but no one led me there. No direction to the chemo unit, they only asked me to follow the signpost which not everyone understood, I didn’t understand either. A little orientation could have help” (P4)*

One participant also stated:

*"I was not giving any orientation at the hospital, I located the lab by myself and the chemo unit also by myself...but at the chemo unit there were two rooms and I didn't know from which one I will receive my treatment, so, I was moving to and fro just to... right now I think I still don't know a lot of places in the hospital and I need some orientation before I get lost" (P6)*

Another participant added:

*"Being in a hospital can be disorienting, especially when you're here for treatments like chemotherapy for the first time, you know! A proper orientation to the various aspects of the hospital...say the laboratory, chemo unit, pharmacy and other places would really help ease some of the anxieties I feel each time I walk through these corridors (P1)"*

Most participants indicated that they were not given reassurance during treatments even though they wanted the reassurance:

*"You know Ghanaian nurses; they talk to you as if you went to school with them. No reassurance, all you are told is that you have cancer so come on 21st for your chemo just like that" (P13)*

*"No one assured me of anything, all the nurses and doctors were interested in was why didn't you come for your medication, go to the lab, do this and do that..." (P20)*

*"...the nurse collected my folder and said to me, madam come here, did they tell you that you have cancer? you need to do some lab test and if you are ok, then you start your chemotherapy at G1...there was nothing like you will be fine or you may experience this or that when you start your chemo, no assurance let alone reassurance and even as we speak, I can tell you that every cancer patient needs assurance because what the chemo will do to you eei!!! hmmm...." (P12)*

Another participant stated:

*"What I need right now, is reassurance that all will be well. You are losing almost everything and no one is reassuring you about a better life after treatment. See my hand, hair, and mouth, when will I recover from this (crying). everyone has changed and I need peace of mind, I want someone to tell me (XXX name mentioned) you will be fine but who?" (P11)*

### 5.6.3 Subtheme 3: Need for Spiritual Support:

Although there were degrees and categories of needs, some common spiritual and religious needs expressed by participants were the need for prayers, the need for communion to be administered to them, and the need for consecration.

*"...I need more prayer. Yes, now am not able to go to church but I always request for prayers from my pastor and I need more prayers to make it through" (P18)*

*"I tell you; cancer is not a normal disease like malaria or diarrhoea. I don't joke with my prayers and I feel sometimes it is not enough so, I ask prophets (XXX... name mentioned) for prayers...I need God's healing powers to help me (pause)..." (P24)*

*"I have been asking around for men of God to pray for me. Please, I need prayers because this battle is not fought on treatment alone" (P1)*

Some participants also revealed that they have faith that if they receive communion, it will sanctify and cure them from the cancer disease.

*"I am a presbyter and I believe when I take communion the blood of Jesus will heal me from this deadly disease...I need to take communion the next time they celebrate it in the church for I know it will work for me" (P8)*

*"...the blood of Jesus will sanctify me when I take communion. For me each time I am sick and I take communion, I get well because it is the blood of Jesus...and the blood of Jesus can redeem you from any sickness. My only challenge now is that am far from home so, how to get it is a problem but I need to take it honestly" (P12)*

Similarly, participants narrated that they needed a consecration service or purification to enable them to receive forgiveness from God.

*"This disease in my view is not from God, in our tradition a woman hardly falls sick of the breast unless there is something wrong, but I can't tell where the problem is, so I will need some purification to be done to help cast out any demons around me" (P2)*

*"I am worried about the cause of my illness...no one, I mean none in our family had ever had breast cancer. For me to be the first, in fact, it requires that I ask for forgiveness from God. I need new baptism and sanctification service for the battle is the Lords, we are not fighting against flesh and blood but evil forces...only sanctification can set me free I tell you" (P19)*

#### **5.6.4 Subtheme 4: Need for Symptoms Management:**

As evident from the experiences of the patients, the cancer and its treatment resulted in various side effects. The need for symptom management was expressed as follows:

*“Today vomiting, tomorrow hair loss another day fatigue, can something be done to assist us manage these distressing symptoms management” (P24)*

*“Physically you are exhausted. If not fatigue, is vomiting...and you live like never before. Something should be done to help improve our lives during treatment” (P15)*

The participants spoke specifically about the pain they experienced and their need for pain management. They experienced background pain as well as pain related to the chemotherapy they experienced. The participants said:

*“Can my pain be better managed to help lessen the pain burden for me?” (P21)*

*“...pain in my throat, abdomen, and chest, it is like an elephant walking on your chest bam, bam, bam, like that...I wish I could stop my chemo because these pains follows right after completing my infusion, how can I avoid this pain from coming back? That is another big challenge for me in this treatment journey” (P4)*

One participant added:

*“The pains come in from several sources, for me, the most painful situation is when the nurses and doctors are looking for a vein in order to set the water on (Infusion) they will puncher your entire hand just to look for a vein, a pain you will never like to bear under any circumstance. So, when it’s getting to my next cycle, I honestly wish I could avoid the pain...” (P18)*

Another participant revealed:

*“If there is anything I need most, right now, it’s how to avoid cancer and chemo pain. I experienced so much pain immediately after the chemo and is not a joke...my whole body is like I am being cooked on fire” (P19)*

Many participants also expressed a wish for improved quality of life.

*“I wish for a better quality of life where I can experience some sense of normalcy, normalcy from pain and fatigue despite undergoing treatment for breast cancer.”(P1)*

*"...I hope for a better quality of life that allows me to spend more time with my family and pursue my hobbies resume normal working hours and also able to sleep at night on my own bed " (P17)*

*"I wish for a future where my basic needs are met, and I can live comfortably without financial stress. And nauseas and vomiting " (P21)*

### **5.6.5 Subtheme 5: The Need for Professional Informational Support**

Several participants reported a lack of basic knowledge and accurate information on breast cancer and chemotherapy.

*"Chemotherapy has been a difficult and scary experience, and I often feel like I'm in the dark about what's happening to my body. I have questions about my treatment, prognosis, and other aspects of my care that I believe I need more professional support and guidance to help me feel informed and empowered." (P4)*

*"I was told cancer had no cure...so errh, that is what we all know or am lying, yes...we were made to believe so. So, when I went to the hospital and was diagnosed with breast cancer I left and was moving from one prayer camp to another for healing until one day when I saw that things were getting worse. My whole arm was swollen and I couldn't lift it nor use it for anything ... I came back to the hospital and this finally landed me here. There are many people out there like me with a wrong understanding and information about cancer so we need help from you people (Nurses and doctors). If you can go to churches, mosques and even market places to educate us the women and to tell us the truth about cancer and its treatment it will help" (P11)*

*"I feel like I'm constantly searching for answers and trying to figure out what's best for me. It would be so helpful to have a reliable source of information and support from professionals." (P5)*

A participant added:

*"Navigating breast cancer and chemotherapy is overwhelming, and I wish I had more professional support and information to guide me through the process (P17)*

Another participant reported:

*"In my village, if a woman gets breast cancer it is called (Jamilo disease) meaning (a harlot disease) and because of this many women are dying slowly because you can't report it at early stages until it gets worse...so we need correct education on the breast*

*cancer so that we can get the support of our husbands to come to the hospital and seek treatment early” (P9)*

Participants grappled with socio-economic challenges, with many experiencing financial constraints that compelled them to postpone or even skip treatments. Additionally, there was a pronounced need for psychosocial support, as evidenced by their expressed desires for counselling, support groups, and reassurance, which play pivotal roles in alleviating emotional distress and addressing fears. Alongside these needs, spiritual and religious support emerged as a significant aspect, with participants seeking prayers, communion, and consecration to navigate their cancer journey. Lastly, a notable gap in informational support was observed, as many participants felt uninformed about breast cancer and its treatments. The trend mostly is that breast cancer and its treatments, including chemotherapy, involve complex medical information that can be challenging for patients to understand (Akhlaghi et al., 2020). The intricacies of treatment options, side effects, and potential outcomes are often communicated using medical jargon, making it difficult for patients to fully grasp the information (Zota et al., 2023). Additionally, the emotional distress associated with a cancer diagnosis can further impair a patient's ability to process and retain information (Akhlaghi et al., 2020)

## **5.7 Summary**

This chapter presented results on the palliative care needs of women receiving palliative chemotherapy for breast cancer. The participants experienced various side effects of chemotherapy such as nausea and vomiting, hair loss (Alopecia), fatigue, mouth and throat sores, and skin and nail changes. Despite coping with these effects through the adaption of a new normal way of life, hope, religion and social support, they still experienced various needs. Their needs included lack of money, need for prayers, need for information support and pain management. In 0 discussion and interpretation of the results of phases 1 and 2 are presented.

# CHAPTER SIX DISCUSSION OF PHASES 1 AND 2

## 6.1 Introduction

The results from phase 1 and the findings from phase 2 were presented in Chapters 4 and 5 respectively. This chapter presents a discussion on the scoping review (phase 1) and interpretation of the findings from phase 2. The evidence from these two phases contributed to the development of the palliative nursing care programme for women with breast cancer and receiving palliative chemotherapy.

## 6.2 Discussion, Phase 1

The scoping review described literature on interventions employed to support women receiving palliative chemotherapy for breast cancer. The review identified six relevant papers published in the USA, Australia, China, Japan and South Korea over a decade (2012-2021).

Considering the ever-increasing burden of cancer and the growth in palliative care services, it might be reasonable to expect that nurses added to the body of knowledge about the care of patients diagnosed with breast cancer and their families along with the expansion of these services. However, as seen from the current review, only six (n=6) studies could be found (Reiser et al., 2019a, Lee et al., 2017b, Yee et al., 2019, Yee et al., 2014a, Komatsu et al., 2020a, Ye et al., 2017a). This number compares negatively to the number of cancer nursing studies published between 2015 and 2019 (n=84) of which only 4.2% (n=2) focused on palliative care (Maree et al., 2021). The global review on cancer nursing output of Molassiotis et al. (2006) likewise paints a bleak picture. Although it was reported that 128 (21.2%) of the 619 studies included in the global review focused on patients with advanced cancer, only 0.5% of the total number of papers originated from Africa with none focusing on breast cancer and palliative chemotherapy (Maree et al., 2023).

While the majority (66.66 %) of studies provided their sampling methods (Komatsu et al., 2020a, Reiser et al., 2019a, Yee et al., 2019, Ye et al., 2017a), two (n=2, 33.33%) studies did not specify their sampling methods (Lee et al., 2017b, Yee et al., 2014a). In the study conducted by Berndt (2020), they reported that the omission of sampling methods details raises concerns about the robustness and replicability of the research. Without this essential information, it becomes challenging for readers and fellow researchers to assess the study's generalizability and the strength of its conclusions.

Similarly, the research conducted by Loris et al. (2022), detailing a pilot and feasibility study of a complex nurse-led patient education programme, aimed to promote cancer patient engagement in healthy lifestyle. The research involved recruiting 40 newly diagnosed adult cancer patients, who were then randomly assigned to either the patient engagement in healthy lifestyle intervention group or the control group using a four-block randomization procedure. The primary focus was on assessing the feasibility of the study, including recruitment and retention rates, protocol adherence, and stakeholder acceptability. However, the article lacks explicit information about the sampling method employed. This lack of transparency on sampling methods not only limits the scientific rigor of the study but also hinders the ability of the scientific community to evaluate the validity of the findings and draw meaningful comparisons with other research in the field (Christensen et al., 2019, Subedi, 2023, Bastiaansen et al., 2020). These examples underscore the importance of reporting sampling methods in research studies. Explicit sampling methods information is crucial for assessing the reliability and validity of study results, ensuring transparency, and facilitating the replication of experiments by other researchers (Bastiaansen et al., 2020, Sürücü and Maslakci, 2020).

Various research designs were employed, with the majority (n=4, 66.66%) using quantitative methods. This is consistent with Maree et al., (2021), and Molassiotis et al., (2006) but in contrast with what was found in the reviews on cancer nursing research entitled, 'Scoping the Landscape of Evidence Focusing on Cancer Care from January 1, 2012 to December 31, 2021 where the majority of the work was qualitative' (Maree et al., 2023). Broeder and Donze (2020) purport that quantitative evidence supports scientific personal and experiential knowledge needed for nursing practice while qualitative research supports the art of nursing practice leading to an understanding of the whole patient as an individual. Thus, both approaches are needed to guide evidence-based palliative nursing care.

The review identified 13 prominent synthesized themes/foci. Informational support need, quality of life, financial, pain, fatigue, nausea/vomiting, sleep disturbance, shortness of breath, appetite changes, dry mouth, social work, social needs, anxiety, and depression support. This is consistent with previous studies (Cherny et al., 2018a, Akuoko et al., 2022, Maree and Wright, 2008).

The scoping review provided evidence that information seeking was the third highest need (33.33%) from the reviewed studies (Reiser et al., 2019a, Ye et al., 2017a). The need for information has consistently been described as an unmet need in cancer care (Chen et al., 2022a, Abdollahzadeh et al., 2014, Cherny et al., 2018b). For instance, a study by Cherny et al. (2018a) reported that oncology clinicians have the potential to significantly reduce anxiety by addressing the emotional and informational requirements of patients and their families throughout the cancer journey. This involves maintaining open communication channels and

a dedication to promptly responding to moments of distress or concern. This could be because of the patient's illness being serious and expected to need additional physical care, which induced more worries and concerns (Cherny et al., 2018a, Husson et al., 2011). The strong need for additional information about the disease, treatment and its effects and symptoms management may be indicative of how information is presented in the care environment (Cherny et al., 2018a). This is a mismatch in content between patient and the information with which they are provided, and the degree to which high-quality educational materials are available to them (Bekker et al., 2020). Patients receiving palliative care services are usually anxious and seek all information available to enable them take decisions on their care (Scott et al., 2023).

Conversely, some patients gain their health care information through trial and error, and/or by informal channels, such as a neighbour or friend (Sudhinaraset et al., 2013). This is similar to what was reported in a care giver burden study by Schubart et al. (2008) conducted in the USA; their need was for the physicians to inform them of what to expect earlier, before the cancer crisis. They needed to be ready to manage the neurocognitive alterations that were likely to occur among cancer patients and to know how to address the health needs of the patient and the behaviour alterations, how to manage the hostile or life-threatening behaviour, and at what time they would need to look for specialised assistance. It is therefore observed from the review studies that palliative care patients revere the professional palliative care information they received as it helps them to make an informed decision with regards to their palliative care needs thus, breast cancer, prognosis, outcomes, symptom management, hospice care, and treatment (Wang et al., 2018, Bore et al., 2023).

This strongly indicates that cancer patients depend heavily on oncology healthcare providers for informational and educational support. Thus, it is necessary for oncology healthcare providers to be prepared to communicate effectively with patients by providing appropriate information in an empathetic manner. Furthermore, interventions such as palliative nursing care programmes would be helpful, not only to meet the unmet palliative care needs of women with breast cancer but also to improve their QoL (Steenbergen et al., 2022, Moudatsou et al., 2020).

Palliative nursing care support for symptoms management in the reviewed studies included pain, fatigue, nausea/vomiting, sleep disturbance, shortness of breath, appetite changes, dry mouth, anxiety, and depression (Reiser et al., 2019a, Yee et al., 2019). This is similar to the result of the study conducted in the US on the psychosocial needs of women with breast cancer, which showed that emotional and psychological/spiritual support are the most prominent areas of care needs by women diagnosed with breast cancer (Hewitt et al., 2004).

This is further supported by Cherny et al. (2018a) in their study on women receiving treatment for breast cancer; their main needs included physical, psychosocial and spiritual needs. The differences observed from the reviewed studies on needs differences priorities were anticipated, and could be attributed to the differences in research setting and context, as well as methodology; in other words, people from different countries may have different palliative care needs (Etkind et al., 2017, Centeno and Arias-Casais, 2019).

That aside, the scoping review revealed a small number of peer-reviewed scientific data on the palliative care interventions in which nurses participated that were used to provide palliative nursing care services for breast cancer patients receiving palliative chemotherapy globally as only six studies were identified. Challenges arose in classifying palliative care services across the domains as each study had its focus except for synthesis of data that made the classifications possible, reflecting the complexity and variability in the patients' experiences. The palliative care needs were prevalent, ranging from 16.66% to 83.33%, surpassing rates reported by the World Health Organisation in the Eastern Mediterranean Region (World Health Organization, 2024). The review emphasized the unique challenges faced by patients receiving palliative chemotherapy for breast cancer.

Additionally, the review also identified a gap spanning the entire breast cancer trajectory, that whereas in developed countries there is a dearth of nurses that participated in intervention studies on palliative nursing care programmes for breast cancer patients undergoing palliative chemotherapy, in Africa, there exists no intervention programme offering palliative nursing care services for breast cancer patients undergoing palliative chemotherapy. The same trend was observed in the African cancer nursing review published in 2021 (Maree et al., 2021). Regrettably, the reason for this trend is unclear. As Sub-Saharan Africa still faces challenges with the integration of palliative care in cancer care and often focus on curative therapies (Ngwa et al., 2022a), as Charlton (1998) puts it, assistance to establish palliative nursing care programmes and conduct research to develop contextual, evidence-based palliative care practice would be more helpful than to write "about us without us". In addition, it is debatable if the current trend is in the best interest of the patients we serve (Maree et al., 2023).

Of concern also is that only one-sixth of the studies included in the review included dry mouth, sleep disturbance, shortness of breath, and social work needs. What was also missing among the studies included in the current review are studies focusing on spirituality of the patients. The focus of the studies diverts from primary palliative care definition described by the World Health Organisation (World Health Organisation, 2020e) that, palliative is about managing life-threatening illness, whether physical, psychological, social or spiritual. Baker et al. (2012) when investigating the effectiveness of an intervention study on physical and psychological effects of an integrated support programme in breast cancer patient, found the interventions

had positive effects on symptom severity, uncertainty, spiritual well-being, and cancer related fatigue. In addition, Santos Carmo et al. (2023) in their scoping review on the relationship between religion/spirituality and the aggressiveness of cancer care reported that high spiritual support from religious communities is associated with less hospice care. The study concluded that faith-based interventions had a positive influence on patients' health outcomes.

Intervention studies are of great importance to improve the lives of patients living with advanced breast cancer, especially in Africa, where many patients and their families do not have access to palliative anticancer treatment and medicines used in palliative care and are unable to afford cancer care as they live in poverty with most of them relying on God for healing (Oliver, 2022).

## **6.3 Discussions on Phase 2**

### **6.3.1 Experiencing the Side Effects of Palliative Chemotherapy**

Participants who were diagnosed with breast cancer in this study had undergone palliative chemotherapy and reported various challenges. These challenges were linked to both the diagnosis and treatment of breast cancer. The study found that these challenges encompassed physical, social, financial, and psychological aspects. These findings align with existing literature (Yousuf Zafar, 2016, Gbande et al., 2020, Chi, 2022, Butow et al., 2015b, Zafar et al., 2013, Ngwa et al., 2022b, Kim et al., 2019a, Akhlaghi et al., 2020b, Sunilkumar et al., 2021, Iddrisu et al., 2020, Konski, 2021).

Fatigue, hair loss, nausea, and vomiting were among the most common physical effects reported by women receiving palliative chemotherapy for breast cancer. This is consistent with literature (Charalambous et al., 2017, Sun et al., 2017). For instance, a study published in Cyprus on the prevalence and severity of physical distress among women with advanced breast cancer receiving palliative chemotherapy found that the most common physical symptoms experienced by patients were fatigue (90%), hair loss (88%), nausea (82%), and vomiting (76%) (Charalambous et al., 2017).

Similarly, a systematic review conducted by Sun et al. (2017) found that fatigue, hair loss, nausea, and vomiting were common side effects reported by breast cancer patients undergoing chemotherapy. The severity of these symptoms varied depending on the type and duration of chemotherapy. The current study supports this finding as newly diagnosed women experienced more nausea and vomiting than those that were on chemotherapy for more than one cycle. The variation in experiences could be due to adaptation to the new normal way of

life by women that are on the treatment for a longer period relative to those that were newly diagnosed.

Inversely, in a randomized controlled trial conducted by Cheng et al. (2015), which investigated the efficacy and safety of capecitabine-based palliative chemotherapy in 120 patients with metastatic breast cancer, the results showed that nausea and vomiting were not reported as significant adverse events. However, fatigue and hair loss were reported in a significant proportion of patients. The authors concluded that capecitabine-based palliative chemotherapy was effective and well-tolerated, with manageable adverse events. The difference in the effects between the present study and that of Cheng et al. (2015) could be related to differences in individual factors that may increase the likelihood of nausea and vomiting during chemotherapy and strategies for managing these symptoms. This reiterates the statement by Williams et al. (2016) that patients' experiences and strategies differ in the way they respond to treatment and side effects of chemotherapy.

Pain can significantly impact the quality of life of women with breast cancer and receiving palliative chemotherapy. Studies have reported that pain is a prevalent symptom among women with breast cancer who are receiving palliative chemotherapy (Lim et al., 2017, Greco et al., 2014). Pain can be multifactorial, arising from the disease itself, its treatment, or its associated complications. The pain experienced by these women can be acute, chronic, or breakthrough pain (Greco et al., 2014). In this study, participants explained that their pains were from different sources and most often came immediately after taking their pain medications affecting every part of their lives including activities of daily living. Other pains came from needle pricks for veins to set infusions. This finding agrees with a study by Shafiei et al. (2020) in which they explored the experiences of pain among women with breast cancer and receiving palliative chemotherapy. The study found that women with breast cancer experienced various types of pain, including physical pain, psychological pain, and social pain.

These reports reiterate the result in a study by Smith et al. (2018) which showed that women with breast cancer experienced pain in different areas of their bodies, including the breasts, chest, and bones. The pain was described as dull, achy, stabbing, and burning, and it interfered with their daily activities, sleep, and quality of life (Smith et al., 2018). This is also consistent with the study of Kiani et al. (2020) aimed to explore the severity and management of pain among women with metastatic breast cancer who were receiving palliative chemotherapy. The study included 100 women who were undergoing chemotherapy for advanced breast cancer. The results showed that 86% of the women experienced pain, with 50% describing it as moderate to severe. The most common areas of pain were the back, chest, and bones. The study also found that pain was inadequately managed, with only 42% of the women receiving appropriate pain management. The present study agrees with this

finding as participants reported severe pain after their pain medications were administered to them but differed in the percentage of pain experienced as the present study did not measure the degree of pain.

Participants also reported that their pain experienced went beyond the physical, social and psychological to spiritual as some participants felt God had left them to their fate and that there was no need to live any longer. This finding is congruent with the study of (Adunlin et al., 2019) conducted in the United State of America. In that study, which aimed to explore the experiences of pain and the coping mechanisms among African American women with breast cancer who were receiving palliative chemotherapy, the results showed that the women experienced different types of pain, including spiritual pain.

Participants also reported loss of hair and appetite, and discoloration of the skin. This agrees with the literature (Chirima et al., 2018, Ogunkorode et al., 2021). For example, according to a study conducted by (Chirima et al., 2018) in Zimbabwe, hair loss and changes in skin pigmentation are among the most common side effects reported by cancer patients receiving chemotherapy. In the study, 85% of the participants reported experiencing hair loss, while 45% reported changes in skin pigmentation. Additionally, loss of appetite was reported by 70% of the participants. The difference however, in this study is that the percentages of experiences were not quantified in this study.

Furthermore, almost all of the participants experienced anxiety, depression, and other psychological distress like sadness. This is in line with literature as several studies have examined the emotional impact of palliative chemotherapy on women with breast cancer (Moodley et al., 2017, Mushi et al., 2019). One study found that women receiving palliative chemotherapy reported higher levels of anxiety, depression, and distress compared to those who were not receiving palliative chemotherapy (Beatty et al., 2011). Another study found that women receiving palliative chemotherapy experienced greater levels of fatigue, pain, and nausea, which were associated with higher levels of anxiety and depression (Kamau et al., 2015). The present study support this finding as many participants revealed their nausea and vomiting experienced were not painful but rather annoying and depressing as the whole day they had to have their heads buried in the water closet or they had to chew gum and cola to help control their nauseating experiences.

Also, the fear of death and uncertainty about the future and disease progression are common psychological concerns for women receiving palliative chemotherapy (Catt et al., 2015). The loss of physical functioning and the sense of control over one's life can also contribute to feelings of depression and anxiety (Mertz et al., 2012). Additionally, the side effects of chemotherapy, such as hair loss, weight gain, and changes in body image, can have a

significant impact on a woman's self-esteem and body image (Dunn et al., 2013). The present study agrees with this finding as most women became extremely worried following their hair loss to chemotherapy. They lost confidence in themselves and that affected their self-esteem. However, they were provided with emotional interventions such as counselling.

This agrees with the study by Faller et al. (2017) in which they reported that emotional interventions strategies such as cognitive-behavioural therapy, counselling, relaxation techniques, and mindfulness-based stress reduction have been shown to reduce anxiety and depression in women receiving palliative chemotherapy.

Similarly, participants reported that they were not introduced to any cancer survivor groups or social clubs, rather, some of their family members and friends were the only people with them during the course of the treatment. This, they reported, affected their hopes and any anticipations of recovery. This is consistent with the studies of Boyes et al. (2012) and Elsherif and Behilak (2023) where they reported that social support from cancer survivor groups, family, friends, social clubs, and healthcare practitioners can help women feel less isolated and provide emotional support during the treatment process.

This study revealed that breast cancer and palliative chemotherapy influenced the woman's social support network. Women in this study experienced a feeling of isolation and loneliness and were unable to work or participate in social activities as a result of their treatment. This agrees with previous studies (Ferrell and Grant, 2013, Ganz, 2012). For example, according to Ferrell and Grant (2013), "the diagnosis of cancer and its treatment have a profound impact on the individual's quality of life, as well as on their family and social relationships and work" (p. 217).

Participants also revealed that a change in their physical appearance and reproductive functioning like menstruation affected their participation in community social events. This supports the findings of (Ganz, 2012) where he reported that social effects of breast cancer and palliative chemotherapy may include changes in body image, sexual function, and intimacy. The study added, women with breast cancer may experience changes in their physical appearance, which can affect their self-esteem and body image. Additionally, the side effects of chemotherapy, such as fatigue, nausea, and hair loss, can limit a woman's ability to participate in social activities and may cause her to feel isolated (Ganz, 2012). This further agrees with the study of Saeed et al. (2014), in which they reported that palliative chemotherapy affects a woman's social life by disrupting her daily routines and limiting her ability to participate in social activities.

In that study, Saeed et al. (2014), indicated that patients receiving palliative chemotherapy reported a decrease in their ability to carry out daily activities, which affected their social and

family roles. These changes, they contend, can lead to a feeling of isolation and depression, as well as a sense of loss of control over one's life. This is consistent with the present study as many participants indicated that due to fatigue, they were not able to work for longer hours while others couldn't go to work at all. Many avoided social gatherings like funerals and naming ceremonies due to the changes in their physical appearance.

Additionally, participants reported economic crises as one of the major negative experiences they had to bear during the course of their cancer diagnosis and treatment. This agrees with (Rosenzweig et al., 2019, Sabulei and Maree, 2019). And also in tandem with the report of Iddrisu et al. (2021) that breast cancer and its treatment can have significant economic impacts on women and their families. In particular, the cost of palliative chemotherapy can be substantial, as it often involves multiple cycles of treatment over an extended period of time (Hewitt et al., 2012). Additionally, breast cancer patients may face reduced income or job loss due to their illness and treatment, and may also experience increased out-of-pocket costs for healthcare expenses as was the case of the women in the present study (Sabulei and Maree, 2019).

A study conducted by Yabroff et al. (2016) estimated the economic burden of breast cancer in the United States, including both direct medical costs and indirect costs such as lost productivity. The study found that the total cost of breast cancer in 2010 was approximately \$88.5 billion, with direct medical costs accounting for approximately \$16.5 billion and indirect costs accounting for the remaining \$72 billion. The authors noted that these costs were likely to continue to rise due to factors such as an aging population and the increasing cost of cancer treatments. Most women in this study reported that on several occasions they had to use all their savings to pay for treatment leaving them without lorry fare back home nor food to eat or clothes to wear. This is consistent with a study in Asia. Regarding the economic impacts of palliative chemotherapy specifically, a study by Yap (2019) in Singapore found that breast cancer patients receiving palliative chemotherapy faced significantly higher healthcare costs than those not receiving palliative chemotherapy. The study also found that patients receiving palliative chemotherapy were more likely to experience financial distress and to report reducing spending on food, clothing, and other basic needs.

Likewise, a systematic review by Khera et al. (2020) on the economic burden of breast cancer in low- and middle-income countries (LMICs) highlighted the significant financial hardship experienced by breast cancer patients in these settings. The review found that breast cancer patients in LMICs often face substantial out-of-pocket costs for treatment and may need to sell assets or borrow money to pay for their care. This financial burden can lead to delays in seeking care and poorer health outcomes. The present study supports this finding as most participants indicated that they took loans from financial institutions, friends and family

members in order to pay for their medical bills. Other participants reported that they had to sell their possessions, such as land, in order to be able to continue with their treatment. These experiences of financial effects are not surprising, bearing in mind the current economic challenges in the country, coupled with the level of poverty and dependence among women within lower-income countries like Ghana, making these challenges anticipated.

There is evidence to suggest that the economic impact of chemotherapy on women varies depending on the country in question. For example, a study published in the journal *Cancer Control* in 2018 found that in low- and middle-income countries, the cost of chemotherapy can be a significant barrier to access for many women (Lopes G et al., 2018). This can lead to delayed or incomplete treatment, poorer outcomes, and increased financial burden for patients and their families. In contrast, in high-income countries with universal healthcare systems, the cost of chemotherapy is typically covered by insurance, which can mitigate the financial impact on patients. That notwithstanding, the economic impact of cancer and chemotherapy is real.

Another study published in the *Journal of Global Oncology* in 2017 found that the economic impact of breast cancer treatment was higher for women in lower-income countries, where out-of-pocket expenses can be prohibitively expensive for many patients (Zelle et al., 2018). The study also found that women in lower-income countries were more likely to experience financial distress, loss of income, and decreased quality of life due to the cost of treatment. The current study supports this assertion as some participants reported that they lost their incomes due to long waiting hours in queues for medical care while others could not work full-time owing to fatigue emanating from chemotherapy effects. These findings suggest that the economic impact of chemotherapy on women is highly dependent on the economic and healthcare context in which they receive treatment.

### **6.3.2 Coping with Breast Cancer and its Treatment**

Chemotherapy remains one of the most common treatments for breast cancer, which can cause a range of physical and emotional side effects, including changes in body image and self-esteem. As a result, many women undergoing palliative chemotherapy for breast cancer may experience changes in their bodies that require adapting to the new way of life (Engelbrecht et al., 2019, Afful et al., 2017). This is congruent with the present study as participants reported to have adopted a new normal way of life, hope or optimism, religion and social support in order to cope with the disease and its effects

In adapting to the new normal way of life, participants reported a change in dressing pattern so as to accommodate the changes in their physical appearances. They adopted long sleeves, gloves and wigs. This is consistent with the previous study of Kim et al. (2019b) as they

reported that changes in dressing patterns can have a significant impact on how women cope with breast cancer and its treatment. In another study, Stergiou-Kita et al. (2014) explored the impact of body image and dressing changes on women undergoing chemotherapy for breast cancer. The study found that women who experienced changes in their physical appearance due to chemotherapy, such as hair loss or weight gain, were more likely to change their dressing patterns to accommodate these changes. Some women choose to wear loose-fitting clothing or headscarves to conceal their physical changes, while others opted for more vibrant and colourful clothing to boost their mood and confidence.

Furthermore, participants adapted to a positive mindset. They told themselves that things will get better as such they avoided negative thoughts about their diagnosis and treatment. This supports the study of Mosher et al. (2012) and Guo et al., (2022) where they reported that a positive mindset is an effective coping mechanism for women undergoing palliative chemotherapy for breast cancer. Such women adopt a more positive outlook on life, setting new goals, and focusing on the present moment.

Moreover, research has shown that a reorientation of the mind can be an effective coping mechanism for women undergoing palliative chemotherapy for breast cancer. For example, a study by Chien et al. (2022) found that women who practiced mindfulness meditation during chemotherapy experienced a significant reduction in symptoms of anxiety and depression. Another study by Zhang et al. (2020) found that cognitive-behavioural therapy improved the quality of life of women undergoing chemotherapy for breast cancer.

Research has shown that social support can have a significant effect on the mental health and quality of life of women with breast cancer. For example, in a study conducted by Kornblith et al. (2019), women who reported higher levels of social support had better mental health outcomes and were less likely to experience depression and anxiety. The present study agrees with the literature above as participants in this study indicated that they received social support and that assisted them to cope with chemotherapy effects. Kornblith et al. (2019) further added that, women who reported higher levels of social support had better mental health outcomes and were less likely to experience depression and anxiety.

Participants in this current study got their social support from family and friends. This is in tandem with previous studies (Boatema Benson et al., 2020, Bonsu et al., 2014b, Badr et al., 2013). Social support from family and friends can play a crucial role in the lives of women receiving palliative chemotherapy for breast cancer. Studies have shown that social support can help reduce stress, improve emotional well-being, and enhance overall quality of life for these patients (Northouse et al., 2012). In addition, social support can also help patients cope

with the physical symptoms and side effects of chemotherapy, such as nausea, vomiting, and fatigue (Northouse et al., 2012).

Some studies examined the relationship between social support and quality of life in women receiving palliative chemotherapy for breast cancer. Studies found that higher levels of social support from family and friends were associated with better physical and emotional functioning, as well as greater satisfaction with social relationships (Badr et al., 2013, Zhang et al., 2017). Other studies explored the impact of social support on symptom burden in women with advanced breast cancer. These studies found that patients who reported higher levels of social support had lower levels of pain, fatigue, and other physical symptoms (Avis et al., 2013, Okati-Aliabad et al., 2022). From the current study, even though participants reported that they received social support, that support was limited to only family and friends. No social groupings like cancer survivor groups or the like were present to offer support and that was a major concern to them because they wanted reassurance from someone who had experienced their situation before but that was not forthcoming. A study by Demark-Wahnefried et al. (2016) published in the *Journal of Cancer Survivorship* found that breast cancer patients who received emotional support from family and friends had better overall health-related quality of life and were more likely to engage in physical activity. Moreover, a study by Barsevick et al. (2020) published in the *Journal of Psychosocial Oncology* found that cancer patients who had access to social support reported less distress and a better quality of life. Based on these studies, it is likely that breast cancer patients receiving palliative chemotherapy would benefit from the support of social groupings such as cancer survivor groups. It is understandable that the absence of such support would be frustrating for some patients.

### **6.3.3 Need of Women Diagnosed with Breast Cancer**

As alluded to in Section 1.2 of Chapter One, palliative chemotherapy for breast cancer is an important treatment modality aimed at reducing cancer-related symptoms and improving the quality of life of patients. However, it is associated with significant side effects, including vomiting, hair loss, loss of appetite and fatigue, which can negatively impact a patient's well-being and limit treatment compliance. As a result, patients undergoing palliative chemotherapy often express the need for symptom management (Molassiotis and Wang, 2023, Maree et al., 2022). The results of the present study support this finding as participants reported that they experienced vomiting, hair loss, fatigue and loss of appetite and wished some interventions could be made to help relieve them from their distressing symptoms. This is also in tandem with one study by Tran et al. (2019) that investigated the symptom burden experienced by women with metastatic breast cancer receiving palliative chemotherapy. The study found that the most common symptoms reported by patients were fatigue and pain (Adamowicz and

Baczowska-Waliszewska, 2020), and nausea/vomiting (Gbande et al., 2020). Hair loss was also reported by a significant proportion of patients. The study highlighted the importance of symptom management so as to help alleviate the suffering of patients undergoing palliative chemotherapy.

In addition, participants reported the need for more potent pain killers to help better manage their pain. They contended that, even though they were given pain medications, it does not last before their pain resurfaces making it unbearable thereby affecting almost all part of their lives including sleep and activities of daily living. This is consistent with existing literature on chronic pain management (Raouf et al., 2018, Oh et al., 2014). According to a study by Oh et al. (2014), patients with chronic pain reported that their pain medications were ineffective in relieving their pain. The study found that patients' pain intensity scores did not significantly improve despite receiving pain medications. Similarly, a review by Cooper et al. (2017) found that patients with chronic pain often require higher doses of opioids to manage their pain. The review also suggested that patients who are resistant to opioids may benefit from other types of pain management strategies, such as cognitive-behavioural therapy or physical therapy.

Participants in this study reported that they wished they could have avoided their pains as it was unbearable for them. This also agrees with the study of (Pergolizzi et al., 2020). Consequently, several studies have also examined the need for pain and symptom management in women with breast cancer receiving palliative chemotherapy. For instance, a study by Bao et al. (2021) aimed to explore the prevalence and factors associated with pain in breast cancer patients receiving palliative chemotherapy. The study found that pain was a significant problem for patients, with nearly 60% of participants experiencing moderate to severe pain. The study also identified factors that contributed to pain, including age, stage of disease, and treatment-related factors such as the use of opioids. On the contrary, the present study did not measure the percentage of pain from the participants and that notwithstanding, the need for pain management was widely expressed by participants in the current study.

Another study by Zhang et al. (2021) aimed to explore the impact of pain on quality of life in breast cancer patients receiving palliative chemotherapy. The study found that pain was a significant predictor of reduced quality of life, with patients experiencing higher levels of pain reporting lower levels of physical, emotional, and social functioning. The present study agrees with the current finding as participants narrated that they could not carry on with activities of daily living nor sleep due to pain.

Some participants also said that they wished their pains could be better managed than they experienced. This is because, in some instances, they were told that pain medications were out of stock from medical stores. and they had to be given prescriptions to purchase these

drugs out of town. This finding is in line with the report of WHO concerning access to opioid analgesics in lower- and middle-income countries (World Health Organization, 1996). Opioid analgesics are an essential component of pain management for cancer patients, including those receiving palliative chemotherapy. However, access to these medications can be challenging in many regions, including West Africa.

In many West African countries, there are significant barriers to accessing opioids for pain management, including legal restrictions, limited availability, and inadequate training of healthcare professionals in their use. Additionally, there are concerns about the potential for opioid diversion and abuse (Harding et al., 2013). The World Health Organisation (WHO) has recognized the importance of ensuring access to opioids for pain management in cancer patients and has developed guidelines for their appropriate use. However, these guidelines are not always followed in practice, and access to opioids remains limited in many low- and middle-income countries, including those in West Africa (Harding et al., 2013). Efforts are being made to improve access to opioids for pain management in West Africa, including increasing awareness among healthcare professionals about the importance of pain management and the appropriate use of opioids. However, much work remains to be done to ensure that all cancer patients in the region have access to effective pain management interventions (Harding et al., 2013)

Despite the challenges associated with managing pain in breast cancer patients receiving palliative chemotherapy, several interventions have been developed to help patients cope with pain and improve their quality of life. For example, a study by Pergolizzi et al. (2020) evaluated the effectiveness of a multidisciplinary approach to pain management in cancer patients. The study found that the approach was effective in reducing pain intensity and improving patient satisfaction with pain management. It is therefore worthy of note that pain and symptom management are critical components of palliative care for women with breast cancer receiving chemotherapy. While some patients may wish to avoid pain altogether, others may benefit from better pain management to minimize the impact of pain on their physical and emotional well-being. Interventions such as a multidisciplinary approach to pain management and education on the possible chemotherapy effects will help patients cope with pain and improve their quality of life.

Lack of basic knowledge and accurate information on breast cancer and chemotherapy was reported by study participants as a major challenge before and during their chemotherapy treatment. Some participants reported that they needed honest answers to their questions about their treatment, prognosis, and other aspects of their care. They were of the opinion that professional supports and guidance on cancer and chemotherapy could help them feel informed and empowered to meet the challenges of cancer chemotherapy. This supports

previous studies by (Zhang et al., 2019, Musa et al., 2020, Weng et al., 2014) Where, for example, several studies have shown that inadequate patient education and low health literacy levels can contribute to poor treatment outcomes, reduced adherence to therapy, and increased healthcare costs (Zhang et al., 2019, Musa et al., 2020).

Furthermore, a systematic review of literature on breast cancer and chemotherapy revealed that many patients have limited knowledge about the disease, its causes, and treatment options (Weng et al., 2014). In particular, there is a lack of understanding about the benefits and side effects of chemotherapy, which can lead to anxiety, distress, and reluctance to undergo treatment. The current study agrees with this finding as participants thought that cancer has no cure and as such, they would rather go to a prayer campus for prayers for divine healing. This is also consistent with the study of Weng et al. (2014) where they reported that patients may have misconceptions about chemotherapy, such as its ability to cure cancer or the belief that all chemotherapy drugs cause hair loss and nausea (Weng et al., 2014). Such misconceptions can lead to unrealistic expectations, treatment decisions based on incomplete or inaccurate information, and suboptimal outcomes. Patients may also have concerns about the safety and efficacy of chemotherapy, particularly if they have heard negative stories from family or friends or have limited access to reliable sources of information (Zhang et al., 2019). The current study supports this finding as some of the women reported a misattribution of the causes of cancer to prostitution.

The current study also found that almost all the participants did not expect their chemotherapy experiences hence were not fully prepared physically, emotionally or psychologically to embrace their cancer and chemotherapy burden. They therefore expressed a wish for professional informational support for themselves and those in their communities such that before they could start chemotherapy, they would have some knowledge of what to expect. This agrees with (Sheikhtaheri et al., 2020, Akuoko et al., 2022). Another argument in favour of providing professional informational support to women receiving palliative chemotherapy for breast cancer is that it can enhance their understanding of the disease and treatment options. This type of support can help patients make informed decisions about their care, which may lead to better outcomes (Sheikhtaheri et al., 2020). Additionally, accurate and up-to-date information can help alleviate patients' anxiety and fears about the treatment process, as well as provide them with a sense of control over their health (Lobb et al., 2013, Sheikhtaheri et al., 2020). Moreover, some studies have shown that informational support can improve patients' psychological well-being. For example, a randomized controlled trial of women with breast cancer receiving palliative chemotherapy found that those who received a tailored information and communication intervention reported less anxiety, depression, and overall distress compared to those who received usual care (Akuoko et al., 2022).

On the other hand, some argue that professional informational support may not always meet patients' needs and could even be harmful. One concern is that patients may become overwhelmed by the information provided, leading to increased stress and confusion. Additionally, some studies have suggested that too much information can lead to decisional conflict, where patients feel unable to make informed decisions about their care (Hirschmann et al., 2018). Furthermore, some argue that informational support may not be enough to address the complex physical, emotional, and spiritual needs of patients with advanced breast cancer. While information can be helpful, patients also need emotional support, symptom management, and assistance with practical issues such as financial concerns and transportation (Jorgensen et al., 2018).

However, according to Sanders et al. (2021), "While it is true that professional informational support may not always meet the needs of palliative care patients, it is still an essential component of their care" (p. 2). Moreover, Sanders et al. (2021) also argue that professional informational support can provide patients with accurate and up-to-date information about their illness, treatment options, and end-of-life care, which can be empowering and help them make informed decisions. Regarding decisional conflict, Sanders et al. (2021) acknowledge that too much information can sometimes be overwhelming for patients. However, professional informational support can be tailored to the specific needs and preferences of each patient, with information presented in a clear and understandable manner. Moreover, a lack of information can leave patients feeling uninformed, or misinformed and disempowered, which can also lead to stress and confusion. By providing them with the necessary information, patients can feel more in control of their care and better able to make informed decisions about their treatment.

Furthermore, according to Reiser et al. (2019b), a support, education, and advocacy programme aimed at providing targeted information to women with metastatic breast cancer in the United States resulted in improved symptom burden and quality of life. The programme was well-received by participants, who reported high levels of satisfaction with the care they received. These findings suggest that nurse-led palliative care programmes, like the supportive, educative programme, have the potential to enhance the quality of life and symptom management of women with metastatic breast cancer.

Given that the burden of cancer in sub-Saharan Africa is significant and rapidly increasing, with an estimated 1.06 million new cases and 693,000 deaths in 2020, and projected to rise to 2.12 million new cases and 1.48 million deaths by 2040 (Ngwa et al., 2022a), the provision of professional informational support is crucial. Interventions that focus on education about breast cancer and its treatment are especially pertinent.

### **6.3.4 Summary of Chapter Six- Phase 1**

The scoping review investigated interventions supporting women undergoing palliative chemotherapy for breast cancer, identifying six relevant studies published globally from 2012 to 2021. The limited number of studies contrasts with the increasing burden of cancer and palliative care services. It was also observed that there is scarcity of research on palliative nursing care, particularly in Africa, where a prominent gap in interventions for breast cancer patients undergoing palliative chemotherapy exists. Only a fraction of the studies addressed a range of palliative care needs, including dry mouth, sleep disturbance, shortness of breath, and social work needs, with an obvious absence of studies on spirituality.

The review highlighted the necessity for transparent reporting of sampling methods in research studies and emphasized the importance of diverse research designs, combining quantitative and qualitative approaches, to guide evidence-based palliative nursing care effectively. Informational support emerged as a significant theme, reflecting a consistent need for information in cancer care. Overall, the findings underscore the need for a professional informational support programme that will help relieve patients of their distressing symptoms and improve their quality of life.

### **6.3.5 Summary of Discussion of Phase 2**

This phase discussed the palliative care needs of women receiving palliative chemotherapy for breast cancer in Ghana. It was observed that the use of palliative chemotherapy resulted in participants experiencing the physical side effects of treatment, psychosocial consequences of the disease and treatment and the economic burden of the treatment. However, participants reported to have coped with these effects by adapting to the new normal way of life and change in mindset, as well as through faith and prayer. That notwithstanding, participants expressed the need for symptoms management and professional information support.

The next chapter discusses the development of the Palliative Nursing Care programme based on the results of phases 1 and the findings of phase 2 of this study.

# CHAPTER SEVEN PHASE 3: DEVELOPMENT/ADAPTATION AND VALIDATION OF THE PALLIATIVE NURSING CARE PROGRAMME

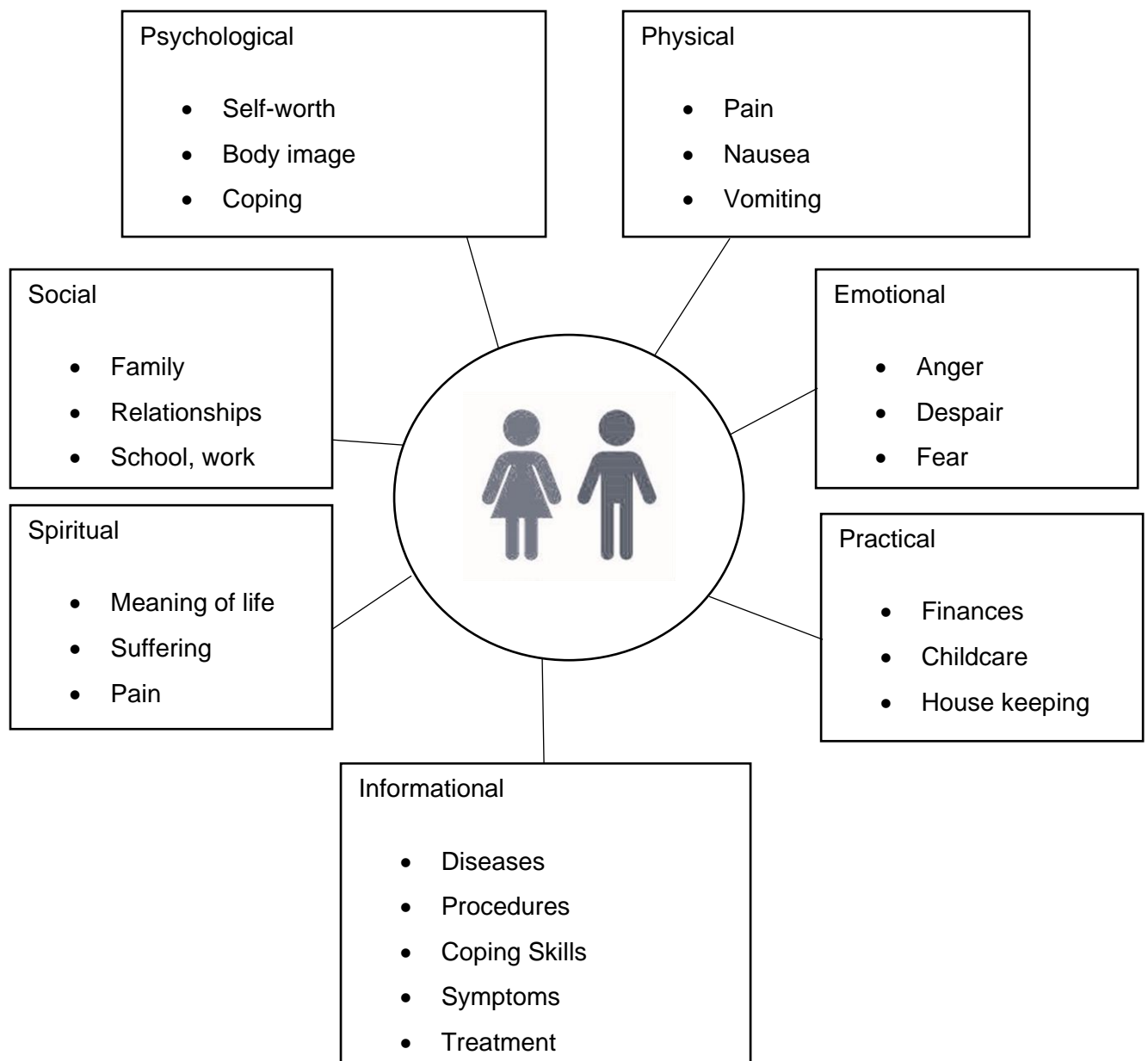
## 7.1 Introduction

The previous chapter presented a discussion on the scoping review (phase 1) and interpretation of the findings from phase 2. The results of the development/adaptation and validation of the palliative nursing care programme (phase 3) are described in this chapter.

## 7.2 Fitch Framework for the Study

The development/adaptation and validation of the palliative nursing care programme was guided by the Supportive Care Framework by Fitch and colleagues (Fitch et al., 2008), (**Error! Reference source not found.**). This framework was deemed appropriate as it was designed as a tool for cancer care professionals and programme managers to conceptualize what type of help cancer patients might require and how planning for service delivery might be approached (Fitch et al., 2008, Fitch, 2015). This framework is also a useful tool for service or programme planning, a basis to organize educational approaches in cancer care, or as a model underpinning research projects (Fitch, 2015). It aims to ensure that all individuals receive supportive care that is relevant to their needs and sensitive to their age, gender, language, culture, sexual preferences, religion, and economic status.

Clinicians and academics have debated the difference between supportive and palliative care for many years. Yet, it seems as if it is the same approach to caring for a person with cancer and in recent years this approach is often referred to as palliative/supportive care. See Figure 7.1 for the supportive care farmwork.



**Figure 7.1: Supportive Care Framework**

(Source: Fitch et al., 2008)

The Supportive Care Framework, as described by Fitch et al. (2008), encompasses various components that can be highly applicable for the development and validation of a palliative nursing care programme for women receiving palliative chemotherapy for breast cancer. Each component of the framework can contribute to providing holistic care for these patients as explained below:

- Physical Support:

Physical support in this context involves developing a programme that addresses the physical symptoms and side effects associated with palliative chemotherapy. It includes pain

management, symptom control (e.g., nausea, fatigue), and ensuring patients' physical comfort (Fitch et al., 2008). This component is essential to enhance the quality of life and reduce suffering.

- Emotional Support:

Breast cancer patients undergoing palliative chemotherapy may experience a wide range of emotional challenges, such as fear, anxiety, depression, and grief. Emotional support can help patients cope with these feelings, improve their mental well-being, and enhance their overall quality of life (Fitch et al., 2008, Fitch, 2015).

- Practical Support:

Practical support may involve assisting patients with daily activities, helping them manage treatment-related logistics, and coordinating home care services (Fitch et al., 2008). This can reduce the burden on patients and their families, allowing them to focus on their well-being and treatment.

- Informational Support:

Developing a programme that provides accurate and clear information about the disease thus, breast cancer, treatment options, and potential outcomes is crucial for empowering patients to make informed decisions. Offering educational resources and explaining the rationale behind treatment choices can alleviate anxiety and foster a sense of control (Fitch et al., 2008).

- Spiritual Support:

Spiritual support is essential for addressing the spiritual and existential needs of patients. It can involve providing access to chaplains, counsellors, or resources that help patients find meaning, purpose, and peace during their journey, even in the face of a terminal illness like breast cancer (Fitch et al., 2008).

- Social Support:

Breast cancer patients receiving palliative chemotherapy may face social isolation due to the effects of their illness and treatments. Developing a programme that builds a support network, connecting them with support groups, and facilitating communication with friends and family can provide much-needed social support, thereby reducing feelings of loneliness (Fitch et al., 2008, Blanco et al., 2023).

- Psychological Support:

Addressing the psychological aspects of care involves identifying and managing psychological distress and mental health issues. This may involve counselling, psychotherapy, or support from mental health professionals to help patients cope with the challenges of their diagnosis and treatment. Intervention programmes should endeavour to include psychological support (Fitch, Porter, & Page, 2009).

### 7.3 Application of the Model

The results of Phases 1 and 2 were used to develop the palliative nursing care programme as guided by the supportive care model. Table 7.1 illustrates how this was done.

**Table 7.1: Link between Fitch’s model and the results of Phase 1 and 2 of the study**

Supportive care model (Fitch et al. 2008)	Results of Phase 1 of the study	Findings of Phase 2 of the study	Application in the palliative care programme (Appendix U).
Physical			
• Pain	YES	YES	8 module 4.-page 31
• Nausea	YES	YES	7 module 3- page 23
• Vomiting	YES	YES	7 module 3- page 23
• Fatigue	YES	YES	7 module 3-page 24
Emotional			
• Anger		YES	8 module 4-page 26

<b>Supportive care model (Fitch et al. 2008)</b>	<b>Results of Phase 1 of the study</b>	<b>Findings of Phase 2 of the study</b>	<b>Application in the palliative care programme (Appendix U).</b>
• Despair	YES	YES	8 module 4-page 26
• Fear	YES	YES	8 module 4-page 26
• Hopelessness	YES	YES	8 module 4-pages 26-27
Practical			
• Finances	YES	YES	8 module 4-pages 28-29
• Childcare			8 module 4-page 29
• House keeping		YES	8 module 4-page 29
• Legal			8 module 4-page 29
Informational			
• Diseases	YES	YES	3 module 1 page's 10-19
• Procedures	YES	YES	8 module 4-page 30
• Coping Skills		YES	7 module 3-pages 23-30
• Symptoms	YES	YES	5 module 1-pages 17-19

Supportive care model (Fitch et al. 2008)	Results of Phase 1 of the study	Findings of Phase 2 of the study	Application in the palliative care programme (Appendix U).
• Treatment	YES	YES	6 Module 2-page 22
• Services	YES	YES	8 module 4-page 32
Spiritual			
• Meaning of life		YES	8 module 4-page-27
• Suffering		YES	8 module 4-page-27
• Pain		YES	8 module 4-page 27
Social			
• Family	YES	YES	8 module 4-page 33
• Relationships	Yes	YES	8 module 4-page 33
• School			8 module 4-page 33
• Work	YES	YES	8 module 4-page 34
Psychological			
• Self-worth		YES	8 module 4-page 27

Supportive care model (Fitch et al. 2008)	Results of Phase 1 of the study	Findings of Phase 2 of the study	Application in the palliative care programme (Appendix U).
<ul style="list-style-type: none"> <li>• Body image</li> </ul>		YES	8 module 4-page 27
<ul style="list-style-type: none"> <li>• Coping</li> </ul>	Counselling (YES)	YES	8 module 4-page 27

## 7.4 Palliative Nursing Care Programme

The programme is designed to meet the needs of women receiving palliative chemotherapy for breast cancer. The programme includes the main domains of palliative care and focuses on physical, social, psychological, and spiritual needs of breast cancer women receiving palliative chemotherapy.

Breast cancer is a challenging disease. The aim of the researcher in developing a Palliative Care Nursing Programme was to empower (mostly) women with knowledge and support about breast cancer and its treatment options, potential side effects, self-care strategies, and available support services. By equipping them with this information, the researcher sought to enhance their understanding, alleviate fears, and promote a sense of control over their breast cancer journey.

### 7.4.1 Objectives of the palliative nursing care programme

The objective was to prepare breast cancer patients by providing them with information (verbal, written) about typical aspects and common issues associated with palliative chemotherapy. The programme seeks to:

- guide and educate by offering participants an opportunity to access information (verbal and written) to enhance their understanding of relevant issues on breast cancer and palliative chemotherapy.
- support participants to identify various palliative care services.
- provide participants with various strategies that may enable them to cope with the effects of palliative chemotherapy during treatment.

- help participants to make sense of and/or find meaning by regulating emotional reactions to the situation, encourage participants to try to see some positive aspects of their experience, and offer access to spiritual guidance.
- Promote self-care by encouraging participants to enhance their physical, social and mental health by promoting regular exercise, enjoyable experiences, satisfactory sleep, healthy diet, and providing advice on relaxation strategies.
- provide options through advocacy to participants by offering them an opportunity to identify issues and plan goals/strategies and engage in important decision making as well as advising them on their rights.

An interactive session will follow every module (Table 7.2) for brainstorming and conversation. See Appendix U for the palliative nursing care programme booklet.

**Table 7.2: Layout Modules of the Programme**

Topic	Activity	Session	Time	Aim	Equipment needed
Module 1					
1. Familiarization	Welcome and Introduction of Participants	Session 1	20 minutes	<ul style="list-style-type: none"> <li>• Make participants familiar with one another</li> <li>• Provide an opportunity to express their ideas, views, and experiences</li> <li>• Facilitate creating a working atmosphere</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
1. What is breast cancer about!	a. Classifications of breast cancer b. Image of a normal breast c. Stages of breast cancer d. Image of abnormal breast and stages of breast cancer abnormality e. Risk factors of breast cancer f. Causes of breast cancer g. signs and symptoms g. Complications	Session 2	45 -60 minutes	<ul style="list-style-type: none"> <li>• Understand the topics of the training</li> <li>• Explain the objectives of the training</li> <li>• Recognise breast cancer</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins
Module 2					
2. Familiarization	Welcome and Introduction of	Session 1	10 minutes	<ul style="list-style-type: none"> <li>• Make participants</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
	Participants			<ul style="list-style-type: none"> <li>familiar with one another</li> <li>• Provide an opportunity to express their ideas, views, and experiences</li> <li>• Facilitate creating a working atmosphere</li> </ul>	
2. Palliative Chemotherapy	a. What is Palliative Chemotherapy? b. Goals and Benefits c. Treatment Duration and Frequency	Session 2	45-50 minutes	<ul style="list-style-type: none"> <li>• Describe the meaning of palliative care nursing and its components, principles and team</li> <li>• Expand the participants capacities to respond to care demands, to maintain their comfort and enhance their QoL, and to prevent or minimise unnecessary distress</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins Other: Refreshments drinks and snacks

Topic	Activity	Session	Time	Aim	Equipment needed
3. Treatment Options for breast cancer	a. Types of Chemotherapy Drugs b. Combination Therapy c. Hormone Therapy d. Targeted Therapy e. Immunotherapy	Session 3	25-30 minutes	<ul style="list-style-type: none"> <li>Provide the appropriate information to participants on the various treatment modalities for advanced breast cancer to empower them</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins Other: Refreshments drinks and snacks
Module 3					
3. Familiarization	Welcome and Introduction of Participants	Session 1	10 minutes	<ul style="list-style-type: none"> <li>Make participants familiar with one another</li> <li>Provide an opportunity to express their ideas,</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
				views, and experiences <ul style="list-style-type: none"> <li>Facilitate creating a working atmosphere</li> </ul>	
4. Potential Side Effects of palliative chemotherapy and self-care strategies	a. Nausea and Vomiting b. Fatigue and Weakness c. Hair Loss d. Skin and Nail Changes	Session 2	60-90 minutes	<ul style="list-style-type: none"> <li>Participants will express their experiences during palliative chemotherapy care</li> <li>Participants will be helped to identify and maintain coping and stress management strategies</li> </ul>	
<b>Module 4</b>					
4. Familiarization	Welcome and Introduction of Participants	Session 1	10 minutes	<ul style="list-style-type: none"> <li>Make participants familiar with one another</li> <li>Provide an opportunity</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
				<p>to express their ideas, views, and experiences</p> <ul style="list-style-type: none"> <li>Facilitate creating a working atmosphere</li> </ul>	
5. Self-Care Strategies for breast cancer	<p>a. Bone Health including myelosuppression</p> <p>b. Neuropathy</p> <p>c. Emotional Well-being</p> <p>d. Exercises and Physical Activity</p> <p>e. Nutrition and Hydration</p> <p>f. Emotional Support and g. coping Mechanisms</p>	Session 2	60-80 minutes	<ul style="list-style-type: none"> <li>Participants will be educated on the various coping mechanisms</li> <li>Educational and Informational support for symptoms management will be provided.</li> </ul>	<p>Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins</p> <p>Other: Refreshments drinks and snacks</p>
Module 5					

Topic	Activity	Session	Time	Aim	Equipment needed
5. Familiarization	Welcome and Introduction of Participants	Session 1	10 minutes	<ul style="list-style-type: none"> <li>• Make participants familiar with one another</li> <li>• Provide an opportunity to express their ideas, views, and experiences</li> <li>• Facilitate creating a working atmosphere</li> </ul>	None
6. Support Services	a. Healthcare Team: Who's Who? b. Palliative Care Specialists c. Support Groups and Peer Counselling	Session 2	45-60 minutes	<ul style="list-style-type: none"> <li>• Practical care, how to deal with common patient symptoms / emotions, and introduce the term of comfort through palliative care nursing programme</li> <li>• Recognize about practical care.</li> <li>• Identify what to do when experiencing certain symptoms and emotions</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins Other:

Topic	Activity	Session	Time	Aim	Equipment needed
	d. Mental Health Support e. Complementary Therapies f. Financial Assistance and Insurance Guidance			<ul style="list-style-type: none"> <li>• Provide participants with advice on where and how and where to find financial and insurance advice and guidance.</li> <li>•</li> </ul>	Refreshments drinks and snacks
7. Conclusion	a. Recap of Key Points b. Encouragement and Empowerment c. Importance of Communication and Advocacy	Session 3	15-20 minutes	<ul style="list-style-type: none"> <li>• Recap of Key Points</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins Other: Refreshments drinks and snacks

## 7.5 Expert Review of the Palliative Nursing Care Programme

The preliminary version of the palliative nursing care programme was shared with the principal researcher's mentor in Ghana, and also sent to the researchers' supervisors, for their review and feedback. In addition, the programme underwent a thorough evaluation process by a panel of experts. The expert group conducted a thorough review of the programme, evaluating its language, clarity, and validity. The goal was to determine whether the programme as designed accurately informed its intended audience what it is intended to.

According to Zamanzadeh et al. (2015) it is advised to have a panel of at least five experts to adequately control chance agreement. Consequently, in order to ensure the face and content validity of the programme in this study, a team of seven experts were formed through invitation to review the programme, following the guidance of Fleiss J.L. (Fleiss, 1971). The experts were invited to participate through a written letter (See appendix H) and a participants' information sheet (See Appendix I). Prior to the study, participants provided their approval and signed a consent form (see Appendix J). The panel of experts involved in this study consisted of the following individuals Table 7.3.

**Table 7.3: Experts Involved in the review programme**

<b>Category of practitioners involved</b>	<b>(n=7)</b>	<b>100%</b>
Oncology Nurse	1	14.3
Chaplain,	1	14.3
Medical doctor	1	14.3
Counsellors/Clinical psychologist	1	14.3
Pharmacists	1	14.3
Dietitians	1	14.3
Social worker	1	14.3

The experts were tasked with evaluating the relevance of the programme items and providing feedback on the need for additional or otherwise of the items (Polit and Beck, 2020a). The review process for the programme encompassed the following criteria as contained in the invitation letter:

- i. Suitability of the programme for the targeted community and/or population.
- ii. Distinctiveness within the community.
- iii. Pertinence of the programme to the community.
- iv. Feasibility of implementing the programme.
- v. Targeted nature of the programme towards the specific population.
- vi. Consideration of cultural sensitivity in the programme.
- vii. Significant contribution or resolution to the problem at hand.

In terms of measurement, the experts were asked to evaluate each item on a five-point Likert Scale ranging from 1 to 4. The scale was as follows: 1 indicates irrelevance: a. (Strongly Disagree), b. (Disagree), c. (Neither Agree nor Disagree), d. (Agree), e. (Strongly Agree); 2 signifies partial relevance: a. (Strongly Disagree), b. (Disagree), c. (Neither Agree nor Disagree), d. (Agree), e. (Strongly Agree); 3 indicates significant relevance: a. (Strongly Disagree), b. (Disagree), c. (Neither Agree nor Disagree), d. (Agree), e. (Strongly Agree), and 4 denotes utmost relevance: a. (Strongly Disagree), b. (Disagree), c. (Neither Agree nor Disagree), d. (Agree), e. (Strongly Agree). Furthermore, the experts were also encouraged to provide comments and recommendations along with their scores.

The quantitative rating provided by the experts, their unanimous agreement, and their recommendations on grammar, word usage, and the appropriate timing and sequencing of content were subsequently adopted (Zamanzadeh et al., 2015).

### **7.5.1 General Comments**

The primary issues centred around the programme's images and its apparent attractiveness, which could potentially influence its acceptability among women with breast cancer. Also, terminology employed, as certain words may prove challenging for the women to grasp. Suggestions were made to either replace complex words and phrases with simpler alternatives that would be more understandable and suitable for the women and the Ghanaian context or incorporate straightforward explanations. Concerns were also expressed regarding the time required for implementing the program. Also, there were suggestions to reduce the time

allotted for education session from two (2) hours to between 45-95 minutes per session. Additional recommendations included:

- Enlarge the images to enable visibility
- Exercise caution when addressing sexual problems, with some experts advising the omission of details related to sexual intercourse. They emphasized that including such information could lead to resistance and alienation since the researcher is of a different gender.
- Add a bible verse from the book of psalms for encouragement during difficult times.
- Recognise the potential sensitivity of discussing sexual matters, taking into account cultural beliefs and norms. Table 7.4 outlines the proposed modifications.

**Table 7.4: Changes suggested by the expert panel (n=7).**

Suggested changes	Number (n)	Percentage (%)
Reduce the time duration for each session from two (2) hours to 45-90 minutes	2	28.57
Enlarge the images and rearrange all details concerning sexual matters.	1	14.28
Revise the language to make it more accessible for the general audience.	2	28.57
Incorporate a Bible text into the spiritual component	3	42.85

Consequently, the palliative nursing care programme was restructured, and the suggested corrections effected after the supervisors agreed to it. Additionally, the team enlisted the services of a professional graphic designer to create a power point and a booklet presenting the intervention programme in its final form. Subsequently, the programme, along with a progress report on phase three (3) was submitted to the Ho Teaching Hospital Research Ethics Committee for ethical clearance before conducting pilot-testing among the women. Accordingly, ethical clearance was granted (see appendix C) and the researcher started the process of preparing for programme implementation.

## **7.6 Summary**

This chapter described the development of the palliative nursing care programme (see appendix U) using the results of Phase 1 and 2 and guided by the supportive care model by Fitch and colleagues. The programme was validated by an expert panel.

The next chapter describes the pilot testing of the palliative nursing care programme.

# CHAPTER EIGHT PHASE 4: PILOT TESTING OF THE PROGRAMME

## 8.1 Introduction

The preceding chapter presented the development/adaptation and validation of the palliative nursing care programme. This chapter describes the programme implementation and pilot testing.

## 8.2 Programme Implementation

Upon validation of the palliative nursing care programme, the finalization process was initiated, leading to the development of learning materials outlined in Appendix U. Subsequently, the researcher convened a brief meeting with the management, staff and patients of the oncology department at the designated hospital at a suitable time. The meeting served a dual purpose: to organise the palliative nursing care programme and to help the researcher assemble the women recruited to attend the sessions.

Acknowledging the time constraints faced by the participants, the programme's content was structured into five (5) modules, spread across a twelve-week timeframe. This pragmatic arrangement allowed the researcher to comprehensively cover the programme's content. The commencement of each session involved the researcher delivering a brief address to welcome the participants. This was followed by a concise introduction to the patients' perspective, outlining the meeting's objectives, benefits, and overarching purpose.

Every session accommodated a participant group ranging from 4 to 7 individuals, with each session's duration spanning between 45 to 90 minutes. The primary teaching aid employed was a PowerPoint presentation. The objectives for each session were meticulously delineated within the palliative nursing care programme documentation.

The programme was structured around several core themes:

- a. Introduction: Establishing the programme's context and objectives.
- b. Programme Objectives: Delving deeper into the programme's aims.
- c. Breast Cancer and Palliative Chemotherapy: Providing general information on these subjects.

- d. Significance of the palliative nursing care programme: Exploring the meaning and relevance of the programme.
- e. Transitioning to Palliative Care Patient Status: Addressing the process of adapting to life as a palliative care patient.
- f. Interactive Exchange: Encouraging questions, clarifications, and open dialogue.

The inception of each session involved participants discussing their insight from the previous session, fostering a culture of shared learning and experience sharing. Below is the Palliative Nursing Care programme.

## **8.3 Pilot Testing the Palliative Care Programme**

### **8.3.1 Research approach**

To pilot test the palliative nursing care programme, pre-test post-test method of data collection was used. Intervention research refers to a distinct approach involving the design, development, implementation, testing, analysis, dissemination, and distribution of interventions (Polit and Beck, 2020b, Lobo et al., 2017). Intervention studies are designed to assess the effects of an intervention on a dependent variable or outcome (Burns and Grove, 2009, Alla, 2016). Within this framework, a research design outlines who receives the intervention, how outcomes are assessed, when the intervention takes place, and its duration (Alla, 2016, Campbell et al., 2007)

Nursing interventions are defined as deliberate cognitive, physical, or verbal actions carried out by healthcare professionals on behalf of individuals and their families, aimed at achieving specific therapeutic objectives related to an individual's health and well-being (Karaca and Durna, 2019, Lopes-Júnior, 2021, Grove et al., 2012, Bulechek et al., 2012). In this context, nursing interventions encompass treatments, therapies, procedures, or actions undertaken by healthcare professionals in specific situations to advance individuals' conditions toward favourable health outcomes (Bulechek et al., 2012, Reising, 2016, Anderson, 1983, Feeley and Côté, 2009).

Interventional study designs, also known as experimental studies, involve the researcher as an active mediator within the study's framework. These designs are typically prospective and explicitly aimed at evaluating the direct effects of treatment or protective measures on a particular condition (Thiese, 2014, Feeley and Côté, 2009, Lopes-Júnior, 2021). According to Burns and Grove (2009) intervention research represents an innovative methodology with

considerable potential for more efficient measurement and analysis of interventions, shifting the focus from causal relationships to causal outcomes.

In this approach, the intervention is administered to a subset of participants, and its outcomes are assessed both before and after the intervention (Krasny-Pacini and Evans, 2018, Jackie and Alba, 1999). The pre-test post-test method is a model designed to evaluate changes in overall critical thinking skills or dispositions within a group that undergoes testing or intervention (Alessandri et al., 2017, Stratton, 2019, Knapp, 2016). It involves the measurement of dependent variables, which include primary and secondary outcomes, at two distinct time points: before and after the intervention (Polit and Beck, 2020b, Marsden and Torgerson, 2012)

### **8.3.2 Pre-test approach**

Before implementing the palliative nursing care programme, women diagnosed with breast cancer and receiving palliative chemotherapy were assessed to determine the influence of the palliative nursing care programme would have on the outcomes.

### **8.3.3 Study Population**

The population consisted of all women aged 18 years and above undergoing palliative chemotherapy for breast cancer at the academic hospital in the Volta Region of Ghana. More information about a study population is presented in 3.3.2.3 of chapter 3.

### **8.3.4 Sampling and sample size**

Sampling involves selecting a subset of the population, or individuals chosen from the entire population, to represent the entire group for the purpose of making inferences and drawing conclusions (Gupta and Gupta, 2022, Seltam, 2018, British Columbia, 2023). In this study, a convenience sampling method was employed. Also, Bell et al. (2018), In (2017), and Thabane et al. (2010) suggested that pilot studies can be used to assess treatments or interventions without the need for sample size calculations. However, Julious (2005) proposed that for a pilot study aiming for adequate power (confidence level) when expecting a medium effect in an intervention study, a sample size of approximately 30 ( $n=30$ ) is sufficient, inversely, Browne (1995) proposed a minimum of 12 ( $n=12$ ) samples per group. For the purposes of this study, 31 ( $n=31$ ) participants who met the inclusion criteria were initially involved in the pilot study,

however, 24 participants completed the programme due to death of three participants and four could not also continue because of time constraints. Thus, the study used a complete case of 24 participants as the sample size.

### **8.3.5 Inclusion Criteria**

The criteria for inclusion encompassed female individuals who had received a diagnosis of breast cancer, were undergoing palliative chemotherapy, were 18 years of age or older, and possessed a Performance Status of two and above as determined by the Eastern Cooperative Oncology Group Score (ECOG) for Cancer Patients (Azam et al., 2020).

Exclusion criteria were women who were receiving palliative chemotherapy for multiple cancers.

### **8.3.6 Recruitment**

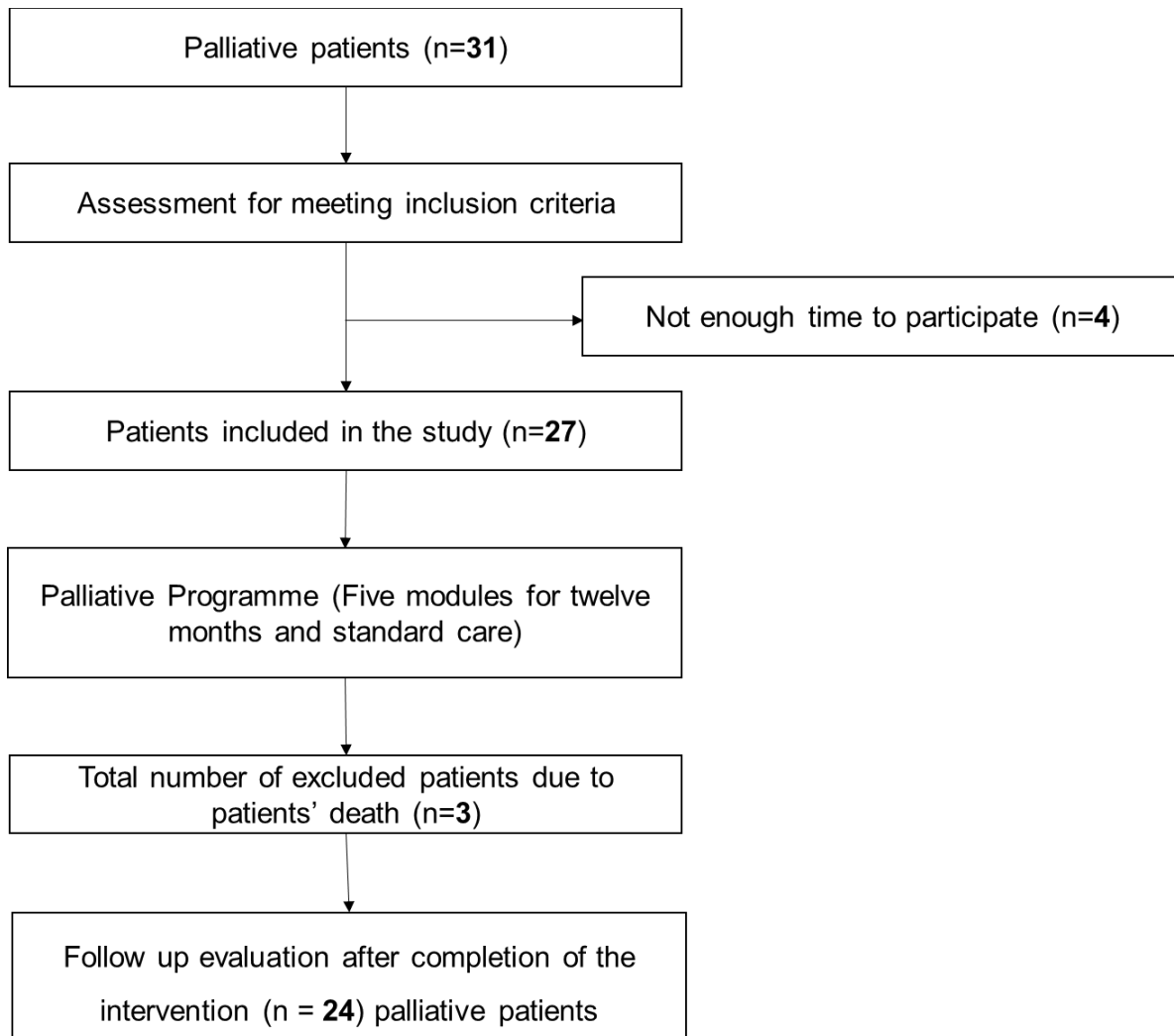
In a meeting the women were grouped as follows: Positive (women who had received a diagnosis of breast cancer, were undergoing palliative chemotherapy, were 18 years of age or older, and possessed a Performance Status of two and above as determined by the Eastern Cooperative Oncology Group Score (ECOG) for Cancer Patients) or negative (women who were receiving palliative chemotherapy for multiple cancers and/or were younger than 18 years). The negative group were given a health talk as well as flyers on causes and prevention of breast cancer and the effects of palliative chemotherapy before being released from the programme. Prior to participation in the pilot study, permission was sought from the women (See appendix I) and a discussion held with those who met the inclusion criteria and the purpose and information regarding the pilot study was given to them (See appendix J). Those who agreed to participate were requested to sign consent forms (refer to appendix E).

### **8.3.7 Data Collection**

Apart from the following, the rest of the data collection process follows the same method as in 3.3.2.4 of chapter 3:

- Participants were conveniently selected as they came for treatment.
- The researcher (on his own) administered the questionnaires to the study participants who consented to the study.

- Initial demographic data were collected through self-administered sociodemographic questionnaires (See appendix N).
- Data collection occurred both before and after the intervention.



**Figure 8.1: Data collection process for Pilot Test**

### 8.3.8 Study Instruments

Five instruments were employed to collect data. Four of these instruments are widely recognized standard tools, notable for their established validity and reliability as evidenced in previous research on cancer and palliative care nursing (Mercieca-Bebber et al., 2019, McCorkle and Young, 1978b, Cleeland and Ryan, 1991, Büssing et al., 2010). The primary outcome focused on the symptoms distress/unmet palliative care needs and the Symptoms Distress Scale (SDS) was used. The secondary outcomes included pain reduction, improve quality of life and meeting their spiritual needs, which were covered by the Brief Pain Inventory

(BPI), the European organisation for research and treatment of cancer quality of life questionnaire (EORTC QLQ-BR45) and the Spiritual Needs Questionnaire (SpQN) respectively. Permission was granted through an email before using the questionnaires. The fifth instrument employed in the study was a sociodemographic questionnaire, specially developed by the researcher for this investigation.

#### **8.3.8.1 Socio-demographic data questionnaire**

The researcher crafted a closed-ended socio-demographic questionnaire (See appendix N) for data collection. This questionnaire was designed with guidance from previous studies that share a common research interest (Carroll et al., 2021, Hughes et al., 2016). It encompasses seven questions pertaining to the participants' age, marital status, number of pregnancies, level of education, the month and year of commencing chemotherapy, religion, and tribal affiliation.

#### **8.3.8.2 Symptom Distress Scale (SDS)**

The Symptom Distress Scale, denoted as SDS, gauges the discomfort level reported by patients in relation to their perceived symptoms, as originally conceptualized by (McCorkle and Young, 1978b, McCorkle et al., 1998). This scale encompasses ten distinct symptoms: nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration, and appearance. Comprising 13 items employing a 5-point Likert-type scale, with 5 signifying the highest distress level, scores of 3 or above are indicative of significant distress. A cumulative score of 25 or higher signifies moderate distress, while scores exceeding 33 signal severe distress necessitating immediate intervention. Previous research has reported reliability through test-retest and reproducibility, as well as internal consistency (Holmes, 1989, Tacón, 2013).

Furthermore, SDS's validity was determined in comparison to Ware's health perception questionnaire among cancer patients and cardiac patients, effectively distinguishing between these two groups (McClement et al., 1997). Notably, SDS scores displayed correlations with survival rates (McCorkle et al., 1989, Sarna and Brecht, 1997, Kukull et al., 1986, Blinderman et al., 2009, Chen et al., 2022b). McCorkle and Young (1978a) conducted a study involving 53 patients with advanced medical conditions, revealing total symptom distress scores ranging from ten to forty-one, with a mean score of twenty. The reliability coefficient alpha was found to be 0.82143, and the standardized alpha was 0.82557 (McCorkle and Young, 1978a). Moreover, various other studies have adopted SDS and have reported consistent results

(Holmes, 1989, Tacón, 2013, Chen et al., 2022b). Symptoms Distress Scale (SDS) has been translated into several languages, including English, Italian, Spanish, Swedish, Taiwanese, and Dutch.

- Scoring

The SDS is constructed with a list of symptoms that individuals may experience.

Participants or patients are asked to rate the severity and distress associated with each symptom. The scoring usually involves assigning numerical values to the responses. For example, a Likert scale, where participants rate each symptom on a scale from 0 to 4 (0 = no distress, 4 = severe distress). The scores for all individual symptoms are then summed to obtain a total score.

- Interpretation

A higher total score indicates a greater overall symptom distress. Researchers or clinicians may establish cutoff points or categories to interpret the severity of symptom distress. For example, they might define ranges such as "mild," "moderate," and "severe" based on the total score.

### **8.3.8.3 Brief pain inventory (BPI) (short form)**

The Brief Pain Inventory, abbreviated as BPI, was originally developed by Charles S. Cleeland in 1991 (Cleeland and Ryan, 1991, Poquet and Lin, 2015). It constitutes a self-administered questionnaire primarily designed to assess cancer-related pain. The BPI is available in both short form (comprising nine items) and long form (comprising 17 items) (Andersson et al., 2020). The short form of BPI is predominantly used for measuring cancer pain and having a Cronbach's alpha for the pain severity scale of 0.80 to 0.89, while for the pain interference scale, it ranges from 0.89 to 0.91 (Andersson et al., 2020, Stenseth et al., 2007, Gress et al., 2020). The study used the short form of the BPI questionnaire and is scored and analysed as follows:

Scoring:

- Severity of Pain:

Patients rate their pain on a numeric rating scale (NRS) from 0 to 10, where 0 represents "no pain," and 10 represents "pain as bad as you can imagine."

The severity of pain is often assessed in terms of the "worst," "least," "average," and "right now" pain over the past 24 hours (Andersson et al., 2020, Stenseth et al., 2007, Gress et al., 2020, Cleeland and Ryan, 1991, Edirisinghe et al., 2021).

- Pain Interference:

Patients rate how much pain has interfered with various aspects of their life using a 0 to 10 NRS, where 0 indicates "no interference" and 10 indicates "complete interference."

Interference items typically include general activity, mood, walking ability, normal work, relations with other people, sleep, enjoyment of life, and overall activity (Kumar, 2011, Edirisinghe et al., 2021).

Analysis:

- Individual Item Analysis:

Each item is scored separately based on the patient's responses. Scores can be analysed individually to understand specific aspects of pain severity and interference (Edirisinghe et al., 2021).

- Pain Severity Scores:

The severity scores (worst, least, average, and right now) are often averaged to provide an overall pain severity score (Edirisinghe et al., 2021).

- Pain Interference Scores:

The interference scores for each item are often averaged to provide an overall pain interference score. This score reflects the impact of pain on various aspects of a patient's life (Edirisinghe et al., 2021).

- Interpretation:

Higher scores indicate greater pain severity or interference. Researchers and clinicians can use these scores to assess the impact of pain on a patient's daily life and functioning (Edirisinghe et al., 2021).

- Clinical Significance:

Clinicians may consider a change of two or more points on the BPI as clinically significant when assessing changes in pain severity or interference over time (Edirisinghe et al., 2021, Bowring et al., 2018).

It is important to note that specific instructions for scoring and analysis may vary depending on the version of the BPI being used and any modifications made by researchers or clinicians (Edirisinghe et al., 2021).

#### **8.3.8.4 European organisation for research and treatment of cancer quality of life questionnaire (EORTC QLQ-BR45)**

The EORTC QLQ-BR45 stands as a widely recognized and extensively employed tool for evaluating the quality of life (QoL) in patients, particularly those receiving palliative care. Interestingly, its scope encompasses aspects unrelated to palliative care services, as noted by de Ligt et al. (2023). Specifically, the EORTC QLQ-BR45 is a questionnaire module designed to investigate various aspects related to breast cancer. It comprises nine multi-item scales aimed at evaluating body image, sexual functioning, breast satisfaction, side effects of systemic therapy, arm symptoms, breast symptoms, symptoms associated with endocrine therapy, skin and mucous membrane symptoms, and endocrine-related sexual symptoms. Additionally, there are individual items that gauge sexual enjoyment, future outlook, and emotional distress caused by hair loss. The scoring methodology for the QLQ-BR45 follows the same fundamental principles as that of the functional and symptom scales and single items in the QLQ-C30. (Fayers et al., 1995, Fayers et al., 2002, Groenvold et al., 1997, Giesinger et al., 2020).

#### **SCALE STRUCTURE OF THE GROUPING OF EORTC QLQ-BR45**

The scale can be analysed as a whole (Bjelic-Radisic et al., 2020) or grouped into the following: 1. Functional Scale, 2. Symptom Scales/Items - Systemic Therapy Side-Effects 3. Symptom Scales/Items - Arm Symptoms, 4. Symptom Scales/Items - Breast Symptoms 5. Target Therapy Scale - Endocrine Therapy Symptoms, 6. Target Therapy Scale - Skin Mucosis Symptoms, 7. Target Therapy Scale - Endocrine Sexual Symptoms, and 8. Satisfaction Scales. The study grouped the scale into 8 groups as proposed by (Bjelic-Radisic et al., 2020, Solikhah et al., 2023, Tsui et al., 2022, Fayers et al., 2002). The student used the 8 groups.

All items within the EORTC QLQ-BR45 employ "4-point Likert scales" that span from "1 (not at all) to 4 (very much)," with one exception: the global health/QoL item utilizes a revised "7-point linear analogue scale" ranging from very poor to excellent QoL with the Cronbach's alpha of 0.68 to 0.95 (Ahlam et al., 2019, Fayers et al., 2002, Bjelic-Radusic et al., 2020).

#### **8.3.8.5 Spiritual needs questionnaire (SpNQ) for adults**

The Spiritual Needs Questionnaire (SpNQ) for adults, developed by Büssing et al. (2010), serves as a self-report tool designed to investigate the spiritual needs of individuals facing an advanced and terminal cancer diagnoses. It comprises a series of statements, each representing a distinct spiritual need, and respondents are prompted to evaluate both the presence and intensity of these needs in their lives.

- **Reliability:** The internal consistency estimates for the SpNQ range from 0.74 to 0.92. This standardized measure has been translated into numerous languages and is widely utilized as a valid and reliable instrument for assessing various spiritual needs in patients with cancer, chronic illnesses, the elderly, adolescents, and even individuals in good health (Salzer et al., 2023, Büssing et al., 2010, Büssing, 2021).
- **Description:** The questionnaire serves dual purposes, functioning as a diagnostic tool or a contextual research instrument with optional items. It differentiates four primary factors according Büssing et al. (2010) and (Salzer et al., 2023):
- **Religious (alpha = 0.92):** Encompassing activities such as praying with or for others, participating in religious ceremonies, reading spiritual/religious texts, and seeking a higher presence (e.g., God, angels).
- **Inner Peace (alpha = 0.82):** Reflecting desires for serenity and tranquillity, appreciation of natural beauty, finding inner peace, discussing fears and concerns with others, and receiving support from others.
- **Existential (Reflection / Meaning) (alpha = 0.82):** Involving contemplation of one's life, discussions about the meaning of life and suffering, addressing unresolved aspects of life, and exploring the possibility of an afterlife.
- **Actively Giving / Generativity (alpha = 0.74):** Focusing on the intention to provide comfort to others, share personal life experiences, and ensure that one's life holds meaning and value
- **Scoring:** Respondents indicate the presence of respective needs (yes/no) and their perceived strength, utilizing a 4-point scale ranging from disagreement to agreement (0 - not at all; 1 - somewhat; 2 - strong; 3 - very strong).

- Consequently, the questionnaire comprises 30 items, each employing a 4-point Likert scale which is analysed as whole (Büssing et al., 2010).

### **8.3.9 Post-test approach**

The researcher administered the palliative care programme over a three-month period, until programme objectives were fully achieved and all programme content had been provided. Following the completion of the programme, researcher-administered questionnaires were used to collect post-test data, including the SDS, SpNQ, BPI, and EQRTC QoL BR45, from 24 participants (n=24) within three weeks.

Notably, 7 participants did not complete the intervention due to time constraints and death, resulting in a 23% attrition rate. Sensitivity analysis was conducted using multiple imputations in STATA 18 to account for missing data, under the assumption that it was missing completely at random (MCAR). However, no substantial differences were detected, and the researcher proceeded with the complete case analysis. The completed questionnaires and consent forms were then placed in sealed boxes, each labelled for its intended purpose.

### **8.3.10 Data management and analysis**

Upon completion of data collection, quality checks were conducted on all questionnaires from the beginning of the study till completion. The questionnaires were meticulously organized, sequentially numbered, cleaned, and subsequently entered into Excel spreadsheets. An analysis of this data was carried out through the utilization of descriptive statistics, facilitated by the STATA 18 computer programme.

Following the completion of data entry, the collected data was securely stored in a locked cupboard, accessible exclusively to the researcher.

### **8.3.11 Level of significance**

The level of significance represents the probability that a detected relationship may be attributed to sampling error, commonly referred to as a Type 1 error (VanVoorhis and Morgan, 2007, Kang, 2021, Banerjee et al., 2009). Specifying an alpha level enables the researcher to control the risk of a Type 1 error, which could lead to the erroneous rejection of a true null hypothesis. In this study, a p-value of  $\leq 0.05$  was chosen to determine the significance of

results. This selection of a 5% level of significance aligns with conventional practice in healthcare research (Banerjee et al., 2009, Oliveira, 2021, Burns and Grove, 2009).

### **8.3.12 Wilcoxon matched-pairs signed-ranks test**

The Wilcoxon matched-pairs signed-ranks test serves as a non-parametric alternative to the paired t-test. It is typically employed to examine variations in the mean or median of related observations, whether these measurements are paired units or pre- and post-measurements on the same unit. Additionally, this test can be applied as a "one-sample" test to determine if a specific sample is derived from a population with a specified median (Byrne and Humble, 2007, MacFarland and Yates, 2016, Manikandan and Ramachandran, 2023).

The Wilcoxon matched-pairs signed-ranks test is a suitable statistical tool for analysing data in a pilot study of a palliative nursing care intervention for breast cancer patients undergoing palliative chemotherapy due to its non-parametric nature and its ability to assess changes within paired observations. In the context of a pilot study of a single arm intervention where sample sizes may be limited, the Wilcoxon test is robust against small sample sizes and does not rely on assumptions of normality. This is particularly advantageous in the palliative care setting, where individual responses to nursing interventions can vary widely. By focusing on the differences between paired observations, the Wilcoxon test accommodates the inherent variability in patient responses, making it a valuable tool for assessing the impact of palliative nursing care interventions on breast cancer patients undergoing palliative chemotherapy in a pilot study.

### **8.3.13 Management of missing data**

Missing data is a common occurrence in research, often arising at the item-level when certain questions are left unanswered by participants or due to participant attrition in longitudinal research (Marino et al., 2021, Forer, 2014, Momeni et al., 2018, Young and Johnson, 2015). In this study, missing data only occurred as a result of participant attrition. To address this substantial absence of data (23%), the researcher conducted sensitivity analysis using multiple imputations in STATA 18. This analysis aimed to determine whether there were significant differences in results compared to the complete case analysis. Ultimately, no substantial differences were observed, leading the researcher to proceed with the complete case analysis.

### 8.3.14 Ethical considerations

The researcher took extensive measures to minimize risks, particularly when dealing with human participants. These measures included obtaining informed consent, safeguarding confidentiality, ensuring data protection, respecting the right to withdraw, and informing participants about potential benefits and harms (Royal College of Nursing, 2009). Ethical clearance for the pilot study (appendix C) and other ethical clearance principles outlined by the Health Professions Council of South Africa (2016) and Ghana were meticulously applied (Ghana Health Service, 2023, Allied Health Professional Council of South Africa, 2016): Aside from this, all other ethical considerations processes followed are described in Section 3.3.2.45 of Chapter 3.

## 8.4 Results and Discussion of the Pilot Study

### 8.4.1 Socio-Demographics Data

Participants of this study were women receiving palliative chemotherapy. A total of 24 participants were involved in the study to evaluate the symptoms level of these patients before and after a specific intervention aimed at addressing the palliative care needs of women. **Error! Reference source not found.** presents a statistical summary of participants' biographical data.

From Table 8.1, half of the participants (n=12; 50%) were within the age of 61 to 70 years, followed by a relative proportion of them (n=6; 25%) who were within the age of 31 to 40 years. However, only few of the participants were within 41 to 50 years (n=2; 8.3%), 51 to 60 years (n=2; 8.3%), and also within 71 to 80 years (n=2; 8.3%).

For marital status, the majority (n=21; 87.5%) of the participants were married, while only n=3 (12.5%) of them were widowed. Concerning records on number of children among the participants, more than half of the participants (n= 13; 54.2%) had 1 to 2 children, followed by n=8 (33.3%) of the participants who had 3 to 4 children. However, only n=3 (12.5%) of the participants in the study had 5 to 6 children.

For educational level, more than half (n=13; 54.2%) of the participants were University graduates, 33.3% (n=8) were Technical University graduates, while only n=3 (12.5%) were Secondary School graduates. The majority (n= 16; 66.7%) of the participants were Christians, 25% (n=6) were Muslims, and only n=2 (8.3%) of them were Traditional people. Since the

study focused on Ewe dominated area, it is not surprising that the majority (n=20; 83.3%) of the respondents were Ewes, while only n=2 (8.3%) each were Ashantis or Hausas.

**Table 8.1: Socio-Demographic Characteristics of Participants (n=24).**

<b>Age</b>	<b>Frequency (n)</b>	<b>Percent (%)</b>
31-40years	6	25.0
41-50years	2	8.3
51-60years	12	50.0
61-70years	2	8.3
71-80years	2	8.3
Total	24	100.0
<b>Marital Status</b>		
Married	21	87.5
Widowed	3	12.5
Total	24	100.0
<b>No. Of Pregnancies</b>		
1-2	13	54.2
3-4	8	33.3
5-6	3	12.5
Total	24	100.0
<b>Level of Education</b>		
Secondary School	3	12.5
Technical University	8	33.3

Age	Frequency (n)	Percent (%)
University	13	54.2
Total	24	100.0
Religion		
Christianity	16	66.7
Muslim	6	25.0
Traditional	2	8.3
Total	24	100.0
Tribe		
Ewe	20	83.3
Ashanti	2	8.3
Hausa	2	8.3
Total	24	100.0

#### 8.4.2 Wilcoxon Signed-Rank Test on Symptoms Distress of Breast Cancer Patients

The Wilcoxon Signed-Rank test is a non-parametric equivalent of the paired t-test. It is generally used to examine the difference in the mean, or median, of paired explanations – whether those measurements occur in pairs of units or pre- and post-measurements on an identical unit. It could also be used on a “one-sample” test to examine whether a certain sample originated from a population with a quantified median (Byrne & Humble, 2007; MacFarland & Yates, 2016).

Table 8.2 shows that majority of the symptoms distress were high among the patients before the intervention and were reduced after the intervention. Before the intervention, nausea, pain, and appearance all had a highest mean score ( $m=4.29$ ;  $SD\pm 0.46$ ), followed by appetite and outlook, both having a high mean score ( $m=3.71$ ;  $SD\pm 0.46$ ), and fatigue which also had a

relatively high mean score ( $m=3.58$ ;  $SD\pm 0.93$ ). Bowel and cough were the symptom distress with the lowest mean score ( $m=1.00$ ;  $SD\pm 0.00$ ) before the intervention and remained same after the intervention.

After the intervention, though the symptoms distress among the patients reduced, appearance still remains unchanged and maintains its highest mean score ( $m=4.29$ ;  $SD\pm 0.46$ ). Since there was no change in appearance, its p-value does not prove to be significant ( $p\text{-value} \geq 1.00$ ). Also, after the intervention, patients outlook increased, resulting in the highest mean score ( $m=4.33$ ;  $SD\pm 0.48$ ). However, all the other distress symptoms reduced after the intervention with a score ( $m \leq 2.00$ ;  $SD\pm 0.00$ ), and are significant at ( $p\text{-value} \leq 0.05$ ).

**Table 8.2: Test between Pre-intervention and Post-intervention of Symptoms Distress of Breast Cancer Patients**

	Pre-intervention		Post-intervention		P-value
	M $\pm$ SD	Range (1-5)	M $\pm$ SD	Range (1-5)	
Nausea ***	4.29 $\pm$ 0.46	4-5	2.00 $\pm$ 0.00	2-2	0.00
Appetite ***	3.71 $\pm$ 0.46	3-4	2.00 $\pm$ 0.00	2-2	0.00
Insomnia ***	2.00 $\pm$ 0.00	2-2	1.00 $\pm$ 0.00	1-1	0.00
Pain ***	4.29 $\pm$ 0.46	4-5	2.00 $\pm$ 0.00	2-2	0.00
Fatigue ***	3.58 $\pm$ 0.93	3-5	2.00 $\pm$ 0.00	2-2	0.00
Bowel	1.00 $\pm$ 0.00	1-1	1.00 $\pm$ 0.00	1-1	1.00
Concentration	1.21 $\pm$ 0.59	1-3	1.00 $\pm$ 0.00	1-1	0.10
Appearance	4.29 $\pm$ 0.46	4-5	4.29 $\pm$ 0.46	4-5	1.00
Breathing ***	1.71 $\pm$ 0.46	1-2	1.00 $\pm$ 0.00	1-1	0.00
Outlook**	3.71 $\pm$ 0.46	3-4	4.33 $\pm$ 0.48	4-5	0.01
Cough	1.00 $\pm$ 0.00	1-1	1.00 $\pm$ 0.00	1-1	1.00

The Wilcoxon rank signed-rank test in Table 8.3 shows that before the intervention total symptoms distress had a high mean score ( $m=2.98$ ;  $SD\pm 0.17$ ), and it reduced to a low mean score ( $m=1.97$ ;  $SD\pm 0.07$ ), with a high significance at ( $p\text{-value} \leq 0.05$ ). This indicates that total symptom distress significantly reduced after the intervention had taken place.

**Table 8.3: Total Symptoms Distress between Pre-intervention and Post intervention.**

	Pre-intervention		Post-intervention		P-value
	M $\pm$ SD	Range (1-5)	M $\pm$ SD	Range (1-5)	
Total Symptom Distress	2.98 $\pm$ 0.17	2.9-3.0	1.97 $\pm$ 0.07	1.9-2.1	0.00

### 8.4.3 Wilcoxon Signed-Rank Test of BPI

The BPI diagram was used to assess patients' pain location. Results showed that the majority of participants ( $n=24$ , 28.9%) had pain in the chest before the intervention, but after the intervention, only a few ( $n=7$ , 15.2%) had pain in the chest. Also, the majority of the participants ( $n=18$ , 21.7%) had pain in the head before the intervention, but after the intervention, only  $n=1$  (2.2%) had pain in the head. Although, some participants ( $n=9$ , 10.8%) revealed that they had pain in the neck and back, after the intervention the number of participants with this pain location reduced to two ( $n=2$ , 4.3%) and three ( $n=3$ , 6.5%) respectively.

Pain in the abdominal regions ( $n=9$ , 10.8%) among the participants was still common among the participants after the intervention ( $n=6$ , 13.0%). Also, pain in the arm ( $n=9$ , 10.8%) among the participants was still common among the participants after the intervention ( $n=7$ , 15.2%).

**Table 8.4: Pain Location by Cancer Patients Using the BPI Diagram.**

	Pre-intervention		Post-intervention	
	Frequency (n)	Percentage (%)	Frequency (n)	Percentage (%)
Whole body	1	1.2	1	2.2

	Pre-intervention		Post-intervention	
	Frequency (n)	Percentage (%)	Frequency (n)	Percentage (%)
Abdominal	9	10.8	6	13.0
Buttocks	1	1.2	12	26.1
Chest	24	28.9	7	15.2
Neck	9	10.8	2	4.3
Legs	2	2.4	1	2.2
Pelvis	1	1.2	7	15.2
Back	9	10.8	3	6.5
Arm	9	10.8	7	15.2
Head	18	21.7	1	2.2

The severity of pain was assessed in terms of the worst pain, least pain, average pain, and pain right now. As indicated in Table 8.5, the levels of pain at its worst, least, average, pain right now were all found to be statistically significant ( $p$ -value  $\leq 0.05$ ). This suggests a significant change in pain levels between the pre-intervention and post-intervention periods.

**Table 8.5: Test between Pre-intervention and Post-intervention of Various Level of Pain.**

	Pre-intervention		Post-intervention		P-value
	M $\pm$ SD	Range (1-10)	M $\pm$ SD	Range (1-10)	
Pain at its worst ***	9.42 $\pm$ 0.93	8-10	2.00 $\pm$ 0.00	2-2	0.00
Pain at its least ***	9.13 $\pm$ 1.39	7-10	3.00 $\pm$ 0.00	3-3	0.00

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-10)	M±SD	Range (1-10)	
Pain at its average***	9.42±0.93	8-10	3.00±0.00	3-3	0.00
Pain right now***	9.42±0.93	8-10	3.00±0.00	3-3	0.00

In regards to BPI as shown in Table 8.6, on a scale of 1 to 10, the Wilcoxon rank signed-rank test shows that before the intervention, severity of pain among patients was high with mean score ( $m=9.34$ ;  $SD\pm 1.04$ ). However, after the intervention, the severity of pain among breast cancer patients reduced, with low mean score ( $m=2.75$ ;  $SD\pm 0.00$ ), and this is significant at ( $p\text{-value} \leq 0.05$ ). Interference of pain in their daily activity was high among breast cancer patients before the intervention with mean score ( $m=8.80$ ;  $SD\pm 0.53$ ), and this increased after the intervention, resulting in a high mean score ( $m=2.57$ ;  $SD\pm 0.00$ ), with a high significance at ( $p\text{-value} \leq 0.05$ ). This indicates that the severity of pain among breast cancer patients and the interference of pain in their daily activity significantly reduced after the intervention had taken place.

**Table 8.6: Test between Pre-intervention and Post-intervention of BPI.**

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-10)	M±SD	Range (1-10)	
Severity of pain***	9.34±1.04	7.7-10.0	2.75±0.00	2.8-2.8	0.00
Interference of pain***	8.80±0.53	8.0-9.1	2.57±0.00	2.6-2.6	0.00

Table 8.7 shows that before the intervention, all the participants used morphine as treatment or medication for pain ( $n=24$ ; 100%), and also after the intervention, they used morphine as treatment or medication for their pain ( $n=24$ ; 100%).

**Table 8.7: Pre-intervention and Post-intervention of Pain Treatment and Medication.**

	Pre-intervention		Post-intervention	
	Frequency (n)	Percentage (%)	Frequency (n)	Percentage (%)
Morphine	24	100	24	100

For pain interference with patents' daily activities, results from Table 8.8 showed that pain interference with general activity, mood, walking ability, and normal work, were high ( $m=9.42$ ;  $SD\pm 0.93$ ), but they all reduced ( $m=3.00$ ;  $SD\pm 0.00$ ), after the intervention. Pain interference with relation with people, sleep, and enjoyment of life, were all high ( $m=9.42$ ;  $SD\pm 0.93$ ), but after the intervention, pain interference with relation with people was reduced ( $m=1.00$ ;  $SD\pm 0.00$ ), pain interference with sleep was reduced ( $m=3.00$ ;  $SD\pm 0.00$ ), and pain interference with enjoyment of life was also reduced ( $m=2.00$ ;  $SD\pm 0.00$ ).

**Table 8.8: Pain interference with daily living activities between Pre-intervention and Post-intervention.**

	Pre-intervention		Post-intervention		P-value
	M $\pm$ SD	Range (1-10)	M $\pm$ SD	Range (1-10)	
General activity ***	9.42 $\pm$ 0.93	8-10	3.00 $\pm$ 0.00	3-3	0.00
Mood ***	9.42 $\pm$ 0.93	8-10	3.00 $\pm$ 0.00	3-3	0.00
Walking ability ***	9.42 $\pm$ 0.93	8-10	3.00 $\pm$ 0.00	3-3	0.00
Normal work ***	9.42 $\pm$ 0.93	8-10	3.00 $\pm$ 0.00	3-3	0.00
Relation with people ***	8.00 $\pm$ 0.00	8-8	1.00 $\pm$ 0.00	1-1	0.00
Sleep ***	8.00 $\pm$ 0.00	8-8	3.00 $\pm$ 0.00	3-3	0.00
Enjoyment of life ***	8.00 $\pm$ 0.00	8-8	2.00 $\pm$ 0.00	2-2	0.00

### 8.4.4 Wilcoxon Signed-Rank Test on Quality of Life using EORTC QLQ-BR45

From Table 8.9 most symptoms under EORTC QLQ-BR45 were high before the intervention and reduced after the intervention. Having dry mouth ( $m=3.42$ ;  $SD\pm 0.50$ ), food and drinks tasting differently ( $m=3.42$ ;  $SD\pm 0.50$ ), hair loss ( $m=4.00$ ;  $SD\pm 0.00$ ), upset by the loss of hair ( $m=4.00$ ;  $SD\pm 0.00$ ), as well as feeling ill and unwell ( $m=4.00$ ;  $SD\pm 0.00$ ), all have high mean scores before the intervention. However, after the intervention, these symptoms reduced to a low mean score of ( $m=2.00$ ;  $SD\pm 0.00$ ). More so, feeling physically less attractive ( $m=3.42$ ;  $SD\pm 0.50$ ), feeling less feminine ( $m=3.42$ ;  $SD\pm 0.50$ ), having problems looking at oneself ( $m=3.42$ ;  $SD\pm 0.50$ ), and also worried about one's health in the future ( $m=3.42$ ;  $SD\pm 0.50$ ) had high mean scores before the intervention and reduced to ( $m=2.00$ ;  $SD\pm 0.00$ ) after the intervention. All these has a high significance ( $p\text{-value} \leq 0.05$ ).

The following symptoms were also low at ( $m=2.00$ ;  $SD\pm 0.00$ ) after the intervention, but had high scores before the intervention: having pain in the shoulder ( $m=4.00$ ;  $SD\pm 0.00$ ), problem raising arm or moving it sideways ( $m=3.42$ ;  $SD\pm 0.50$ ), swollen affected breast area ( $m=3.42$ ;  $SD\pm 0.50$ ), oversensitive affected breast area ( $m=3.42$ ;  $SD\pm 0.50$ ), skin problem on affected breast area ( $m=3.58$ ;  $SD\pm 0.50$ ), feeling dizzy ( $m=3.58$ ;  $SD\pm 0.50$ ), and having soreness in mouth ( $m=3.42$ ;  $SD\pm 0.50$ ). All these had a high significance ( $p\text{-value} \leq 0.05$ ).

There was no change in weight gain ( $m=2.00$ ;  $SD\pm 0.00$ ) after the intervention, hence this does not have a high significance level ( $p\text{-value} \geq 0.05$ ).

**Table 8.9: Test between Pre-intervention and Post-intervention of EORTC QLQ-BR45.**

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-4)	M±SD	Range (1-4)	
Functional Scale:					
Felt physically less attractive***	3.42±0.50	3-4	2.00±0.00	2-2	0.00

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-4)	M±SD	Range (1-4)	
Felt less feminine***	3.42±0.50	3-4	2.00±0.00	2-2	0.00
Had problems looking at yourself naked ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00
Dissatisfied with your body ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00
Worried about your health in the future ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00
Have been interested in sex ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Have been sexually active ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Has sex been enjoyable for you ***	3.17±1.01	2-4	2.00±0.00	2-2	0.00
Satisfied with the cosmetic result of the surgery ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00
Satisfied with the appearance of skin of the affected breast ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00
Symptom Scales/Items - Systemic Therapy Side-Effects:					
Had a dry mouth ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00
Food and drink tasted differently ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-4)	M±SD	Range (1-4)	
Painful, irritated or watery eyes	1.00±0.00	1-1	1.00±0.00	1-1	1.00
Hair loss ***	4.00±0.00	4-4	2.00±0.00	2-2	0.00
Upset by the loss of your hair ***	4.00±0.00	4-4	2.00±0.00	2-2	0.00
Felt ill or unwell ***	4.00±0.00	4-4	2.00±0.00	2-2	0.00
Had hot flushes ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Had headache ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Symptom Scales/Items - Arm Symptoms:					
Had pain in your arm or shoulder ***	4.00±0.00	4-4	2.00±0.00	2-2	0.00
Had a swollen arm or hand ***	3.00±0.00	3-3	1.00±0.00	1-1	0.00
Had problems raising arm or moving it sideways ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00
Symptom Scales/Items - Breast Symptoms:					
Had pain in the area of affected breast ***	3.00±0.00	3-3	2.00±0.00	2-2	0.00
Affected breast area swollen ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00
Affected breast area oversensitive ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-4)	M±SD	Range (1-4)	
Skin problems on affected breast area ***	3.58±0.50	3-4	2.00±0.00	2-2	0.00
Target Therapy Scale - Endocrine Therapy Symptoms:					
Sweat excessively ***	3.58±0.50	3-4	2.00±0.00	2-2	0.00
Had mood swings ***	3.58±0.50	3-4	2.00±0.00	2-2	0.00
Have been dizzy ***	3.58±0.50	3-4	2.00±0.00	2-2	0.00
Had problems with joints	2.17±1.01	1-3	2.00±0.00	2-2	0.41
Had stiffness in joints ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Had pain in joints ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Had aches or pain in bones ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Had aches or pains in muscles ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Target Therapy Scale - Skin Mucositis Symptoms:					
Had soreness in mouth ***	3.42±0.50	3-4	2.00±0.00	2-2	0.00
Had reddening in mouth ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Had pain in your hands or feet ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00
Had reddening on your hands or feet ***	2.58±0.50	2-3	2.00±0.00	2-2	0.00

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-4)	M±SD	Range (1-4)	
Had tingling in fingers or toes	2.00±0.00	2-2	2.00±0.00	2-2	1.00
Had numbness in fingers or toes ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00
Target Therapy Scale - Endocrine Sexual Symptoms:					
Have gained weight	2.00±0.00	2-2	2.00±0.00	2-2	1.00
Has weight gain been a problem	1.58±0.50	1-2	2.00±0.00	2-2	1.00
Had a dry vagina ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00
Had discomfort in your vagina ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00
Had pain in vagina during sexual activity ***	1.42±0.50	1-2	1.00±0.00	1-1	0.00
Experienced dry vagina during sexual activity ***	1.42±0.50	1-2	1.00±0.00	1-1	0.00
Satisfaction Scales:					
Satisfied with the cosmetic result of the surgery ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00
Satisfied with the appearance of skin of the affected breast ***	1.58±0.50	1-2	2.00±0.00	2-2	0.00

Table 8.10 shows that Total EORTC QLQ-BR45 was high among the patients before the intervention with a high mean score  $m=2.79$  ( $SD\pm 0.14$ ), and reduced after the intervention resulting in a low mean score  $m=1.94$  ( $SD\pm 0.00$ ). The total change in EORTC QLQ-BR45 is highly significant ( $p\text{-value} \leq 0.05$ ). This implies that Quality of Life concerns reduced significantly after the intervention.

**Table 8.10: Total EORTC QLQ-BR45 between Pre-intervention and Post-intervention.**

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (1-4)	M±SD	Range (1-4)	
Total EORTC QLQ-BR45***	2.79±0.14	2.6-2.9	1.94±0.00	1.9-1.9	0.00

#### 8.4.5 Wilcoxon Signed-Rank Test on Spiritual Need

The Wilcoxon rank signed-rank test in Table 8.11 shows that spiritual needs before the intervention was low with mean score ( $m=1.04$ ;  $SD\pm 0.00$ ), and it increased to a high mean score ( $m=3.00$ ;  $SD\pm 0.00$ ), with a high significance ( $p\text{-value} \leq 0.05$ ). This indicates that total spiritual needs of patients increased significantly after the intervention.

**Table 8.11: Test between Pre-intervention and Post-intervention of Spiritual Need.**

	Pre-intervention		Post-intervention		P-value
	M±SD	Range (0-3)	M±SD	Range (0-3)	
Spiritual Need***	1.04±0.00	1-1	3.00±0.00	3-3	0.00

## 8.5 Discussion

### 8.5.1 Outcome of the Palliative Nursing Care Programme

From the data, there was a significant improvement in nausea, appetite, insomnia, pain, fatigue, concentration, breathing, and coughing. The findings align with several previous studies that have reported improvements in these symptoms after interventions or treatments for breast cancer (de Souza et al., 2021, Steindorf et al., 2014, Ligibel et al., 2016, Chan et al., 2020b, Özdelikara and Tan, 2017). For example, a study by Özdelikara and Tan (2017) involving breast cancer patients attending the ambulatory chemotherapy unit of Ondokuz Mayıs University medical faculty hospital in Türkiye on reflexology for 30 participants observed a significant reduction in nausea, vomiting, and fatigue among breast cancer patients post-chemotherapy treatment. Similarly, in a randomized, parallel-group clinical trial for 34 women diagnosed with breast cancer and received chemotherapy in Brazil, de Souza et al. (2021) reported an improvement in fatigue and appetite among breast cancer patients undergoing chemotherapy treatment through a nutritional-based intervention.

From the data, the study showed no change in the appearance concern of participants. This is consistent with the study of Zhu et al. (2022) where they reported in their meta-analysis study involving seven studies, including two RCTs and five quasi-experimental studies, from 1994 to 2022, that there were no significant changes in appearance care on body image for women receiving chemotherapy for breast cancer. Inversely, the finding that appearance remained unchanged after the intervention contradicts some earlier research (Sebri et al., 2021, Chan and Chow, 2023, Lewis-Smith, 2017). For instance, a systematic review by Sebri et al. (2021) showed that implemented psychosocial interventions for breast cancer patients, including appearance-related components, reported a significant improvement in body image and appearance concerns. The three-level meta-analysis showed a statistically significant effect for Body Image [ $g = 0.50$ ; 95% CI (0.08; 0.93);  $p < 0.05$ ]. This inconsistency might be attributed to differences in the nature and focus of the interventions between the current study and those reporting positive changes in appearance.

Furthermore, from the study, the outlook was positive. The improvement in outlook post-intervention is consistent with studies emphasizing the psychological well-being of breast cancer patients (Kubzansky et al., 2023, Levine et al., 2021, Steinhäuser et al., 2017). For example, Melnyk et al. (2020) conducted a similar study and found that interventions targeting patients' outlook and mental health significantly contributed to improved overall well-being.

The study showed an improvement in EORTC QOL symptoms as there were reductions in symptoms like dry mouth, body pain, and ill feeling. This is also in tandem with findings from studies focused on supportive care interventions during cancer treatment (Chan et al., 2020b, Wang et al., 2023, Getu et al., 2022, Heidary et al., 2023, Getu et al., 2023). For instance, a research investigation carried out at Tikur Anbessa Specialized Hospital in Addis Ababa, Ethiopia, utilized the EORTC Breast Cancer Specific Quality of Life Questionnaire QLQ-BR45 to evaluate the effect of cognitive-behavioural therapy integrated with activity pacing on cancer-related fatigue, depression, and quality of life among patients with breast cancer undergoing chemotherapy in a group of 88 breast cancer patients. The findings reported a significant improvement in patient quality of life after intervention (Getu et al., 2023). The significant reduction in the total EORTC QOL mean score after the intervention aligns with the broader literature on interventions aiming to enhance QOL in cancer patients undergoing radiotherapy (Getu et al., 2023, Imran et al., 2019, Chan et al., 2020a, de Souza et al., 2021). Such interventions often involve a combination of medical, psychosocial, and supportive care measures, leading to an overall improvement in QOL (Anderson and Ozakinci, 2018, Senchak et al., 2019).

From the study, there was no change in the outcome for hair loss. The lack of change in hair loss scores despite the intervention contrasts with findings from previous studies exploring the impact of interventions on alopecia in cancer patients undergoing chemotherapy treatment (Macduff et al., 2003, Mols et al., 2009, Robinson et al., 1987, Michel et al., 2023). Similarly, in a network of meta-analysis and a systematic review of the efficacy of interventions for the prevention of chemotherapy-induced alopecia, Shin et al. (2015), using a frequentist framework, performed a test to evaluate the relative effects of different interventions on chemotherapy-induced alopecia. The study included 17 trials with 1378 patients. The results showed that both scalp cooling and scalp compression were significant in preventing chemotherapy-induced alopecia. The odds ratio for scalp cooling was 0.13 (95% confidence interval, 0.07-0.25), and for scalp compression, it was 0.13 (95% confidence interval, 0.03-0.52). The efficacy rankings indicated that scalp cooling was the most effective method for preventing chemotherapy-induced alopecia, followed by scalp compression with tourniquets, topical Chinese medicine, and oral Chinese medicinal herbs. The study concluded that scalp cooling is the most effective method for preventing chemotherapy-induced alopecia during cancer treatment. The absence of a change in hair loss outcomes in the current study may be linked to the fact that participants were still being administered with the treatment of palliative chemotherapy whose side effects include alopecia.

Similarly, the current study found no significant change in sexual inactivity before and after the intervention. This contradicts some interventions that have shown positive effects on maintaining or improving sexual functioning during cancer treatment (Elyasi et al., 2023, Lin et al., 2023). For instance, a study on the effect of a social network-based supportive program on the sexual self-concept of women with breast cancer, a single-blind randomized controlled trial, reported that the generalized equation estimation test demonstrated a significant increase in the positive sexual self-concept score for the intervention group compared to the control group, showing a rise of 15.67 points ( $P < 0.001$ , effect size = 2.00) one month after the intervention. During the same period, the negative sexual self-concept score exhibited a decrease of 2.65 points ( $P < 0.001$ , effect size = 0.74), while the situational sexual self-concept score showed an increase of 6.82 points ( $P < 0.001$ , effect size = 2.08) within the intervention group. Furthermore, the sexual quality of life score for the intervention group, in comparison to the control group, demonstrated an overall increase of 13.82 points ( $P < 0.001$ , effect size = 2.08) one month following the intervention (Elyasi et al., 2023). The lack of significant change in this study may similarly be attributed to the fact that the side effects of palliative chemotherapy were still present in participants because data collection occurred concurrently with participants' reception of their treatment.

Furthermore, the present study indicated a significant change in the level of spiritual needs among participants before and after the intervention, from  $1.04 \pm 0.00$  to  $3.00 \pm 0.00$ , with a p-value of 0.00. This is consistent with the study of Leão et al. (2021) where they reported in a randomized controlled trial (RCT) examining the impact of a spirituality-based intervention on cancer patients. The study found a significant increase in spiritual well-being scores after the intervention. The study utilized a pre-test/post-test design and found a p-value of 0.02, supporting the idea that spiritual interventions can positively affect spiritual needs. This also aligns with the study of Jones and Brown (2021) who conducted a longitudinal study on the effects of mindfulness-based interventions on spiritual needs among female breast cancer participants. Jones and Brown observed a marked improvement in spiritual well-being. The intervention group demonstrated a statistically significant increase in spiritual need scores ( $p < 0.05$ ), aligning with the current study's findings.

From the study, there was a significant reduction in the severity of pain and interference of pain in daily activities among breast cancer patients after the intervention. This is consistent with previous studies (Bilmiç et al., 2023, Valenta et al., 2022), For example, in a randomized control trial of the effect of spiritual care on pain among breast cancer patients in Isfahan, Iran, the mean scores of pain severity dimensions had a p-value of ( $P=0.004$ ) among the intervention group as compare to the controlled group. The study, therefore, concluded that

spiritual care is effective in the reduction of pain severity and its adverse effects on the lives of breast cancer patients (Jahanizade et al., 2017). This also agrees with the nurse-led pain management program by Germossa et al. (2019) conducted in Ethiopia, where they reported that there was a general decrease in the average pain interference with both physical and emotional functions. These reductions were found to be statistically significant, with a p-value ( $p < 0.01$ ). This further strengthens the current study's findings.

## **8.6 Limitations of the Study**

Although the study took several measures to enhance its validity, including the utilization of multiple methods and multiple data sources, several limitations were recognized. The study comprised four phases, each with distinct limitations outlined for their respective stages.

Phase 1. The review had some limitations that require acknowledgement, as they were traditional scoping reviews focusing only on peer-reviewed articles. It is possible that there exists unpublished work on palliative nursing care or that relevant information may have been disseminated through alternative channels or venues. In addition, citations that might be in the reference lists of the excluded studies could have been missed. It could also have been possible that articles were missed because keywords were missing.

Phase 2: The qualitative enquiry was conducted in one region. Therefore, the results of this study cannot be generalised to all the communities in Ghana. Additionally, some of the participants became emotionally distressed during interviews and therefore referred to the clinical psychologist for counselling.

Phase 3: As mentioned before, and according to the validation of the support programme, by using expert group opinion, their response and advice ( $n=2$ ) was not to discuss the sexual life with the participants, as this did not suit the gender difference between the researcher and participants and the culture of the setting. This could lead to the women withdrawing from the programme; the experts concluded that communication between patients and healthcare practitioners on the importance of sexual relationships and ways to raise them in a culturally sensitive manner, may help to address this potentially hidden need. This made it a challenge for the research to address some of the concerns of the women with altered sexual functioning.

Phase 4 was the pilot test of the support programme directed in the exact selected area using a convenience sampling method; consequently, the results cannot be generalised. In addition, the sample for the pilot-test was small. This further underscore the point that the findings cannot be generalized. Due to the lack of a comparable control group, it is not probable to

appeal final decisions about the influence of the support programme, as it is likely that the influence achieved might be the effect of time.

Due to the disease burden of the participants, some of them struggled to complete the full session (45-90 minutes) thereby leading to intermittent interruption in the programme administration.

## **8.7 Summary**

This chapter described the programme implementation and pilot testing of the palliative nursing care programme. Pre-post research design, details about the population, sampling and size determination, ethical considerations, recruitment procedures, data collection instruments, and data analysis procedures were also described in this chapter.

From the pilot test, the intervention resulted in notable improvements in symptoms such as nausea, appetite, insomnia, pain, fatigue, aligning with prior research. However, contrary findings were observed in appearance-related aspects, with some studies reporting positive changes while others, like the current study, did not find improvements. Regarding EORTC QOL-BR45 symptoms, the intervention effectively addressed specific issues like dry mouth, body pain, ill feeling, and appearance concerns. The total EQQRT QOL mean score significantly decreased post-intervention, in line with broader literature on enhancing QOL in cancer patients undergoing chemotherapy. Lastly, the study demonstrated a significant reduction in pain severity and interference in daily activities among breast cancer patients' post-intervention, aligning with findings from previous randomized controlled trials and prospective cohort studies.

The next chapter delves into the implications for practice and recommendations for future research and conclusion.

# **CHAPTER NINE IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS FOR FUTURE RESEARCH AND CONCLUSION**

## **9.1 Introduction**

This chapter provides the conclusion to the study, focusing on implications for practice and offering recommendations aligned with the study's purpose and objectives and provides the researcher's reflection on the study.

## **9.2 Implications for Practice and Recommendations for Future Research**

The implementation of a palliative nursing care programme tailored for women receiving palliative chemotherapy in Ghana represents a groundbreaking development in nursing practice. The primary objective of the palliative nursing care programme is to alleviate distressing symptoms associated with palliative chemotherapy. This includes but is not limited to pain, fatigue, nausea, and emotional distress. Through this specialized intervention programme, patients experienced improved comfort and well-being during the pilot study. The challenge is that palliative care is not only about managing symptoms but also about enhancing the overall quality of life of patients and this must be delivered by a palliative/oncology specialist. While the programme holds great promise, concerns may arise regarding the competency of general nurses and healthcare assistants in effectively implementing it. Specialized training and education will be crucial to ensure that these healthcare professionals acquire the necessary skills and knowledge to provide optimal care. Additionally, continuous support and supervision from experienced palliative/oncology nurses can help bridge the competency gap. Therefore, the following recommendation are made.

### **9.2.1 Education and practice:**

Given the specialized nature of palliative care, there is a pressing need for training and recruitment of more speciality palliative/oncology nurses. This will ensure that a skilled workforce is available to implement and sustain the palliative nursing care programme effectively.

### **9.2.2 Management and administration:**

Management plays a pivotal role in the success of any healthcare initiative. It is recommended that healthcare management actively supports the implementation of the programme by providing resources, facilitating training programmes, and creating a conducive environment for its seamless integration into existing healthcare systems.

### **9.2.3 Future research:**

To maximize the benefits of the programme, future research should focus on its continuous assessment and improvement. This includes evaluating the effectiveness of current interventions and identifying additional elements that could be incorporated for the comprehensive benefit of women undergoing palliative chemotherapy for breast cancer.

## **9.3 Conclusion of the Study**

The research employed a sequential multi-method approach comprising four phases. The first phase involved a scoping review. The objective of this phase was to describe literature on interventions employed to support women receiving palliative chemotherapy for breast cancer using search engines such as Cumulative Index to Nursing and Allied Health Literature (CINAHL) complete, PubMed, MEDLINE Complete, SCOPUS, and ProQuest. As a result, six (n=6) articles from both qualitative and quantitative studies were found to be suitable and the data were analysed through a descriptive statistics and content analysis. In all, 14 themes/focus of the studies were identified from the data and discussed.

In phase 2, the study utilized a qualitative descriptive design, employing a semi-structured interview guide for data collection as the objective this phase was to describe the palliative care needs of women receiving palliative chemotherapy in an academic hospital in the Volta region of Ghana. The study population included all women receiving palliative chemotherapy for breast cancer at the academic hospital. A purposive sampling method was used to recruit participants till data saturation (n=24). The study analysed that data through a content analysis process. Overall, three (3) themes and twelve (12) sub-themes were generated and discussed as well.

In phase 3 of the study, the results of phases 1 and 2 were used to develop the palliative nursing care programme as guided by the supportive care model. This stage saw the triangulation of expert reviewed data, both quantitative and qualitative data (experts, n=7), together with the constructs of Fitch model and the outcomes of phases 1 and 2 to develop the programme.

Phase 4, the final phase of the study, saw the pilot testing of the programme, using an intervention approach and a pre-test post-test method for data collection. The primary outcome was on symptoms distress, with data collected using the symptoms distress questionnaire. Additionally, the secondary outcomes included pain, quality of life, and spiritual needs. The outcome of the pilot study was statistically significant as the Wilcoxon rank signed-rank test shows that before the intervention, severity of pain among patients was high with mean score ( $m=9.34$ ;  $SD\pm 1.04$ ). However, after the intervention, the severity of pain among breast cancer patients reduced, with low mean score ( $m=2.75$ ;  $SD\pm 0.00$ ), and this is significant at ( $p\text{-value} \leq 0.05$ ). The women also experienced improved quality of life and their spiritual needs met.

## **9.4 Reflection of the Study**

As a male nurse researcher, I had the opportunity to conduct a study among women diagnosed with breast cancer who were receiving palliative chemotherapy. This was a challenging and eye-opening experience for me as it required me to step outside of my own perspective and understand the unique experiences of these women.

From the very beginning, I recognized that my gender could be a barrier in building trust with the participants. Therefore, I made sure to establish clear boundaries and emphasize the confidentiality of the study. I also approached the participants with a non-judgmental and empathetic attitude, which helped to break down any potential barriers that might exist.

Throughout the study, I was struck by the resilience of these women. Despite facing a terminal illness, they were determined to make the most of their time and live their lives to the fullest. They were incredibly open and honest with me, sharing their fears, hopes, and struggles, which allowed me to gain a deeper understanding of their experiences.

One of the most significant challenges that I faced during the study was the emotional toll it took on me. As a nurse, I am trained to care for patients, but being involved in research, I had to maintain a professional distance. However, it was difficult not to get emotionally invested in their stories and feel a sense of empathy for what they were going through.

Ultimately, the study was a rewarding experience that taught me a great deal about the unique challenges that women with breast cancer face. I learned that it's essential to approach each patient with an open mind, empathy, and a willingness to listen, regardless of gender or background. I also learned that conducting research in this area is emotionally challenging, but the insights gained are invaluable and have the potential to make a significant impact on the care of these patients.

In conclusion, my experience as a male nurse researcher conducting a study among women diagnosed with breast cancer receiving palliative chemotherapy was both challenging and rewarding. It required me to step outside of my own perspective and empathize with the experiences of these women. Through this experience, I learned the importance of building trust with participants, maintaining professional boundaries, and approaching each patient with empathy and a willingness to listen.

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## APPENDICES

### Appendix A ETHICAL CLEARANCE FROM WITS

<p>UNIVERSITY OF THE WITWATERSRAND. JOHANNESBURG</p> 	<p>HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)</p>
--	--

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO: Mr S Gbande  
School of Therapeutic Sciences  
Department of Nursing Education  
Medical School  
University  
E-mail: 2536535@students.wits.ac.za

cc: Supervisor: Professor J Maree and Dr O Obiora  
<[Lize.Maree@wits.ac.za](mailto:Lize.Maree@wits.ac.za)> and <[HREC-Medical Research Office@wits.ac.za](mailto:HREC-Medical Research Office@wits.ac.za)>

FROM: Mr Iain Burns  
Human Research Ethics Committee (Medical) Tel: 011 717 1252  
E-mail: [Iain.Burns@wits.ac.za](mailto:Iain.Burns@wits.ac.za)

DATE: 2022/08/04

REF: R14/49

PROTOCOL NO: M220540 (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: A nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer in Ghana

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.



MSWorks2000/lain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND

JOHANNESBURG

R49 Mr S Gbande

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M220540

NAME: Mr S Gbande

(Principal Investigator)

DEPARTMENT: School of Therapeutic Sciences  
Department of Nursing Education  
Medical School University

PROJECT TITLE: A nurse-led palliative care programme for women receiving palliative chemotherapy for breast cancer in Ghana

DATE CONSIDERED: 2022/05/27

DECISION: Approved unconditionally

CONDITIONS:

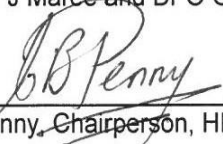
If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>

NOTE:

SUPERVISOR:

Professor J Maree and Dr O Obiora

APPROVED BY:

  
\_\_\_\_\_  
Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 2022/08/04

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

---

#### DECLARATION OF INVESTIGATORS

To be completed in duplicate and ONE COPY returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. I agree to submit a yearly progress report. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in May and therefore reports and re-certification will be due in the month of May each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

---

Signature of Principal Investigator

---

Date

# Appendix B ETHICAL CLEARANCE FROM HO TEACHING HOSPITAL

In case of reply the number  
And the date of this  
Letter should be quoted  
*My Ref. No. HTH/  
Your Ref. No....*  
**Our Core Values:**  
• Commitment  
• Accountability  
• Dedication  
• Integrity  
• Professionalism  
• Innovation  
• Teamwork  
• Safe Care



HO TEACHING HOSPITAL  
P O BOX MA-374  
HO  
Tel:+233-(036) 2027318-20/2028207  
Fax:+233-(036) 2027323  
Email: [info@hth.gov.gh](mailto:info@hth.gov.gh)  
Website: [www.hth.gov.gh](http://www.hth.gov.gh)

22<sup>nd</sup> March, 2022

## ETHICAL APPROVAL

Principal Investigator: **Mr. Gbande Sulleh**

Protocol ID NO: **HTH-REC (08) FC\_2022**

Protocol Title: **"A Nurse-led palliative care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer in Ghana."**

The Ho Teaching Hospital Research Ethics Committee upon considering the ethical merits have approved your proposal. This approval requires that you fulfil the following conditions.

- Submit periodic progress report during field work and submit final or study closure report to the HTH-REC.
- The HTH-REC may perform periodic monitoring and evaluation to ensure compliance with the protocol as approved.
- You are to report adverse event related to this study verbally within one week and in writing within two weeks.
- Any significant protocol amendment must be resubmitted to the committee for approval before implementation.
- You are required to notify the committee before publishing any research finding related to this study.

This approval is valid until 21<sup>st</sup> March, 2023 after which you have to apply for renewal. Please quote protocol identification number in future correspondence related to this protocol.

Rev. Dr. S.T.K. Dzokoto  
Chairman, Research Ethics Committee (REC)

**HTH - REC APPROVED**  
REC NUMBER: HTH-REC(08)FC-2022  
REC REFERENCE DATE: 21/03/22  
REC EXPIRATION DATE: 21/03/23  
REC ADMIN SIGN: [Signature]

## Appendix C ETHICAL CLEARANCE FOR PILOTING THE PALLIATIVE NURSING CARE PROGRAMME

In case of reply the number  
And the date of this  
Letter should be quoted  
My Ref. No.  
Your Ref. MA... Our  
Core Values:



HO TEACHING HOSPITAL  
P O BOX MA-374  
110  
+233-(036) 2027323-2028207 /  
Fax: +233-(036) 2027323  
Email: [info@hth.gov.gh](mailto:info@hth.gov.gh)  
Website: [www.hth.gov.gh](http://www.hth.gov.gh)

Commitment  
Accountability  
Dedication  
Integrity  
Professionalism  
Innovation  
Team Work  
Safe Care

Principal Investigator: Gbande Sulleh

Protocol ID. No. HTH-REC (08) FC 2022

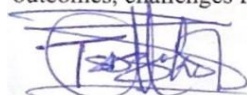
### APPROVAL OF REQUEST FOR EXTENSION OF TIME TO PILOT PALLIATIVE NURSING CARE (PNC) PROGRAMME

I write to inform you that your request for an extension of time for piloting the Palliative Nursing Care programme under the "A Nurse-led Palliative Care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer" with Protocol Identification No. HTH-REC (08) FC 2022 has been approved. The new timeline for the project will be from July to November 2023.

Please be advised that your revised timeline from July to November 2023 will be considered as the official period for piloting the PNC programme.

The HTH-REC may perform periodic monitoring and evaluation to ensure compliance with the protocol as approved.

Once the piloting phase is complete, we expect you to provide a detailed report on the outcomes, challenges



Rev. Dr. S.T.K. Dzokoto outcomes, c Henges faced, and recommendations.

Chairman

Ho Teaching Hospital Research Ethics Committee (HTH-REC)

Research Ethics Committee (REC)  
Ho Teaching Hospital,  
P.O. Box MA 374, 110, Ghana  
TCI: 233-37-200-0180. Email: [Info@hth.gov.gh](mailto:Info@hth.gov.gh)

## Appendix D PERMISSION TO CONDUCT A STUDY IN HO TEACHING HOSPITAL

### APPENDIX D: PERMISSION TO CONDUCT STUDY IN HO TEACHING HOSPITAL

In case of reply the number  
And the date of this

Letter should be quoted

**My Ref. No. HTH/RPPME/ERC-1/**

**Your Ref. No....**

**Our Core Values:**

- Commitment
- Accountability
- Dedication
- Integrity
- Professionalism
- Innovation
- Teamwork
- Safe Care



HO TEACHING HOSPITAL

P O BOX MA-374 HO

Tel:+233-(036) 2027318-  
20/2028207 Fax:+233-(03)  
2027323

Email: [info@hth.gov.gh](mailto:info@hth.gov.gh)

Website: [www.hth.gov.gh](http://www.hth.gov.gh)

16th September, 2021

#### To Whom It May Concern

Dear Sir/Madam,

#### **PERMISSION TO CONDUCT STUDY IN HO TEACHING HOSPITAL**

I write to confirm that **Mr. Gbade Sulleh** has been granted permission to conduct the study titled "**A Nurse-led palliative care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer**" in the Ho Teaching Hospital.

However, before he is allowed to carry out the study, He will be required to provide the ethical approval certificate obtained for inspection.

Thank you.

[Simon Dzokoto]

Deputy Director, Research, Policy Planning Monitoring and Evaluation

## Appendix E PARTICIPANT INFORMATION SHEET

Name: S. GBANDE

Student Number: 2536535

Study title: A Nurse- led palliative care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer in Ghana

Reference Number: .....

Principal Researcher: Gbande Sulleh

Address: PMB 31, UHAS-HO, Ghana

Contact Number: +233 241382869

### Introduction

Good day Sir / Madam,

My name is Gbande Sulleh, a student at the University of the Witwatersrand studying towards a Doctor of Philosophy in Nursing Science. I am conducting research on the development of an intervention programme to improve the quality of life of breast cancer patient receiving palliative chemotherapy in the Volta Region of Ghana. Research is a process of looking for answers or getting more understanding about a particular problem. In this study I intend to describe the palliative care needs of women receiving palliative chemotherapy for breast cancer, explore literature on interventions employed to support women receiving palliative chemotherapy for breast cancer globally, develop and validate a Nurse- Led palliative care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer in Ghana and pilot test the palliative nursing care programme.

### Invitation to participate

I am inviting you to participate in an interview where you will share your knowledge and experiences about breast cancer and chemotherapy. You are invited to participate in this study because you are a woman aged 18 years or older and you stay in the Volta Region. Your participation in this study is entirely voluntary. You have full right to decline the interview partly or totally without any effect on the care provided to you or your significant

others. In addition, you are also free to withdraw from the study at any point during the interview or study, without any penalty or loss of benefits that you may be entitled to.

What is involved in the study?

If you do consent to participate, the study will take place between January 2021 and October 2022. Persons who will participate in this research will be interviewed individually. Interviews will happen at an agreed venue which both participant and interviewer find comfortable and private. The interview is expected to take approximately 45-60 minutes. I kindly request you to provide me your honest answer to the questions you want to respond as this would help me to come up with genuine conclusions and recommendations that would potentially help the Ministry of Health and the Ghana Health Service to implement policies that improve the quality of life of breast cancer patients receiving palliative chemotherapy. Therefore, you will be encouraged to express your views freely. No names will be used for identification; instead, sequential numbers will be used. If you agree to participate in this study and have the discussion audio recorded, I kindly request you to read and sign the attached Declarations of Consent to participate and audio recording.

#### Risks and Benefits

No physical risks are anticipated in this study. However, some participants may experience psychological stress due to the in-depth interview. In case of such participants, they will be referred to the counsellor Reverend Albert Adai who agreed to offer counselling services when required. There may be no direct benefit to every participant of this study. However, it is anticipated that, findings shall help provide efficient nursing care for the same patient in the future should there be a reoccurrence of breast cancer. Furthermore, it is expected that the findings of this study will inform the Ministry of Health, the Ghana Health Service and Social Services and relevant stakeholders about barriers of screening and the outcomes of the intervention programme. The findings from this study will be communicated to the chief executive officer of the Teaching Hospital

Reimbursements for “out of pocket” expenses.

I undertake to provide refreshments during the interview and no costs are anticipated to be incurred by the participant.

Who to contact if you have been harmed or have any concerns

Permission to conduct this research will be granted by the Human Research Ethics Committee (HREC) of the University of Witwatersrand as well as the Biomedical Research

Ethics Committee (BREC) and Research Ethics Committee (REC) of the Academic Hospital in the Volta Region. The study will be conducted according to accepted and applicable national and international ethical guidelines and principles, including those of the International Declaration of Helsinki (2012). If you have any concerns about the research, you may please contact my supervisors;

Prof Lize Maree

Former Head of Department –Nursing education

Email [lize.maree@wits.ac.za](mailto:lize.maree@wits.ac.za)

Tel 0114884272/4196

Fax 011 488 4195 4268 0865297385

7 York Road, Parktown.2193 University of the Witwatersrand

OR

Dr. Loveth Obiora

Email [loveth.obiora@wits.ac.za](mailto:loveth.obiora@wits.ac.za)

Further, if you have any concern about the conduct of this study, your welfare or your rights as a research participant, you may contact

The office of the chairman

Research ethics committee

Ho Teaching Hospital

Tel. 030-2027319

Email: [infor@hth.gov.gh](mailto:infor@hth.gov.gh)

Confidentiality

I undertake to take all the necessary precautions to keep all personal information confidential. All paper-based data gathered from the research will be kept in a safe lockable

cabinet while electronic data will be stored in a password-locked computer whose access is restricted to me only. All data will be deleted two years post the study publication or six years after data collection if the study is not published. The researcher pledges to present the study findings based on actual facts and no false information shall be included.

If you are willing to participate in this study and have it audio recorded, please read and sign the attached Declarations of Consent for participation and audio recording.

## Appendix F INFORMATION CONSENT

THE STUDY

DECLARATION BY PARTICIPANT FOR PARTICIPATING IN

By signing below, I.....agree to take part in the research

**study entitled:** A Nurse-led palliative care Programme for Women Receiving Palliative  
Chemotherapy for Breast Cancer in Ghana

I declare that:

I have read the attached information sheet and it is written in a language with which I am comfortable with.

I have had an opportunity to ask and questions I had and all my questions have been answered to my satisfaction.

I understand that taking part in this study is **voluntary** and I was not forced to participate.

I may opt to withdraw my participation in this study at any point and will not be penalized in any way whatsoever.

Name of participant:.....

Date:.....

Place:.....

Signature of participant:.....

**Witness by**

Name of witness:.....

Date:.....

Signature of witness.....

**Name:** GBANDE SULLEH    **Student Number:** 2536535

HTH - REC APPROVED  
REC NUMBER..... HTH-REC (08) FC-2022  
REC REFERENCE DATE..... 20/03/2022  
REC EXPIRATION DATE..... 21/01/2023  
REC ADMIN SIGN.....

## Appendix G INTERVIEW GUIDE – Sections A and B

### INTERVIEW GUIDE FOR WOMEN RECEIVING PALLIATIVE CHEMOTHERAPY FOR BREAST CANCER

#### SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

**Name:** S. GBANDE

**Student Number:** 2536535

**Research title:** A Nurse-Led palliative care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer in Ghana

Instruction: - please provide short answer to the socio-demographic questions

Sequential number		Questions	Coding categories	Code	Skip
	Participant sequential number:				
1.1.		Age in completed years			
1.2.		Tribe	Ewe	1	
			Ashanti	2	
			Fanti	3	
			Mole-Dagbon	4	
			Dagaaba	5	
			Ga-Dangme	6	
			Other	7	
1.3.		Religion	Islam	1	

SECTION B

**Name:** S. GBANDE

**Student Number:** 2536535

1. Please can you tell me your experience following palliative chemotherapy treatment for breast cancer?
2. How has the experience affected or influenced your life?
3. Please describe the most difficult time for you during treatment?

Probe:

-Why is that the most difficult?

4. What is it like for you to live with advanced breast cancer?
5. What did you do by yourself that kept you going through the palliative chemotherapy treatment?

Probes:

-Confidence

-Inner strength –

Hope

-Pray

6. What are your palliative care needs at this stage?

Probe:

Why is this, the most difficult need?

How can we care for you to make your cancer journey easier?

7. Is there any other thing that I have not asked you that you want me to know?

## **Appendix H EXPERTS INVITATION LETTER FOR THE REVIEW OF THE PALLIATIVE NURSING CARE PROGRAMME**

GBANDE SULLEH

C/O SCHOOL OF NURSING AND MIDWIFERY, DEPARTMENT OF NURSING

PMB 31, UHAS-HO,

Dear Sir/Madam,

INVITATION TO PARTICIPATE IN EXPERT REVIEW: DEVELOPMENT AND PILOTING OF A PALLIATIVE NURSING CARE PROGRAMME AMONG WOMEN RECEIVING PALLIATIVE CHEMOTHERAPY FOR BREAST CANCER.

I am a Ph.D. student at the University of the Witwatersrand, and currently conducting a study entitled "A Nurse-led palliative care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer in Ghana" under the supervision of Professor Lize Maree and Dr. Loveth Obiora all of the University of the Witwatersrand, Department of Nursing Education, South Africa. The purpose of this study is to develop and pilot a nurse-led palliative care programme to improve the health outcomes and quality of life of women receiving palliative chemotherapy for breast cancer in Ghana.

The study will be conducted in four phases.

Phase 1, is the scoping literature review aimed at exploring literature on nurse-led or nurse participated programmes designed to support women diagnosed with breast cancer and are receiving palliative chemotherapy

In phase 2, a qualitative descriptive data will be gathered on the palliative care needs of women receiving palliative chemotherapy for breast cancer.

Phase 3, involved the development, validation of the Palliative Nursing Care programme.

Phase 4 involved piloting of the Palliative Nursing Care.

I hereby invite you as a member of the expert panel to review the designed intervention programme (PNC)

I would like to assure you that participation in the intervention programme review process is confidential and that you may withdraw your participation at any time.

Thank you in advance for your valuable input and participation.

Yours Sincerely,

-----

Gbande Sulleh

Student

-----

Prof. Lize Maree

1st Supervisor

-----

Dr. Loveth Obiora

2nd Supervisor

## **Appendix I EXPERT PARTICIPANTS INFORMATION LETTER AND GUIDING QUESTIONS FOR REVIEW**

The expert review of the palliative nursing care programme will be guided by the following questions;

1. Suitability of the programme for the targeted community and or population.
2. Distinctiveness within the community.
3. Pertinence of the programme to the community.
4. Feasibility of implementing the programme.
5. Targeted nature of the programme towards the specific population.
6. Consideration of cultural sensitivity in the programme.
7. Significant contribution or resolution to the problem at hand

## Appendix J CONSENT FORM FOR EXPERTS

I ----- hereby confirm that I have read the information letter and I understand the purpose of the, study, the research process and the possible positive health outcomes to promote health and improve quality of life among women receiving palliative chemotherapy for breast cancer

I therefore freely consent to participate in the expert review process. I understand that I may at any time of the study withdraw my consent and participation in the study.

Signature of participant

Date

Researcher

Date

## **Appendix K RESPONSES OF THE EXPERT PANEL GROUP IN VALIDATION OF THE PALLIATIVE NURSING CARE PROGRAMME**

- The oncology nurse who received her training from the Ghana Collage of Nurses and Midwives and had over five (5) years of working experience advises caution regarding the time allocated for participants. *“Due to long travel distances, tiredness, and potential discomfort that participants may experience, I suggested you reduce the time duration for each session from two (2) hours to 45-90 minutes”*. She added further, *“...also, terminologies employed “palliative, chemotherapy etc.” are not common to the non-science people... as such, these words may prove challenging for the women to grasp. So, I suggestions you get words to either replace such complex words and phrases with simpler alternatives that would be more understandable and suitable for the women and the Ghanaian context or incorporate straightforward explanations”* The oncology nurse scored 4 out of 4 on the self-design scoring sheet (4 question – 4 Strongly Agree).
- The oncologist who doubled as the head of the oncology department who had over 10 years of experience with oncology patients, says the following *“Enlarge the images of the normal breast and that of the stages of breast cancer for clear visibility and rearrange all details concerning sexual matters and possible add a scripture for encouragement and finding meaning out of this cancer thing”*. The score of the self-design scoring sheet for the oncologist (4 question – 4 Strongly Agree).
- The pharmacists who also have over seven (7) years of working experience remarked “my only concern is the cover page and the arrangement of the content. Is suggest you get a graphic designer to do the cover page for you and also to arrange the programme into sessions (4 question – 4 Strongly Agree).
- The Chaplain who is not a full staff but have been visiting the patients at the oncology unit for more than 10 years had this to say *“I agree with everything that you have done however, I think you should include one or two bible verses. Because, when I interact with them, I notice that some have some bible verses that they prefer. Other patients also ask for prayers and all that (4 question – 4 Strongly Agree).*
- Social worker who has over five (5) years of working experience also had this to say “...for me, your programme is timely but what I can add, is to encourage you to also encourage the patients and their significant others to seek assistance from the social worker as we also provide support services...personally I am a Christian and you know how we associate

everything to spirituality so please add a bible quotation for those who are like me” (4 question – 4 Strongly Agree).

The dietitians assigned to the oncology unit has over 3 years of working experiences and he also had this to say “Overall your programme is great however, revise the language to make it more accessible for the general audience as the content will be good for even people who are not receiving palliative chemotherapy and reduce the time as well” (4 question – 4 Strongly Agree).

## **Appendix L PRE-INTERVENTION (PILOTING) PARTICIPANTS CONSENT LETTER**

I,.....have read and understood the content of the information sheet which invites me to take part in the research study: Thus, pilot testing of a nurse-led palliative care programme termed the (PNC) in Ho, Ghana, and I have been given the opportunity to ask questions I might have regarding the process and procedure and my consent to being included in the study.

I understand that:

- Participation will involve me completing questionnaires and participating in a face-to-face palliative nursing care programme for 3 months
- Participation is voluntary
- I may refuse to participate or withdraw my consent and stop taking part in the study at any time without penalty.
- My names will not be mentioned anywhere in the report only codes will be use to identify my response throughout the study.

I hereby freely consent to participate in this research study

Participant's Signature .....

Date .....

Researcher' signature .....

Date.....

## **Appendix M PRE- INTERVENTION (PILOTING) PARTICIPANTS INFORMATION LETTER**

Hello,

Thank you for agreeing to be part of this pilot study by filling the Symptoms Distress Scale (SDS) to assess the effects of a nurse-led palliative care programme.

I would therefore like to request that you be part of the group of women that are going to be involved in the intervention programme.

This part of the study involves filling Symptoms Distress Scale (SDS), Quality of Life questionnaire, brief pain inventory and spiritual need questionnaire. Please note that you will be requested to fill in the same questionnaire three months after the intervention (as a member of the pilot testing group) in order to assess the success of the programme.

Participation in this study is entirely voluntary. You may choose not to participate or withdraw from the study at any time, which will have no effect on the services you receive from this institution or the health care providers. Should you agree to participate; a date and time convenient for you will be scheduled for the research activity. Thus, your privacy is assured.

You will be requested to sign a consent form and then fill in the questionnaire. Filling in of the questionnaire will take less than 30 minutes and I will be available to assist should you need help.

Your identity will not be revealed in any reports of this study. Results of the study will be given to you should you so wish.

For more information or queries regarding the study or your rights as a study participant, I can be reached on +23241382869 (cell) and email: [2536535@students.wits.ac.za](mailto:2536535@students.wits.ac.za) or my supervisors Prof. Lize Maree on Tel 0114884272/4196 with email: [lizemaree@wits.ac.za](mailto:lizemaree@wits.ac.za) or Dr. Loveth Obiora on email: [loveth.obiora@witsac.za](mailto:loveth.obiora@witsac.za) of the University of the Witwatersrand.

However, should you have any problems or complaints that you have with this research process you may also contact the University of the Witwatersrand's Human Research Ethics Committee (Medical):

Administrative Officer: 011 717 1234 direct

E: [Rhulani.mkansi@wits.ac.za](mailto:Rhulani.mkansi@wits.ac.za)

Office email: hrec-medical.researchoffice@wits.ac.za

W: [www.wits.ac.za/research/about-our-research/ethics-and-research-integrity/](http://www.wits.ac.za/research/about-our-research/ethics-and-research-integrity/)

or the office of the chairman, research ethics committee, Ho Teaching Hospital on 030-2027319/infor@hth.gov.gh

Thank you for taking time to read this letter.

Yours Sincerely,

-----	-----	-----
S. Gbande	Prof Lize Maree	Dr. Loveth Obiora
Student	Supervisor	Supervisor

## Appendix N SELF-DESIGNED QUESTIONNAIRE FOR SOCIODEMOGRAPHIC DATA FOR PILOT STUDY

### SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

**Name:** S. GBANDE

**Student Number:** 2536535

**Research title:** A Nurse-Led palliative care Programme for Women Receiving Palliative Chemotherapy for Breast Cancer in Ghana

Instruction: - please provide short answer to the socio-demographic questions

Sequential number		Questions	Coding categories	Code	Skip
		Participant sequential number:			
1.1.		Age in completed years			
1.2.		Tribe	Ewe	1	
			Ashanti	2	
			Fanti	3	
			Mole-Dagbon	4	
			Dagaaba	5	
			Ga-Dangme	6	
			Other	7	
1.3.		Religion	Islam	1	
			Orthodox	2	
			Catholic	3	

Sequential number		Questions	Coding categories	Code	Skip
			Hindu	4	
			Protestant	5	
			African tradition	6	
			Other	7	
1.4		Marital status	Never married	1	
			Married	2	
			widow or widower	3	
			Separated/divorced	4	
1.5		Level of education	Never went to school	1	
			Basic education	2	
			Senior high education	3	
			Tertiary	4	
1.6		Number of pregnancies	Never	1	
			1-3	2	
			4-5	3	
			More than 5	4	
1.7		History of chemotherapy treatment	No	1	
			Yes	2	
1.8		Current employment	Employed	1	
			Unemployed	2	

<b>Sequential number</b>		<b>Questions</b>	<b>Coding categories</b>	<b>Code</b>	<b>Skip</b>
		status / occupation			

## Appendix O SYMPTOMS DISTRESS SCALE

### Instructions

Below are 5 different numbered statements. Think about what each statement says, then place a circle around the one statement that most closely indicates how you have been feeling lately.

The statements are ranked from 1 to 5, where number one indicates no problems and number five indicates the maximum number of problems. Numbers two through four indicate you feel somewhere in between these two extremes. Please circle one number on each card.

### Degrees of Distress

#### Nausea (1)

1	2	3	4	5
I seldom if ever have nausea	I have nausea once in a while	I have nausea fairly often	I have nausea half the time at least	I have nausea continually

#### Nausea (2)

1	2	3	4	5
When I do have nausea, it is very mild	When I do have nausea, it is mildly distressing	When I have nausea, I feel pretty sick	When I have nausea, I usually feel very sick	When I have nausea, I am as sick as I could possibly be

#### Appetite

1	2	3	4	5
I have my normal appetite and enjoy good food	My appetite is usually, but not always, pretty good	I don't really enjoy my food	I have to force myself to eat my food	I cannot stand the thought of food

## Degrees of Distress

### Insomnia

1	2	3	4	5
I sleep as well as I always have	I occasionally have trouble getting to sleep and staying asleep	I frequently have trouble getting to sleep	I have difficulty getting to sleep and staying asleep almost every night	It is almost impossible for me to get a decent night's sleep

### Pain (1)

1	2	3	4	5
I almost never have pain	I have pain once in a while	I have pain several times a week	I am usually in some degree of pain	I am in some degree of pain almost constantly

### Pain (2)

1	2	3	4	5
When I do have pain, it is very mild	When I do have pain, it is mildly distressing	When I do have pain, it is usually fairly intense	The pain I have is very intense	The pain I have is almost unbearable

### Fatigue

1	2	3	4	5
I seldom feel tired or fatigued	There are periods when I am rather tired or fatigued	There are periods when I am quite tired and fatigued	I am usually very tired and fatigued	Most of the time, I feel exhausted

## Degrees of Distress

### Bowel

1	2	3	4	5
I have my normal bowel pattern	My bowel pattern occasionally causes me some discomfort	My present bowel pattern occasionally causes me considerable discomfort	I am usually in considerable discomfort because of my present bowel pattern	I am in almost constant discomfort because of my bowel pattern

### Concentration

1	2	3	4	5
I have my normal ability to concentrate	I occasionally have trouble concentrating	I occasionally have considerable trouble concentrating	I usually have considerable difficulty concentrating	I just can't seem to concentrate at all

### Appearance

1	2	3	4	5
My appearance has basically not changed	Occasionally I am concerned about the worsening of my physical appearance	I am not often concerned that my appearance is worsening	Most of the time I am concerned that my physical appearance is worsening	The worsening of my physical appearance is a constant, preoccupying concern

### Breathing

1	2	3	4	5
I usually breathe normally	I occasionally have trouble breathing	I often have trouble breathing	I can hardly ever breathe as easily as I want	I almost always have severe trouble with my breathing

## Degrees of Distress

### Outlook

1	2	3	4	5
I am not worried or frightened about the future	I am slightly worried but not frightened about things	I am worried and frightened about things	I am very worried and frightened about things	I am terrified by thoughts of the future

### Cough

1	2	3	4	5
I seldom cough	I have an occasional cough	I often cough	I often cough, and occasionally have severe coughing spells	I often have persistent and severe coughing spells

## Appendix P EORTC QOLBR45 QUESTIONNAIRE



### EORTC QLQ-BR45

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

---

During the past week: Not at A      Quite   Very

All    Little   a Bit   Much

- |     |  |   |   |   |   |
|-----|--|---|---|---|---|
| 31. | Have you had a dry mouth?  | 1 | 2 | 3 | 4 |
| 32. | Have food and drink tasted different than usual?                                   | 1 | 2 | 3 | 4 |
| 33. | Have your eyes been painful, irritated or watery?                                  | 1 | 2 | 3 | 4 |
| 34. | Have you lost any hair?  | 1 | 2 | 3 | 4 |
| 35. | Answer this question only if you have lost any hair:                               |   |   |   |   |
|     | Have you been upset by the loss of your hair?                                      | 1 | 2 | 3 | 4 |
| 36. | Have you felt ill or unwell?   | 1 | 2 | 3 | 4 |
| 37. | Have you had hot flushes?  | 1 | 2 | 3 | 4 |
| 38. | Have you had headaches?  | 1 | 2 | 3 | 4 |
| 39. | Have you felt physically less attractive as a result of your disease or treatment? | 1 | 2 | 3 | 4 |
| 40. | Have you felt less feminine as a result of your disease or treatment?              | 1 | 2 | 3 | 4 |

41. Have you had problems looking at yourself naked? 1 2 3 4
42. Have you been dissatisfied with your body? 1 2 3 4
43. Have you worried about your health in the future? 1 2 3 4

During the past four weeks: Not at A Quite Very

All Little a Bit Much

44. Have you been interested in sex? 1 2 3 4
45. Have you been sexually active  
(with or without intercourse)? 1 2 3 4
46. Has sex been enjoyable for you? 1 2 3 4

Please go on to the next page

During the past week: Not at A Quite  
Very

All Little a Bit Much

47. Have you had any pain in your arm or shoulder? 1 2 3 4
48. Have you had a swollen arm or hand? 1 2 3 4
49. Have you had problems raising your arm or moving  
it sideways? 1 2 3 4
50. Have you had any pain in the area of your  
affected breast? 1 2 3 4
51. Has the area of your affected breast been swollen? 1 2 3 4
52. Has the area of your affected breast  
been oversensitive? 1 2 3 4
53. Have you had skin problems on or in the area of  
your affected breast (e.g., itchy, dry, flaky)? 1 2 3 4
54. Have you sweated excessively? 1 2 3 4

55. Have you had mood swings? 1 2 3 4
56. Have you been dizzy? 1 2 3 4
57. Have you had soreness in your mouth? 1 2 3 4
58. Have you had reddening in your mouth? 1 2 3 4
59. Have you had pain in your hands or feet? 1 2 3 4
60. Have you had reddening on your hands or feet? 1 2 3 4
61. Have you had tingling in your fingers or toes? 1 2 3 4
62. Have you had numbness in your fingers or toes? 1 2 3 4
63. Have you had problems with your joints? 1 2 3 4
64. Have you had stiffness in your joints? 1 2 3 4
65. Have you had pain in your joints? 1 2 3 4
66. Have you had aches or pains in your bones? 1 2 3 4
67. Have you had aches or pains in your muscles? 1 2 3 4
68. Have you gained weight? 1 2 3 4
69. Has weight gain been a problem for you? 1 2 3 4

During the past four weeks: Not at A Quite Very

All Little a Bit Much

70. Have you had a dry vagina? 1 2 3 4
71. Have you had discomfort in your vagina? 1 2 3 4

Please answer the following two questions Not at A Quite Very

only if you have been sexually active: All Little a Bit Much

72. Have you had pain in your vagina during sexual activity? 1 2 3 4

73. Have you experienced a dry vagina during sexual activity? 1 2 3 4

During the past week: Not at All Little a Bit Much Quite Very

74. Have you been satisfied with the cosmetic result of the surgery? 1 2 3 4

75. Have you been satisfied with the appearance of the skin of your affected breast (thoracic area)? 1 2 3 4

Were there any symptoms or problems that were not covered by the questionnaire, but were relevant for you in the past week?

76. \_\_\_\_\_ 1 2 3  
4

77. \_\_\_\_\_ 1 2 3  
4



## Appendix R SPIRITUAL NEEDS QUESTIONNAIRE (SPNQ) FOR ADULTS

Each person has its own and unique point of view. The following statements may thus not necessarily apply to yours. Please read the statements you will find here carefully and then indicate how true each is for you and your current situation by circling one number per line. When you do have a respective need (“Yes”), then indicate how strong it is. Otherwise, circle the “No” option. Please be as honest and true as possible: There is no ‘right’ or ‘wrong’ answer.

During the last time, did you have had the needs ...		No	If YES, how strong is this need ?		
			some- what	strong	very strong
N2	To talk with others about your fears and worries?	0	1	2	3
N3 *	That someone of your religious community (i.e. pastor) cares for you or come to see you?	0	1	2	3
N4	To reflect back on your life?	0	1	2	3
N5	To dissolve / clarify open aspects of your life?	0	1	2	3
N6	To plunge into beauty of nature?	0	1	2	3
N7	To dwell at a place of quietness and peace?	0	1	2	3
N8	To find inner peace?	0	1	2	3
N10	To find meaning in illness and/or suffering?	0	1	2	3
N11	To talk with someone about the question of meaning in life?	0	1	2	3
N12	To talk with someone about the possibility of life after death?	0	1	2	3
N13	To turn to someone in a loving attitude?	0	1	2	3
N14	To give away something from yourself?	0	1	2	3
N15	To give solace to someone?	0	1	2	3
N16	To forgive someone from a distinct period of your life?	0	1	2	3
N17	To be forgiven?	0	1	2	3
N18	To pray with someone?	0	1	2	3
N19	That someone prays for you?	0	1	2	3
N20	To pray for yourself?	0	1	2	3
N21	To participate at a religious ceremony (i.e. Sunday service)?	0	1	2	3
N22	To read religious / spiritual books?	0	1	2	3
N23	To turn to a higher presence (i.e., God, Allah, Angels, Saints)?	0	1	2	3
N25*	To feel connected with family?	0	1	2	3
N26	To pass own life experiences to others?	0	1	2	3
N27	To be assured that your life was meaningful and of value?	0	1	2	3
N28*	To be re-involved by your family in their life concerns?	0	1	2	3
N29*	To be invited by friends?	0	1	2	3
N30*	To receive more support from your family?	0	1	2	3
In case you have further specific needs you would like to let us know:					
X1			1	2	3
X2			1	2	3
X3			1	2	3

**Appendix S SAMPLE OF HOW CODING, THEMES AND SUB-THEMES WERE FORM**

I < 1. TELL ME YOUR EXPERIENCES FOLLOWING PALLIATIVE CHEMOTHERAPY

P, < If I'm being honest, I don't recall the precise day that my chemotherapy began, but I can tell you that given what I'm going through, chemo is hell. I have been <sup>Effects (Physical)</sup> vomiting since yesterday... this mostly happens immediately. I take my infusion and the whole day; I will <sup>Effects (Physical)</sup> not be able to cook, wash, and even <sup>Effects (Physical)</sup> speak. At this time, the anti-nausea <sup>Effects (Physical)</sup> medication is rubbish, so I spent my time with my head in the chamber pot like a baby. I had a lot of nausea during my first treatment, and I feared I could pass out. I became too <sup>Effects (Physical)</sup> weak. I was <sup>Effects (Psychological)</sup> shocked and <sup>Effects (Psychological)</sup> depressed due to my experiences of chemotherapy effects. From the day I was told I had breast cancer until the second dose of chemotherapy, that's when I started to see some prospects in my treatment. It all started as a joke, but with each passing day, I realized how much I was missing out <sup>Effects (Economic)</sup> financially. I was <sup>Effects (Economic)</sup> demoted at work and my salary was cut down for the <sup>Effects (both physical & economic)</sup> four months I couldn't go to work because of chemotherapy (tears <sup>tear notes on audit form</sup> welling up in my eyes pause)

Thank God we are here for the interview today because it was not easy at all.

Q 2. HOW HAS THE EXPERIENCE AFFECTED YOUR LIFE?

P<sub>1</sub> It has had a tremendously bad impact on me...  
I can't go to work as frequently as I used to. I feel worn out and exhausted and I now have to keep spending money on therapies and additional research.  
My encounters have generally been bad. It all started as a joke, but with each passing day I realized how much I was missing out financially, I was demoted at work and my salary was cut down for the four months I couldn't go to work because of the chemotherapy (tears welling up in my eyes, pain)  
Thank God we are here for the interview today because it was not easy at all.

Q 3. DESCRIBE THE MOST DIFFICULTY TIME FOR YOU DURING TREATMENT.

P<sub>1</sub> For the most difficulty time for me was when I was told that I had cancer... I was shocked and depressed.  
Aside from this, I think the chemotherapy effect like fatigue, vomiting, and the rest are all part of the difficulties. I have been vomiting since yesterday...  
This mostly happens immediately. I take my infusion and the whole day; I will not be able to cook, wash and even speak. The pain sometimes is too much. ↓

remembers during my second cycle, I experienced difficulty in breathing and chest pain. It was the most difficult part for me because I don't have enough money for my cancer care and the chemo effects were also worrying, .... affecting all parts of your life... hmmm.

Q. < 4. What did you do by yourself that kept you going through the chemotherapy treatment?

A. < I have been asking around for men of God to pray for me. <sup>Prayer is a coping mechanism</sup> Please I need prayers because this battle is not fought on treatment alone. Also, my husband <sup>copy mechanism</sup> was very supportive during my treatment. I remember one day, I was sitting down sad because of what I was experiencing due to chemotherapy. That day he dressed up and was about to go to work and when he turned to see the way, I was sitting on the sofa, he drew closer and said "B" <sup>foot note in a notebook</sup> (Name of wife mentioned) this is not your fault; unlike STIs where we will be wondering who cheated on the other... Cancer are no one's fault... easy "B" <sup>ambit part</sup> (xxx... name of wife mentioned), that gesture alone was enough for me to fight for my life. I needed to live for him (name of husband mentioned). What really helped me is prayers.... I used to pray <sup>Coping mechanism</sup>

Q 25. What is it like for you to live with advanced Breast Cancer?

p 1 Living with breast cancer is terrible... When I say terrible, I mean the word terrible... There are times where you are <sup>effects (psychical)</sup> anxious or <sup>effects (psychical)</sup> stressed up and that continues up until now. Feelings are constantly changing. When you ask someone with cancer how they feel, they may hesitate. Some of the hesitations may be wondering if they should tell you the truth lest they receive a lecture beginning with, you need to stay positive. But another reason for the hesitation could be their mind asking for clarification: do you mean 11 p.m. or 9 a.m. this morning, at noon, or at 2 p.m. this afternoon? Not only is there a large span of emotions experienced with cancer, but the entire spectrum can occur within a 16-hour day.

I - 6. What are your healthcare needs at this stage?  
 R - Hmmm... <sup>(positive care needs)</sup> no one supports us in decision making during our treatment, all we get from the staff is orders... do this, don't do that... I mean. You have <sup>(need for autonomy)</sup> no right in the facility because if you joke and say this is <sup>(no autonomy)</sup> my right, no one will mind you again... I'm sad the doctors even talk to us nically than the nurse. I also need money because of treatment costs and other investigations. Though I had support <sup>(positive care needs)</sup> from family and friends, I believe that when we get more <sup>(positive care need - support)</sup> support from people during our care it will help... for example, here in <sup>(can't do it)</sup> (xxx... name of town mentioned) there are no <sup>(support needs)</sup> social clubs of breast cancer people for us to join or for them to even visit us and share their experiences but we often hear them on TV but I have never seen any here since I started chemo. And I also believe that we need <sup>(important PC needs)</sup> a counselor or a <sup>(important PC needs)</sup> psychologist to counsel us because, I can tell you that if you are not prayed or hopeful in life and they diagnosed you of breast cancer, you can die before your second cycle. I also need <sup>(important physical needs)</sup> my pain and other symptoms to be managed so that we can be free as it is not easy receiving chemo. I also think <sup>(important professional information)</sup> health education and information on breast cancer can help as I

PC needs  
 ① Professional health info  
 ② S/S right

**Appendix T CERTIFICATE OF EDITING**

*Catherine A. Bell*

P O Box 489  
Strathavon  
2031  
Tel: 082 558 2912

**CERTIFICATE OF EDITING**

To whom it may concern:

This letter confirms that, the thesis detailed below was edited for English language grammar, language, spelling and punctuation.

**Date:** 14 February 2024

**Description:** A Nurse-Led Palliative Care Programme for Women Receiving  
Palliative Chemotherapy for Breast Cancer In  
Ghana

**Thesis Author:** Gbande Sulleh

**Institution:** Faculty of the Faculty of Health Sciences, University of the  
Witwatersrand

*C. A. Bell*

**Appendix U PALLIATIVE NURSING CARE PROGRAMME**

# PALLIATIVE NURSING CARE PROGRAMME

**FOR WOMAN RECEIVING PALLIATIVE  
CHEMOTHERAPY FOR BREAST CANCER**

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## **1. INTRODUCTION**

This programme is designed in an attempt to meet the needs of women receiving palliative chemotherapy. The programme includes the main domains of palliative care and focuses on physical, social, psychological, and spiritual needs of breast cancer women receiving palliative chemotherapy.

I understand that this is a challenging disease, and my aim is to empower you with knowledge and support about breast cancer and its treatment options, potential side effects, self-care strategies, and available support services. By equipping you with this information, I hope to enhance your understanding, alleviate fears, and promote a sense of control over your breast cancer journey.

## **2. OBJECTIVES OF THE PALLIATIVE NURSING CARE PROGRAMME**

1. prepare participants by providing them with information (verbal, written) about typical aspects and common issues associated with their palliative chemotherapy. Thus, the training seeks to;
2. guide and educate by offering participants an opportunity to access information (verbal and written) to enhance their understanding of relevant issues on breast cancer and palliative chemotherapy.
3. support participants to identifying the various palliative care services
4. provide participants with the various strategies that can enable them cope with the effects of palliative chemotherapy during treatment
5. help participants make sense of and/or find meaning by regulating emotional reactions to the situation, encourage participants to try to see some positive aspects of their experience, and offer access to spiritual guidance
6. Promote self-care by encouraging participants to enhance their physical, social and mental health by promoting regular exercise, enjoyable experiences, satisfactory sleep, healthy diet, and advice on relaxation strategies
7. provide options through advocacy to participants by offering them an opportunity to identify issues and plan goals/strategies, and engage in important decision making as well as advising them on their rights. An interactive session will follow every module for brainstorming and conversation.

Table 1.1 LAYOUT OF THE PROGRAMME

Topic	Activity	Session	Time	Aim	Equipment needed
Module 1					
1. Familiarization	Welcome and Introduction of Participants	Session 1	20 minutes	<ul style="list-style-type: none"> <li>• Make participants familiar with one another</li> <li>• Provide an opportunity to express their ideas, views, and experiences</li> <li>• Facilitate creating a working atmosphere</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
1. What is breast cancer about!	a. Classifications of breast cancer b. Image of a normal breast c. Stages of breast cancer d. Image of abnormal breast and stages of breast cancer abnormality e. Risk factors of breast cancer f. Causes of breast cancer g. signs and symptoms g. Complications	Session 2	45 -60 minutes	<ul style="list-style-type: none"> <li>• Understand the topics of the training</li> <li>• Explain the objectives of the training</li> <li>• Recognise breast cancer.</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins
Module 2					

Topic	Activity	Session	Time	Aim	Equipment needed
2. Familiarization	Welcome and Introduction of Participants	Session 1	10 minutes	<ul style="list-style-type: none"> <li>• Make participants familiar with one another</li> <li>• Provide an opportunity to express their ideas, views, and experiences</li> <li>• Facilitate creating a working atmosphere</li> </ul>	None
2. Palliative Chemotherapy	<p>a. What is Palliative Chemotherapy?</p> <p>b. Goals and Benefits</p> <p>c. Treatment Duration and Frequency</p>	Session 2	45-50 minutes	<ul style="list-style-type: none"> <li>• Describe the meaning of palliative care nursing and its components, principles and team</li> <li>• Expand the participants capacities to respond to care demands, to maintain their comfort and enhance their QoL, and to prevent or minimise unnecessary distress</li> </ul>	<p>Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins</p> <p>Other:</p> <p>Refreshments drinks and snacks</p>

Topic	Activity	Session	Time	Aim	Equipment needed
3. Treatment Options for breast cancer	a. Types of Chemotherapy Drugs b. Combination Therapy c. Hormone Therapy d. Targeted Therapy e. Immunotherapy	Session 3	25-30 minutes	<ul style="list-style-type: none"> <li>Provide the appropriate information to participant on the various treatment modalities for advanced breast cancer to empower them</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins  Other:  Refreshments drinks and snacks
Module 3					
3. Familiarization	Welcome and Introduction of Participants	Session 1	10 minutes	<ul style="list-style-type: none"> <li>Make participants familiar with one another</li> <li>Provide an opportunity to express their ideas, views, and experiences</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
				<ul style="list-style-type: none"> <li>Facilitate creating a working atmosphere</li> </ul>	
<p>4. Potential Side Effects of palliative chemotherapy and self-care strategies</p>	<p>Symptoms such as</p> <ul style="list-style-type: none"> <li>a. Nausea and Vomiting</li> <li>b. Fatigue and Weakness</li> <li>c. Hair Loss</li> <li>d. Skin and Nail Changes</li> <li>e. Bone Health including myelosuppression</li> <li>f. Neuropathy</li> <li>G. Emotional Well-being</li> <li>H. Exercises and</li> <li>I. Physical Activity</li> </ul>	Session 2	60-90 minutes	<ul style="list-style-type: none"> <li>Participants will express their experiences during palliative chemotherapy care</li> <li>Participants will be helped to identify and maintain coping and stress management strategies</li> </ul>	

Topic	Activity	Session	Time	Aim	Equipment needed
	J. Nutrition and Hydration  K. Emotional Support and  L. Coping Mechanisms				
Module 4					
4. Familiarization	Welcome and Introduction of Participants	Session 1	10 minutes	<ul style="list-style-type: none"> <li>• Make participants familiar with one another</li> <li>• Provide an opportunity to express their ideas, views, and experiences</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
				<ul style="list-style-type: none"> <li>Facilitate creating a working atmosphere</li> </ul>	
<p>5. Self-Care Strategies</p> <p>for managing breast cancer and palliative chemotherapy burden</p>	<p>Selcare strategies including 1. Emotional, 2. Practical, 3. Informational, 4Spiritual, 5. Social, and 5 psychological</p>	Session 2	60-80 minutes	<ul style="list-style-type: none"> <li>Participants will be educated on the various coping mechanisms</li> <li>Educational and Informational support for symptoms management will be provided.</li> </ul>	<p>Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins</p> <p>Other:</p> <p>Refreshments drinks and snacks</p>
Module 5					
5. Familiarization	Welcome and Introduction of Participants	Session 1	10 minutes	<ul style="list-style-type: none"> <li>Make participants familiar with one another</li> <li>Provide an opportunity to express their ideas, views, and experiences</li> </ul>	None

Topic	Activity	Session	Time	Aim	Equipment needed
				<ul style="list-style-type: none"> <li>Facilitate creating a working atmosphere</li> </ul>	
6. Support Services	a. Healthcare Team: Who's Who?  b. Palliative Care Specialists  c. Support Groups and Peer Counselling  d. Mental Health Support  e. Complementary Therapies  f. Financial Assistance and Insurance Guidance	Session 2	45-60 minutes	<ul style="list-style-type: none"> <li>Practical care, how to deal with common patient symptoms / emotions, and introduce the term of comfort through palliative care nursing programme</li> <li>Recognize about practical care.</li> <li>Identify what to do when experiencing certain symptoms and emotions</li> <li>Provide participants with advice on where and how and where to find financial and insurance advice and guidance.</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins  Other:  Refreshments drinks and snacks

Topic	Activity	Session	Time	Aim	Equipment needed
7. Conclusion	a. Recap of Key Points  b. Encouragement and Empowerment  c. Importance of Communication and Advocacy	Session 3	15-20 minutes	<ul style="list-style-type: none"> <li>Recap of Key Points</li> </ul>	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins Other:  Refreshments drinks and snacks

The researcher began with a small speech to welcome the participants, provided a brief introduction on palliative chemotherapy for breast cancer, the described benefit of participants and the purpose of the meeting. Participants supporting the programme will learn basic information about breast cancer, and its treatment. The training includes 5 modules of the palliative nursing care programme. The duration of each daily session is 45-60 minutes (one session per week/group) that will last for three months.

Finally, the researcher declares the official opening of the training of women receiving palliative chemotherapy for breast cancer on the outcome of the palliative nursing care programme. For a successful training programme over the next 12 weeks, all participants are encouraged to become actively engaged in the various course sessions and discussions on the subject matter. The researcher wishes all participants 12 fruitful weeks of an interesting and beneficial programme.

Before starting with the palliative nursing care programme, the researcher will describe the following concepts. 1. What stage of breast cancer diagnosis qualifies a patient for palliative chemotherapy? 2. Breast cancer patients' perspectives

### **3. DEFINITION: WHAT STAGE OF BREAST CANCER DIAGNOSIS QUALIFIES A PATIENT FOR PALLIATIVE CHEMOTHERAPY?**

Palliative chemotherapy may be considered at various stages of breast cancer, depending on the individual patient's circumstances and the goals of treatment. Palliative chemotherapy is typically used when the cancer is advanced and unlikely to be cured. It aims to manage symptoms, improve quality of life, and slow down the progression of the disease.

The decision to initiate palliative chemotherapy is based on several factors, including the extent of the cancer, the overall health of the patient, and their preferences. Here, palliative chemotherapy is considered for Metastatic Breast Cancer (Stage IV) thus, when breast cancer has spread to distant organs or tissues beyond the breast and nearby lymph nodes, it is considered metastatic.

### **4. PERSPECTIVES OF WOMEN DIAGNOSED WITH BREAST CANCER**

Palliative chemotherapy for breast cancer patients is a crucial aspect of cancer care that aims to alleviate symptoms, improve quality of life, and extend survival. Understanding the perspective of breast cancer patients receiving palliative chemotherapy across the illness trajectory involves considering various stages of their cancer journey. Here are some key aspects to consider:

- **Diagnosis and Initial Treatment:**

Patients receiving palliative chemotherapy often have advanced-stage breast cancer that has spread beyond the breast or lymph nodes. The initial diagnosis can be emotionally overwhelming, and patients may experience a range of emotions, including fear, anxiety, and uncertainty about the future. The decision to pursue palliative chemotherapy may involve discussions with healthcare providers about treatment goals, potential benefits, and side effects.

- **Treatment Decision-Making:**

Patients may grapple with the decision to undergo palliative chemotherapy, weighing the potential benefits against the burdens of treatment. Discussions with healthcare professionals should include a clear understanding of treatment goals, potential side effects, and the expected impact on quality of life.

- **Physical and Emotional Impact:**

Palliative chemotherapy aims to manage symptoms, control tumor growth, and enhance overall well-being. Patients may experience side effects such as fatigue, nausea, pain, and changes in physical appearance, impacting daily life and emotional well-being. Ongoing communication with healthcare providers is crucial to address side effects promptly and adjust treatment plans as needed.

- **Quality of Life and Symptom Management:**

Improving or maintaining quality of life is a primary goal of palliative care. This involves managing physical symptoms, addressing psychological and spiritual concerns, and optimizing overall well-being. Palliative care teams may include not only oncologists but also specialists such as pain management experts, psychologists, and social workers.

- **Advanced Care Planning:**

As the illness progresses, discussions about advanced care planning become essential. Patients may need support in making decisions about end-of-life care, including preferences for location of care and types of interventions. Open and honest communication between patients, their families, and healthcare providers is crucial in navigating these challenging discussions.

- Transition to End-of-Life Care:

Some patients may eventually transition from palliative chemotherapy to end-of-life care. This phase requires a compassionate and supportive approach to manage symptoms and provide emotional and spiritual support. Supportive care measures, such as hospice services, may become more prominent in ensuring a comfortable and dignified end-of-life experience.

## **5. MODULE ONE: INTRODUCTION AND INFORMATION ABOUT BREAST CANCER**

**Session (1):** Participants introducing ----- (10:00-10:20).

**Aim:** Participants were familiar with each other, and provide the opportunity to express their views, ideas, and experience besides, creating a working atmosphere.

Equipment: None

**Session (2):** What is breast cancer about! ----- (10.20-11.20).

**Aim:** Understand the topics of the training, explain the objectives of the training, recognize breast cancer (Classifications of breast cancer, image of a normal breast, stages of breast cancer, image of abnormal breast and stages of breast cancer abnormality, risk factors of breast cancer, causes of breast cancer, signs and symptoms and complications)

**Equipment:** Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins

### **Understand what Breast Cancer is About!**

- Definition of breast cancer

Breast cancer is a type of cancer that forms in the cells of the breast. It can occur in both men and women, but it is much more common in women. Breast cancer develops when cells in the breast begin to grow out of control, forming a tumour that can invade nearby tissues or spread to other parts of the body.

- Classifications of breast cancer

Breast Cancer can be classified as benign tumour or malignant.

- Benign breast tumour

A benign breast tumour is an abnormal growth of cells in the breast that is not cancerous. These tumours can develop in any part of the breast tissue and can vary in size and shape. Benign breast tumours are not life-threatening and do not spread to other parts of the body like malignant tumours, but they can still cause discomfort, pain, and other symptoms. Some common types of benign breast tumours include fibroadenomas, papillomas, and cysts. It is important to have any new lumps or changes in the breast tissue evaluated by a healthcare professional to determine if further testing or treatment is needed.

- Malignant breast tumour

A malignant breast tumour refers to cancerous growth that has developed in the breast tissue. Breast cancer is the most common type of cancer in women worldwide, although men can also develop breast cancer. Malignant breast tumours can be classified based on their type and stage.

Breast tumours can be classified into two main types: non-invasive (in situ) and invasive. Non-invasive breast tumours, also known as ductal carcinoma in situ (DCIS), are confined to the milk ducts and have not spread to other tissues. Invasive breast tumours, on the other hand, have grown beyond the milk ducts and can spread to other parts of the body.

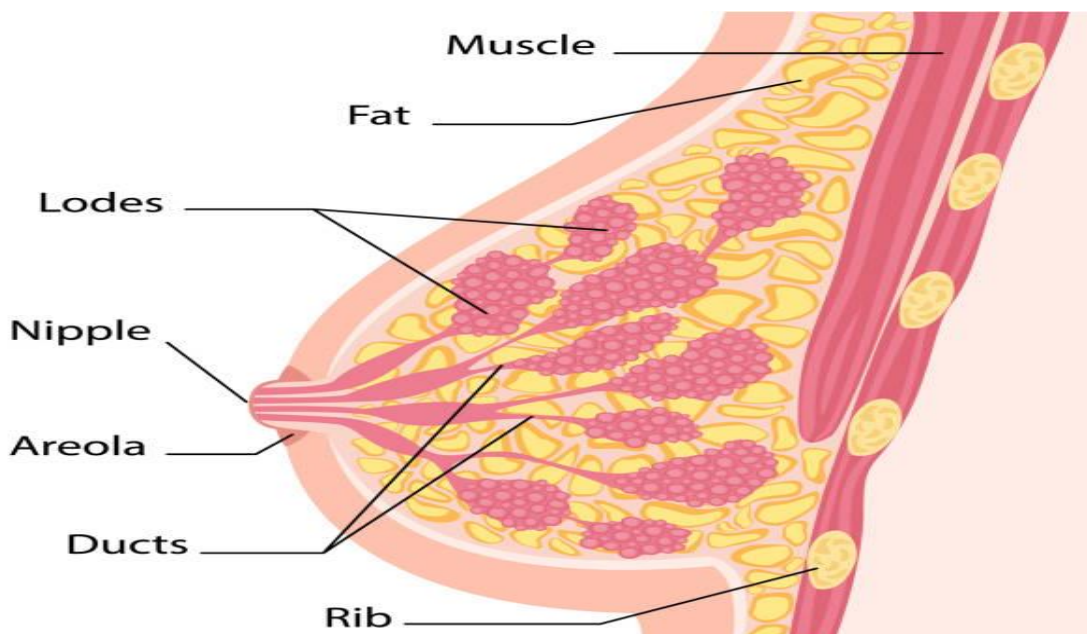


Figure 1.1 Image of the Normal Breast

- Stages of breast cancer

Breast cancer is typically staged using the TNM system, which stands for tumour size, lymph node involvement, and distant metastasis. The stages range from 0 to IV, with higher numbers indicating more advanced disease. Here are the stages of breast cancer:

**Stage 0:** This stage is also known as ductal carcinoma in situ (DCIS). The cancer cells are contained within the ducts of the breast and have not spread to nearby tissue.

**Stage I:** The cancer is small and localized to the breast tissue. It has not spread to the lymph nodes or distant organs.

**Stage II:** The cancer has grown and may have spread to the nearby lymph nodes, but it has not yet spread to distant organs.

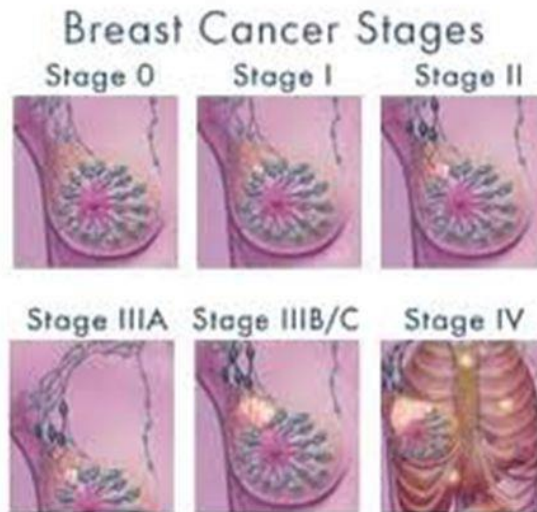
**Stage III:** The cancer has spread to nearby lymph nodes and may have invaded surrounding tissue. It has not yet spread to distant organs.

**Stage IV:** The cancer has spread to distant organs, such as the bones, liver, or lungs.

The stage of breast cancer is an important factor in determining the most appropriate treatment options and the patient's prognosis. See figure 1.1 for details on the stages of breast cancer.



# Breast Cancer Staging



## 5-year survival

- Stage 0: 99-100%
- Stage 1: 95-100%
- Stage 2: 86%
- Stage 3: 57%
- Stage 4: 20%

## Takes into account:

- Tumor size
- Degree of penetration
- Invasion to lymph nodes and adjacent organs
- Presence of metastasis

Figure 1.2 Image of Breast Cancer Stages

- Risk factors of breast cancer

There are many risk factors associated with breast cancer, some of which include:

**Age:** The risk of breast cancer increases with age, with the majority of cases occurring in women over the age of 50.

**Family history:** Women with a family history of breast cancer, particularly in first-degree relatives (mother, sister, or daughter), have an increased risk of developing the disease.

**Genetic mutations:** Mutations in certain genes, such as BRCA1 and BRCA2, increase the risk of breast cancer.

**Personal history of breast cancer:** Women who have had breast cancer in one breast have an increased risk of developing cancer in the other breast.

**Reproductive factors:** Women who have not had children or who had their first child after age 30 have a slightly higher risk of breast cancer. Women who started menstruation early (before age 12) or reached menopause late (after age 55) also have a slightly higher risk.

**Hormone therapy:** Hormone therapy after menopause, particularly combined oestrogen and progesterone therapy, has been shown to increase the risk of breast cancer.

**Alcohol consumption:** Regular and excessive alcohol consumption has been linked to an increased risk of breast cancer.

**Obesity:** Being overweight or obese increases the risk of breast cancer, particularly in postmenopausal women.

**Radiation exposure:** Women who have had radiation therapy to the chest area, such as for the treatment of Hodgkin's lymphoma, have an increased risk of developing breast cancer.

- Causes of breast cancer

Breast cancer is a complex disease that can arise from a combination of genetic, environmental, and lifestyle factors. Some of the known causes of breast cancer include:

**Genetic factors:** Inherited gene mutations such as BRCA1 and BRCA2 genes increase the risk of breast cancer.

**Age and gender:** Women who are older than 50 years old are more likely to develop breast cancer than younger women, and breast cancer is rare in men.

**Family history:** Women with a family history of breast cancer in a first-degree relative (such as a mother, sister, or daughter) are at a higher risk of developing the disease.

**Hormonal factors:** Exposure to hormones such as oestrogen and progesterone, whether naturally occurring or from hormonal therapies, can increase the risk of breast cancer.

**Lifestyle factors:** Certain lifestyle factors such as lack of physical activity, obesity, alcohol consumption, and smoking may increase the risk of breast cancer.

**Environmental factors:** Exposure to environmental pollutants, such as radiation, pesticides, and industrial chemicals, may also increase the risk of breast cancer.

It's important to note that not all women who have one or more of these risk factors will develop breast cancer, and some women without any known risk factors may still develop

the disease. Early detection through regular mammograms and other screening tests is the key to successful treatment and recovery.

- The treatment modalities available for breast cancer

There are several treatments for breast cancer, and the specific treatment or combination of treatments used will depend on the type and stage of the cancer, as well as the individual patient's medical history and overall health. Some common treatments for breast cancer include:

**Surgery:** Surgery is often used to remove the tumor and surrounding tissue. The type of surgery may vary, depending on the size and location of the tumor, as well as other factors. Common surgical procedures include lumpectomy (removal of the tumor and a small amount of surrounding tissue) and mastectomy (removal of the entire breast).

**Radiation therapy:** Radiation therapy uses high-energy radiation to kill cancer cells. It is often used after surgery to destroy any remaining cancer cells in the breast and reduce the risk of recurrence.

**Chemotherapy:** Chemotherapy involves the use of drugs to kill cancer cells throughout the body. It may be used before or after surgery, or in some cases, as the primary treatment for breast cancer.

**Hormone therapy:** Hormone therapy is used to block the effects of hormones (such as oestrogen) that can promote the growth of certain types of breast cancer. It may be used as a standalone treatment or in combination with other treatments.

**Targeted therapy:** Targeted therapy uses drugs or other substances to target specific molecules or pathways involved in the growth and spread of cancer cells. It may be used in combination with other treatments, such as chemotherapy or hormone therapy.

**Immunotherapy:** Immunotherapy uses the body's immune system to fight cancer cells. It may be used to treat certain types of breast cancer that are more likely to respond to this type of treatment.

Note that each person's breast cancer diagnosis and treatment plan will be unique, and it's important to work closely with the palliative care team to determine the most appropriate treatment options to suite your specific needs.

- Signs and symptoms of breast cancer

-Lump or Thickening: A lump or thickening in the breast or underarm is one of the most common early signs.

-Changes in Breast Size or Shape: Any noticeable changes in the size or shape of the breast.

-Unexplained Pain: Persistent pain or discomfort in the breast or nipple that is not related to the menstrual cycle.

-Changes in the Skin: Skin changes on the breast, such as redness, dimpling, or puckering.

-Nipple Changes: Changes in the nipple, such as inversion, discharge (other than breast milk), or changes in appearance.

-Swelling: Swelling or distortion of part of the breast.

-Unexplained Weight Loss: Sudden and unexplained weight loss.

-Skin Rash or Irritation: Unexplained rash or irritation on the breast.

- Signs and Symptoms of Metastatic Breast Cancer (cancer that has spread beyond the breast):

-Metastatic breast cancer symptoms may vary depending on the location of metastasis. Common sites include the bones, lungs, liver, and brain.

-Bone Pain: Pain in the bones, especially the back, hips, or other large bones.

-Shortness of Breath: Difficulty breathing or persistent cough, which may indicate lung involvement.

-Jaundice: Yellowing of the skin and eyes, which may suggest liver involvement.

-Neurological Symptoms: Headaches, seizures, confusion, or other neurological symptoms may indicate brain metastasis.

-Swelling: Swelling in the affected areas, such as the legs, may occur due to lymph node involvement.

- Complications of breast cancer

Breast cancer can lead to various complications, and the severity of these complications depends on factors such as the stage at which the cancer is diagnosed and individual health conditions. Here are some common complications associated with breast cancer:

-Metastasis: Breast cancer cells can spread to other parts of the body, a process known as metastasis. Common sites for metastasis include the bones, lungs, liver, and brain. The spread of cancer to other organs can significantly impact overall health and prognosis.

-Lymphedema: Surgical removal of lymph nodes or radiation therapy can disrupt the normal flow of lymph fluid, leading to swelling in the arms or legs. This condition is known as lymphedema and is a common complication of breast cancer treatment.

-Surgical complications: Procedures such as mastectomy or breast-conserving surgery can have associated risks, including infection, bleeding, and issues related to anesthesia.

-Palliative Chemotherapy side effects: Chemotherapy, a common treatment for breast cancer, can cause side effects such as nausea, vomiting, fatigue, hair loss, and an increased susceptibility to infections.

-Radiation therapy side effects: Radiation therapy may lead to skin changes, fatigue, and, in some cases, long-term damage to the heart or lungs if these organs are in the treatment field.

-Hormone therapy side effects: Hormone therapy, often used in hormone receptor-positive breast cancer, can cause menopausal symptoms, including hot flashes, mood swings, and an increased risk of osteoporosis.

-Psychological and emotional impact: A breast cancer diagnosis and treatment can have a significant psychological and emotional toll on individuals. Depression, anxiety, and fear of recurrence are common concerns.

-Infertility: Some treatments, such as certain chemotherapy regimens, may affect fertility, leading to temporary or permanent infertility.

-Cardiovascular issues: Certain treatments, such as certain chemotherapy drugs and radiation therapy to the chest area, can increase the risk of cardiovascular problems in the long term.

-Cognitive issues: Some individuals may experience cognitive difficulties, commonly referred to as "chemo brain," which includes problems with memory, concentration, and mental clarity during and after cancer treatment.

## 6. MODULE TWO: UNDERSTAND WHAT PALLIATIVE CHEMOTHERAPY IS ABOUT

**Session (1):** Familiarization ----- (10:00-10:10).

**Aim:** Participants were familiar with each other, and provide the opportunity to express their views, ideas, and experience besides, creating a working atmosphere.

Equipment: None

**Session (2):** Definition of Palliative Chemotherapy, goals, benefits, treatment duration and frequency ----- (10:10-10:59).

**Aim:** Describe the meaning of palliative care nursing and its components, principles and team. Expand the participants capacities to respond to care demands, to maintain their comfort and enhance their QoL, and to prevent or minimize unnecessary distress

**Equipment:** Computer, LCD, whiteboard, markers, comfortable chair, paper, and

pins Other: Refreshments drinks and snacks

**Session (3):** Explain the types of chemotherapy drugs thus, combination therapy, hormone therapy, targeted therapy, and immunotherapy ----- (11:00-11.42).

**Aim:** Provide the appropriate information to participant on the various treatment modalities for advanced breast cancer

**Equipment:** Computer, LCD, whiteboard, markers, comfortable chair, paper, and

pins Other: Refreshments drinks and snacks

### Understand what Palliative Chemotherapy is about:

- Palliative Chemotherapy

Palliative chemotherapy refers to the use of chemotherapy drugs in the treatment of advanced or metastatic cancer with the goal of managing symptoms, improving quality of

life, and prolonging survival. Unlike curative chemotherapy, which aims to completely eradicate cancer, palliative chemotherapy focuses on controlling the disease and relieving symptoms, without aiming for a cure.

- Purpose and goals of palliative chemotherapy

The purpose of palliative chemotherapy is to provide relief from cancer-related symptoms and improve the overall well-being of patients. The goals of this approach can vary depending on individual circumstances.

- Goals and potential benefits of palliative chemotherapy

**Symptom management:** Palliative chemotherapy can effectively reduce the size of tumors or slow their growth, leading to a reduction in cancer-related symptoms. For example, chemotherapy drugs can shrink tumors that are causing pain or pressure on nearby structures, alleviating discomfort. By managing symptoms such as pain, nausea, and fatigue, patients may experience an improved overall sense of well-being.

**Improved quality of life:** Palliative chemotherapy can have a positive impact on a patient's quality of life. By managing cancer symptoms and reducing their impact on daily life, patients may experience an improvement in physical functioning, emotional well-being, and overall satisfaction. This can enable them to engage in activities they enjoy, spend time with loved ones, and maintain a sense of normalcy.

**Prolonged survival:** Although the primary aim of palliative chemotherapy is not to cure cancer, it can sometimes slow down disease progression and extend a patient's lifespan. By controlling the growth of cancer cells, chemotherapy may help patients live longer and potentially achieve important personal goals or milestones.

**Psychological and emotional support:** Palliative chemotherapy involves close monitoring and regular visits to healthcare professionals, providing patients with an opportunity to discuss their concerns, fears, and emotional well-being. This ongoing support can offer comfort, reassurance, and guidance throughout the treatment process.

**Tailored treatment approach:** Palliative chemotherapy takes into account a patient's overall health, treatment preferences, and individual circumstances. The treatment plan is designed to align with the patient's goals, allowing for a more personalized approach to care.

- Overview of palliative chemotherapy treatment schedule and duration.

The treatment schedule and duration for palliative chemotherapy can vary depending on various factors, including the type and stage of cancer, the overall health of the patient, and the specific chemotherapy drugs being used. However, here is an overview of a typical treatment schedule and duration for palliative chemotherapy:

**Initial Assessment:** Before starting palliative chemotherapy, a thorough evaluation will be conducted to assess your overall health, performance status, and goals of care. The oncologist will review your medical history, perform physical examinations, and order relevant tests to determine the most appropriate treatment plan.

**Treatment Plan:** Based on the assessment, the oncologist will develop a personalized treatment plan, considering factors such as the type and location of the cancer, previous treatments received, and your preferences. The treatment plan will include the specific chemotherapy drugs, dosages, and the duration of treatment cycles.

**Treatment Cycles:** Palliative chemotherapy is typically administered in cycles, with each cycle consisting of a period of active treatment followed by a rest period. The duration of each cycle can vary, but it is often around 2-4 weeks. During the active treatment phase, you will receive chemotherapy drugs, either orally or intravenously, as prescribed by the oncologist. The rest period allows the body to recover from the side effects of the treatment.

**Number of Cycles:** The number of treatment cycles for palliative chemotherapy can vary depending on the goals of care and your response to the treatment. In some cases, a fixed number of cycles may be planned from the beginning, while in others, treatment may continue until disease progression or unacceptable toxicity occurs. The oncologist will regularly evaluate your response to treatment through physical examinations, imaging tests, and other assessments.

**Treatment Modifications:** Throughout the course of palliative chemotherapy, the oncologist may make adjustments to the treatment plan based on the patient's tolerance to the chemotherapy drugs, the response of the cancer, and the occurrence of side effects. Modifications may involve changes in drug dosages, switching to different chemotherapy drugs, or incorporating other supportive treatments to manage symptoms and improve quality of life.

**Duration of Treatment:** The duration of palliative chemotherapy can vary significantly depending on the individual patient and the progression of the disease. Some patients may receive chemotherapy for a few months, while others may continue treatment for a year or longer. The treatment duration is often determined by the balance between the benefits of continued chemotherapy and the potential risks and side effects.

## Treatment Options:

- Types of Chemotherapy:

**Combination Therapy:** Palliative chemotherapy often involves using a combination of different drugs to improve treatment effectiveness. These drugs may have different mechanisms of action, targeting various aspects of cancer growth and spread. Combining drugs can enhance their individual effects, potentially leading to better outcomes for patients.

**Hormone Therapy:** Hormone therapy is a treatment approach used for certain types of cancer, such as breast and prostate cancer, that are hormone receptor-positive. In palliative chemotherapy, hormone therapy may be employed to block or interfere with the hormones that promote cancer growth. By inhibiting hormone signaling, this therapy aims to slow down or shrink tumors and alleviate symptoms.

**Targeted Therapy:** Palliative chemotherapy may involve targeted therapies that specifically target molecular markers found on cancer cells. These therapies are designed to interfere with the specific molecules or pathways involved in cancer growth and survival, while minimizing damage to healthy cells. By focusing on the unique characteristics of cancer cells, targeted therapies can be more effective and have fewer side effects than traditional chemotherapy.

**Immunotherapy in breast cancer treatment:** Immunotherapy is an innovative approach to cancer treatment that aims to harness and enhance the body's immune system to fight cancer cells. In breast cancer treatment, immunotherapy may involve the use of immune checkpoint inhibitors or other immune-stimulating agents. These therapies work by blocking inhibitory signals that cancer cells use to evade the immune system, allowing immune cells to recognize and attack cancer cells more effectively. Immunotherapy has shown promise in improving outcomes for some breast cancer patients, particularly those with certain subtypes of the disease.

## 7. MODULE THREE: UNDERSTAND SELF-CARE STRATEGIES FOR MANAGING POTENTIAL BREAST CANCER AND PALLIATIVE CHEMOTHERAPY SIDE EFFECTS

**Session (1):** Familiarization ----- (10:00-10:10).

**Aim:** Participants were familiar with each other, and provide the opportunity to express their views, ideas, and experience besides, creating a working atmosphere.

Equipment: None

**Session (2):** Identify the potential side effects of palliative chemotherapy ----- (10:10-11:20).

**Aim:** Participants will express their experiences during palliative chemotherapy care.

Participants will be helped to identify and maintain coping and stress management strategies

**Equipment:** Computer, LCD, whiteboard, markers, comfortable chair, paper, and

pins Other: Refreshments drinks and snacks

### **Potential Side Effects and Self-Care Strategies:**

Nausea and Vomiting:

- Take antiemetic medications on time and don't skip a dose. These may include drugs like ondansetron, metoclopramide, or prochlorperazine.
- Eat small, frequent meals throughout the day instead of large meals.
- Avoid greasy, spicy, or strong-smelling foods that can trigger nausea.
- Stay hydrated by sipping fluids slowly throughout the day, such as water, ginger ale, or herbal teas.
- Try ginger, either in the form of ginger candies, ginger tea, or ginger supplements, as it may help alleviate nausea.
- Relaxation techniques, such as deep breathing exercises or meditation, may help manage nausea and vomiting.

Fatigue and Weakness:

- Plan your activities and prioritize tasks to conserve energy. Delegate tasks when possible.
- Take regular rest breaks throughout the day to prevent excessive fatigue.
- Maintain a balanced diet and stay hydrated to support your energy levels.

- Engage in light to moderate exercise, such as walking or gentle stretching, as it can help reduce fatigue.
- Ensure you are getting enough sleep and establish a consistent sleep routine.
- Talk to your healthcare provider about medications that may help manage fatigue.

#### Hair Loss:

- Consider cutting your hair short before starting chemotherapy. This can make hair loss less noticeable.
- Use gentle hair care products and avoid harsh chemicals or heat styling tools.
- Protect your scalp from the sun by wearing hats, scarves, or using sunscreen.
- Explore options like wigs, hairpieces, or head coverings to enhance your self-esteem and confidence.
- Connect with support groups or counseling services to discuss emotions related to hair loss.

#### Self-Care Management for Dry Vagina and Pain During Sexual Intercourse

- Report any changes in your vagina promptly.
- Should you experience dry vagina during sexual intercourse use moisturizers such as water-based, hypoallergenic vaginal moisturizers to alleviate dryness. Apply the moisturizers regularly, especially before sexual activity, to enhance comfort. You may also use vaginal lubricants that does not irritate the vagina: Stop using harsh soaps, douches, and other potential irritants that may worsen dryness.
- Staying well-hydrated, as hydration can influence mucous membrane health. Therefore, drink adequate amount of water daily.
- Should your vaginal pain persist, assessment will be done and appropriate analgesics given, following the palliative care plan.
- Feel free to also see the clinical psychologist for free counseling should you need emotional support

#### Skin and Nail Changes:

- Use gentle, fragrance-free skincare products to minimize skin irritation.
- Protect your skin from the sun by applying sunscreen with a high SPF.
- Keep your skin moisturized with fragrance-free lotions or creams.
- Avoid hot baths or showers and opt for lukewarm water to prevent dryness.

- Wear gloves when handling household chemicals or doing tasks that may strain your nails.
- Keep your nails trimmed short and moisturize your cuticles regularly.
- Avoid using nail polish or opt for chemical-free, hypoallergenic options.

#### Bone Health:

- Ensure an adequate intake of calcium and vitamin D through your diet or supplements, as recommended by your healthcare provider.
- Engage in weight-bearing exercises like walking, dancing, or lifting light weights to promote bone health.
- Avoid smoking and limit alcohol consumption, as they can negatively impact bone health.
- Talk to your healthcare provider about the need for bone density scans and potential medications to support bone health during treatment.

#### Neuropathy:

- Report any symptoms of neuropathy to your healthcare provider promptly.
- Manage pain associated with neuropathy using prescribed medications or over-the-counter pain relievers.
- Protect your hands and feet from extreme temperatures and injuries.
- Wear comfortable shoes with cushioning and avoid high heels or tight-fitting footwear.
- Engage in gentle exercises like walking or swimming to promote circulation.

#### Emotional Well-being:

- Seek emotional support from loved ones, support groups, or professional counsellors.
- Consider joining a breast cancer support group where you can connect with others going through similar experiences.
- Practice stress management techniques such as deep breathing exercises, meditation, or mindfulness.
- Engage in activities that bring you joy and relaxation, such as hobbies, reading, or listening to music.
- Communicate openly with your healthcare team about any emotional

Engage in stress-reduction techniques such as mindfulness, meditation, journaling, or engage in safe environment such as proper disposal of waste, cleaning and disinfecting

equipment, and eating nutritious diets so as to reduce the risk of exposure to infections due to prevent potential sources of infection due to myelosuppression

## **8. MODULE FOUR: UNDERSTAND SELF-CARE STRATEGIES FOR MANAGING POTENTIAL BREAST CANCER AND PALLIATIVE CHEMOTHERAPY BURDEN**

**Session (1):** Familiarization ----- (10:05-10:15).

**Aim:** Participants were familiar with each other, and provide the opportunity to express their views, ideas, and experience besides, creating a working atmosphere.

Equipment: None

**Session (2):** Understand self-care strategies for managing breast cancer and palliative chemotherapy burden ----- (10:15-11:40).

**Aim:** Participants will be educated on the various coping mechanisms and self-management strategies for breast cancer burdens and chemotherapy effects.

**Equipment:** Computer, LCD, whiteboard, markers, comfortable chair, paper, and

pins Other: Refreshments drinks and snacks

### **Self-Care Strategies for Managing Breast Cancer and Palliative Chemotherapy Burden**

**Anger:** Feeling angry or frustrated about the diagnosis, treatment, or changes in daily life.

Self-Care Strategies:

- Seek support from a mental health professional or counselor.
- Join support groups to connect with others who may share similar feelings.
- Engage in stress-relief activities such as meditation, deep breathing, or yoga.
- Communicate openly with loved ones about your emotions and needs.

**Despair:** Overwhelming sadness or a sense of hopelessness.

Self-Care Strategies

- Establish a support network of friends, family, or support groups.
- Consider participating in activities that bring joy or a sense of accomplishment.
- Journaling or expressing emotions through art can be therapeutic.
- Professional counseling or therapy may be beneficial in navigating these feelings.

**Fear:** Anxiety or fear related to the uncertainty of the future.

Self-Care Strategies:

- Educate yourself about the treatment process and potential outcomes.
- Practice mindfulness or meditation to manage anxiety.
- Share fears with healthcare providers to gain reassurance and understanding.
- Engage in activities that promote relaxation and stress reduction.

**Hopelessness:** Feeling a lack of hope or optimism about the future.

Self-Care Strategies:

- Set small, achievable goals to foster a sense of accomplishment.
- Focus on positive aspects of life, even in challenging times.
- Establish routines that provide comfort and stability.
- Connect with individuals who inspire hope and positivity.

Meaning of Life

Potential Side Effect: Patients may grapple with existential questions and a sense of purpose.

Self-Care Strategies:

- Encourage open communication with loved ones and healthcare providers.
- Consider spiritual or existential counseling.
- Engage in activities that bring joy and fulfillment.

Suffering:

Potential Side Effect: Emotional distress, fear, anxiety, and feelings of helplessness.

Self-Care Strategies:

- Seek support from mental health professionals, support groups, or counselors.
- Practice mindfulness and relaxation techniques.
- Maintain a journal to express feelings and thoughts.

Pain (spiritual):

Prayer and Rituals:

- Engaging in prayer or participating in religious rituals can offer comfort and a sense of connection to a higher power.
- Encourage patients to engage in practices that align with their religious or spiritual beliefs. Refer to the role of the chaplain.

Other services include

- Offer access to spiritual counsellors, chaplains, or clergy who can provide support and guidance.
- Discussing existential concerns and finding meaning in the face of illness can be part of spiritual counselling.
- Joining a spiritual or faith-based support group can create a sense of community and provide a platform for sharing experiences and coping strategies.
- Encourage patients to spend time in nature, whether through walks, meditation in a natural setting, or simply enjoying the outdoors.
- Foster connections with loved ones and nature to nurture the patient's sense of purpose and belonging.
- Art, music, or dance therapy can provide a creative outlet for emotional expression and exploration of spiritual themes.
- Writing about one's feelings, thoughts, and experiences can be a therapeutic way to process emotions and find spiritual insights.
- Suggest inspirational literature, poetry, or sacred texts that resonate with the patient's beliefs, offering comfort and encouragement.
- Engaging in acts of kindness or volunteering can create a sense of purpose and fulfillment, contributing to the patient's spiritual well-being.

- Reflect on your life, share your stories, and consider leaving a legacy, which can bring a sense of purpose and closure.

Self-Worth:

Potential Side Effect: Changes in appearance and physical abilities may impact self-esteem.

Self-Care Strategies:

- Focus on aspects of oneself beyond physical appearance.
- Seek support from friends, family, or counselors to discuss self-worth concerns.
- Engage in activities that bring a sense of accomplishment.

Body Image:

Potential Side Effect: Changes in body image due to surgery, hair loss, or weight changes.

Self-Care Strategies:

- Explore options like wigs, scarves, or hats to manage hair loss.
- Participate in support groups for individuals experiencing similar changes.
- Embrace self-acceptance and focus on inner qualities.

Coping:

Potential Side Effect: Emotional challenges and difficulties adjusting to the changes.

Self-Care Strategies:

- Develop coping strategies such as deep breathing or visualization.
- Engage in activities that bring joy and relaxation.
- Connect with support networks, friends, and family.
- Consider professional counseling or psychotherapy.

**Finances:** High medical expenses, reduced ability to work or loss of income during treatment and additional costs for transportation and accommodation.

Self-Care Strategies:

- **Financial Planning:** Consult with a financial advisor to create a budget and explore potential sources of financial assistance.
- **Insurance Coverage:** Understand your insurance coverage and explore options for assistance programs.
- **Employment Assistance:** Communicate with your employer about flexible work hours or options for medical leave.

**Child Care:** Limited energy and time for children due to treatment side effects. Difficulty managing school drop-offs, pick-ups, and extracurricular activities.

Self-Care Strategies:

- **Support System:** Seek help from family, friends, or support groups for child care.
- **Routine Planning:** Establish a predictable routine for children and communicate openly about changes.
- **Educational Support:** Inform teachers and school staff about your situation, and explore options for academic support.

**Housekeeping:** Fatigue and physical limitations for household chores. Difficulty maintaining a clean and organized living space.

Self-Care Strategies:

- **Delegating Tasks:** Enlist the help of friends, family, or consider hiring temporary assistance for housekeeping.
- **Prioritizing Tasks:** Focus on essential tasks and let go of non-urgent responsibilities.
- **Home Organization:** Simplify your living space to reduce the effort required for upkeep.

**Legal Considerations:** Need for legal documentation, such as advance directives and power of attorney.

Navigating employment and disability-related legal issues.

Self-Care Strategies:

- **Legal Assistance:** Consult with an attorney specializing in healthcare and employment law to address legal concerns.
- **Advance Care Planning:** Establish advance directives and communicate your wishes to your family and healthcare providers.

- Employment Rights: Understand your rights in the workplace and explore accommodations or disability benefits.

NOTE:

Diseases: Breast Cancer

Palliative chemotherapy is often considered for advanced or metastatic breast cancer, where the disease has spread to other parts of the body.

Procedures: Palliative Chemotherapy

Palliative chemotherapy involves the use of drugs to slow down the progression of cancer, relieve symptoms, and improve the quality of life. It differs from curative chemotherapy, as the goal is not to cure the disease but to manage symptoms.

Coping Skills:

- Emotional Support: Seek support from friends, family, or support groups to cope with the emotional challenges.
- Counselling: Professional counselling or therapy can help individuals and their families navigate the emotional aspects of living with advanced cancer.
- Mindfulness and Relaxation Techniques: Practices like meditation or deep breathing may aid in managing stress and anxiety.

Symptoms:

Palliative chemotherapy aims to alleviate symptoms such as pain, fatigue, and other discomforts associated with advanced breast cancer hence this programme

Treatment: Palliative Chemotherapy for Breast Cancer

- Medications: Chemotherapy drugs like paclitaxel, doxorubicin, or capecitabine may be used to target cancer cells.
- Pain Management: Palliative care includes pain relief through medications and other interventions such as;

Physical Therapy:

Techniques like massage, stretching, and exercises can improve flexibility and reduce muscle tension contributing to pain.

#### Psychosocial Support:

- Counseling and support groups help address emotional and psychological aspects of pain, improving overall well-being.

#### Mind-Body Techniques:

- Practices like mindfulness, meditation, and guided imagery can contribute to pain relief and stress reduction.

#### Heat and Cold Therapy:

- Application of heat or cold packs can help reduce localized pain and inflammation.

#### Nutritional Support:

- Ensuring proper nutrition can support overall health and potentially enhance the response to pain management.

#### Complementary Therapies:

- Therapies such as aromatherapy, music therapy, or art therapy may offer additional comfort and distraction.

#### Hospice Care:

- In advanced stages, transitioning to hospice care can provide comprehensive support for pain management and end-of-life care.

#### Collaborative Care:

- A multidisciplinary approach involving oncologists, pain specialists, nurses, and other healthcare professionals to tailor pain management strategies to individual needs.

#### Note:

Your pain will also be assessed through the following ways: thus, assessing your pain. This involves looking at its intensity, location, duration, and character. We use validated tools to quantify and document your pain levels. This helps us track your progress and make adjustments as needed.

- Choose Appropriate Analgesics:

For milder pain, you will begin with non-opioid analgesics like acetaminophen or nonsteroidal anti-inflammatory drugs (NSAIDs). As pain progresses, opioids such as morphine, oxycodone, or fentanyl for moderate to severe pain will be introduced.

- Titration and Adjustment:

Starting with the lowest effective dose, then, adjust upwards based on your response and tolerance. The goal is to maintain adequate pain control while minimizing side effects.

- Combination Therapy:

In some cases, a combination of different analgesics for a more effective outcome will be used. Additionally, adjuvant medications like anticonvulsants, antidepressants, or corticosteroids for specific pain types may also be introduced.

- Patient Education:

It's crucial for you and your caregivers to understand your prescribed medication regimen. Potential side effects and how to manage them. Please feel free to report any changes in your pain levels promptly.

- Regular Monitoring:

You will not be left on your own. Regular assessments using established tools will help monitor your pain levels. Based on any changes in your condition or response to treatment, adjustment will be made for the pain management plan accordingly.

- Addressing Psychological and Spiritual Aspects:

Pain is not only physical; it can affect your emotions and spirit too. As such, there will be incorporation of psychological support, counseling, and spiritual care into your overall pain management plan. Techniques like relaxation and mindfulness can complement medications.

- Consultation with a Palliative Care Team:

This journey involves a team, not just one person. A multidisciplinary palliative care team, which includes specialists in pain management, will be around to provide comprehensive

care that will help address not only physical symptoms but also emotional, social, and spiritual aspects of pain.

- Communication with the Patient:

Your input is vital. You are encouraged to open up and communicate honestly regarding your pain management. Please don't hesitate to share any changes or concerns you may have.

**Hormone Therapy:** In cases where breast cancer is hormone receptor-positive, hormone therapy drugs may be considered.

Services:

Palliative Care Services: Like this programme

Hospice Care: For some individuals, hospice services become appropriate as the focus shifts to end-of-life care and comfort.

Self-Care Strategies:

- Nutrition: Maintaining a balanced diet is crucial to support the body during treatment.
- Exercise: Gentle exercises can help manage fatigue and improve overall well-being.
- Rest: Adequate rest is essential for the body to recover from treatments.
- Communication: Open communication with healthcare providers helps in managing expectations and making informed decisions.
- Education: Understanding the disease, treatment options, and potential side effects empowers individuals to actively participate in their care.

Social support-Family:

Strategies

- Open Communication: Maintain open and honest communication with family members about your needs, concerns, and feelings. Encourage them to share their thoughts as well.

- **Delegate Responsibilities:** Delegate household tasks and responsibilities to family members. This will help distribute the workload and ensure that everyone is contributing to the best of their abilities.
- **Emotional Support:** Seek emotional support from family members and let them know how they can provide comfort. Encourage open conversations about emotions and fears.

Relationships:

Strategies

- **Quality Time:** Prioritize quality time with your partner and loved ones. Engage in activities that bring joy and relaxation, fostering a positive environment.
- **Educate Loved Ones:** Help your close ones understand the nature of palliative chemotherapy, its effects, and the importance of emotional support. Knowledge can reduce misconceptions and enhance empathy.
- **Counseling:** Consider couples or family counseling to address any challenges that may arise during this difficult time. Professional guidance can help navigate emotional complexities.

School:

Strategies

- **Communication with Educators:** Communicate with school administrators and teachers about your situation. Discuss potential accommodations, flexible schedules, or remote learning options if necessary.
- **Self-Advocacy:** Be an advocate for yourself. Communicate your needs and limitations to educators and classmates, promoting understanding and support.
- **Balanced Approach:** Find a balance between academic responsibilities and self-care. Prioritize tasks, and consider reducing non-essential commitments to manage your energy levels effectively.

Work:

Strategies

- **Open Dialogue with Employer:** Have an open and honest dialogue with your employer about your health condition. Discuss potential accommodations, such as flexible work hours or remote work, to help you manage both work and treatment.

- Pacing Yourself: Prioritize tasks at work, focusing on essential responsibilities. Communicate with colleagues about your situation, so they can offer support and understand your priorities.
- Utilize Support Services: Many workplaces offer employee assistance programs or counseling services. Take advantage of these resources to manage the emotional challenges that may arise.

## 9. MODULE FIVE: SUPPORT CARE SERVICES

**Session (1):** Familiarization ----- (10:00-10:10).

**Aim:** Participants were familiar with each other, and provide the opportunity to express their views, ideas, and experience besides, creating a working atmosphere.

Equipment: None

**Session (2):** Describe the healthcare team: Who is Who? (palliative care specialists, support groups and peer counseling, mental health support, complementary therapies, financial assistance and insurance guidance-----)(10:10-11:10).

**Aim:** For participants to practically know how to deal with common patient symptoms / emotional issues, thus, identify what to do when experiencing certain symptoms and emotions, provide participants with information on financial assistance organizations and insurance guidance.

**Equipment:** Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins

Other: Refreshments drinks and snacks

**Session (3):** Conclusion----- (11:10-11:30).

**Aim:** For participants to recap of key points. Encouragement and empowerment of participants and reminding them of the importance of communication and advocacy in breast cancer care

**Equipment:** Computer, LCD, whiteboard, markers, comfortable chair, paper, and

pins Other: Refreshments drinks and snacks

## Support Services

- Healthcare Team: Who is Who?

When receiving palliative chemotherapy for breast cancer, you will interact with a team of healthcare professionals who work together to provide comprehensive care and support. Here are some of the key individuals you may encounter:

**Oncologist:** An oncologist is a medical doctor who specializes in the diagnosis, treatment, and management of cancer. They will oversee your chemotherapy treatment plan and monitor your progress.

**Palliative Care Specialist:** Palliative care specialists focus on managing symptoms, improving quality of life, and providing emotional support to individuals with serious illnesses like cancer. They work alongside your oncologist to ensure that you receive holistic care throughout your treatment.

**Oncology Nurses:** Nurses play a vital role in your care, administering chemotherapy drugs, monitoring your vital signs, and providing education and support. They also assist with managing side effects and coordinating your overall treatment plan.

**Nurse Navigator:** A nurse navigator serves as a guide throughout your cancer journey. They help coordinate your appointments, provide education and resources, and offer emotional support to ensure a smooth experience.

**Social Worker:** A social worker can help address the social and emotional challenges that may arise during your treatment. They provide counseling, connect you with support services, and assist with practical matters such as transportation and financial concerns.

**Psychologist/Psychiatrist/counsellor:** Mental health professionals can help you cope with the emotional impact of your diagnosis and treatment. They provide counseling, therapy, and support for managing anxiety, depression, and other psychological aspects.

**Nutritionist/Dietitian:** A nutritionist or dietitian can offer guidance on maintaining a healthy diet during treatment, managing side effects, and optimizing your overall well-being.

**Physical Therapist/Occupational Therapist:** These professionals can help manage physical challenges, restore function, and enhance your quality of life during and after treatment.

**Chaplain:** They will provide spiritual support: Chaplains will offer you with spiritual support and guidance to you and your families, respecting your individual beliefs, values, and religious or philosophical traditions. They also provide rituals and sacraments services by facilitating religious or non-religious rituals and sacraments as requested, such as prayers, blessings, sacraments, and meaningful ceremonies, providing comfort and solace. Chaplains also provides existential and meaning-making support by exploring existential questions and finding meaning for you and your family,

offering a safe space for reflection and spiritual exploration. Other roles they play include.

- **Emotional and Moral Support:** They provide emotional and moral support to patients, families, and the healthcare team, serving as a compassionate presence and a source of strength during times of crisis and decision-making.
- **Communication and Conflict Resolution:** Chaplains assist in communication and conflict resolution, promoting dialogue and understanding between patients, families, and healthcare providers, especially in situations where differing beliefs or values may arise.
- **Bereavement Support:** Chaplains offer bereavement support to families, providing spiritual care and rituals during the grieving process and collaborating with other members of the interdisciplinary team to address spiritual needs.

Remember, facing a health challenge like breast cancer can be incredibly difficult. While the Bible may not specifically mention modern medical treatments, it does offer words of comfort, encouragement, and hope. Here are some verses that may provide solace for you those undergoing palliative chemotherapy and dealing with the burdens of disease and treatment effects. You can read yourself or your chaplain may read some for your during ministrations:

-Isaiah 41:10 (NIV): "So do not fear, for I am with you; do not be dismayed, for I am your God. I will strengthen you and help you; I will uphold you with my righteous right hand."

-Psalm 34:18 (NIV): "The Lord is close to the broken-hearted and saves those who are crushed in spirit."

-Psalm 139:13-14 (NIV): "For you created my inmost being; you knit me together in my mother's womb. I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well."

-2 Corinthians 1:3-4 (NIV): "Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves receive from God."

-Philippians 4:13 (NIV): "I can do all this through him who gives me strength."

Psalm 23:4 (NIV): "Even though I walk through the darkest valley, I will fear no evil, for you are with me; your rod and your staff, they comfort me"

### **Support Groups and Peer Counselling:**

Joining support groups and connecting with other women who have similar experiences of receiving palliative chemotherapy for breast cancer can offer numerous benefits:

1. **Emotional Support:** You will be introduced to support groups that will provide you with a safe space for sharing feelings, fears, and concerns as they are individuals who understand the challenges of receiving palliative chemotherapy. Connecting with you who are going through similar experiences can alleviate feelings of isolation and provide a sense of belonging.
2. **Shared Knowledge and Information:** Support groups will allow you to exchange information about treatment options, side effects management, and coping strategies. Learning from others' experiences can empower you to make informed decisions about your treatment and improve your overall well-being.
3. **Coping Skills Development:** By engaging with other women who faced or are facing similar challenges, you can learn effective coping mechanisms and strategies for managing your emotional and physical impact of palliative chemotherapy. Sharing experiences and hearing success stories can provide hope and inspiration during difficult times.
4. **Empowerment and Advocacy:** Support groups can empower you to become advocates for your own healthcare. By sharing their stories and knowledge, you can collectively raise awareness, promote better care, and influence policies related to breast cancer treatment.

**Mental Health Support:** Emotional Impact: The diagnosis of breast cancer and undergoing palliative chemotherapy can lead to a range of emotions such as anxiety, fear, depression,

and grief. To address these emotional challenges, you will be introduced to a professional counsellor should you have an emotional challenge.

**Complementary Therapies:** You will be introduced to supplementary symptom management such as relaxation and stress reduction, meditation and message to help alleviate treatment-related side effects like pain, fatigue, nausea, and anxiety.

## 10. CONCLUSION

Recap of Key Points: Summarizing the main topics covered in the educational material.

1. Encouragement and Empowerment: Offering words of encouragement, emphasizing the strength and resilience of women facing breast cancer.
2. Importance of Communication and Advocacy: Encouraging open communication with your healthcare team, active participation in treatment decisions, and advocating for your needs and preferences.
3. By providing you with a comprehensive information on treatment options, potential side effects, self-care strategies, and available support services, this educational material aims to empower you (women) with breast cancer and are receiving palliative chemotherapy. Remember, you are not alone in this journey, and with knowledge, support, and self-care, you can navigate this challenging phase with strength and resilience.