SCHOOL OF NURSING AND MIDWIFERY
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA, LEGON

CHRONIC PAIN EXPERIENCES AMONG ADVANCED CANCER PATIENTS IN THE ACCRA METROPOLIS.

BY
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JULY, 2017
DECLARATION

This is to certify that, this thesis is the result of a study undertaken by Frank Delasi Amenorpe towards the award of a Master of Philosophy Nursing Degree in the School of Nursing and Midwifery, University of Ghana. Apart from the references made from other studies and writers which have been duly acknowledged, this thesis is my original work and has not been submitted anywhere for academic award either in this University or any other University.

Frank Delasi Amenorpe
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Signature	Date

The undersigned hereby certify that this thesis was duly supervised in accordance with procedures laid down by the University of Ghana, Legon.

Dr. Lydia Aziato
Signature	Date

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Signature	Date
ABSTRACT

Chronic pain among advanced cancer patients (ACP) has several devastating effects on the patient’s quality of life and need to be understood for effective pain management. However, there is lack of literature on chronic pain experiences among ACP in Ghana. This study aimed to explore and describe chronic pain experiences among ACP in the Accra Metropolis. A qualitative approach with exploratory-descriptive design was used for this study. The Multidimensional Model of Cancer Pain was used as an organising framework for the study. A semi structured interview guide was used to collect data from 13 purposively sampled participants. The data were analysed using thematic content analysis. Findings indicated seven (7) major themes: sensory dimension, cognitive dimension, behavioural dimension, affective dimension, sociocultural dimension, pain coping strategies and pain management. Chronic pain was multi-sited, described in terms of known pain descriptors such as burning, shooting, sharp, piercing and tingling. The pain was of high intensity especially at night. Participants were knowledgeable about their pain and they interpreted their pain as: a progression of their cancer, emergence of death and ineffective medication. Furthermore, participants were preoccupied with death wishes, suicidal ideations/tendencies. They responded to pain behaviourally by communicating their pain using pain behaviours, verbally or being stoical. Chronic pain related symptoms such as disturbed sleep, fatigue and sexual difficulties were identified. Affectively, participants responded to their pain with negative emotions. Additionally, advanced cancer patients’ sociocultural characteristics influenced their perception of the pain, coping strategies, management of the pain and the overall pain experience. In conclusion, chronic pain has devastating effect on quality of life of patients with advanced cancer. It was recommended that, regular assessment of the pain and multidisciplinary approach is necessary for effective chronic pain management.
DEDICATION

This thesis is dedicated to my wife and children for their support and understanding throughout this journey.
ACKNOWLEDGEMENT

I am very grateful to the almighty God for the abundant favour and protection throughout the programme. My sincere gratitude to my supervisors, Dr. Lydia Aziato and Prof. Ama de-Graft Aikins both of University of Ghana for their immense guidance, critical review and enlightenment during this study. My appreciation also goes to the lecturers of School of Nursing and Midwifery, University of Ghana, Legon for their guidance and tutorship which helped me to go through the course work and this thesis.

I am also grateful to the staff of Ridge Hospital, Accra for their support especially during data collection stage of this study. Last but not the least; I would like to acknowledge all my research participants for availing themselves for such an insightful work to be a success. God bless you all.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ACP</td>
<td>Advanced Cancer Patients</td>
</tr>
<tr>
<td>CAM</td>
<td>Complementary and Alternative Medicine</td>
</tr>
<tr>
<td>CP</td>
<td>Chronic pain</td>
</tr>
<tr>
<td>GHS</td>
<td>Ghana Health Service</td>
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<td>IASP</td>
<td>International Association for the Study of Pain</td>
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<tr>
<td>KBTH</td>
<td>Korle Bu Teaching Hospital</td>
</tr>
<tr>
<td>MMCP</td>
<td>Multidimensional Model of Cancer Pain</td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NHIS</td>
<td>National Health Insurance Scheme</td>
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<tr>
<td>NMC</td>
<td>Nurses and Midwives Council</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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CHAPTER ONE

INTRODUCTION

This chapter involves the background to chronic pain experiences among advanced cancer patients, the statement of problem, the purpose of the study, specific objectives, research questions and significance of the study. Finally, this chapter concludes with definition of key terms used in the study.

1.1 Background

Chronic pain continues to be a major source of distress to advanced cancer patients’ quality of life (Butow & Sharpe, 2013; Edrington et al., 2010; O’Brien & Breivik, 2012; Tavoli, Montazeri, Roshan, Tavoli, & Melyani, 2008) and a concern to their caregivers (Hackett, Godfrey, & Bennett, 2016). Globally, cancer is the leading cause of death with a burden of 14.1 million new cases and 8.2 million cancer deaths in 2012 and projected to further increase to 19.3 million new cancer cases per year by 2025. This increase could lead to a dramatic rise in the number of patients with cancer accessing health services (Ferlay et al., 2015; Torre et al., 2015). In low and middle income countries including Ghana, the incidence of cancer is increasing steadily with 56.8% of cancers occurring in individuals less than 65 years of age (Ferlay et al., 2015). With an estimated 16580 new cancer cases in the year 2008 in Ghana (Ferlay et al., 2015), the incidence is expected to be far higher today as a result of changing lifestyle, diet, growth and aging population (Chalkidou et al., 2014; Torre et al., 2015). The Radiotherapy and Oncology department in Korle Bu Teaching Hospital (KBTH) which treats patients with solid cancers recorded 9,163 cancer cases in 2013 out of which 1,118 were newly diagnosed (KBTH, 2013).
In view of the increasing incidence of cancer globally (Ferlay et al., 2015; Torre et al., 2015), cancer patients in high income countries are more successful in controlling their cancers as a result of early detection and advances in cancer treatment (Altekruse, Henley, Cucinelli, & McGlynn, 2014; Graziottin, Gardner-Nix, Stumpf, & Berliner, 2011). In contrast, patients in low and middle income countries including Ghana report late for treatment with already advanced cancers as a result of financial constraints, poor accessibility to health care facilities, cultural and belief systems and ignorance (Ekortarl, Ndom, & Sacks, 2007; Gueye et al., 2017; Mwaka et al., 2016). This may result in several challenges to the patients themselves as well as caregivers/clinicians.

Pain is one of the several consequences associated with the diagnosis of cancer (Alexopoulos, Koutsogiannou, Moratis, Mestousi, & Jelastopulu, 2011; Gupta, Sahi, Bhargava, & Talwar, 2015; van den Beucken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, & Janssen, 2016). The International Association for the Study of Pain (IASP) defined pain as "an unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage" (IASP, 1979, p. 249). It is one of the most prominent symptoms associated with cancer as 70-95% of cancer patients report the existence of pain (Alexopoulos et al., 2011; Bruera & Portenoy, 2009; Gupta et al., 2015; Matthie & McMillan, 2014; Twycross, Parker, Williams, & Gibson, 2015). In spite of the prominence of pain among cancer patients, it is perhaps one of the most feared symptom due to its’ prolong devastating consequences on the patient (Dunham, Ingleton, Ryan, & Gott, 2013; Jain, Pai, & Chatterjee, 2015; Nilmanat et al., 2010). Chronic pain experience is a frequent phenomenon among cancer patients and more importantly those in their advanced stages of the disease (Belfer et al., 2013; Bredal, Smeby, Ottesen, Warncke, & Schlichting, 2014; Gauthier et al., 2009). It affects 64-66.4% of patients with advanced malignancies (Gupta et al., 2015; van den Beucken-van
Everdingen et al., 2007) and accounts for one of the major reasons for seeking help and hospitalization among patients (Dunn, Finan, Tompkins, Fingerhood, & Strain, 2015; Iwase et al., 2015; Zaki & Hairi, 2014). The experience of chronic pain among cancer patients is complex and multifaceted (Hackett et al., 2016; Krause & Stanford, 2011; Zhu & Weingart, 2012) and therefore requires multimodal or interdisciplinary approach in its management (Fallon, 2013; Krause & Stanford, 2011).

The World Health Organisation (WHO) developed an ‘analgesic ladder’ which consisted of non-opioids, opioids and adjuvants pharmacologic agents three decades ago to guide clinicians in relieving cancer patients of their pain (World Health Organization, 1986). Even though, the analgesic ladder is reported to be effective among 20% to 100% of cancer patients when used correctly, issues are constantly raised regarding its failure to include contemporary pharmacologic agents and non-pharmacologic pain interventions (Carlson, 2016). Additionally, evidence suggests cancer patients continue to experience unrelieved pain as a result of poor treatment of their pain and in some cases the pain is completely ignored by caregivers (Abdulla et al., 2013; Wilson, 2007; Zalon, 1995; Zhu & Weingart, 2012). The consequences of these include poor quality of life of the patients (Butow & Sharpe, 2013; Dunham et al., 2013; Edrington et al., 2010) and huge socioeconomic burden on the society and the nation at large (Gaskin & Richard, 2012). In recognition of the complex and multifaceted nature of chronic pain experience among cancer patients (Hackett et al., 2016; Krause & Stanford, 2011; Zhu & Weingart, 2012), it requires better understanding to effectively manage it to improve the quality of life of patients who experience it (Sullivan & Ballantyne, 2016). This experience is influenced by the several domains including physiological, sensory, cognitive, affective, behavioural and sociocultural (Silkman, 2008).
Physiologically, the cause of chronic pain among advanced cancer patients has been associated with the presence of the cancerous tumour, the manifestations of its metastatic spread including infection and ischemia, and/or from its treatment: radiation therapy, chemotherapy, or surgery (Andersen & Kehlet, 2011; Bredal et al., 2014; Burton, Fine, & Passik, 2012; Lowery et al., 2013; Mejdahl, Andersen, Gärtner, Kroman, & Kehlet, 2013). Other growing evidence also suggests chronic pain may result from inadequately treated acute pain (Burton et al., 2012), young age, depression and anxiety (Bredal et al., 2014).

The intensity of the chronic pain, its location and the quality relate to the sensory dimension of the pain experience (Hackett et al., 2016; Silkman, 2008). Pain intensity is one of the most relevant aspects of the pain experience. It is quantified through a comprehensive pain assessment and directs the urgency of treatment and the titration of the appropriate pain control medication (Zhu & Weingart, 2012). Guptal et al. (2015) suggest 62.7% of advanced cancer patients experience moderate to severe pains. The location of the pain among advanced cancer patients may be visceral, bony (musculoskeletal) and somatosensory (neuropathic) depending on the structures of the body involved although some patients may have pain occurring at multiple sites (Matthie & McMillan, 2014; Treede et al., 2015). Additionally, the nature of pain experienced by cancer patients may determine whether the pain is neuropathic, sensory or nociceptive (Lowery et al., 2013). Pain experienced by cancer patients may be dull aching, stabbing, pricking, burning, throbbing and shooting (Jain et al., 2015; Matthie & McMillan, 2014).

Undoubtedly, the affective dimension of the advanced cancer patient’s chronic pain experience can never be ignored. The patient’s emotional response: mood, fear, anxiety, feeling of helplessness and suffering may all be influenced by the presence of chronic pain (Dunham et al., 2013; Edrington et al., 2010; Lowery et al., 2013;
Chronic Pain Experiences in Advanced Cancer

Miaskowski et al., 2012; Petkova, Nikolov, Galabova, & Petrova, 2010). Studies among cancer patients have associated high levels of depression, fear, anxiety, suffering and feeling of helplessness to the experience of moderate to severe pain (Dunham et al., 2013; Edrington et al., 2010; Lowery et al., 2013; Miaskowski et al., 2012; Petkova et al., 2010). Dunham et al. (2013) suggested that, an increase in the severity of pain among cancer patients generates significant fear in them as the patients interpret it to be worsening of their condition.

Cognitively, the meaning patients associate with their pain, their previous experience/knowledge about pain, their beliefs about the pain, strategies they employ to adjust to the pain and the impact of the pain on their thought processes influence their pain experience (Silkman, 2008). An individual’s way of coping with pain is influenced by the thoughts about his/her pain and what the pain means to him/her (Petkova et al., 2010). Some patients with advanced cancer may surpass the experience of pain and develop new perspectives of living with cancer (Dunham et al., 2013); many others tend to be preoccupied with suicidal ideations due to the persistence and the devastating nature of their pain (Lowery et al., 2013). Additionally, a patient’s beliefs about the experience of pain may influence his or her intervention. It is extremely important for nurses and other clinicians assessing pain in cancer patients to be aware of the impact pain cognitions have on patients’ pain experience (de Wit, van Dam, Litjens, & Abu-Saad, 2001).

The behavioural aspect of pain refers to pain behaviours exhibited, communication of pain and associated symptoms including sleeplessness and fatigue. Several studies have reported the negative impact of chronic pain experienced by advanced cancer patients on their overall quality of life including the coexistence of fatigue and sleeplessness (Butow & Sharpe, 2013; Edrington et al., 2010; O’Brien & Breivik, 2012; Tavoli et al., 2008). Gibbins and her colleagues suggest advanced cancer patients usually exhibited stoicism
with regard to their pain until it threatens their normal daily activities (Gibbins, Bhatia, Forbes, & Reid, 2014).

The cultural background, family dynamics and caregivers’ perspective culminate to give the sociocultural dimension of chronic pain experience among cancer patients. The experience of pain among advanced cancer patients is significantly influenced by culture as different cultural groups react differently to pain ranging from relative tolerance to over reaction (Khan, Raza, & Khan, 2015). Gender, religious and ethnic differences in the perception of pain have all been well documented (Khan et al., 2015). Additionally, lack of continuous assessment of pain and trivializing pain on the side of healthcare providers has been reported as the reasons for advance cancer patient’s reluctance to complain about their pain (Gibbins et al., 2014).

In view of these, it is extremely important for caregivers/clinicians to understand the multidimensional nature of chronic pain experiences among advanced cancer patients and its effect on their existence for effective management.

1.2 Problem statement

The increasing incidence of cancer (Ferlay et al., 2015) and those who present with far advanced stages of cancers in low and middle income countries including Ghana (Mensah, Yarney, Nokoe, Opoku, & Clegg-Lamptey, 2016) are estimated to increase the number of cancer patients experiencing pain (van den Beuken-van Everdingen et al., 2007). Majority of advanced cancer patients experience moderate to severe chronic pain (van den Beuken-van Everdingen et al., 2007). Chronic pain continues to be a major source of distress to advanced cancer patients’ quality of life as they are unable to meaningfully perform activities of daily living (Butow & Sharpe, 2013; Edrington et al., 2010; O’Brien & Breivik, 2012). It is also a concern to their caregivers (Hackett et al., 2016). Additionally, the presence of chronic pain among patients have huge
socioeconomic burden on the patients themselves, the society and the nation at large (Gaskin & Richard, 2012). For instance, between 560 to 635 billion dollars is estimated to be drained annually from the United State of America’s economy as a result of pain treatment and reduced productivity of the affected individuals (Gaskin & Richard, 2012).

In spite of the advancement in cancer treatment, pain among advanced cancer patients is undertreated and in some cases its management is completely ignored (Abdulla et al., 2013; Wilson, 2007; Zhu & Weingart, 2012). Consequently, majority of those suffering unrelieved chronic pain are in low- and middle-income countries including Ghana (WHO, 2004). Meanwhile, pain relief/management is a fundamental right for each and every individual and all effort should be made to ensure maximum pain relief for all patients including advanced cancer patients (Brennan, Carr, & Cousins, 2007; WHO, 2004).

To successfully manage chronic pain among advanced cancer patients, an in-depth understanding of its multidimensional nature is crucial. However, in Ghana, there seem to be limited studies on chronic pain experiences among patients including cancer patients (Atobrah, 2014) despite an estimated increasing incidence of cancer cases (Ferlay et al., 2015) with its corresponding increase in patients who experience pain during the course of the disease or their treatment (Torresan et al., 2015). The few studies carried out are limited to post-operative surgical pain, sickle cell crisis, labour pain and dysmenorrhea (Adzika, Glozah, Ayim-Aboagye, & Ahorlu, 2017; Ampofo & Caine, 2015; Ampomah et al., 2015; Aziato & Oluyinka Adejumo, 2015; Aziato, Dedey, & Clegg-Lamptey, 2015; Aziato, Ohene, Dedey, & Clegg-Lamptey, 2016). It is therefore imperative to explore and describe chronic pain experiences among advanced cancer patients in the Accra Metropolis in Ghana for an improved pain management.
1.3 Purpose of the Study

The purpose of this study was to explore and describe chronic pain experiences among advanced cancer patients in the Accra metropolis.

1.4 Objectives of the study

The objectives of the study were:

- To describe the characteristics of chronic pain among advanced cancer patients
- To explore the cognitive influence on chronic pain experiences among advanced cancer patients.
- To explore how advanced cancer patients respond to their chronic pain.
- To describe the sociocultural influence on chronic pain experiences among advanced cancer patients.
- To investigate coping strategies adopted by advanced cancer patients when in pain.

1.5 Research questions

- What are the characteristics of chronic pain experienced by advanced cancer patients?
- What are the cognitive influences on chronic pain experiences among advanced cancer patients?
- How do advanced cancer patients respond to their chronic pain?
- What are the sociocultural influences on chronic pain experience among advanced cancer patients?
- What are the coping strategies adopted by advanced cancer patients when in pain?

1.6 Significance of the study

The findings of this study are expected to give valued information/understanding on chronic pain experiences among advanced cancer patients to caregivers/clinicians...
which would improve upon their quality of care. It will also give an in-depth knowledge and understanding about chronic pain experiences among advanced cancer patients to health policy developers to be able to develop effective policies in the management of cancer related pain and cancers at large. Additionally, the result of this study adds to knowledge on chronic pain experience among advanced cancer patients which will be used in teaching and further research among health professionals.

1.7 Operational definitions

**Advanced cancer**: diagnosis of cancer which has spread/metastasized to regional or distant tissues (stage III and IV).

**Advanced cancer patient**: any person with metastatic cancer

**Survivor**: a person continuously living after cancer diagnosis and treatment

**Experience**: a situation which affects cancer patient on a daily basis.

**Chronic pain**: pain persisting for more than three months.

**Coping strategies**: are self-adopted methods employed by advanced cancer patients in order to make out of life as they experience the symptoms and treatment side effects such as pain.
CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter focuses on the description of the conceptual framework: Multidimensional Model of Cancer Pain (MMCP), justification of its use in the study and review of related literature on CP experience among ACP relevant to the objectives of the study. Literature related to chronic pain experience among advanced cancer patients was reviewed using the MMCP (Ahles & Martin, 1992) as an organising framework and in accordance to the objectives of the study.

Relevant literature was searched from the University of Ghana databases including: “EBSCOhost”, “PUBMED”, “JSTOR”, “ScienceDirect”, “CINAHL”, “Sage”, and “Wiley Online Library” in addition to Google Scholar. Key words such as ‘chronic pain experience’ were used together with ‘cancer’, ‘advanced cancer patients’, ‘cancer pain experience’, ‘pain dimensions’, ‘coping’, ‘influence’, ‘sleep’, ‘anxiety’, ‘depression’, ‘meaning’ ‘sociocultural influence’ either individually or in combination in order to identify relevant studies.

2.1 Conceptual framework (Multidimensional Model of Cancer Pain)

The MMCP was initially developed by Ahles, Blanchard and Ruckeschel in 1983. Having realised the complexity of pain experienced by cancer patients, Ahles and his colleagues sought to understand this phenomenon. Following their study, they suggested five dimensions of pain experience among cancer patients: physiological, sensory, cognitive, affective and behavioural dimensions. The Physiological dimension described included the onset, duration and aetiology of the pain. The severity of the pain, its location and the quality constituted the sensory domain of the pain experience. Additionally, the
cognitive dimension of pain experiences as described by Ahles and colleagues determined the meaning of the pain to the patient, coping style, attitude, beliefs, knowledge and cognitive level as well as the influence of pain on thought processes. The behavioural dimension of pain was determined by the pain behaviour exhibited by the patient, communication of the pain and pain associated symptoms such as sleep and fatigue. Finally, the emotional response to pain: mood, fear, anxiety, suffering and helplessness constituted the affective dimension of pain experience (Ahles, Blanchard, & Ruckeschel, 1983).

Following the development of the five dimensional cancer pain model, McGuire (1992) carried out several studies to confirm these dimensions. However, she realized the influence of social response; family dynamics and the cultural beliefs on pain experience among cancer patients. Eventually sociocultural dimension was added to the model based on her findings (McGuire, 1992). This dimension describes the pain experience of the cancer patient in the context of his/her cultural background, family dynamics, caregiver perspective and the work role. Further study by Ahles and Martin involving 40 cancer patients and other researchers in their quest to better understand the complex experiences of cancer pain confirmed the sociocultural dimension of cancer pain experiences (Ahles & Martin, 1992; McGuire, 1992).
2.2 Justification and Relevance of the Model to the Study

In selecting a conceptual framework for the study, the researcher had Biopsychosocial model by Engel (1977), Loeser’s conceptual model of pain (1982) and the Multidimensional Model of Cancer pain by Ahles and Martin (1992) in mind. The Multidimensional Model of Cancer pain was selected over the Biopsychosocial model and
Loeser’s conceptual model of pain due to its direct association with cancer pain. Both the Biopsychosocial model and Loeser’s conceptual model of pain did not reflect on the meaning that patients associate with their pain which seemed to be important in the Ghanaian context for effective coping and management. Unlike the other two models, the MMCP has an expansive view of chronic pain experiences and also assesses the meaning the patient associate with the pain. The MMCP explores all aspects of the subjective cancer pain experiences of patients. These include the physiological, sensory, cognitive, affective, behavioural and the sociocultural dimensions. In Ghana, it appeared no study had utilized the Multidimensional Model of Cancer Pain to understand the complex nature of pain experiences among cancer patients during the researcher’s search for literature. It was therefore necessary to employ this model to understand the complexities of chronic pain experiences among advanced cancer patients in the Ghanaian context.

For the purpose of this study, the researcher focused on the sensory, cognitive, affective, behavioural and the sociocultural dimensions of chronic pain experience among advanced cancer patients. In understanding the sensory dimension, the severity, location and the quality of the pain were explored.

The meaning of the pain perceived by advanced cancer patients, their knowledge on the pain being experienced and its management, attitude and beliefs pertaining to the pain and influence of the pain on patients’ thought processes as well as the coping strategies adopted by the patient were explored under the cognitive dimension of pain experience. Additionally, the patients’ mood, anxiety, fear and suffering associated with chronic pain experiences among advanced cancer patients under the affective dimension were investigated as well as any other relevant information pertaining to this dimension.

Furthermore, the pain related behaviours exhibited by these patients in their experience of pain, communication of pain to their clinicians and significant others were
explored under the behavioural dimension of pain experience. Other symptoms associated with pain experience were also explored depending on the participants’ responses. Finally, the influence of the patient’s cultural background and family dynamics on the experience of pain among the patients were investigated to understand the role of culture and other demographic variables in the pain experience.

2.3.0 Dimensions of chronic pain experience

The increasing incidence of cancer and the presence of advanced staged cancers have significantly accounted for the presence of pain among cancer patients (van den Beuken-van Everdingen et al., 2016). Pain is one of the most feared consequences of cancer among patients (Dunham et al., 2013; Jain et al., 2015; Nilmanat et al., 2010). It is a major reason for seeking help and hospitalization among patients (Boni & Afrane, 2016; Lam et al., 2009; Zaki & Hairi, 2014). The presence of chronic pain among cancer patients may be due to a number of factors; The increasing size of the tumour including its metastatic spread and the treatment options: radiotherapy, chemotherapy and surgery account for pain experience among cancer patients (Bredal et al., 2014; Eccleston, Morley, & Williams, 2013; Lowery et al., 2013; Mejdahl et al., 2013; Mirabile et al., 2015). The experience of chronic pain among cancer patients is complex and multidimensional that requires better understanding for effective management (Hackett et al., 2016; Krause & Stanford, 2011; Zhu & Weingart, 2012). For the purpose of this study, the sensory, cognitive, affective, behavioural and the sociocultural dimensions of chronic pain experiences among advanced cancer patients as well as other themes that emerged from the data are reviewed. The term pain and chronic pain are used interchangeably in most cases to mean pain persisting beyond three months. It is also worth knowing that, these dimensions are interrelated.
2.3.1 Sensory dimension of cancer pain experience

This dimension explains the characteristics of the chronic pain experienced by the patient. It include the location, the quality and the intensity/severity of the pain (Dalal & Bruera, 2012; Hackett et al., 2016; Ngamkham, Holden, & Wilkie, 2011; Silkman, 2008). The location of cancer pain is significant during assessment of the pain. It enhances understanding of the pain for effective management (Matthie & McMillan, 2014). Chronic pain among cancer patients may exist at a single or multiple sites (Matthie & McMillan, 2014; Valeberg et al., 2008). For instance, Matthie and McMillan (2014) in their study among 717 advanced cancer patients with varied cancers at a hospice reported that, the participants identified up to three sites that pain was being experienced concurrently. Similarly, majority (73%) of 217 oncology out patients in Norway experiencing both cancer and/or non-cancer pain identified more than a single pain site when they were asked of their pain locations in a study (Valeberg et al., 2008). Eventhough this study was not explicit on the staging of the participants’ cancers and the presence of non-cancer pain, majority (74.7%) had cancer pain which were located at multiple sites.

However, the number of pain locations among cancer patients is believed to correspond with the metastatic spread of the disease; though enough research has not been conducted to substantiate this argument (Jordan, Hayward, Blagojevic-Bucknall, & Croft, 2013; Ngamkham et al., 2011). Additionally, the location of the pain may contribute to the determination of the category of pain experienced by the patient. Somatic pain is usually associated with the musculoskeletal tissues and it is localized. On the other hand, visceral pain involves internal organs of the body and are usually not localized (Matthie & McMillan, 2014; Valeberg et al., 2008). Furthermore, the location of the pain may be peculiar to a specific cancer type (Bredal et al., 2014; Jordan et al., 2013). For instance, pain associated with breast cancer is mostly perceived at the breast, the axillary region,
arms, shoulders and the fingers (Bredal et al., 2014; Guerreiro Godoy Mde, Pereira de Godoy, Barufi, & de Godoy, 2014). Others are of the view that, the location of pain also serves as a marker in diagnosing specific cancer type. This was suggested after a strong association was made between musculoskeletal pain sites (hip, back and neck) and prostate cancer among patients during their primary care consultations in the United Kingdom (Jordan et al., 2013).

The quality of chronic cancer pain described by patients has contributed to effective assessment of pain and its management (Ripamonti et al., 2012). Nociceptive pain which is caused by continuous somatic or visceral tissue damage are identified with pain descriptors such as aching, throbbing, pressure, cramping, gnawing and sharp. Likewise, neuropathic pain which emanates from damage or dysfunction in the nervous system are described as shooting, sharp, stabbing, tingling, ringing (Ripamonti et al., 2012; Sun, Borneman, Piper, Koczywas, & Ferrell, 2008). However, burning, stinging, scorching, pulling and radiating are used to describe the nature of pain among patients including head and neck cancer patients at various stages of cancer and after radiation therapy (Aziato & Adejumo, 2015; Schaller, Larsson, Lindblad, & Liedberg, 2015). Furthermore, the most selected words to describe the quality of pain among a group of young and old patients with advanced cancers are aching, tiring-exhausting, sharp, and dull (Gauthier et al., 2014). Interestingly, the quality of chronic pain that cancer patients experience has significant cognitive, affective and physical impacts that require effective assessment for its management (Klepping, 2012; Ngamkham et al., 2011). Unfortunately, some advanced cancer patients are unable to describe the quality of the pain they experience (Bender et al., 2008; Klepping, 2012). They are either ignorant about the pain descriptors or they do not understand their individual meaning. They may therefore be doubtful if they are communicating their pain in the right context to their caregivers. In
such situations they describe their pain using analogies (Bender et al., 2008; Rustoen, Gaardsrud, Leegaard, & Wahl, 2009).

The intensity of chronic pain explains the severity of the pain as perceived by patients. Several studies have reported varying degrees (on a scale of 0-10 where 0 indicates no pain and 10 indicates the most severe pain) of chronic pain intensity among cancer patients (Gupta et al., 2015; Iwase et al., 2015; Kahan, 2014; Lowery et al., 2013; Ngamkham et al., 2011; Schaller et al., 2015; van den Beuken-van Everdingen et al., 2007). This variation may be dependent on the type of cancer or the stage of the cancer (Hackett et al., 2016; Matthie & McMillan, 2014; Pina, Sabri, & Lawlor, 2015). Patients with advanced cancers tend to experience intense pain than those with non-advanced/non-metastatic cancers (Alexopoulos et al., 2011; van den Beuken-van Everdingen et al., 2016). However, the intensity of chronic pain among cancer patients is well understood from the patients’ perspective (van den Beuken-van Everdingen et al., 2016; Weingart et al., 2012; Zhu & Weingart, 2012). A survey among breast cancer survivors two to six years after surgical and adjuvant therapy in Norway suggested almost half of the participants had persistent pain with varying degrees of intensity. Mild, moderate and severe chronic pain is reported among 51%, 41% and 8% of the participants respectively (Bredal et al., 2014). Though the above study was limited to breast cancer survivors, the intensity of chronic pain varied among patients several years after treatment. Others in communicating the intensity of their pain frequently use descriptors such as agonizing, tugging and soreness to portray the unbearable nature of the pain being experienced (Ferreira, Guirro, Dibai-Filho, Ferreira, & de Almeida, 2015). However cancer patients are reported to use the Numeric Rating Scale (NRS) in describing the intensity of their pain appropriately than the Verbal Rating Scale (VRS) (Brunelli et al., 2010). More importantly, the intensity of pain experienced by patients determines the urgency in
initiating interventions as well as the class of analgesics used by clinicians (Sullivan & Ballantyne, 2016; Zhu & Weingart, 2012).

The intensity of pain among cancer patient may influence their daily activities and consequently their entire quality of life. Pain in its severe form experienced by cancer patients negatively affects the patient’s ability to perform activities including activities of daily living (Alexopoulos et al., 2011; Davies et al., 2013; McPherson, Hadjistavropoulos, Devereaux, & Lobchuk, 2014; Utne et al., 2009). Time variations in pain intensity have also been documented among patients experiencing pain though this pain was not limited to patient with cancer. The intensity of pain is known to be mostly severe during the night (Aziato & Adejumo, 2015; Aziato, Ohene, Norman, & Antwi, 2016). Other factors such as the activity level (Brown, Constance, Bedard, & Purden, 2013; Guerreiro Godoy Mde et al., 2014; Larsson, Ekvall Hansson, Sundquist, & Jakobsson, 2016), sociocultural background (Petkova et al., 2010; Pillay, Zyl, & Blackbeard, 2014), weather (Guerreiro Godoy Mde et al., 2014; Lowery et al., 2013) and economic status (Pillay et al., 2014) are believed to influence the intensity of pain experienced by cancer patients. The intensity of pain among cancer patients is reported to be aggravated by activities such as overextending, walking, climbing stairs, excretion, standing and other factors such as the weather and stress (Andersson et al., 2017; Brown et al., 2013; Guerreiro Godoy Mde et al., 2014; Lowery et al., 2013). Contrary to this view, other studies suggest that, the engagement in activities such as changing positions, active range of motion exercises, muscle stretching among others reduce the intensity of pain experienced by patients (Jebakani, Sethu, Pahinian, Tipandjan, & Devi, 2015; McPherson et al., 2014).

2.3.2 The cognitive dimension of chronic pain experience

The knowledge/cognitive levels on pain, attitude and beliefs regarding pain, meaning that patients derive from pain, their coping styles when in pain, and the influence
of pain on their thought processes constitutes the cognitive dimension of pain experience (Ahles & Martin, 1992; Petkova et al., 2010; Tavoli et al., 2008).

One’s knowledge, belief and attitude about cancer pain and its management may significantly influence his/her experience with the pain (Geneen et al., 2015; Park, Park, & Park, 2015). Patients’ level of educational attainment significantly affects their knowledge about the pain they are experiencing and its management. Higher educational level is reported to be associated with increased knowledge on chronic pain and its management whereas lower educational level or lack of formal education is associated with inadequate knowledge on chronic pain and its management (Baker, O'Connor, & Krok, 2014; Luckett et al., 2013; Turner et al., 2017). Additionally, patients who are given prior education or counselling on their disease process and pain and trust their physicians are likely to be knowledgeable on their pain and are able to cope or manage their pain better than those without prior education or counselling on pain (Baker et al., 2014; Geneen et al., 2015; Kwon, 2014; Luckett et al., 2013; Yu et al., 2016). Baker et al. (2014), in their study further suggested that, patients’ self-efficacy for pain management, pain interference and the severity of the pain are indicators of the pain experience. Eventually, they concluded that, beliefs and misconceptions about cancer related pain can be modified through education.

The beliefs, attitudes and the knowledge about pain among patients may be interrelated and may influence the experience of pain (Shen, Redd, Winkel, & Badr, 2014). An individuals’ belief about pain is to a large extent influenced by his/her knowledge gained on the pain and eventually affects his/her attitude towards the pain (Shen et al., 2014). Patients’ beliefs about their pain such as the permanence of the pain, its consistency and the cause: self-blame and the mysteriousness of the pain contribute to the pain experience (Babadag, Alparslan, & Gulec, 2015; Tavoli et al., 2008). For
instance, patients who have higher belief about the permanence of their pain present with higher levels of depression (Tavoli et al., 2008). Moreover, the patient’s beliefs about the pain may also influence the management of the pain and consequently his/her adherence to the management course (Babadag et al., 2015; Bostick, Carroll, Brown, Harley, & Gross, 2013; McPherson et al., 2014). Patients who are of the belief that their pain is caused by a disease part of their body or an injury are likely to poorly cope with the pain and feel helpless; they are more likely to use more opioids to control their pain. On the other hand, patients who perceive their pain to stem from non-organic sources or from psychological sources actively get involved with their pain management (Babadag et al., 2015). Patients’ beliefs about analgesic use as well as other pain interventions may also influence the experience of pain among cancer patients. A study among colorectal cancer patients suggest cancer patients who are of the belief that pain killers/analgesics can be addictive endure their pain and reserve the pain killers for worse pain situation and they are also less likely to complain of their pain (Brown et al., 2013). Though this study is limited to only colorectal cancer patients, it suggests the importance of adequate assessment of patients’ beliefs about their pain in enhancing treatment adherence. Invariably, pain attitudes significantly influence the pain behaviours exhibited by the cancer patient. Pain attitudes measured with the brief version of the Survey of attitude including solicitude, emotions, disability, cure and medication were positively associated with pain behaviours in the experience of cancer pain (Bostick et al., 2013; Shen et al., 2014).

The experience of pain may have several meanings among cancer patients. While there seem to be no studies on the meaning of pain experience in advanced cancer patients in the Ghanaian context, the severity and persistence of cancer related pain among advanced cancer patients is recognized as the worsening or the progression of their cancerous state. A change in the severity of the pain or the location of the pain implies a
metastatic spread of the disease to other parts of the body. Consequently, it signifies to the patient the emergence of death (Gibbins et al., 2014; Hackett et al., 2016). Several other studies seeking the meanings that patients attach to their pain have alluded to the above findings (Bender et al., 2008; Coyle, 2004; Flemming, 2010; Gibbins et al., 2014; Kwok & Bhuvanakrishna, 2014; McPherson et al., 2014). Additionally, others acknowledge the experience of pain as an interruption/limitation to their therapy (chemotherapy). They therefore refuse to accept its existence and complain to their caregivers. Such patients believe this will permit them to continue with their chemotherapy which will eventually prolong their lives (Gauthier et al., 2009).

The meanings patients draw from their pain experience influence their acceptance of the pain and subsequent management (Gauthier et al., 2009; Hackett et al., 2016). Patients who perceive their pain to be one that cannot be completely eliminated but can be controlled tend to accept their pain (McPherson et al., 2014). However, patients’ acceptance of pain is also related to their psychological wellbeing and plays an important role in coping with the pain. Those who are psychologically healthy; free from depression and anxiety may accept the pain and employ positive coping strategies (Gauthier et al., 2009).

The presence of pain influences a patient’s ability to make meaningful judgement and perform certain vital roles in life which eventually impact negatively on his/her pain experience (Calati, Laglaoui Bakhiyi, Artero, Ilgen, & Courtet, 2015; Stubbs, 2016; Torresan et al., 2015). Pain among cancer patients impaire their concentration in all spheres. Consequently, they may not be able to contribute meaningfully to the course of events and their own care which may negatively affect their quality of life (Nuhu, Odejide, Adebayo, & Yusuf, 2009). The presence and persistence of cancer pain also create thoughts, images, beliefs and convictions that impede reasoning and affect all aspects of a
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patient’s quality of life (Torresan et al., 2015). Moreso, patients who experience physical pain in its severe form without relief are reported to be preoccupied with either a life time or current death wish, suicidal ideations, suicidal wish or suicidal plans (Calati et al., 2015; Ohnsorge, Gudat, & Rehmann-Sutter, 2014; Stubbs, 2016). Others have been able to exhibit these thoughts behaviourally in the form of suicide attempts and eventually death (Calati et al., 2015; Stubbs, 2016).

2.3.3 Behavioural dimension of pain experience

Patients experiencing pain in the course of their disease may exhibit observable behaviours. These behaviours may help in communicating the pain being experienced or conceal it. Additionally, how this pain is communicated to the clinician or significant others and the symptoms associated with the pain such as sleep disturbance and fatigue elucidate the behavioural dimension of pain experience (Ahles et al., 1983; Silkman, 2008).

Patients in pain exhibit varied behaviours (Aziato & Adejumo, 2015; Chen et al., 2011; Leung & Chung, 2008; Puntillo et al., 2004; Romano et al., 2016; Roulin & Ramelet, 2014). Puntillo and colleagues (2004) in a multinational study explored specific pain behaviours engaged by critically ill patients following procedures such as turning in bed, setting central venous catheter, removal of wound drain, wound dressing, tracheal suctioning, and femoral sheath removal. Findings of the study suggest patients who had procedural pain presented more pain related behaviours as compared to their counterpart who did not experience procedural pain. Additionally, grimacing, wincing, rigidity; clenching of fists, closing of eyes, verbalization and moaning are the most frequent behaviours exhibited by patients experiencing pain (Puntillo et al., 2004). While this study may seem to be limited to the western setting and its applicability in Africa for that matter Ghana may be questioned due to ethnic and cultural disparities, Aziato and Adejumo
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(2015) identified crying, shouting grimacing and groaning as pain behaviours among patients experiencing pain post operatively in Ghana. Several other studies have alluded to these pain related behaviours among patients (Chen et al., 2011; Franck, Noble, & Liossi, 2010; Jacobson et al., 2015; Rahu et al., 2013; Romano et al., 2016; Roulin & Ramelet, 2014). Similarly, cancer patients experiencing pain exhibit such behaviours including whimpering, holding/rubbing the affected part or massaging and taking analgesics (McPherson et al., 2014). Pain behaviours are reported to be prominent among patients who experience high intensity of pain and low attitude towards cure for the pain (Shen et al., 2014).

Essentially, these behaviours help to communicate the intensity (Rogers & Todd, 2010; Romano et al., 2016; Shen et al., 2014), location (Roulin & Ramelet, 2014), frequency and in some cases the quality (Rowbotham, Holler, Lloyd, & Wearden, 2014) of the pain to significant individuals or their health professionals for effective management (McPherson et al., 2014). Similarly, while pain behaviours complement the understanding of pain experience among patients who can communicate their pain verbally; they turn to serve as the only means in majority of patients who are unable to communicate their pain verbally. This category of patients may include critically ill patients, patients utilizing artificial ventilators, patient under anaesthesia among others (Chen et al., 2011; Gélinas, 2016; Gélinas, Harel, Fillion, Puntillo, & Johnston, 2009; Payen et al., 2007). In assessing pain among such patients, pain behaviours such as facial expression, movement of upper limbs or muscle tone and compliance with ventilation/procedure have been suggested by researchers to prompt clinicians and significant others about the experience of pain (Chen et al., 2011; Gélinas, 2016; Gélinas et al., 2009; Payen et al., 2007). Furthermore these behaviours assist the patient to cope with the pain as well as the disease trajectory (Deroche, Woodman, Stephan, Brewer, & Le Scanff, 2011).
Consequently, pain related behaviours coupled with the coping strategies may influence the patient’s adherence to the treatment regimen, functional ability as well as quality of life (Deroche et al., 2011; Romano et al., 2016). For instance, the use of opioid analgesics at home among cancer patients experiencing pain is associated with patients who frequently report their pain and analgesic-taking to their clinicians and adjusting their medication regimen when there are changes in their pain pattern. Other behaviours include adhering to the prescribed regimen; soliciting for help and managing concerns with regard to the treatment (Liang, 2008). Moreover, these behaviours may be necessitated in situations where self-efficacy beliefs are likely to change or when there is an impediment in the performance of a particular behaviour (Liang, 2008).

Verbal communication of pain is a two-way affair between the patient and the clinician or between the patient and significant others including family caregivers (McPherson et al., 2014). Effective communication of pain is in no doubt a significant element in effective pain management (Baker et al., 2016; Larsson & Wijk, 2007; Rana et al., 2011). It is enhanced by a trusting relationship between the patient and his/her caregiver or clinician (Larsson & Wijk, 2007). More often, cancer patients are ready and willing to discuss their pain with their caregivers/clinicians if it is of concern to them or if it becomes unbearable (Aziato & Adejumo, 2015; Haskard-Zolnierek, 2012; McPherson et al., 2014; Rogers & Todd, 2010). They do so by initiating the discussion on the pain, use reemphasizing words and employ several tactics to keep their clinicians’ attention on the distressing nature of their pain for a relief (Haskard-Zolnierek, 2012; Rogers & Todd, 2010). Others are more willing to communicate their pain if they are with individuals they trust could offer the necessary support (Collins, de Vogel-Voogt, Visser, & van der Heide, 2008). This may probably be in terms of clinical expertise or knowledge, encouragement and financial assistance.
On the contrary, some cancer patient may be reluctant to report their pain for various reasons (Carr, 2007; Champman, 2012; Christo & Mazloomdoost, 2008; Rustoen et al., 2009). They employ strategies to minimize their pain even when discussions on pain are initiated by their caregivers/clinicians (Rogers & Todd, 2010). While some patients think clinicians are expert to detect their pain and do not want to distract them from their disease condition, others maintain communicating their pain may require the intake of pain medications which will eventually mask any clue relating to the progression of their cancer (Carr, 2007; Champman, 2012; Christo & Mazloomdoost, 2008; Rustoen et al., 2009). The latter is perceived to delay the consultation for review by patients (Carr, 2007).

In contrast to Car’s view on why patients feel reluctant to communicate their pain, Rogers and Todd (2010) hold the view that cancer patients want to mask any clue relating to the progression of their cancer; as pain is perceived to indicate a progression of the disease (Gibbins et al., 2014; Hackett et al., 2016). Additionally, the side effects associated with pain medication and the cultural and ethnic dispensations of the patient also influence the communication of pain (Carr, 2007; Champman, 2012; Christo & Mazloomdoost, 2008; Rustoen et al., 2009).

Other reason why cancer patients prefer to either reveal or conceal their pain are explored in the work of Larsson & Wijk (2007) who sought to understand the pain experience among terminally ill cancer patients. Three terminally ill cancer patients who were being managed on intra-theca pain medications at a pain unit in Sweden were recruited for the study. Data gathered from the patients during unstructured interviews were analysed. The study revealed that, cancer patients employed various strategies to communicate or conceal their pain. According to the researchers, cancer patients freely communicate their pain when they realize there are avenues to relieve their pain. Consequently, patients who trust clinicians for the relief of their pain report their pain.
However, patients conceal their pain when they are with significant others such as close relations because of the cause and consequences which eventually will hurt them too (Larsson & Wijk, 2007). Notwithstanding the appropriateness of the design for the study, the small sample size may not elicit more diverging views on cancer pain experience. Furthermore, these views may not reflect the views of Ghanaians due to ethnic and cultural disparities.

The experience of pain and sleep disturbances are related in a reciprocal and bidirectional manner. An increase in pain intensity interrupts the sleep pattern of the individual experiencing the pain. Similarly, a disturbed sleep/poor sleep intensifies the experience of pain (Brennan & Lieberman, 2009; Doghramji, 2012; Lavigne, Nashed, Manzini, & Carra, 2011; Wright et al., 2009). The influence of pain on sleep quality of patients is enormous (Hong, Kim, Shin, & Huh, 2014). Cancer patients who experience pain are known to have interruption in their quality of sleep. They experience poor quality of sleep which is continuous and gets poorer over a period of time (Furlani & Ceolim, 2006; Krause & Stanford, 2011; Mercadante et al., 2015). However, Mercadante and colleagues in their work reported that, cancer patients with mild pain intensity are less likely to experience sleep disturbances (Mercadante et al., 2015).

In spite of the fact that pain (Eccleston et al., 2013; Mirabile et al., 2015) and fatigue (Xiao et al., 2016) are described as symptoms among cancer patients, there is no reservation about their relatedness. An increase in the intensity of pain among cancer patients significantly results in a corresponding increase in the intensity of fatigue expressed by the patient (Cheng & Lee, 2011; Yennurajalingam et al., 2012). In a retrospective study comparing the characteristics of two groups of advanced cancer patients with fatigue, Yennurajalingam and colleagues sampled 337 patients in cancer-related fatigue control trial and 1252 outpatient palliative care patients all in a cancer...
centre in Texas for the study. Pain was seen as one of the major predictors of the intensity of fatigue expressed among outpatient palliative cancer patients as compared to the patients in the cancer-related fatigue control trials (Yennurajalingam et al., 2013). While the unequal group size in the study may be perceived to account for the disparities in the findings; other studies alluded to the findings of Yennurajalingam and colleagues (Cheng & Lee, 2011; Yennurajalingam et al., 2012).

2.3.4 The affective dimension of chronic pain experience

The emotional responses: mood, fear, anxiety, depression and suffering in the presence of pain constitutes the affective dimension of pain experience (Petkova et al., 2010; Silkman, 2008). The experience of pain is associated with emotional feelings such as anxiety, depression (Davies, 2013; Delgado-Guay et al., 2011; Dunham et al., 2013; Edrington et al., 2010; Honerlaw, Rumble, Rose, Coe, & Costanzo, 2016; Hong et al., 2014; Kanatas, Ghazali, Lowe, & Rogers, 2012; Krause & Stanford; Kyranou et al., 2013; Laird et al., 2011; Miaskowski et al., 2012; Miaskowski et al., 2014; Petkova et al., 2010; Williams, Pasco, Jacka, Dodd, & Berk, 2012), fear (Dunham et al., 2013) and suffering (Schaller et al., 2015). Patients who experience pain coupled with its persistence suffer mood/emotional symptoms such as anxiety and depression (Davies, 2013; Delgado-Guay et al., 2011; Dunham et al., 2013; Edrington et al., 2010; Honerlaw, Rumble, Rose, Coe, & Costanzo, 2016; Hong et al., 2014; Petkova et al., 2010). Contrary to this view, some authors assert anxiety and depression rather causes pain among patients (Honerlaw et al., 2016; Williams et al., 2012). Comparatively, others are of the view that anxiety has an independent effect on the burden of pain among cancer patients whereas depression does not (Belfer et al., 2013).

Even though, anxiety and depression are common psychosocial issues during the cancer disease trajectory (Cheng & Lee, 2011; Cvetkovic & Nenadovic, 2016; Kyranou et al., 2013; Tang et al., 2014), the influence of pain on anxiety and depression remain
undisputable among cancer patients who experience chronic pain (Delgado-Guay et al., 2011; Hong et al., 2014; Kyranou et al., 2013; Laird et al., 2011; Miaskowski et al., 2012; Miaskowski et al., 2014; Petkova et al., 2010). Similarly, patients who are free from cancer after treatment but experiencing persistent pain from the side effects of their treatment also experience anxiety and depression (Lowery et al., 2013). Generally, anxiety and depression among cancer patients who experience pain are much higher than in cancer patients without pain (Bredal, Smey, Ottesen, Warncke, & Schlichting, 2014; Tavoli et al., 2008). However, others argue cancer patients with persistent pain are not significantly more anxious and depressed than those without pain (Sheridan et al., 2012).

While there seem to be paucity of knowledge on the relationship between pain, anxiety and depression among cancer patients in Ghana, cancer patients in the United State of America (Miaskowski et al., 2012; Miaskowski et al., 2014) and Bulgaria (Petkova et al., 2010) who experience chronic pain consequently experience anxiety and depression. Coupling the presence of pain with its severity, Miaskowski and colleagues suggested chronic pain in its moderate and severe forms among cancer patients translate into high levels of depression and anxiety (Miaskowski et al., 2012; Miaskowski et al., 2014). However, their studies focused on only breast cancer patients and cancer patients without distant metastasis. Their findings therefore may not be generalizable to all cancer patients including those with distant metastasis/advanced cancers.

Consequently, the presence of anxiety and depression among patients with persistent pain negatively affect their functional status and overall quality of life (Cheng & Lee, 2011; Hong et al., 2014; Miaskowski et al., 2012; Miaskowski et al., 2014; Petkova et al., 2010). Anxiety and depression result in patients’ inability to perform certain crucial activities in life which result in overall decrease in quality of life (Cheng & Lee, 2011; Miaskowski et al., 2012; Miaskowski et al., 2014).
Due to the devastating nature of chronic pain to patients, it is most likely to cause considerable level of fear among them (Crombez, Viane, Eccleston, Devulder, & Goubert, 2012; Dunham et al., 2013; Jain et al., 2015; Nilmanat et al., 2010). The presence of cancer related pain and its persistence have been noted to create significant fear among patients (Dunham et al., 2013). According to Dunham et al. (2013), this fear is not only related to the pain the cancer patient is experiencing but extends to include fear of the side effects associated with the analgesics used to control the pain (Dunham et al., 2013). Several other studies have alluded to the views of Dunham and colleagues (King, Forbes, Hanks, Ferro, & Chambers, 2011; Krause & Stanford, 2011). Additionally, fear among cancer patients with pain is created in the recognition that their pain is a sign of their disease progression (Dunham et al., 2013). However, patients experiencing non cancer specific pain are also noted to present enormous fear coupled with negative emotions (Crombez et al., 2012).

2.3.5 The sociocultural dimension of chronic pain experience

The experience of pain is influenced by the culture and belief system of the patient as well as his/her interactions with significant others and the environment (Dunham et al., 2013; Khan et al., 2015). Variations in the cultural and belief system, ethnicity, gender and age among patients experiencing pain, and their location may influence their pain perception, communication and management (Ham, Chee, & Im, 2016; Im et al., 2008; Kwok & Bhuvanakrishna, 2014; Pillay et al., 2014). While some patients freely express their pain, others remain stoical (Pillay et al., 2014). For instance, cancer patients of Asian descent are known to record higher scores on drug tolerance and fatalism as perceived barriers to pain management as compared to their counterpart of the western descent. Consequently, patients who perceive higher barriers to pain management underutilize
analgesics and this eventually result in under treatment of their pain (Kwok & Bhuvanakrishna, 2014).

Similarly, Hispanics, blacks and Spanish-speaking Latina cancer patients are reported to have higher prevalence of pain as compared to their white counterparts (Chen, Tang, & Chen, 2012; Kwok & Bhuvanakrishna, 2014). Im and the colleagues (2008) in a qualitative study comparing four different ethnic groups (whites, Hispanic, African-Americans and Asians) on their cancer pain experiences in United States (US) alluded to the findings above. Coupled with the above, the whites race exhibit enormous control over their pain and treatment selection process (western medicine). They protest against clinicians who ignore their pain and its management and do not hesitate to change them for others who are ready to focus on the management of their pain (Im et al., 2008). In contrast, other minority ethnic groups associate their pain with progression of their cancer which is perceived to be unworthy discussing. Consequently, they are reluctant to report their pain (Im et al., 2008). This presumably explains their dependence on their religious faith for comfort (Dunn et al., 2015; Im et al., 2008; Kwok & Bhuvanakrishna, 2014). Although gender differences were also noted in the experience of pain among the patients in the study by Im et al. (2009), there were no significant ethnic disparities. Women were reported to tolerate pain more than men but were not given the needed attention for their pain management as compared to their male counterpart.

Notwithstanding the individual role patients play in the perception and management of their pain, the supporting networks available for such patients indisputably influence their effort in managing the pain and their overall quality of life (Paterson, Robertson, & Nabi, 2015; Sjolander & Ahlstrom, 2012; Torres, Dixon, & Richman, 2016; Yamaguchi, Cohen, & Uza, 2016). These support networks available for the patients may be from the patient’s family members/relatives, friends, the church, co-workers and other
significant people most of whom are essentially related to the patient (Craft, Patchell, Friedman, Stephens, & Dwyer, 2016; Doku, Dotse, & Mensah, 2015; Torres et al., 2016; Yamaguchi et al., 2016). These supporting networks provide emotional, spiritual and physical support for the patient and may positively enhance their management (Craft et al., 2016; Im et al., 2009; Sjolander & Ahlstrom, 2012; Torres et al., 2016). In some cultures, the support offered to patients by close relations are regarded as expected responsibilities on the part of the supporting individuals in paying back to patients what they have previously gained from them. In this situation, the patients and those supporting them form a team geared towards the management of the patients’ condition as well as the distressing symptoms associated with it such as pain (Aziato, Ohene, Norman, et al., 2016; Im et al., 2009; Yamaguchi et al., 2016). However, there have been reported situations where patients including cancer patients are unable to gain the necessary support from these networks (Reavley, Pallant, & Sali, 2009); as a result, they are likely to experience much severe pain (Astrup, Rustoen, Miaskowski, Paul, & Bjordal, 2015).

The form of upbringing, religious beliefs and practices of an individual is also reported to influence the experience of pain among patients (Aziato & Adejumo, 2015; Ellis et al., 2015; Finney et al., 2015; Pillay et al., 2014). Individuals who had strict or harsh upbringing tolerate pain and are more stoical than those without strict upbringing (Aziato & Adejumo, 2015; Pillay et al., 2014). Similarly, the religious beliefs and practices significantly influence the perception of pain, management and the overall quality of life of the patient (Babadag et al., 2015; Ellis et al., 2015; Finney et al., 2015). Patients who are of strong religious beliefs perceive their pain as part of their religious struggle; they engage in several practices including prayers with heightened hopes for relief and comfort which consequently minimise their pain (Buck & Meghani, 2012; Finney et al., 2015; Shilling & Mellor, 2010).
While there seem to be paucity of literature on pain experience in the Ghanaian context especially regarding cancer related pain, the subjectivity of pain perception is still maintained among Ghanaians. The perception of pain is influenced by the patients’ previous pain experience, attitude of clinicians in the management of the pain and the decision made regarding pain prior to treatment such as surgery (Aziato & Adejumo, 2015). Other factors include the society as well as the cultural background of the patient (Aziato & Adejumo, 2015) as suggested in other studies elsewhere (Im et al., 2008; Kwok & Bhuvanakrishna, 2014; Pillay et al., 2014). The society/setting and the cultural background play an important role in pain perception and management. Patients from the northern part of Ghana are believed to tolerate pain more than those from the south. Invariably, the societal beliefs about pain affect the patient’s perception and management of pain. For instance, patients who were cautioned by their relatives that pain intensity increases when they talk about it rarely reported their pain. More so, pain after surgery may be regarded as a normal phenomenon and patients do all they can to cope with it (Aziato & Adejumo, 2015).

2.3.6 Pain coping strategies

Patients including those with cancer experiencing pain employ several mechanisms/strategies to tolerate, deal with and minimize the pain (Im et al., 2009). According to Bender and colleagues (2008), because cancer patients experiencing pain do not want their pain to disrupt their lives and enjoyment, they are ready to learn and subsequently employ various interventions to cope with their pain. As a result, they are likely to employment strategies that make them feel less victimized. Patients experiencing cancer related pain tend to employ various strategies including cognitive and/or behavioural strategies to cope with their pain (Dunn et al., 2015; Khalili, Farajzadegan, Mokarian, & Bahrami, 2013; Meints, Miller, & Hirsh, 2016; Somers et al., 2015).
Cognitive coping strategies may include catastrophizing, distraction, hoping/praying, ignoring pain, wishful thinking, reinterpreting pain and calming self-statements. Behavioural coping strategies on the other hand include asking for assistance, depending on others, exercise and stretching, guarding, increasing behavioural activity, reducing demands and seeking support. Other interventions under the behavioural coping strategies are task persistence, using medications, restricting functions and self-care (Jacobson et al., 2015; McPherson et al., 2014; Meints et al., 2016).

The type of coping strategies employed by patients experiencing pain may be due to several factors including their ethnicity or cultural orientation (Meints et al., 2016); meaning attached to the pain and its acceptance (McPherson et al., 2014) and intensity of pain (Utne et al., 2009). A meta-analysis involving the black and white races suggested significant differences in pain related coping strategies among blacks and whites in America (Meints et al., 2016). Meints and colleagues selected 19 studies for their work with eligibility criteria including patient self-reported pain coping strategies, comparative study between black and the white race, study involving adults above 18 years and studies with calculated effect sizes. Coping in this study was measured using various pain coping scales including Stone and Neale Daily Coping Inventory adapted for pain, Pain Catastrophizing Scale (PCS), Vanderbilt Multidimensional Pain Coping Inventory, Emotional Approach Coping Scale or Profile of Chronic Pain. Although this study was not specific to cancer patients, participants were engaged in pain coping strategies such as hope and prayer, catastrophizing, diverting attention, reinterpreting pain sensations, task persistence, ignoring pain sensation, exercising and stretching, relaxation, seeking social support, increasing behavioural activities and guarding. The authors suggested that, blacks employed more pain related strategies than whites. Blacks were frequently engaged in
hoping and praying, catastrophizing and diverting attention strategies whereas the whites frequently employed only task persistence to cope with their pain (Meints et al., 2016).

Similarly, several studies among cancer population most of whom were advanced cancer and experiencing chronic pain reported variety of coping strategies employed by the patients during their pain experience. These include cognitive coping strategies such as: positive self-statements, distraction, pleasant imagery, repressing/enduring and hoping/faith in God (Booker, 2016; Guerreiro Godoy Mde et al., 2014; Paterson et al., 2015; Syrjala et al., 2014). Others employed behavioural coping strategies such as: praying, partaking in religious activities/practices, catastrophizing, sharing their thoughts and feelings with friends, isolating themselves, resting/relaxation, engaging in social support activities, taking pain medications and avoiding movement (Booker, 2016; Guerreiro Godoy Mde et al., 2014; Paterson et al., 2015; Syrjala et al., 2014). In spite of these, some advance cancer patients are engaged in self-care efficacy skills such as avoiding irritant drinks and taking copious fluids together with some of the afore stated strategies which they perceive to be beneficial in improving their quality of life (Paterson et al., 2015).

Usually, patients who engage in positive/adaptive coping interventions are reported to have a reduction in their pain intensity and an improved quality of life (Khalili et al., 2013; Prasertsri, Holden, Keefe, & Wilkie, 2011; Price et al., 2013; Torresan et al., 2015). On the contrary, those who employ maladaptive coping strategies are likely to experience poor quality of life including depression (Prasertsri et al., 2011). For instance, some cancer patients experiencing pain avoid friends and other people to deal with their pain while others widen their acquaintance to positively cope with their pain (McPherson et al., 2014; Torresan et al., 2015). This may consequently influence their interpersonal relationship with significant others in the society.
2.3.7 Pain management

Effective pain management among patients is considered crucial due to its multifaceted effect on patients’ functional level and overall quality of life (Rustoen, Geerling, Pappa, Rundstrom, Weisse, Williams, Zavratnik, & Wengstrom, 2013). Hence, caregivers are expected to make use of all available avenues to ensure each and every individual is free from pain as it is their fundamental human right (Brennan et al., 2007; WHO, 2004). Chronic pain management among cancer patients is a multimodal and multidisciplinary approach requiring the input of all team members within the healthcare arena for its effective management (Binczak et al., 2014; Schellack & Annor, 2016). Evidence suggests a combination of both pharmacological and non-pharmacological approaches enhance effective pain management among patients and improves their quality of life (Aziato, Ohene, Norman, et al., 2016; Binczak et al., 2014; Champman, 2012).

Various pharmacological agents are available for managing chronic pain among patients including advanced cancer patients. In recognising the distressing nature of chronic pain in cancer patients, the World Health Organisation’s ‘analgesic ladder’ for managing pain was adopted (World Health Organization, 1986) and has been the mainstay of pain management in combination with non-pharmacological interventions (Champman, 2012; Schellack & Annor, 2016). The WHO ‘analgesic ladder’ comprise of non-opioids analgesics, weak opioids, strong opioids and adjuvants which are used either as single medication or in combination to achieve a synergistic analgesia (World Health Organization, 1986). However, there is an increasing need to move away from purely medical driven pain management to patient centred, multidisciplinary and complementary pain management. This approach actively involves patients, the use of pharmacological and non-pharmacological interventions for effective pain management (Gonella, Garrino, & Dimonte, 2014; Muthuuri, 2012; Vargas-Schaffer & Cogan, 2014). The non-
pharmacological interventions patients undertake include: physiotherapy, occupational therapy, acupuncture, transcutaneous electrical nerve stimulation, massage, cognitive-behavioural therapy, diet and exercise (Aziato, Ohene, Norman, et al., 2016; Muthuuri, 2012; Shah, Nan, Hui, Islahudin, & Hatah, 2017; van Tonder, Herselman, & Visser, 2009; Vargas-Schaffer & Cogan, 2014).

The utilization and adherence to these interventions by patients may be motivated by several factors. For instance, in a systematic review to explore the perception of acute, persistent and disease specific pain and treatment options among African Americans, Booker, (2016) identified that: African Americans utilised various interventions including medication and complementary, alternative and folk medicine as well as surgery for their pain management. Some of the participants in the study were reluctant to take the analgesics as prescribed. They took lesser doses and reduced the frequency of taking them for fear of addiction, side effects and over reliance. Others took their medication strictly per their prescriptions and were more likely to use over the counter drugs, non-prescribed drugs and medicated creams. Other factors identified to be associated with analgesic intake were clinicians’ reluctant to prescribe opioid analgesics, cost of medication and its availability. Furthermore, Booker revealed common among the complementary, alternative and folk medicine approach used among African Americans were prayer, faith in God, religion, herbal remedies. Additionally, African Americans were reluctant to undergo surgery for treatment of their pain and those who perceived prayer to be helpful with their pain were much reluctant to undergo surgery (Booker, 2016).

While the above findings seem not to be representative of cancer patients with regard to factors informing their preferred interventions due to its’ non-limiting sample in terms of disease condition; other studies revealed that, the efficacy of the drug, cost and side effect of the drug may account for drug preference/adherence among cancer patients.
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(Good et al., 2014; Naveh, Leshem, Dror, & Musgrave, 2011). Similarly, Broom, (2009) identified that: the need for control, having a sense of autonomy and power over the disease and treatment process and seeking inner peace and/or relaxation to be key motivating factors for cancer patients using variety of complementary and alternative medicine.

In spite of the orthodox/conventional interventions for pain and cancer management, some patients still perceive the efficacy of traditional herbal medicine. They complement the orthodox interventions with these herbal product or use the herbal products alone in the form of mixtures to be taken orally or applied topically (Lee et al., 2015; Okello, Nyunja, Netondo, & Onyango, 2010; Sait et al., 2014; Seraj et al., 2012). For instance, in a systematic review of randomised control trial on traditional herbal medicine in cancer pain management, Lee and colleagues revealed that, the number of patients with cancer pain decreased significantly in the treatment group. There was also a significant reduction in the intensity of pain among the patients in the treatment group. Finally, Lee and colleagues concluded that, traditional herbal medicine is efficacious when used as an adjuvant therapy as compared to using only western medicine (Lee et al., 2015).

Similarly, the importance of spirituality as an intervention for pain and cancer among cancer patients have been widely documented (Buck & Meghani, 2012; Craft et al., 2016). Cancer patients are known to engage in prayers, faith in God and other spiritual practices primarily to achieve inner peace and comfort as well as to be connected to the spiritual world. Consequentially, these distract patients’ focus on the pain and enhance their pain experience (Broom, 2009; Buck & Meghani, 2012; Craft et al., 2016). Others utilise this intervention based on recommendations from family or friends with much consideration of the existing cultural and belief system as they perceive it to be effective in
achieving healing (Craft et al., 2016). Essentially, health professionals must take keen interest in understanding these factors influencing their clients’ preferences in order to select the most appropriate interventions for an improved adherence and effective pain management (Vargas-Schaffer & Cogan, 2014).

The economic repercussions of chronic pain on patients has been posited by several studies (Ekortarl et al., 2007; Gueye et al., 2017; Ham et al., 2016; Martinez, Snyder, Malin, & Dy, 2014; Mwaka et al., 2016; Park et al., 2015). Cancer patients are reported to unduly delay with the presentation of their cancer including its distressing symptoms to the health facility as a result of financial constraint (Ekortarl et al., 2007; Gueye et al., 2017; Mwaka et al., 2016). Others seek treatment from traditional/herbal practitioners due to financial difficulties which further delay their cancer treatment and worsen their pain (Park et al., 2015). However, patients who experience severe chronic pain are mostly not economically productive due to the negative impact of their pain and this affects their quality of life (Rustoen, Geerling, Pappa, Rundstrom, Weisse, Williams, Zavratnik, & Wengstrom, 2013). Consequently, patients experiencing severe chronic pain are reported to battle with several financial challenges. They are unable to meet up with the high cost of treatment for their disease as well as the pain; and they tend to experience worsened pain intensity as well as low quality of life (Aziato & Adejumo, 2015; Ham et al., 2016; Martinez et al., 2014; Nuhu et al., 2009; Park et al., 2015).

Health professionals of various disciplines including nurses play key role in the management of chronic pain among patients. Their attitude: whether good or bad may have significant influence on the patients’ chronic pain experience (Aziato & Adejumo, 2015; Moceri & Drevdahl, 2014; Rustoen et al., 2009; Schreiber et al., 2014; Tse & Ho, 2014). Cancer patients described good and caring nurse as one who is helpful, empathetic; ready to listen and share information on their pain management with them as well as pre-
empt their pain and offer the most beneficial pain interventions such as analgesics on time to optimise their pain. Additionally, a caring nurse should be: kind, understanding, forthcoming and taking patients’ pain seriously (Rustoen et al., 2009; Torres et al., 2016). These attitudes in addition to courteous relationship between the health professional and the patient are likely to enhance reporting and expression of pain among patients for better understanding and management (Aziato & Adejumo, 2015; Torres et al., 2016). However, negative attitudes of health professionals regarding pain assessment, medication/prescription with more emphasis on opioids, communication and affection/empathy have been noted among health professionals mostly nurses (Aziato & Adejumo, 2014; Aziato & Adejumo, 2015; Moceri & Drevdahl, 2014; Oware-Gyekye, 2008; Schreiber et al., 2014; Torres et al., 2016; Tse & Ho, 2014). These attitudes may prevent pain reporting among patients resulting in inadequate pain assessment, discomfort and under treatment of patients’ pain (Aziato & Adejumo, 2014; Aziato & Adejumo, 2015; Torres et al., 2016).

2.4 Summary of the literature

Literature was reviewed on chronic pain experiences among advanced cancer patients. Both qualitative and quantitative research articles were reviewed. The review focused on sensory, cognitive, behavioural, affective and sociocultural dimensions of chronic pain experiences. Additionally, articles relating to pain coping strategies and management were also reviewed in this study.

The review showed chronic pain among cancer patients were experienced in more than a single location and varied in quality and intensity. A patient’s knowledge, beliefs and attitude about pain being experienced, the meaning associated with the pain as well as the influence of the pain on his/her thought processes affect the pain experiences. Additionally, pain is expressed by patients in various ways and it is accompanied by related symptoms as well as emotions. Patients therefore adopt various measures to cope
and manage their pain. Invariably, the experience of pain poses significant challenges on the patient’s functionality and overall quality of life.

The detailed review above shows that most of the studies were done outside Ghana and only four studies were conducted in Ghana. The studies conducted in the Ghanaian context were focused on post-operative pain, pain and aches among the elderly, dysmenorrhea and labour pains other than chronic pain experiences among advanced cancer patients. Therefore, the use of qualitative approach to study this phenomenon in the Ghanaian context for better understanding and effective management is important.
CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter outlines the methods used for the study. It presents the research design, the setting, target population, sample size and sampling technique. Additionally, this chapter describes the data collection tool and procedure, data management and analysis, how the researcher ensured methodological rigour and ethical considerations of the study.

3.1 Research Design

Research designs are strategies and measures for research that span the decisions from broad assumptions to detailed approaches of data gathering and analysis. They include qualitative, quantitative, and mixed method approaches and provide specific direction for procedures in a research (Creswell, 2009, 2013). A qualitative approach which is exploratory and descriptive in nature was used to explore and describe chronic pain experiences among advanced cancer patients.

Qualitative research is an inductive approach used to gain an in-depth information/knowledge about the phenomenon under study. It aims to get a better and deeper understanding of a phenomenon through first-hand experience, truthful reporting and quotations of actual conversation (Polit, Beck, & Hungler, 2001). Qualitative approach in general does not rely on quantification of its observations during analysis as well as interpretation. Instead, it explores and describes all dimensions of a phenomenon or experience for better understanding (Brockopp & Hastings-Tolsma, 2003; Kornhaber, de Jong, & McLean, 2015). Exploratory research investigates the full nature of phenomena rather than simply observing and explaining the phenomena. It provides an insight into
comprehension of an issue or situation. It is aimed at investigating the full nature of the phenomenon, the manner in which it is manifested and factors with which it is related (Brink & Wood, 1998; Polit & Beck, 2008).

Exploratory-descriptive design is considered appropriate for this research as it sought to investigate and describe in detail chronic pain experiences among advanced cancer patients which is a subjective phenomenon for a better understanding (Brink & Wood, 1998).

3.2 Research Setting

The study was carried out in the Accra metropolis with the out patient’s department of Ridge Hospital serving as the outlet for recruiting the participants for the study. Accra metropolis is one of the sixteen districts of the Greater Accra Region of Ghana and the capital city of both Greater Accra Region and Ghana at large. It covers a land size of about 173 square kilometres with a total population size of about 1,665,086 people (Ghana Statistical Service, 2012). The metropolis is subdivided into 11 sub-metropolitan areas namely: Ablekuma Central; Ablekuma North; Ablekuma South; Ashiedu Keteke; Ayawaso Central; Ayawaso East; Ayawaso West-Wuogon; La, Okaikoi North; Okaikoi South; and Osu Klottey. The housing facilities within the metropolis can be classified into three broad categories: the low income; middle income; and high income areas.

The main indigenes of the metropolis are the Ga with fishing and trading being their primary occupation. However, nearly half of the populations in Accra are migrants with diverse ethnic characteristics and cultures making the city cosmopolitan in nature. Apart from the Ga language, other languages such as Twi, Ewe, Hausa and Adangbe are spoken by people in the Accra metropolis. Ghana’s premier University (University of Ghana) in addition to other state and private owned educational facilities are located in the
metropolis. With regards to health, there are several health facilities in the metropolis including government, quasi-government, mission and private facilities which provide healthcare services.

Ridge Hospital is the Greater Accra regional hospital within Osu Klottey sub-metro of the Accra Metropolis. The facility is a 198 bed capacity hospital and was undergoing expansion project to increase its capacity at the time of the study. The facility is a referral centre and receives referrals from all parts of the region and beyond. The facility provides a range of out-patient services including general out-patient department service, radiology, physiotherapy, ‘cervicare’, emergency recovery/casualty services to its clients including those with cancer. Furthermore, other specialist services such as internal medicine, urology, clinical psychology, obstetrics and gynaecology, surgery, neurosurgery, mammography among others are also offered at the facility to help meet the needs of almost all of its clients. Cancer patients at varied stages of diagnosis also visit the facility and they are managed either surgically or conservatively. Other cancer patients who are referred to other tertiary facilities for radiotherapy or chemotherapy usually return to the facility for management of their cancer/treatment related symptoms including pain. The out-patients department of the Ridge Hospital therefore provides a suitable participants recruitment site for exploring and describing chronic pain experiences among advanced cancer patients in the Accra metropolis.

Accra metropolis was considered appropriate site for the study by the researcher due to its cosmopolitan nature in order to derive understanding of advanced cancer pain experiences from participants of diverse cultural/ethnic background.

3.3 Target Population

The target population for the study were advanced cancer patients experiencing chronic pain and living in the Accra Metropolis.
3.3.1 Inclusion Criteria

The inclusion criteria for the study were patients with: (a) any type of advanced cancer/s, (b) pain exceeding three months, (c) can express themselves in Twi, Ewe (local dialect) or English which are the languages the researcher speaks fluently, (d) those who reside in the Accra metropolis and (e) those willing to take part in the study.

3.3.2 Exclusion Criteria

The following criteria were used to exclude participants from the study: (a) patients below 18 years of age with advanced cancer and are in pain; (b) Those who are too ill to participate; (c) patients who cannot communicate verbally; and (d) those with other comorbidities that impaired their memory such as dementia.

3.4 Sampling technique and Sample size

According to Polit & Beck (2008) the issue of sampling in research is a search for typicality of the population. Purposive sampling technique was employed to select participants for the study. Purposive sampling involves handpicking of the cases to be included in the sample on the basis of the researcher’s judgment of typicality or possession of particular characteristics being sought within the population. In this way, the researcher builds a sample that is satisfactory to his/her specific needs (Rapley, 2014). In this study, the researcher discussed the inclusion criteria with the nursing staff at the recruitment outlet to assist in identifying patients who were within the inclusion criteria. Further discussions on the study were done with the potential participants through the use of the information sheet prepared (See Appendix A) and those who were willing to participate in the study were recruited. Purposive sampling technique was deemed appropriate for this study because, the researcher had the opportunity to recruit participants within the inclusion criteria who were able to narrate their lived experiences of chronic pain. Participants were interviewed one after the other until the thirteenth participant when an
in-depth understanding of the phenomenon under study was gained or when subsequent participants seemed to be giving same responses already given. This alerted the researcher of having reached data saturation and data collection was halted after the thirteenth participant (Bowen, 2008).

3.5 Data Collection Tool and Procedure

The researcher used a semi-structured interview guide (See Appendix B) to conduct in-depth face-to-face interviews with the participants. The interview guide had two sections (section A and B) which guided the data collection process. The section A of the interview guide captured the participants’ demographic data including their: age, sex, place of residence, marital status, number of children, occupation, level of education, type of cancer (diagnosis) and duration of the disease and the pain as well as the type of treatment they were undertaking. The section B of the interview guide was developed based on the constructs of the guiding model: Multidimensional Model of Cancer Pain by Ahles and Martin, (1992) and the objectives of the study. This section of the interview guide consisted of open ended questions which explored the participants’ chronic pain experiences without any limitation. In-depth interview was appropriate as it gave the researcher the opportunity to get detailed understanding of participants’ lived experiences and perceptions regarding the phenomenon under study (Rosenthal, 2016). Additionally, semi-structured interview guide was employed as a data collection tool over structured questionnaire as this gave the researcher the opportunity to explore/probe participant’s experiences relating to chronic pain which were not captured in the interview guide (Ritchie, Lewis, Nicholls, & Ormston, 2013). Data collection was also enhanced by taking field notes. Data which were not verbally articulated such as facial expressions and mannerisms as well as the context under which data were collected were captured in the field notes during the interviews to enrich the meaning of participants’ pain experiences.
Permission letter (See Appendix C) together with ethical clearance certificates from the Institutional Review Board of the Noguchi Memorial Institute of Medical Research, University of Ghana, Legon and the Ethical Review Committee of the Ghana Health Service, Accra (See Appendices D and E respectively) were sent to the institutional head of the recruitment outlet for permission to recruit participants. After the approval from the recruitment outlet, potential participants were identified through the assistance of the staff at the outlet and an overview of the study discussed with them. Following the briefing on information about the study including the purpose of the study, a venue and time for the interview sessions were agreed upon with participants who voluntarily accepted to partake in the study. Each participant was given two consent forms (See Appendix A) which were completed prior to each interview.

In each interview session, participants’ demographic data were captured directly from participants and/or their folder before the main interview. The researcher started the main interview with a general question on chronic pain experience. To ensure a relaxed atmosphere and free expression of participants’ thoughts, flexible open ended and descriptive questions as well as intentional silence during the interview were employed (Rapley, 2004). Detailed information were obtained through probing for a better understanding of the participants’ chronic pain experiences (Rapley, 2004). All the participants were either interviewed in English or Twi based on their preferences. All the interviews were audio recorded with an audio recorder after participants consented to the recordings. Each interview lasted between 45 minutes to 70 minutes. Data collection commenced in December, 2016 and ended in March, 2017.

3.6 Pretesting of interview guide

The interview guide was pretested among two advanced cancer patients receiving treatment at the 37 Military Hospital who meet the inclusion criteria. This ascertained the
clearly of the questions in the interview guide and also determined whether the questions meet their intended purpose for the study (Hilton, 2017).

The details of the study were discussed with the identified piloting participants who met the inclusion and the exclusion criteria after they were presented with information sheet for the study (See Appendix A). The two who were willing to participate were scheduled for the interview based on their preferred time and venue. On the day of the interview, the participants were given two consent forms each to sign/thumbprint prior to the commencement of the interviews after which one of the consent forms were given to them and the other kept by the researcher. The first interview was transcribed verbatim and was used to improve the clarity and the efficacy of the questions for the second interview and subsequently, the actual interviews for the study as the necessary amendments and modifications were made to the questions to ensure full understanding of chronic pain experience among the participants.

3.7 Data management and Analysis

Qualitative data management is aimed at organizing and storing data in a manner to enhance easy accessibility and interpretation of the data collected (Ritchie, Lewis, Nicholls, & Ormston, 2013). The researcher employed both manual and computer based data management software (NVivo 11) to manage and assist in the analysis of data generated. Interviews conducted in English were transcribed verbatim while those conducted in Twi (local dialect) were translated into English based on meaning by the researcher and were cross checked by an expert in the Twi language for accuracy. However, participants’ confidentiality was ensured by not attaching participants’ identity to the transcripts during the process. Each interview was labelled with number codes starting from 001 to 013 according to the sequence of the interviews for easy identification by the researcher. The number codes were later replaced with pseudonyms such as Afua,
Betty, Mary to ensure anonymity of the participants. Participants with pseudonyms: Edmund, Edem, Edwin, Elorm, Ken and Emmanuel were males while the remaining participants were females. Soft copies of the transcripts were saved on a password protected computer and an external hard drive while the hard copies and the signed consent forms were kept separately under lock and key by the researcher.

Data collection and data analysis were conducted concurrently. This improved upon the depth and quality of the interview as the initial analysis directed the researcher in the subsequent interviews (Vaismoradi, Turunen, & Bondas, 2013). Both thematic and content analyses were used during the analysis of the data. Thematic analysis was deemed appropriate because the researcher employed a conceptual model to guide the study. However, content analysis was also helpful in the emergence of themes which were not part of the main constructs of the model used but were relevant to chronic pain experiences among advanced cancer patients in the study. Braun and Clarke (2006) six phases thematic analysis procedure was followed to gain meaning from the data collected and other themes also emerged out of content analysis.

1. The researcher read the transcripts several times to gain understanding of the whole phenomenon/experience as captured from the participants’ view point. This gave the researcher the opportunity to get immersed with the data (Braun & Clarke, 2006).
2. Further reading of the transcript was done by the researcher in a systematic manner to identify/label interesting features/statements in the data which were related to chronic pain experiences (coding).
3. This was followed by collation of consistent codes to develop potential themes and sub-themes. Because the researcher’s work was being guided by a conceptual model (Multidimensional Model of Cancer Pain), most of the themes and sub-themes were
based on the construct of the model. However, other themes and sub-themes which were not consistent with the model also emerged out of content analysis of the data.

4. The themes and sub-themes were reviewed to ensure that, they clearly described the codes under them.

5. Furthermore, the themes were defined and refined by identifying the ‘essence’ of each theme and were captured to reflect the exact description of the data they sought to describe.

6. Finally, the researcher’s report based on the analysis was produced and was validated with extracts from the data (Braun & Clarke, 2006).

3.8 Methodological rigour

Methodological rigour refers to a framework used in establishing integrity and credibility in a qualitative research process (McBrien, 2008). To ensure trustworthiness in qualitative research, credibility, transferability, dependability and confirmability have been identified as the major criteria by Lincoln and Guba (1985).

3.8.1 Credibility

Credibility explains the extent to which participants and readers of the research identify the phenomena/experiences described in the research as reality or in some instances similar to their own experiences (Lincoln & Guba, 1985; McBrien, 2008; Shaw, 2013). In ensuring credibility in the study, the researcher pre-tested the interview guide among two advanced cancer patients who meet the inclusion criteria for the study. This gave the researcher the opportunity to make necessary modification to the interview guide to ensure relevant data were collected. Additionally, purposive sampling technique was employed to ensure only participants who were within the inclusion criteria and could give a vivid account of their chronic pain experiences were recruited for the study. Probing and iterative questioning was also employed to elicit responses from participants and situations
where there were discrepancies in the responses; clarifications were sought from the participants. Member checking after each interview session was done. During this process, key issues which emerged after the interviews were discussed with participants to achieve congruence between both the researcher and the participants’ perceptions/interpretations. More so, frequent debriefing sessions were held with the researcher’s supervisors to ensure accurate description of the data collected.

3.8.2 Transferability

Transferability refers to the extent to which the results of a study can be applied to other similar situations or settings (Lincoln & Guba, 1985; Shenton, 2004). The researcher ensuring transferability gave detailed/thick descriptions of the setting for the research, data collection tool, procedure for data collection and the background of the participants as well as sampling of the participants. The researcher also kept records of the transcribed interviews and the analysis as well as the results of the study for audit trail (McBrien, 2008). These will ensure replication of the study in similar situations or settings.

3.8.3 Dependability

The extent to which similar studies in the same context using the same method among the same participant yields similar results over a period of time determines the dependability of the study (Shenton, 2004). The researcher in ensuring dependability in the study used an interview guide for all the interviews to ensure the line of questioning were consistent among the participants. Detailed description of the study design, procedures for sampling participants, and gathering and analysing data in the final report were documented without any ambiguity to permit replication.
3.8.4 Confirmability

Confirmability determines the degree to which the findings of a study can be re-established or authenticated by others. It is to ensure that the researcher’s beliefs and assumptions do not alter/influence the interpretation of the data collected (Shaw, 2013; Shenton, 2004). To ensure confirmability, the researcher documented the context in which data were collected in a field note during the interview. This enhanced interpretation of the data during analysis which reflected the exact responses of the participants. The researcher also bracketed his experiences and presuppositions with regard to chronic pain experience during the interview sessions as well as analysis of the data in order to prevent their influence in the interpretation and analysis of the data.

3.9 Ethical Considerations:

The researcher sought ethical approval from the Institutional Review Board of the Noguchi Memorial Institute of Medical Research at the University of Ghana, Legon and the Ethical Review Committee of the Ghana Health Service before embarking on participants’ recruitment and data collection. Permission was also obtained from the head of the recruitment outlet for the recruitment of participants.

The purpose, objectives and any potential risk of the study were explained to the participants in Twi or English as preferred by participants before the commencement of each interview. These were also provided in an information sheets attached to the consent form which were given to each participant to be abreast with the study prior to the interview. Afterwards, they were required to voluntarily sign two consent forms for their participation. One of the consent forms were kept by the researcher and the other by the participants. Additionally, participants were informed of their liberty to withdraw from the study at any point they wish until data analysis was completed. The researcher again emphasised on the fact that participants are not oblige to answer all questions during the
interview. Participants were therefore free to refuse to answer questions they felt uncomfortable answering. Interview sessions were arranged at times and locations convenient to participants.

For the purposes of privacy and confidentiality, participants were assigned pseudonyms to maintain their anonymity. Other identifying features of participants in the data were also removed. The researcher carefully saved the raw data on a password protected computer and hard copies of the transcripts were kept under lock and key. The raw data: transcripts and the recorded audiotapes and the consent forms were only accessible to the researcher and the supervisors and will be kept for at least 5 years before their destruction.
CHAPTER FOUR

FINDINGS

4.0 Introduction

This chapter presents the findings of the study. The findings of this study have been organised according to the constructs of the Multidimensional Model of Cancer Pain by Ahles and Martin (1992) and the objectives of the study. The demographic profile of all the participants, the themes and sub-themes as well as verbatim quotations from the participants to support the themes and sub-themes are described in this chapter.

4.1 Demographic profile of participants

A total of 13 advanced cancer patients of varied ages ranging from 26 years to 72 years with an average age of 50 years participated in the study. All the participants were Ghanaians and were residing in the Accra Metropolis. The marital status of the participants were as follows: married (8) with 3 not staying with their husbands at the time of the interview, single (2), widowed (2) and one (1) divorced prior to being diagnosed of cancer. With the exception of two (2) of the participants who were unemployed and a student, the occupation of the participants included: trading (3), hairdressing (1), teaching (1), evangelist (1), plastic waste recycling (1), security (1), electrician (1), gold miner (1) and a civil servant. However, none of the participants were actively working at the time of the interview. All the participants except one (1) had formal education with varied levels of attainment on the educational ladder: primary/elementary level (1), secondary level (6) and tertiary level (5). Languages spoken by participants included: English, Twi, Ewe, Hausa, Fanti, Ada and Ga. Eleven (11) of the participants were Christians with the remaining two (2) being Muslims. Though all participants had advanced cancers, there were varied cancer types among participants which include: breast cancer (4), prostate
cancer (3), cancer of the rectum (1), cancer of the vulva (1), bladder cancer (1) and uterine cancer (1). The remaining participants had multiple organ cancers which include: ovarian cancer and hepatocellular carcinoma (1) and osteosarcoma with metastasis to the lungs (1).

All the participants at the time of interview had undergone either surgery, chemotherapy or both for managing their cancers except two who were being managed conservatively. All the participants were experiencing pain with duration since onset ranging from 3 months 3 weeks to 3 years. The details of the participants’ demographic profiles are presented in appendix F.

4.2 Organization of themes

The participants’ chronic pain experiences in the study were structured under seven (7) major themes which were identified from the data. These major themes were: sensory dimension, cognitive dimension, behavioural dimension, affective dimension, sociocultural dimension, pain coping strategies and pain management. Five (5) of the themes: sensory dimension, cognitive dimension, behavioural dimension, affective dimension and sociocultural dimension were consistent with the main domains of the Multidimensional Model of Cancer Pain by Ahles and Martin (1992). The remaining two (2) major themes: pain coping strategies and pain management were additional findings to the model. All the major themes had various sub-themes under them and in all, twenty (20) sub-themes were identified with most of them being consistent with the model used to guide this study.

The major themes with their sub-themes which emerged from the data are presented in table 4.1 below.
Table 4.1: Chronic pain experiences among advanced cancer patients: organisation of themes and sub-themes

<table>
<thead>
<tr>
<th>Major themes</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| Sensory dimension   | ➢ Location of chronic pain  
                      ➢ Quality of chronic pain  
                      ➢ Severity of chronic pain |
| Cognitive dimension | ➢ Knowledge of pain  
                      ➢ Attitude and beliefs  
                      ➢ Meaning of pain  
                      ➢ Influence on thought processes |
| Behavioural dimension | ➢ Pain behaviours  
                         ➢ Verbal communication of pain  
                         ➢ Pain associated symptoms |
| Affective dimension | ➢ Anxiety and fear  
                      ➢ Mood changes |
| Sociocultural dimension | ➢ Family dynamics  
                         ➢ Cultural background and belief system |
| Pain coping strategies | ➢ Cognitive coping strategies  
                         ➢ Behavioural coping strategies |
| Pain management     | ➢ Orthodox management  
                      ➢ Complementary and Alternative Medicine (CAM)  
                      ➢ Economic challenges  
                      ➢ Health professionals’ attitude |
Characteristics of chronic pain

In the pursuit to answer the first research question of the study: “what are the characteristics of chronic pain experienced by advanced cancer patients”, the sensory dimension of chronic pain as a main theme was identified.

4.3 Sensory dimension of chronic pain

Chronic pain was characterised based on the location of the pain being experienced, the intensity of the pain and the quality of the pain. The study revealed that, chronic pain among advanced cancer patients was felt at multiple locations with a participant identifying just a single location. The quality of the pain could not be described by all the participants. Instead, some participants likened the quality of chronic pain they were experiencing with other familiar pain phenomena such as child birth and being cut with a sharp object. Additionally, participants described the severity of their pain with descriptive words including: very severe, very, very painful, terrible and unbearable. The severity of chronic pain was also rated within 5 to 10 on a scale of 0 to 10 where 0 indicates the absence of pain and 10 indicating the most severe form of pain. Three sub-themes: location of chronic pain, severity of chronic pain and quality of chronic pain were identified.

4.3.1 Location of chronic pain

The location of the pain describes the part of the body the pain was felt by the participants. All the participants except one experienced the pain at multiple sites of the body including: the breast, chest, neck, back, waist, arm, abdomen, ribs, heart and others said the pain was all over the body.

“I had severe pain at my back, the back of my neck... Later, my breast began to ache to the extent that I hardly got relief. Sometimes the pain is associated with the neck and the ribs... Similarly, when I started sweeping, I felt the pain in my arm” Emefa
“The pain was all over my body... yeah, there was pain all over my body...My waist, my knees, shoulders, back, neck, everywhere, everywhere was painful.”

Edmund

However, the locations of the pain among most of the participants increased during the disease trajectory:

“I started feeling the pain in my left knee... After the amputation I was experiencing the pain at the amputation site [stump; above knee amputation]...I started feeling pains in the chest, my ribs, my back and my leg all started paining very severely.”

Edem

“Afterwards, I started experiencing pain in the left arm... recently it’s been continuous and now involving the left axillar.” Betty

The locations of the pain were also identified to be related to the disease site or the type of cancer diagnosed. For instance, participants with breast cancer commonly reported their pain locations to include the breast whereas those with prostate cancer often identified their pain location to include the waist.

“I don’t really feel severe pains but once a while some little pains are experienced in my breast and it becomes tender.” Evelyn (Breast cancer)

“I have pains in my breast. It often pains me.” Esi (Breast cancer)

“At times I feel the pain in my waist” Elorm (Prostate cancer)

“It [pain] will come to my waist and since last month I started using cosset” Edmund (Prostate cancer)

Furthermore, a participant with cancer of the vulva identified the vulva and its adjacent structure, the anus as the only locations of her pain.

“I experience pain at the vulva and the anus. Apart from my vulva and the anus, I do not feel the pain anywhere else.” Afua (Cancer of vulvar)

The only participant who experienced the pain at a single location said the pain was only felt at the abdomen.
“All this side (right lower quadrant of the abdomen) has become very hard and painful. The abdominal pain is very severe. It is only in the abdomen and nowhere else.” Mary

4.3.2 Quality of chronic pain

The quality of chronic pain among advanced cancer patients were varied among the participants. Most participants described the quality of their pain to include pain descriptors such as: burning, shooting, sharp, piercing, tingling and pulling:

“The pain is just like having a boil with shooting effect. The pain in the leg is usually tingling with the outer part burning.” Edwin

“The pain is burning and shooting everyday unless I take a pain killer... I experience pain at the vulva and the anus as if someone is pulling on it.” Afua

“First, the pain in the leg [stump] was shooting... I now feel sharp pain and is like the thing wants to come out with force. With my chest, it is as if something is piercing through it.” Edem

Others who could not exactly describe the pain in terms of the pain descriptors likened the quality of the chronic pain they were experiencing to other pain phenomena such as: being cut with sharp object, child bearing/pregnancy and hitting the leg on a stone:

“Eeei, the pain is just like when they use a knife to cut your body.” Elorm

“The pain is not easy. It is very severe and can be likened to being cut with a sharp object that will make you scream and say mmmmh... For now the pain grips my abdomen and pulls on it intermittently at different parts in the abdomen. At times also it can be likened to pains associated with child bearing.” Erica

“Ooh, sometimes excuse me to say if you hit your big toe on a stone, the sensation you get which I do not know how to say it.” Emefa

It was also revealed that, while the description of chronic pain could be likened to child bearing/birth, chronic pain among the participants was continuous without periods of relief unlike child birth which is intermittent:

“This is how I feel it ooo [holding onto the skin and pulling] sometimes too it can be likened to the pain a pregnant woman feels when the foetus moves in the abdomen. This pain becomes severe and will be pulling on me for a long time... Unlike child
birth which gives you relief in between the pains, this pain is continuous and does not give you any relief.’’ Esi

Some claimed they did not have the expertise to describe it and thought the doctors could describe it better. Others were also of the view that it is an unfamiliar phenomenon and lacked the exact words to describe how they felt:

“Hmm I don’t know what to say but the doctors will know better... I can’t describe the pain because I don’t have the word to describe it. I believe doctors will have a better word. Because I just don’t know of a word.” Edem

“I don’t know of any word that would let you understand the severity of the pain. I don’t know of any word that befits the pain.” Betty

“Hmmm in fact the pain let’s say, I can’t describe how it is... You know I had a wound which was painful; but that one I knew there was a wound there but now I don’t have a wound.” Edmund

Edmund further described the pain as aggressive. He explained it was aggressive because its victim became helpless when it starts:

“... but this one is very terrible, yes very terrible and I will describe it as an aggressive pain. Because when it comes, I do not have any choice. It is something aggressive and attacking you and you are helpless. I always consider it as an aggressive pain.” Edmund

4.3.3 Severity of chronic pain

The severity of chronic pain among advanced cancer patients illuminates the intensity or the magnitude of the pain being experienced. The severity of chronic pain among advanced cancer patients was described as very severe, very, very painful, terrible and unbearable:

“Hmm if you want to talk of pain, I am really experiencing very severe pains” Mary

“Oh, first I was having a prostate problem and when it started, it [pain] was very terrible in my waist... Very severe, as for that I can’t joke with it. It is very very painful.” Edmund

“Am going through severe pain which tells you the pain is unbearable.” Erica
Others describing the severity of their pain lamented that, pain of such severity had never been felt and could not be compared to anything while others maintained it was more severe than child birth:

“This is very, very painful. People say child birth is painful; I have delivered 3 times but have not experienced this sort of pain before.” Mary

“Oh yeah, if not because of this pain, I wouldn’t know painful sensations existed.” Emmanuel

“Hmm this is very painful. There is nothing painful like this. Though there is pain associated with delivery but that pain goes away after delivery.” Afua

All the participants rated their pain above 5 on a scale of 0 to 10 with majority of them (8 out of 13 participants) rating their pain to be 10.

“Well, currently if I say my pain is not up to 10 then I’m being untruthful.” Emefa

“I will rate it at 10 or even more”. Ken

“I will rate it [pain severity] at 10. Edwin

However, the severity of chronic pain among advanced cancer patients was not static; instead it usually ranged from 5 to 10 on a scale of 0 to 10 as described by the participants:

“Well at times it will be at 5 then get worsened to 6, 7 and graduate upwards.” Erica

“The pain will be at 10 though not always. At times it will come to six which is normal for me to go about. I walk in pain and if I am going somewhere, I know I’m in pain but I still go. I know it has reduced a bit.” Edmund

“It is not permanent. It changes over time. At times the pain become severe, and at some times, it reduces.” Evelyn

“Currently, the severity of the pain will be 8 though it is not always at this level.” Edem

Chronic pain among advanced cancer patients was also revealed to be more severe during the night and usually reached its peak at midnight and gradually reduced during the day:
“... during the day its severity reduces. But from 10:00pm going it becomes unbearable ... At 12:00 midnight that is when I feel the severity of the pain at its highest peak.” Edwin

“The pain was not easy... hmm especially when it gets to 12:00 midnight it is not easy” Emefa

“It becomes more severe at night.” Edem

The data also showed that, the severity of chronic pain among the participants was associated with factors including: the treatment (Chemotherapy and surgery) the participants were undertaking, changing of participants’ body positions, engaging in activities such as exercising, working and talking and extremes of temperature.

While some participants were of the view that chemotherapy and surgery worsened the severity of their pain, others argued surgery rather reduced the severity of their pain:

“Now the pain has reduced since they have removed blood and lumps from it [breast]. But previously, it was very painful.” Esi

“The pain was usually severe one to two weeks following each session of the chemo until I start eating well” Emefa

“The pain became worse again after the surgery.” Emmanuel

The study further revealed participants’ pain worsened whenever they were changing their body positions:

“Hmm, even turning like this [turning sideways] gives me a severe pain.” Afua

I have realised that turning myself in bed worsens the pain. For instance as I’m sitting upright like this, the pain is quiet manageable but when I want to get back to the bed it become severe.” Erica

“It hurt so much if I change my position on the bed... if I sleep at one side of my body and I want to turn, I experience severe pains at my chest and breast.” Evelyn

More so, the severity of participants’ pain worsened as participants engaged themselves in activities including: exercising, over working and talking:

“This morning I woke up to do some exercise but when I stretched backwards and turning to the left side of the body, I started experiencing severe pain and I had to
quit the exercise... for now I’m no more working; unlike first when I had to stand plaiting peoples’ hair, fetch water, wash towels which worsen the pain when I get back to the house.” Emefa

“Because the more you talk, the more the pain becomes severe.” Edem

“When I over work myself in the house the pain gets bad.” Edmund

Additionally, some participants identified that, extremes of temperature worsened their pain. According to them, the pain worsened whenever the weather is too cold or too hot:

“When the weather is cold at night and the fan is on, I begin to feel the pain severely... honestly this pain is not a good thing because any type of weather that comes up comes with this pain. When the weather is hot the pain increases and when it becomes cold, the pain increases.” Ken

However, some participants could not link the severity of the pain to any worsening factor. According to them, the pain occurred or worsened without any provocation:

“I have not recognized anything that worsens the pain so far but what I know is the pain just become severe.” Afua

“As we are here now, the pain is reduced but it can just worsen without any trigger factor.” Edwin

“I have not identified anything that makes the pain severe.” Betty

Consequently, the severity of the pain determined participants’ willingness to seek for treatment. It was one of the most prominent reasons why participants sought for treatment of their cancer:

“It took me three weeks to decide for the surgery and it was also because the pain was becoming very severe.” Edem

“The thing was very painful so we went and met a doctor who also used a machine to examine and confirmed it was prostate cancer.” Edwin

Cognitive influences in chronic pain experiences

In answering the second research question: “What are the cognitive influences on chronic pain experiences?” the cognitive dimension was identified as a theme to describe the cognitive influences on participants’ chronic pain experiences.
4.4 Cognitive dimension

This theme describes the advanced cancer patients’ cognition, beliefs and perception about the pain and the influence of the pain on their thought processes. Participants had knowledge about the pain they were experiencing as most of them received counselling on it by their clinicians and this prepared them towards their pain experience. They held the belief that their pain was caused by the cancer they were suffering from which was a natural occurrence even though few of them could not discount spiritual/supernatural involvement. However, all the participants were hopeful of a better outcome of their pain as they heavily relied on God. Also, participants interpreted the presence of chronic pain and its severity as: a persistence and/or progression of their cancers whereas others interpreted it to be the emergence of death or ineffective medications. Furthermore, chronic pain among the participants triggered a lot of thinking and distorted their understanding as some wished for death and others were preoccupied with suicidal ideas and/or tendencies.

Four sub-themes were identified under this theme: knowledge on pain, meanings associated with pain, attitude and beliefs and influence of pain on thought processes. All the sub-themes were consistent with the model used in the study.

4.4.1 Knowledge on pain

Participants knew their pain was caused by the cancer they have been diagnosed of. They lamented they were without pain until the cancer ensued and others stated that, their pain was caused by the cancer.

“One thing is, I know this pain is as a result of the cancer so I usually do not think of something else apart from the disease. Because I didn’t have this pain until I was diagnosed of this disease which is causing the pain.” Betty

“I have realised the pain is as a result of the disease [cancer]. I used to think it was due to the work [hair dressing] when I was actively engaged in.” Emefa

“All this pain started after I had the prostate problem [cancer].” Elorm
Participants further narrated they knew about their pain from their doctors. The data revealed most of the participants were either informed of their pain being the consequence of their cancer or they had prior information about their pain from their doctors. According to the participants, these information enhanced their psychological preparation and coping with the pain.

“I was earlier told by a doctor that, this disease will trigger pains in my body as time goes on... And because the doctor told me to expect pain with this disease and that the pain will not kill me, I have also made up my mind to endure it... The doctor told me as much as the condition persists there will be pain so I have to be prepared for it.” Edwin

“I quiet remember when I went to the hospital; the doctor told me if I do not accept to undergo the surgery and be put on the chemo, it will get to a time when I may not be able to work because of the pain.” Emefa

“According to the doctors, they said it is the nerves and anything connected to the nerves is very painful... They said the thing is a tumour pain and once it is spreading, the pain will still be there.” Edem

However, few of the participants had no idea of what could possibly be causing their pain. They narrated though they were experiencing pain, they did not know the cause of the pain they were experiencing. Some reiterated their doctors educated them on the disease but could not recall being told about issues regarding their pain:

“Oh not a single day that I won’t be in pain. And I don’t know what is causing the pain.” Edmund

“No, I don’t know what is causing the pain. I can only remember being told there are stagnated blood in the lower abdomen or where I urinate from.” Emmanuel

4.4.2 Attitude and beliefs

Most of the participants believed their pain was of natural cause and did not associate it to any supper natural forces. According to them, they are just victims of circumstances to be attacked by an existing cancer which is giving rise to the pain:
“For me I do not believe I have been cursed; rather, this pain is as a result of an emerging disease which has found its way into my body” Emefa

“Yes, because what I know or what I have learnt is that, my grandfather in 1976 was killed by this same cancer. So when this came, I knew it was a family thing and not spiritual.” Edmund

Another participant reiterated that, the pain was not a result of any supernatural force or a curse and further suggested such thoughts could only be imagined if there had been some wrong doing; example sleeping with someone’s wife or being a womaniser:

“No no, no. You will only think of that [cursed] if you have gone to pick someone’s wife or you are a womanizer.” Elorm

Other participants reported the involvement of curse or spiritual forces as the cause of their pain. However, they further suggested they did not focus on that or have relegated that belief upon further spiritual encounter (prayers):

“Yes, spiritual forces can also be behind it but I don’t want to focus on that.” Edem

“Well, at first I thought probably I might have had misunderstanding with someone concerning money who may have cursed me with this. You know as traders we do have misunderstanding among ourselves and sometimes our customers especially with money. However, upon praying to God am confident nothing of that sort has happened. Even though I still owe some people but do not think I have been cursed.” Mary

However, a participant still believed she was cursed or charmed with the cancer which is giving rise to the pain she is experiencing. According to her, her assertion is based on the circumstances which preceded her current state. She believed she was cursed looking at the challenge brought before her and the pouring of water on her:

“The thing started like a boil when a friend came to tell me: ‘irrespective of how big I am, I am small’ after throwing water on me... Yes looking at what she came to tell me, I am sure that person used a charm on me... Yes the pain is from the disease she cursed me with.” Afua
Irrespective of the participants’ beliefs regarding the cause of their pain, they were all hopeful of a positive outcome. They believed they will be relieved of their pain over time or gradually until it finally disappear:

“I believe I will be relieved of this pain very soon since I can confidently say it is better now than previously.” Emmanuel

“I’m hoping it will one day go. Because if there is no believe that it will one day go, there wouldn’t be a reason to be here [hospital]. I believe through one or two medications, it will go down bit by bit and finally off totally.” Edem

“For me I know it shall be ok especially if I compare my situation to when it [pain] started.” Edwin

Additionally, the data revealed participants were hopeful of their pain relief as they relied mostly on God. They were confident that, God/Allah will relieve them of their pain and suffering as they did their part undertaking the treatment. Participants also relied on God to provide them with benevolent individuals for assistance with their treatment as well as directing their doctors regarding the appropriate treatment/medication:

“But I’m hopeful God will manifest Himself through someone to support me. I’m sure God will redeem me from this situation by getting me a benevolent person to assist me and even directing the doctors to the best medication to use for me.” Erica

“I believe that God willing, I will be cured if I undergo all the necessary process and medication.” Esi

“But in life if you want to be free, whatever that comes your way give it to God. Because whatever you do depends on Him [shedding tears]... For me I’m a Muslim and the Quran advises that, everything that comes your way, do your best and leave the rest for Allah. So I’m here doing my best but the final judge is Allah. Hmm rich men are dying here and the poor man is lying down and this shows truly God loves me.” Ken
4.4.3 Meaning of pain

This sub-theme describes how advanced cancer patients interpreted the chronic pain they experienced. Participants mostly interpreted their experience of chronic pain to mean the progression or the worsening of their cancer. Some further described the worsened state of their chronic pain to be due to the progression of their cancers.

“So experiencing the pain, I knew it was because of the prostate cancer. The last time I went for surgery the prostate was 156 and they stated in my folder ‘aggressive Ca’. And any time I go for PSA, it increases so I know the pain is as a result of the disease progressing.” Edmund

“It [pain] sometimes also alerts me, the actual disease [cancer] is getting worse.” Afua

“I know the disease is the one causing the pain and as the disease is progressing the pain is also becoming worse.” Erica

Others interpreted their chronic pain to mean the persistence of their cancer or were either not on the right medication or the medications were ineffective which could have probably worsened their cancer as well as the pain.

“So haven’t studied the fact that I have not been able to work for the past six to seven months because of the pain, I still think the problem is persisting.” Emefa

“The pain makes me think that perhaps I am not on the right medication.” Esi

“I think the pain is as a result of the chemo which did not work and has made the disease worse. Because at first it was something little. According to them [doctors], it has now become big. For three months now, the pain has become very huge. The doctors also said the chemo fights the cancer cell and when they stop fighting them, the cell becomes much stronger. So as the chemo didn’t work the cells have become stronger and have made it spread.” Edem

Also, chronic pain among advanced cancer patients was revealed to have signalled the participants about possible death. Participants interpreted the presence of pain to mean death was approaching and whenever the pain reduced, death was seen to be far from them:
“Hmmm, experiencing this pain I know death is nearer to me... But today that the pain has gone down I perceive death to be far away from me.” Edmund

“... whenever I feel the pain, It tells me death is approaching.” Afua

However, a participant interpreted the experience of pain to mean the depletion of blood caused by cancer; this led to weakness and subsequent collapse:

“Anytime I feel the pain, the disease depletes my blood and that is what makes me weak and leads to collapsing.” Mary

4.4.4 Influence of pain on thought processes

The study revealed that, the presence of chronic pain among advanced cancer patients influenced them to think a lot. Usually their thoughts were focused on the pain as they were not expecting to be in such a situation:

“I think, I think a lot... Because I was not expecting to be in this painful situation; several thoughts comes into my mind.” Emefa

“You are at that moment feeling the pain and your entire mind is focusing on the pain you are going through.” Elorm

Others echoed chronic pain affected their thought and impeded their understanding. They lamented they sometimes lose their senses and were unable to understand anything:

“Yes, as for that one [pain altering decision making] it is true. When the pain comes, it makes me think and talk differently.” Edem

“When I’m in this pain, it is difficult to understand what someone says.” Afua

The study further revealed chronic pain coupled with its severity influenced participants’ thought and made them wished for an end to their lives. Some bargained with God for death instead of enduring the pain:

“At times the pain becomes very severe that I tell my mother I prefer to die than to live. She will tell me not to say that and go ahead to encourage me. Yeah it becomes severe that I really want to die instead of enduring the pain... I just want to die
because at times the pain is very severe that, you wish you were not alive to endure such pain.” Edem

“When I experience this pain, the only thought that intrudes is: it worth dying than to go through such pain.” Afua

“Because at that time the pain was very severe and I did not know what to do, I became fed up with the pain... and I prayed to God to end my life if this pain will continue.” Edmund

The experience of chronic pain among advanced cancer patients also influenced their thoughts in several ways to cut themselves or to commit suicide. Participants were preoccupied with cutting off pain affected body parts and using objects to commit suicide:

“If it happens like that, I just wish I could use a knife to cut off my abdomen to get relief.” Emefa

“In that situation [pain] you may want to use any object at your reach to kill yourself... I have thought of suicide several times.” Afua

“I usually tell my children I wish I could kill myself and end all this suffering but they insult me... Some time ago I wanted to use a sharp object to penetrate my abdomen to end all this suffering but my children came to intervene and insulted me.” Erica

However, participants narrated they no longer have those suicidal thoughts nor death wish following encouragement from relatives; putting their faith in God and after coming back to their senses. Some realized it was against their religious values and immediately asked for forgiveness from God:

“I have not tried that again. I have now realised I have to put my faith in God and that thought has not occurred to me again.” Erica

“But I later knew it was the devil’s ploy to deceive me so I have stopped thinking about that idea” Edo

“After talking about it [wish for death], it came to me that why am I saying that? The lord has seen me through this several years. I regretted it and asked for forgiveness.” Edmund

“I have stopped thinking about that. It was not a normal thought but appears when you are in severe pain... When I said the thing was so painful that I wanted to die, I immediately asked for forgiveness when I came back to my senses” Edem
Responses to chronic pain

In the quest to answer the third research question: “How do advanced cancer patients respond to their chronic pain?” Two main themes were identified and were also consistent with the main constructs of the Multidimensional Model of Cancer Pain. They included: behavioural dimension and affective dimension. Each of these themes had sub-themes under them to describe participants’ responses to chronic pain.

4.5 Behavioural dimension

This theme describes the observable behaviours that advanced cancer patients experiencing chronic pain exhibited, their willingness to communicate the presence of their pain and pain-related symptoms. This study revealed that, advanced cancer patients experiencing chronic pain responded to their pain with a variety of pain behaviours including: shouting, moaning, changing facial expression, crying, rubbing and holding affected part of the body. They were unwilling to communicate their pain to others for fear of gossip. Others perceived the nurses to be aware of all their problems including the presence of pain since they were professionals. Also, participants were unwilling to communicate their pain in order to sustain their families’ happiness. However, those who communicated their pain did so when they realised the pain had become severe. The presence of pain was communicated to only those who were perceived by the participants as capable in relieving their pain or assist towards their care. Furthermore, chronic pain among advanced cancer patients was associated with symptoms including sleeplessness, fatigue, inability to perform house chores, inability to work as well as impaired activities of daily living.

Three sub-themes were identified under this theme: pain behaviours, communication of pain and pain associated symptoms. All the sub-themes were consistent with the sub-themes under the behavioural construct of the Multidimensional Model of Cancer Pain.
4.5.1 Pain behaviours

This sub-theme describes observable behaviours participants expressed to indicate the presence of pain. The study revealed chronic pain among advanced cancer patients was expressed in a variety of behaviours.

Participants mostly expressed the presence of pain through ‘crying’, ‘shouting/screaming’, ‘groaning’ and ‘moaning’:

“What I do when I am in pain is crying.” Mary

“It got to a time when just like I’m having a conversation with you, the pain intrudes and I will be shouting: ‘agyei’, ‘agyei’, ‘agyei’.” Emefa

“I will be moaning and moving up and down all because of the pain... With this, my wife easily detects I’m in pain.” Elorm

“When I am in pain, I usually do not do anything apart from groaning until I get some relief spontaneously.” Erica

A participant further indicated she groans especially when the pain is severe:

“Especially when the pain is severe, doctors will be around and I will be groaning mmmh, mmmh, mmmh.” Erica.

Other participants echoed that: they changed their facial expressions by squeezing the face. They also squat, rub the thumb on the middle finger swiftly, rub and hold the affected part when they experienced the pain:

“Sometimes you will know through my facial expression. I may squeeze my face when in pain and you will get to know there is something wrong with me.” Emmanuel

“When I am in pain, I will be rubbing my hands on the leg especially if the pain is in my leg... Sometimes too I hold on the leg for some time and change the position.” Edwin

“When I’m in pain, my facial expression will tell you. I’m that type who likes laughing a lot; so when you come and I’m somehow moody, you will know there is something wrong... At times my body language. The way I will be rubbing my thumb on the middle fingers or the way I will be twisting my body will indicate I’m in pain.” Betty
“When the pain starts, you will see me squatting until I experience some level of relief.” Emefa

The study further identified a change in breathing pattern, high temperature, angry way of answering questions and perspiration as additional pain behaviours exhibited by participants:

“My breath control pattern also changes when I am in pain... I don’t breathe as I do normally though I may not be able to describe it... I have been experiencing high temperature when the pain becomes severe... Any time I experience the pain then my temperature goes up.” Edem

“At times too, the way and manner I answer questions from people can also inform the individual I’m in pain... When I am greeted in that painful situation, I just respond to it swiftly or angrily.” Elorm

4.5.2 Verbal communication of pain

This sub-theme describes participants’ willingness to express or verbally communicate the presence of pain to their caregivers and other significant individuals. The study revealed some of the participants were willing to disclose the existence of their pain whereas others were not.

Some of the participants who disclosed or were willing to disclose the presence of pain narrated they disclosed the presence of the pain to anyone when asked; when there is pain and/or when the pain became ‘severe/uneasy’:

“Yes I do complain when I experience severe pain... I just complained to the nurses and they made me see the Doctor.” Evelyn

“When my wife asks me about the pain, I tell her about the pain in the abdomen and sometimes the penis when I’m urinating... The last time, it started around dawn 2am; I woke up from sleep and told my wife I was in pain.” Elorm

“When I am in pain, I call the nurses to come to my aid... any nurse on duty or at times the doctors... I also report the presence of pain to my family members in the house.” Emmanuel
It was also evident from the study that, participants complained of their pain only to individuals who were resourced or had the avenue to assist them to either relief them of their pain or assist them in their care:

“This morning, someone came to me from the social welfare, because I knew there can be some assistance from there; I told her all about the pain I’m going through. But for the nurses I tell them because we are the reason why they are here. When you call them when you are in pain, they come with drugs and assist you” Mary

“When I come to the doctor, I explain to him all that I am going through with the pain... because I want solution from him and I’m sure I can get the solution from him. He may say, go and do this or buy this and take.” Edmund

“I am willing to report my pain if only I am complaining to the right source... As I was told you are working on cancer pain, it links so is necessary I talk to you. I know you may have a lot of information to give me that I don’t know.” Betty

A participant reiterated the only person he complained of his pain to is his doctor and not even the nurse:

“Apart from my doctor I don’t tell anybody. Not even the nurses. Though my wife knew my sickness but she did not know about the pain I was going through. I will explain to her they said I should do this or that test but she did not know about the pain.” Edmund

The study further identified that, participants who reported their pain were satisfied when there was an intervention. However participants who complained of pain but were not attended to were dissatisfied as their pain became worse and this prevented them from further reporting of their pain:

“If I complain always and something is done, I feel ok but when nothing is done I feel worse.” Edem

“Yes I tell them but they don’t mind me. It has happened several times... I call on them that I am feeling pain but no one minds me so if you come later to ask me, why should I mind you? I will have nothing to tell you.” Afua

Among participants who were unwilling to complain about their pain, they enumerated reasons such as fear of gossip about their cancer, unwilling to answer a lot of questions at
that moment, and the perception that their care providers (Nurses) are professionals and they are aware of their pain:

“Sometimes you may not know whom you are talking to. If you disclose to them you are in pain as a result of cancer, before you realise it is being spread around that this person is suffering from breast cancer and if it happens she will be screaming.” Emefa

“They will be asking too many questions if you tell them you are in pain. May be, you may not be ready to answer at that point in time. While you are in pain, they are now asking what is wrong with you. How did it happened and a whole lot of questions. So you wouldn’t want to answer any of such questions.” Betty

“I know they are aware that I am in pain, because as professionals caring for us they know what is wrong with us all” Erica

Others did not want to complain about their pain to their family members or significant others to prevent them from being emotional/sad about their pain. According to the participants if their family members get to know they are in pain, they will be emotional and may not be able to eat, sleep and will destroy the entire happiness of the family which would eventually worsen their pain:

“I want my family to know I am a happy man so I don’t complain. I don’t want them to know that I am in pain so that they won’t feel happy and be sad. I don’t discuss my pain with them... So instead of that, I will keep quiet and we will pray together so that I will not feel bad myself... Because if I cause them emotional pain by telling them, my pain will be worse... I have a daughter over there and when she sees I’m in pain, she will be very sad. She will not eat and this will dampen my spirit. So why should I tell them no, no, no [shook the head] I will not do that. It won’t help me, it will spoil all the family’s happiness.” Edmund

“I have realized when I tell them [family members], they are not able to sleep as well... My nephew and sister are unable to sleep especially if they see me groaning in pain.” Edwin

4.5.3 Pain associated symptoms

The study revealed chronic pain interrupted the sleeping pattern of advanced cancer patients and prevented them from sleeping. According to participants, they were
either not able to sleep or were awakened from their sleep when they experienced the pain and/or when the pain became severe:

“I’m unable to sleep. The pain becomes very severe in such a way that I shiver and sleeping becomes difficult... For the past four days, the pain has been worse and I have not been able to sleep in the night. I have been the watchman for the other patients in the room... Sometimes as soon as you are about to doze off the pain interrupts the sleep.” Mary

“In that situation [painful situation], my heart beats very fast and I’m unable to sleep. In that painful instance, I would not know what to do to myself. Yesterday for instance, I was sleeping when it started aching me and I had to wake up and sit. I was feeling sleepy but could not slept due to the pain.” Betty

“Pain [loudly] at times when it comes I can’t sleep, I have to sit down. At times in the mid-night I start to feel the pain and I have to get up. I cannot sleep and I have to sit down or walk about.” Edmund

Participants also lamented that, the presence of pain weakened them and they were unable to do anything by themselves including activities they were able to perform previously such as sitting upright, walking, bathing and cooking:

“Because of the pain, I am unable to walk fast. You know when the pain comes, I become very weak oo, and I’m messed up to the extent that I cannot do anything by myself. I may not be able to even bath myself... it got to a time when I couldn’t sit upright. The pain became soo painful that it weakened all my joints.” Emefa

“Yes, I cannot sit upright nor walk. Initially, I was able to bath myself but now am not able to do it again because of the pain... when I started feeling the pain, I have not been able to move the leg that often because all this place [pointing to the stump] has become stiff and painful.” Edem

“You cannot do anything. Yes, until the pain subsides am not able to do anything. I can’t cook nor perform other activities” Betty

A participant further echoed during the experience of pain, she falls if there is no one closer to hold onto or lean on:

“When the pain comes I experience extreme weakness in the legs and am unable to move the legs... One thing is if the pain becomes severe and there is no one closer to hold or lean on, I fall because all my joints suddenly become very weak.” Mary
The experience of pain also impacted negatively on the physical development of the participant. According to the participants, the experience of pain affected their growth physically; they lost appetite and had a reduction in their body size:

“I was growing lean and very pale when the pain started.” Esi

“The pain started 3 months ago which made me began growing lean. I couldn’t eat nor did drink and I start reducing in size.” Erica

“Physically, when I’m in pain too, I’m not able to grow well. It’s like I am weakened within me, I’m not able to grow well. I have reduced in size. When I am in pain, my body do not function well. How the body is supposed to grow will not grow like that. It’s like for the past few weeks I have grown lean even though am not a fat person. I can see I have reduced due to the pain.” Betty

Additionally, the study identified that, the presence of pain influenced participants’ ability to have sex with their partners. According to the participants, the presence of pain and/or the pain associated with ejaculation during sex prevented them from having sex with their partners:

“Because of the pain, I have ceased myself from having sex...Something I feel like enjoying and upon going ahead to do it [sex], I end up experiencing pain; what kind of enjoyment is that? I have to leave it... Obviously I don’t have sex because of the pain and also the pain I will experience afterwards.” Elorm

“Another thing is due to the pain, I am not able to have sex with my wife at all.” Edwin

4.6 Affective dimension

This theme describes the emotional responses from participants as they experienced chronic pain. The study identified emotional responses including: anxiety and fear which was related to the side effects of the pain killers/analgesics the participants were taking for their pain, death caused by the pain and the occurrence of pain at night and when travelling. Additionally, changes in mood which included a feeling of unhappiness,
sadness and/or depression as well as a feeling of suffering were also expressed by participants as emotional responses during their chronic pain experience.

Two sub-themes were identified: Anxiety and fear and Mood changes. The theme and sub-themes were all consistent with the domains of the Multidimensional Model of Cancer Pain.

4.6.1 Anxiety and Fear

Chronic pain elicited much anxiety and fear among the participants. Participants narrated they lived in fear anticipating the occurrence of the next episode of severe pain especially at night and when they were travelling which interrupted their sleep and had made them suspend all travels respectively:

“When it is getting to the night, I become scared. Because I will not be able to sleep; I become scared because the pain would not let me sleep.” Edwin

“At times before I go to bed, I will be scared and be thinking; so what happens if this abdominal pain ensues again this night?” Emefa

“So if I’m travelling, I am always anxious anticipating the pain mid-way to my journey. This [anxiety] has made me suspend all my travelling.” Edmund

The study further revealed participants were also scared of the side effects of the drugs they were taking for the relief of their chronic pain:

“I am scared. For instance, when I was coming here [hospital], I was scared that probably the pain killers are what are giving me the problem... I was afraid that may be my kidneys have been damaged as a result of the side effects of the pain killers which will add up to my problems. I have been taking pain killers for more than a year.” Edmund

Participants were also afraid the experience of the pain could cause them loss their lives. According to the participants, they used not to experience such pain and despite the drugs they were taking for relief of the pain, the pain was still worsening. They were therefore scared of losing their lives through the pain:
“Because any time I experience the pain I know the prostate is not normal so I lived in fear not knowing what to do again. I take my medication but still the pain is worse. So I was in fear that I may loss my life through this.” Edmund

“I am scared because I used not to have this pain. It is not my normal habit. I am scared because it can send me away. I may die out of it. Day in and out, this pain does not go out and I don’t know whether it will even increase because people are dead today because of this same sickness.” Elorm

### 4.6.2 Mood changes

The study revealed the presence of pain changed participants’ mood. According to the participants, the presence of pain changed their mood and made them felt unhappy, sad and/or depressed:

“When I wake up and I experience the pain, it changes my mood. I will not feel happy again. So it changes my lifestyle and my day. Yeah, I will be sad and depressed at the same time.” Betty

“There have been several differences especially with this sort of pain. I am always in discomfort, I’m no more the happy person I used to be, not even the slightest amount of happiness all because of this pain.” Mary

Participants further stated they felt sad and depressed during their pain experience mostly because they were unable to perform activities they used to because of the pain and also when no one came to their rescue:

“I feel very sad because now I can’t do this or that even though I was able to do them some time ago. Now to even lift something up, am not able to do it; so I feel very sad about it.” Edmund

“I feel very sad when I am in pain and no one comes to my rescue. It simply tells me, this world is not pleasant.” Afua

Additionally, the experience of pain also elicited anger among the participants. Participants lamented they became angry when they were in pain to the extent that they avoided picking calls, were against anyone who did not support their course and they said a lot of things:
“Especially when I am in pain and my phone rings, it angers me more... I get angry when I even hear the sound of the phone ringing. If I’m suffering and the phone rings, I just push it somewhere.” Betty

“When I’m in pain, I become angry and against anyone who is not in support of me and I say a lot of things.” Edem

However, a participant also narrated the experience of pain brought to him a feeling of suffering and lamented there was no need undergoing the treatment if he still had to suffer after the treatment:

“If after going through all these treatment and am still suffering like this, then there is no issue going through them.” Edem

**Sociocultural influences on chronic pain experience**

What are the sociocultural influences on chronic pain experience among advanced cancer patients? In answering this research question, the sociocultural dimension was identified as a theme from the data.

**4.7 Sociocultural dimension**

This theme describes the relationship and the interactions between advanced cancer patients experiencing chronic pain and their family and significant others, the influence of their culture, belief system and upbringing on their chronic pain experience. The study revealed that: the participants had a lot of support from their family and church members. These support they gained consoled and encouraged them during their pain experience. However, participants who had no close relatives hardly got support. Additionally, participants who were stubborn during their formative years or were secretive were stoical about their pain and endured it. The culture and belief system of the participants also prevented them from expressing their pain to others.

Two sub-themes: family dynamics and cultural background and belief system were identified. The main theme and the sub-themes were all consistent with the domains of the Multidimensional Model of Cancer Pain.
4.7.1 Family dynamics

This sub-theme describes the relationship and the interactions between the participants, their family members and significant others as well as the participants’ upbringing and its influence on their chronic pain experience.

From the study, participants were immensely supported by their family members. According to participants, the family supported in purchasing of drugs prescribed and other requirements, visitation and calling to check on them and in the performance of things they could not do by themselves as well as encouraging and giving them hope:

“I have a daughter who works at the bank, another one gainfully employed, good brothers and good nephews who support me. Without them, I wouldn’t have survived... they have been very very supportive; my sisters, my wife oooh... it got to a time when I had to do some tests: one was 750.00 and another 950.00 Ghana cedis. I didn’t have that money. It was my nephews in the US who sent the money for the tests to be done.” Ken

“... my family is very supportive. They visit me frequently at the hospital. My brother and sister run shift in visiting me. Even after the operation, it was my sister who used to wash my things for me and tidy me up when I couldn’t do that by myself.” Evelyn

“The family visits more often and those who are not able to come also call. And it helps. They encourage me at all times and give me hope.” Edwin

Additionally, the church, prayer camps and other individuals also supported participants in prayers, donations, and words of encouragement/assurance which participants were proud of:

“I will say the support and contribution from the church is 100%. I have a Christian mother in the church, so when the illness started, my church donated three 50kg bags of rice, one thousand Ghana cedis and communion on Christmas day. Every week they come and pray for me. Even the Senior Presbyter made four church members donate blood for me towards my treatment. Currently, my Christian mother is not around. She has travelled abroad. She told me that she has informed the church to assist me if I need any help.... Where I go for prayers too, that church members also brought me three bags of pure water, oaths, milks, tom brown, a box of sugar, rice and cooking oil on Christmas day... Honestly the church has really
helped me and I am happy and proud of that. Their contribution towards my health even surprises residents in my area.” Esi

“The church, even though a small congregation at my place, they made contributions to support me… they also went to radio stations to announce for help for me to start with the chemo. Someone also heard and gave us 5,000.00 Ghana cedis. We used that 5000 for the chemo… My mum took me a television station where I was given another 5000 and we continued the 2nd and 3rd chemo with it. Other individuals also come to our aid and encouraged me to have hope.” Edem

However, other participants lamented they had no support during their pain experience:

“For my family members, apart from my brother whom I’m staying with, none of them border to look for me.” Emefa

“When I call my relatives, they do not even pick for me to get a chance to say at least good morning. I have stopped calling them and I’m looking up to God… My younger sister visited me from Nsawan; she remembered to pick transportation fare in and out but told me she forgot to pick money for my chop money. Such a person do you think if you go to her for assistance or loan she will yield to your demand? She forgot money to give me for food. I’m here because I do not have the people to support me. This hospital is not my home.” Mary

According to participants they gained no support because, those who could have supported them including their husbands and mothers were either dead or not available and others were not directly related to them in the family:

“If I had a husband, he would have been the person to take care of me but my husband is dead and I have no one to assist. My mother who used to assist me also is dead recently. For my siblings, am the eldest and used to take care of them when I was working; so there is no one.” Mary

“You see these pillows on the bed [pointing to three different pillows on her bed]. These pillows can be likened to the family and each and every member knows his/her children and the children also identify that linage. In my case we are left with 3 me, a brother and a sister and I’m the eldest so I do not rely or even think of any assistance from the family.” Erica

“Sometime I just want someone to tell me God is in control and that I will be fine but I do not get. For instance if I had a husband in this painful situation and I am curdled by my husband well, I will look good and even people outside will say I am living well despite my disease state. They may not know the happiness within me in the house which is reflecting in my outward looks.” Emefa
A participant also narrated others including the sister did not want to support, visit or call for the fear of contracting cancer:

“They do not want to support me because of the cancer. May be when they call, they will also suffer from cancer. So they will not call you. My own sister has stop visiting and calling me because she doesn’t want to get cancer.” Emefa

The study also revealed chronic pain experiences among advanced cancer patients was influenced by the individual’s upbringing. Participants who were stubborn and secretive during their formative years were stoical about their pain and endured it:

“Expression of pain depends on the way the person was brought up. For instance, I was the secretive type when I was growing up. I keep things to myself but someone will not do that. Someone will openly tell people about the pain he/she is going through but I will be in my room and endure it. That is how I am. I don’t like sharing... I find it difficult to discuss with people about myself. I don’t like it.” Betty

“Well, as a child I was very stubborn. If there is something paining me, I won’t tell you. And if you do something bad to me, even though I may want to retaliate; I will not show any sign but I will do what I want to. As I’m here, if something is paining me I don’t show it out. If I don’t tell you, you may not know. That is my nature.” Edmund

4.7.2 Cultural background and belief system

The study revealed participants’ culture and belief system had an influence on their chronic pain experience. Participants described crying as a man or an elderly person in front of one’s wife and children during painful situations as disgraceful and unrespectable. In their narration, a man has to be strong and endure painful situation:

“If it is a small boy, he will cry. But because I’m an elderly person feeling it [pain], it will be a disgrace on my part if my wife and children are there and I’m crying. Though I may feel like crying, I have to endure the pain without crying... As an elderly if you experience pain and you cry, what will a child also do? I have to be quiet to show some kind of respect for myself. Because if I cry, people will use it to mock at me.” Elorm

“As a man, even though you are dying in pain, you don’t have to let people know you are. Like if I’m dying here now just like when I was initially brought here in a
severe and painful state with oxygen on me, my wife was sitting here with me but I did not show any sign of me going down with the pain. So when they were here, they were happy praying for me you see.” Edmund

“As a man you must endure some of these painful experiences.” Edwin

Participants further identified the male gender to be strong and enduring as compared to their female counterpart:

“Definitely, as a man if my mother or father dies, I don’t have to cry. If women go through same you will see them crying but as for a man, the only thing I can do is to wipe my tears.” Elorm

“You see, women are different but as a man, you have to be strong and enduring.” Edmund

However, a participant echoed the perception of pain is the same among different genders provided the causality is also the same:

“My background has not affected the pain. Since we are all humans and have the same blood running through our veins; if I go through this pain and you also suffer the same illness, you will go through the same pain. So the background does not matter. For instance, if you are a man and you are going through pain, it is the same pain a female will also go through provided it is the same illness the two of you are suffering from.” Betty

The cultural background and the belief system also influenced the participants in identifying the possible cause of the chronic pain they were experiencing. A Participant from the northern part of Ghana narrated pain relating to the penis are associated with men who are womanisers as a result of being charmed by the husbands of the women they flirt with:

“You know our people [Northerners], they have this black power. So if you go and flirt with his wife, you can get that kind of pain [penile pain]. You can get it... We call something ‘babaso’ which is just like gonorrhoea and if only you are a womanizer, you will think about that.” Elorm
4.8 Pain coping strategies

What are the coping strategies adopted by advanced cancer patients when in pain?

In the quest to answer this research question, the study identified pain coping strategies as a major theme to describe how advanced cancer patients experiencing pain minimised or tolerated their pain. The study revealed that, participants employed diverse cognitive measures including hoping, enduring, diverting attention, ignoring/not thinking about the pain and positively thinking about the pain to minimise or tolerate the pain. Others also employed behavioural strategies including: praying, isolating self, engaging in activities, taking pain medications as well as inactivity to deal with their pain.

Subsequently, two sub-themes were identified: cognitive coping strategies and behavioural coping strategies.

4.8.1 Cognitive coping strategies

This theme describes the psychological strategies participants employed to either reduce or tolerate the pain they were experiencing.

Participants in the study were hopeful of a better outcome of their pain and the disease at large. They were hopeful mostly in God to relief them of their pain or condition:

“I am hopeful in the name of God I will be relieved of this pain.” Emefa

“I know my redeemer [God] is alive. Ones He has been able to deliver others from their problems, He will by all means do mine for me... I Pray to God because he is the one I’m relying on now. Ones He was able to bring life into dry bones, I’m confident He will be able to bring the pieces of my life together by relieving me of this pain.” Mary

“I know He is a great healer and no matter the pain I’m going through, it is nothing before Him. He will deliver me from this suffering.” Betty

However, a participant and an amputee who was hoping for relief of his pain bargained he would be appreciative of his life even with one leg without the pain:
“I am just hoping I can just be free from this pain so that I can just live normally. If even with one leg and I don’t feel this pain, I will be ok.” Edem

Participants also coped with their pain cognitively by enduring their pain. According to participants, they *endured* the pain mostly when the time for taking their pain medications is not due as shouting and crying usually do not reduce their pain:

“I endure the pain; so hardly will you see I am in pain. Unless I tell you... I endure the pain because, even if I express feeling of the pain by crying or shouting, it won’t reduce it. So, I think the best thing to do is to keep it to myself.” Esi

“When I am in pain and the medication is not due, I endure the pain until the time is due... So I endure the pain especially when the time for the pain killer is not due.” Edwin

Other coping strategies adopted by participants in this study included: not thinking about the pain and diverting attention from the pain being experienced. Participants narrated they avoided thinking about the pain as that worsened their pain and in some situations, they engaged in other activities to redirect their focus away from the pain:

“I usually don’t think about the pain. Although, I was affected unexpectedly but there is no need for me to be thinking about it since if I do that, I will be worsening my situation.” Evelyn

“Even though I was in pain, I will start cracking jokes with those I am with and also I love to play with children. We will sit down and play together and laugh as well... Though I’m in pain, I will go about and share jokes with you and go my way. As I share the jokes and laugh over with them, I forget about the pain. Because we will joke, laugh and laugh and I forget everything about this pain.” Edmund

“Well when I’m in pain and someone is with me communicating, the pain reduces as I forget about the pain but when I’m alone the pain worsens.” Emefa

However, a participant echoed he coped with the pain by having positive mentality about his pain and the disease:

“In the midst of this pain and the disease, I am always confident I will live with this pain and sickness and they will not kill me; whatever I will do to let this sickness go away I will do it.” Edmund
4.8.2 Behavioural coping strategies

This sub-theme describes the physical or observable mechanisms participants employed to deal with their pain. The study discovered participants mostly prayed to God for relief of their pain:

“When the pain comes I only focus on prayers for God to relieve me of the pain. I don’t joke with my prayers when I am in pains. If God were to be a human, He would have complained to leave Him alone because I have been worrying Him with prayers.” Mary

“When I am in pain, I pray. I pray to God to take this pain away from me.” Betty

Participants narrated they either prayed alone or together with other people or family:

“Sometimes I pray alone in my own room and at times I involve others.” Betty

“My husband and I pray a lot when the pain occurs as we believe and trust God for healing.” Esi

A participant in sharing her experience narrated she prayed over water whenever she was in pain and drunk it for relief of her pain:

“Sometimes I will fetch water and pray over it that God should deliver me from this trouble before drinking” Mary

Additionally, participants coped with their pain by taking pain killers when the pain was unbearable and those who saw the pain killers to be non-beneficial resorted to drinking lots of water as they reported it relieved them of their pain:

“When the pain becomes unbearable I take the pain killers for relief.” Edmund

“I have studied myself such that if I experience the pain I’m given pain killers but naturally, I don’t like pain killers. If I take pain killers the pain will go for a short while but the one that will occur afterwards will be more severe than what previously existed. So I drink a lot of water which tends to reduce the pain. If you drink a lot of water, whatever the pain is it will go down. Even fire is afraid of water. So if you have a serious pain, just drink a lot of water... Yeah, it does and that is why I have a lot of water beside me [pointing at five Voltic bottles full of water on a desk closer to him].” Ken
The study also revealed participants engaged in activities such as exercising, adjusting their position and massaging the affected part of the body to cope with their pain:

“When I experience pain, I do exercise.” Evelyn

“When I experience the pain in the breast, I fold a cloth to pad beneath the breast just like you are breastfeeding a baby to put him/her to sleep... Sometimes too, you will see me massaging my flanks while walking. When I do all these, it reduces the pain and am able to get some sleep... As I’m speaking with you now, I have started experiencing the pain at the neck and I have to be rotating the head, flexing and extending the neck until it creates a sound to see if I can get some relief. At times I have to be stretching backwards for relief.” Emefa

“When it becomes painful, I adjust my position or use my hand to massage the site gently for some relief.” Edem.

However, other participants coped with their pain by disengaging themselves from all sort of activities and isolated themselves from others to prevent them from talking or being disturbed:

“When I experience the pain, I usually sit idle for a while until the pain goes down before I can proceed to do whatever I want to do.” Erica

“When I am in pain, I do not want to talk. I only want to lie quietly and think about my pain and my life whether I have wrong someone in life. When I am in pain, I want to be left alone.” Afua

“When am in pain I don’t want anybody to come closer to me or come and talk plenty.” Betty

4.9 Pain management

This theme emerged as an additional finding relating to participants’ chronic pain experiences. The theme describes how advanced cancer patients experiencing pain managed their pain and factors such as health professionals’ attitude and economic challenges that influenced their pain management and experience in the study. The study identified pain to be the driving force for participants to seek for treatment. Advanced
cancer patients experiencing chronic pain sought for treatment for their pain and cancer from a variety of settings including the orthodox health system and complementary and alternative medicine system. Participants’ pain and cancer were managed with: pain killers including injections, tablets and ointments, herbal preparations as well as scarification. Artefacts including oil and Florida water were also used. Other treatments participants underwent included: massage, cold and warm compresses. Furthermore, participants were burdened with economic challenges including difficulty in assessing treatment and caring for other family members. The attitude of health professionals also influenced participants’ pain management and experience in this study.

Four sub-themes were identified under this theme: Orthodox management and Complementary and Alternative Medicine (CAM) management, economic challenges and health professionals’ attitude. The theme and the sub-themes were not consistent with the domains of the Multidimensional Model of Cancer Pain.

4.9.1 Orthodox management

This sub-theme describes the chronic pain experiences of participants with regard to managing their pain at the orthodox health facilities.

The study revealed participants were prompted to seek treatment at the hospitals/clinics mainly because of the pain they were experiencing and its severity:

“I went to the hospital because of the pain. Even though the swelling was there, I started seeking for treatment when it [vulva swelling] was accompanied with the pain.” Afua

“I was later brought to the hospital at the time when the pain became unbearable... So when it was getting worse I was brought to the hospital.” Erica
Participants mostly used variety of pharmacological agents (analgesics) prescribed or given to them by their clinicians to control their pain. According to the participants, these drugs were able to relieve their pain to some extent:

“Yesterday it was very painful so I called the nurse who told me to insert one of the suppository diclofenac [pain killer]. So when the pain comes, I take some of the pain killers prescribed for me including Paracetamol. Even though it [pain] doesn’t go completely, it subsides a bit.” Betty

“I was given pain killers. They keep changing the pain killers. When I take them for the first week, the pain reduces... I take pain killers that has been prescribed by the hospital.” Evelyn

“I have some drugs which if they [Clinicians] give me, it brings the pain down... When I’m given this injection [Pethidine], it reduces the pain for about 2 hours. Apart from the pethedine, I also took paracetamol in addition to others I cannot remember now... I have been taking morphine now.” Edem

Some of the pain killers participants used were also secured from the open market or ‘over the counter drug’ sources:

“When I go to the drugs store and tell them I am in pain, they give me some pain killers...Yes it [pain killer] reduces the pain somehow.” Afua

“I use some pain killers to calm the pain... I occasionally use ‘Gebedol’ which I usually buy from a druggist at our area.” Elorm

The study also discovered that, some of the participants were unable to identify the pain medications they were taking by their names. According to participants, they do not know the names of the pain killers they were taking:

“I don’t know the name of the drug they give me for the pain but it helps me. It is able to reduce the pain.” Evelyn

“I don’t know the names of the pain killers they give me.” Afua

“No I don’t know the names of the drugs I am taking for the pain but my daughter may know.” Erica

Additionally, participants took the drugs strictly as they were prescribed by their caregivers:
“I take them as ordered; one tablet at a time and it relieves me of the pain... I take the drugs which are given to me on timely basis by the nurses. I take whatever drug they give me until it finishes.” Emmanuel

“I take all the drugs including those for the pain as I have been ordered.” Edwin

However, some participants did not adhere to the prescription order. They either took overdose of the prescribed drugs or under dosed themselves. Their reasons for their action included the quest to get maximum pain relief and the avoidance of the side effects of the drug:

“The doctor prescribed a pain killer for me to be taking one at a time but I have been taking two... I do this just to relief me of the pain so I can have some sleep no matter how brief it will be.” Mary

“You see, I don’t go by their normal routines that take this pain killer 3 times daily or 2 times daily. But I will just take it ones a day instead of the two or three times daily. Also I don’t take it every day. May be the interval will be like 3 days... you know taking pain killer always is not good... What I learnt is, it will destroy my kidneys. If I continue taking the pain killer it will spoil my kidneys so I don’t take it always.” Edmund

A participant further narrated he injected pethidine wrongly through his intravenous cannula when he was denied by the nurse on duty as the time for that injection was not due:

“I told her to inject me with the pethidine which was given to me around 6pm but she refused and said that it will be given at 12:00 midnight. So when she left, I also took the medicine and injected myself. I injected myself through the cannula on my hand. Later the nurse came and said it is not done that way and that it has to be injected through my buttocks or my thigh.” Edem

The study also revealed the pharmacological agents participants used were only effective in relieving their pain for a short duration and others were ineffective. According to the participants they had stopped taking some of these pain killers and had refused procuring additional ones due to their ineffectiveness:
“I have been coming to this hospital and they have been giving me pain killers here and there a lot. I have been taking pain killers continuously for more than six months... When I take the pain killer, it reliefs me of the pain for let’s say the first week and from there onwards the pain reappears.” Edmund

“One thing is I have been taking this drug for some time now but I still experience the pain; so I have stop taking it. The last prescription they gave me for the pain has not been bought. I take them [drugs] but they do not help. I have taken that for the morning and afternoon today but am still experiencing pain.” Mary

4.9.2 Complementary and Alternative Medicine (CAM)

This sub-theme describes other non-orthodox pain management such as traditional/herbal management, spiritual management among others participants utilised to manage their pain.

4.9.2.1 Traditional/herbal management

From the study, participants resorted to the use of herbal preparations for managing their pain and the cancer at the initial stages of their condition. Participants were convinced that, using the herbal preparation was going to dissolve their cancer and subsequently control the pain but when they realized they were not getting the optimum result they aborted its use:

“When the pain started, someone accompanied me to a herbalist who gave me some herbal medicine I used to be taking... Over there [herbalist’s place], he charged me 400.00 Ghana cedis and promised to melt all the mass causing the pain with his drugs. I paid 200.00 Ghana cedis and I visited the place for several times but without any result. Am still experiencing the pain.” Mary

“Initially I thought it was fibroid so I was using herbal preparations. You know fibroid can also give you such pain and there are potent herbal preparations which can reduce the pain and melt the fibroid... I was taken to a traditional herbalist for treatment several times but to no avail.” Erica

“Well at the initial stages, I tried some traditional herbal mixture but did not go far with it. I stopped taking the herbal mixture because the pain became unbearable.” Edwin
However, a participant resorted to the use of the herbal preparations after visiting the orthodox facility for the fear of losing her breast through surgery. Participant narrated she was introduced to different herbal doctors in Kumasi (a city in Ghana) but could not get relieved:

“I was afraid upon hearing from the doctor my breast will be cut. When I informed my husband, he suggested a herbal doctor in Kumasi to me so I resorted to herbal treatment there but I wasn’t getting better. He later recommended another herbal centre still in Kumasi; I went there too but I was still not getting better.” Esi

The data also revealed participants used the herbal preparations as a mixture and drunk them whereas others applied and/or bandaged them at the affected parts of the body:

“Once, I feel the pain, I tell my husband to give me my herbal medicine to take and apply some on my breast.” Esi

“I then resorted to using herbal medicine to bandage the knee. I did this for three consecutive times.” Edem

Additionally, some participants used the herbal preparations together with the orthodox medications. A participant narrated he took the orthodox medications in the morning and complemented it with the herbal preparation in the evening:

“What I decided was to use the orthodox drug from the hospital in the morning and use the herbal mixture in the evening but I tried this for some few days.” Edwin

4.9.2.2 Spiritual management

The study revealed that, participants complemented the management of their pain and cancer with spiritual backings. Participants echoed they visited prayer camps and churches for prayers and in some situations men of God were invited to pray for them in their houses when they were experiencing the pain:

“I was still experiencing the pains in my breast so I started going for prayers... I was moving from one prayer camp to the other hoping and believing that I would be cured... At times, my husband calls his pastors to come home to pray for me.” Esi
“Yes, I went for prayers and even went to a prayer camp at Mamfe [a town in eastern region of Ghana] where I spent almost a week looking for solution to my pain and condition.” Edwin

“I could not walk better because of the pain so I went to a church for prayers.” Edwin

Other participants were lured to visit traditional priest or spiritualist for intervention to their pain and cancer. Participants followed their friends to these spiritualists after they were told they might have been cursed:

“Well, sometime past a friend told me my condition could be as a result of a charm/curse so I went somewhere [deity] far in the Volta region for an intervention.” Edwin

“My friends who are Ewes said I may have been cursed. They took me to a spiritualist who did some cutting on my leg and other stuff all in a bid to relief me of the pain and the cancer.” Edwin

The study also revealed participants who visited these prayer camps, pastors and traditional priests saw mysterious occurrences. A participant was made to believe mysterious causes of his pain and the cancer after which artefacts such as oil and Florida water were used on him for relief of his pain and the cancer:

“Later my mum took me to a church and the pastor said someone did this to me so he told us to bring eggs for intervention. He tied the eggs we brought around my leg. At that time my leg had not been amputated. Afterwards, he bathed me with oil and asked me to lie down in front of the pulpit. He also gave me Florida water to drink. The pastor started breaking the eggs on my legs. I saw some nails, needles and a rope coming out of the eggs. He then told me he has removed all the spiritual impediments to my condition so am ok... One of the pastors said the witches have used one of my legs as chopping board and they have been cutting meat on it. He prayed for me and gave me some spiritual directions but it did not work.” Edwin

However, participants lamented that, all the spiritual management they went through were not beneficial as they were either still experiencing the pain or their pain got worse:

“The prayer camp I went was not helpful... I didn’t see any improvement afterwards.” Edwin
“I went to one prayer camp for prayers but it was not helpful. They told me I have to leave my husband’s house which I ignored.” Afua

“I went to two traditional priests and 4 or 5 prayer camps and churches but it didn’t work... the pain became worse... My mother took me there [prayer camp] at the time that I was unable to sit. I sat from morning about 7am to evening 4pm. The pain in the legs became more severe so it did not work. May be because I did not get the right place.” Edem

However, the study also identified that, participants underwent other forms of non-pharmacologic treatment for their pain relief including: massage, warm compress and cold compress. These treatments were used either alone or together with pharmacological agents such as the application of balms or deep heat ointments:

“When the pain started, I went to a nearby clinic at my area for a massage. They kept massaging the site for me... I also applied some Chinese balm I bought from some people at Ashaiman [A town in Ghana] after the massage. It helped but when it got finished, I started experiencing the pain again.” Esi

“Because of the burning nature of the pain, I usually wrap a wet towel on the legs to soothe it.” Edwin

“My Auntie usually prepares warm water and with a towel she applies it at my back and smear deep heat ointment on it to calm the pain down.” Betty

4.9.3 Economic challenges

The study identified that, participants encountered financial challenges during their pain experience as well as the disease process. Participants went through financial difficulty which delayed them from seeking treatment at the hospital instead of the traditional/herbal treatment which was not yielding result and worsened their pain:

“If we had money, I would have attended the hospital earlier for treatment instead of using the herbal medicine which was not yielding any result. I would not be suffering like this... I strongly believe that, had it not been financial challenges which delayed me in the house, my condition wouldn’t have worsened for me to experience such severe pain.” Esi
“If my children had money or got someone to support me at the early stages I wouldn’t have been in this painful situation now... If the 7 of them (children) all had money and had contributed for me to seek treatment earlier, would I have been in this state? But here is the case I don’t have the money and I am experiencing this severe pain.” Erica

“It is because of the money that most of us stayed long in the house resorting to traditional medicine.” Emefa

Additionally, participants narrated the pain had a toll on their finances as they were unable to work for income coupled with the high cost of their treatment. They were therefore unable to afford their medications as well as other investigations which kept them thinking and worsened their pain:

“I am an electrician and I used to get contracts to work but because of the nature of my sickness, I can’t go about looking for contracts. I mean the pain so I can’t go about looking for contracts. Even if they call me, I can’t work because I can’t climb the ladder to do anything because of the pain. So you see, I have been sitting at home without any work.” Edmund

“The issue is I have been diagnosed of cancer and majority of my problem boils down to money. Because of the pain, you are unable to work for any income. Yeah, now I don’t have any money now. Even my last chemo will soon be due and that has been one of my major worry because I do not have the money for it.” Emefa

“Hmmm, you don’t have money for treatment, when they prescribe any drug for you, you are unable to buy. This alone will make you think and the pain will even go up. As am here now I have a prescription which I have not been able to purchase. You will definitely think and your pain will worsen.” Erica

Participants further described the extent of their financial difficulty as they had been without any pain medication two weeks following their admission because they had not been able to purchase their prescriptions and others were unable to cater for their dependents:

“Yesterday marked two weeks since I was admitted here and I’m not taking any medication for the pain. If they prescribe any medication for me, I am unable to purchase because my brother who used to buy them for me has no money now... Even my last born: a female who is attending a day secondary school at Teshie is...
A participant lamented she could not call on neighbours to assist her when she was experiencing severe abdominal pain because she had no money for them to take her to the hospital:

“Recently when I had severe abdominal pain, I couldn’t call anyone to take me to the hospital because I had no money on me.” Emefa

Participants subsequently recommended assistance from capable individuals and the inclusion of cancer treatment on the National Health Insurance Scheme (NHIS) to help moderate their financial difficulty with their treatment as well as preventing treatment delay:

“I would want people to assist me financially to be able to undergo the surgery so that I can be free from this pain.” Afua

“The drug is very expensive. Most of us do not have money to undergo the treatment. We will appreciate it if you advocate for the insurance to cover for us. It would be a great relief to us financially as you people (health workers) are saying we should not stay in the house with the disease.” Emefa

However, the only participant who although thought the drugs were expensive but was prepared for the task echoed he had no financial difficulty with the treatment. According to him, he had made provisions for his expenses and other family members were also supporting with the treatment:

“Well money is not a problem. I am old but a successful gold miner and I have enough provisions for my treatment. The family is also well to do. My sister in Germany has been insisting I should not use my money for the medical bills and she is the one sponsoring my medical bills. So I don’t have problem with money. Even though the drugs are expensive there is this proverb that, ‘don’t stand ideal close to a stick and allow a dog to bit you’. So no matter the cost as much as the money is there, I will buy it.” Edwin
4.9.4 Health professionals’ attitude

The study revealed the attitude of the health professionals also influenced the chronic pain experiences among advanced cancer patients. Participants described health professionals including nurses to be ‘helpful’ and supported them in relieving their pain through the administration of drugs/injections, education, words of reassurance and responding to their calls:

“The nurses do help me when I complain about the pain. They take their time to listen to me patiently and whatever assistance they can offer, they do.” Evelyn

“The nurses came and gave me some injections and stood with me from around 8:00 pm until 4 am when I was able to catch some sleep… The last time I was in severe pain even the senior-most nurse came to assist and they gave some injection which reduced the pain and I was able to sleep for a while. They reassured me and gave me hope.” Mary

“Anytime I come to clinic and I talk to the doctor about the pain, he educates me on the pain and tells me it will gradually be relieved so there is nothing to panic about. Some of this is usually helpful.” Edmund

Participants also stated the nurses were supportive in situations where they could not directly assist by calling the doctors to intervene:

“When the nurses realized the situation was beyond them, they allowed me to see the Doctor.” Evelyn

“Some of the nurses were able to call the doctor for me so that new drugs can be prescribed.” Mary

A participant further described some of the nurses as being ‘empathetic’ as such nurses frequently came to check on them and served their due medications:

“Some of the nurses come; especially those who are empathetic. They come and give me the due medications… There is this nurse who is so empathetic and always come to ask of how I am doing.” Afua

However, participants also described some of the health professionals including doctors and nurses as unhelpful and had no love for fellow humans. Participants lamented on how
some health professionals ignored them in their pain experience and insulted them during situations they thought they needed their help:

“Hmmm, this place, they [health professionals] are not helpful. They do not have love for fellow humans… The nurses come and insult me that I have messy the place. Last time, one came and told me I have made the place dirty so she will not come to me. Truly she did not come. Even at the time when I was shouting in pain, no one came… They question why I don’t pack all the soaked sanitary pads in one poly bag instead of me dumping them on the floor. But the issue is I don’t have the strength to get out of bed to do that. I feel very dizzy and am afraid I may fall down if I get up from the bed… The doctors also don’t mind me. As for them when they see me, they dodge. One came here to review me when I was in pain and bleeding profusely. I told him I didn’t have sanitary pad then but will be grateful if he could get someone to come for money to buy one for me. The next thing I realised was to send someone to come and pick a note pad and a stethoscope he left on that locker and he never returned.” Afua

“I was once admitted and the day I was discharged, I was experiencing severe pain. When I told them, they said ones I have been discharged there is nothing they can do about it so I should go home and come later.” Edwin

A participant further lamented he was saddled and cried following the uncompromising response from the health professionals:

“I was so saddled with their response but I had no option than to go home. That day I cried; I cried a lot.” Edwin

The study also revealed nurses were unwilling to attend to participants when they experienced pain in between their medication times as well as serving pain medications when the prescribed time is not due unless otherwise ordered by a doctor:

“At times I call the nurses when I am in pain and they tell me it is not yet time… Well, when it is time for them to give me the medication they do. But when it is not time, they tell me to wait until it is time… According to them they work with the prescription by the doctors in the folder. So when the time is not due, they don’t want to administer any drug unless the doctor has instructed them to do otherwise.” Edem

“When I feel the pain in between the medication times no one comes.” Afua
A participant further echoed some nurses were unwilling to serve their medications for their pain even when the time was due:

“The nurse came in and attended to the first person [patient] who was lying in bed A and jumped to C and D before coming to me at B. But I thought it should have been A, B before C and D. Notwithstanding that, she was dancing for a long time before she came to me at B and gave me the tablet [Morphine]. You can see even the tablet, she did not want to give it to me.” Edem

4.10 Summary of findings

A total of 13 advanced cancer patients experiencing chronic pain were interviewed in the study with their ages ranging from 26 to 72 years. Participants had varied type of cancers in their advanced stages. Seven major themes were identified in the study. Five of the major themes identified during the study including: sensory dimension, cognitive dimension, behavioural dimension, affective dimension and sociocultural dimension were consistent with the main domains of the Multidimensional Model of Cancer Pain by Ahles and Martin (1992) which was used to guide the study. The remaining two: pain coping strategies and pain management also emerged from the data but were not consistent with the model.

The characteristics of chronic pain experienced by the participants were captured under sensory dimension which described the location, quality and severity of the pain. Findings of the study revealed chronic pain was experienced at multiple locations among the participants with very few identifying just a single location. The number of pain locations increased during the disease trajectory and were associated with the site of the cancer. Participants described the quality of their pain as: burning, shooting, sharp, piercing, pulling and aggressive. Others who could not describe the quality of their pain for lack of appropriate words or ignorance associated it with other pain phenomena such as: child birth, pregnancy, being cut with a sharp object and hitting your leg on a stone.
The severity of chronic pain among the participants was described as: ‘very severe’, ‘very, very painful’, ‘terrible’ and ‘unbearable’. The findings also revealed the severity of the pain was not static; instead it fluctuated from 5 to 10 on a scale of 0 to 10 where 0 means the absence of pain and 10 indicated the most severe form of the pain. Participants further identified the peak intensity of their pain to be 10 and mostly occurred at midnight. Also, the severity of chronic pain was influenced by the treatment participants were undertaking as well as other activities including: changing positions, exercise, working, talking and extremes of temperatures.

Cognitively, the study revealed participants had knowledge on the pain they were experiencing as most of them were counselled on the pain by their clinicians at the early stages of their consultation. This essentially, prepared them towards their pain experience. They held the belief that, their pain was caused by the cancer they were suffering from but others could not discount the involvement of spiritual or supernatural forces. However, all the participants were hopeful of a positive outcome of their pain as they relied on God. The study also revealed that, participants interpreted their pain and its severity to include: progression of their cancer; the persistence of their cancer or were either not on the right treatment or their medications were ineffective and the emergence of death. Also, the experience of pain altered the participants’ thought processes as some wished for death and others were preoccupied with maiming themselves or committing suicide to end their suffering.

Furthermore, participants responded to their pain behaviourally and affectively. Behaviourally, participants exhibited observable cues (pain behaviours) including: shouting, moaning, changing facial expressions, crying, rubbing and holding the affected part of the body when in pain. They were unwilling to communicate their pain for the fear of gossip. Others were unwilling to communicate their pain because they perceived nurses
to be aware of all their problems including the pain as they are professionals. Participants who communicated their pain did so when the pain became severe and this was done to people they were confident of getting assistance from for the relief of their pain. Furthermore, chronic pain among the participants was associated with symptoms such as sleeplessness, fatigue, inability to perform house chores as well as activity of daily living. The affective dimension described the emotional responses from participants. Anxiety and fear relating to the side effects of the analgesics and the anticipation of pain occurring at night as well as when travelling were identified among the participants. Others felt sad and/or depressed as they experienced the pain.

The sociocultural dimension describes the relationship and the interactions between the participants and their relations, the influence of their culture and belief system and upbringing on their chronic pain experience. The participants had a lot of support from their family and church members. The support they gained consoled and encouraged them during their pain experience. However, participants who had no close relatives hardly got support. Additionally, participants’ upbringing and culture influenced their chronic pain experience.

Participants employed both cognitive and behavioural coping strategies to deal with or to tolerate their pain. Among the cognitive strategies participants employed included: hoping, enduring, diverting attention, ignoring/not thinking about the pain and positively thinking about the pain to minimise or tolerate the pain. The behavioural coping strategies employed were: praying, isolating self, engaging in activities, taking pain medications as well as inactivity to deal with their pain.

Finally, the participants in their quest to seek relief to their pain resorted to diverse settings. Participants initially sought for treatment from complementary and alternative medicine sources. Treatment from the orthodox settings was mostly resorted to during the
advanced stages of the cancer. However, participants complemented their treatment with spiritual interventions from churches, prayer camps and shrines. Furthermore, chronic pain and cancer created economic burden among the participants including difficulty in assessing treatment and caring for other family members. The attitude of health professionals also influenced the pain management and the experience among the participants.
CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 Introduction

This chapter discusses the key findings of this study and relates it to existing literature pertaining to the findings. The study explored and described chronic pain experiences among advanced cancer patients in the Accra metropolis. The discussion is organised based on the major themes of the study: sensory dimension, cognitive dimension, behavioural dimension, affective dimension, sociocultural dimension, pain coping strategies and pain management. The study was guided by the Multidimensional Model of Cancer Pain by Ahles and Martin (1992). The demographic profile of the participants are presented first and followed by the themes.

5.1 Demographic profile of the participants

The age range of participants in this study was from 26 to 72 years with an average age of 50 years. According to Weiler and Schoonover (2001), these are productive years in life. This may probably result in reduced productivity and subsequent economic burden on the participants as they are in constant pain and may not be able to work. Even though majority of the participants had an occupation, none of them was working as at the time of the study. It is quite obvious the presence of chronic pain among the participants disengaged them from working (O’Brien & Breivik, 2012). All the participants except one had some level of formal education which is perhaps a prerequisite for participants understanding and management of their pain (Baker et al., 2014). Most of the participants were therefore able to associate their pain with the cancer they were suffering from which may have been possible due to their level of education.
The large majority of the participants (11) being Christians demonstrate the religious domination of Christians in the Accra Metropolis. The remaining two of the participants were Muslims. According to the Ghana Statistical Service report (2014), majority of residents in the Accra Metropolis (78.8%) are Christians with 17% affiliated to the Islamic religion. However, the failure of other religious orientations such as the traditionalist to be part of the study could probably be due to their minimal representation (0.3%) in the Metropolis (Ghana Statistical Service, 2014).

Breast and prostate cancers were identified to be the most diagnosed advanced cancers among the participants. This may be as a result of their high incidence in Ghana and the sub region. According to a study in Kumasi, breast cancer is the most common cancer diagnosed among females and prostate cancer being the second after liver cancer among males (Laryea et al., 2014). While issues could be raised with regard to the differing settings, Kumasi and Accra are perhaps the major cities in Ghana and may share cosmopolitan features and may reflect the similarities in the incidence of cancer in the two Metropolis. Similarly, prostate cancer is reported to account for the most increased incidence of cancer among males globally (Fitzmaurice et al., 2015).

Participants in the study underwent chemotherapy and/or surgery for the management of their cancers whereas others were managed consecutively. The cancer and/or the treatments participants underwent could all contribute to the pain participants experienced (Bredal et al., 2014b; Eccleston et al., 2013; Lowery et al., 2013; Mejdahl et al., 2013; Mirabile et al., 2015).

5.2 Sensory dimension of chronic pain experiences

Pain locations during pain assessment may give the clinician or the caregiver an insight as to the type of pain, its management and could also help in making a diagnosis. Participants in this study reported multiple locations for their pain including the waist,
breast, neck, back, abdomen, ribs and general body pains. The pain sites increased during the disease process. These findings are consistent with other studies which identified multiple chronic pain sites among cancer patients (Matthie & McMillan, 2014; Valeberg et al., 2008). Furthermore, the type of cancer and its’ location was related to the location of the pain. The increased number of pain sites is likely to have resulted from the progression or the metastatic spread of the cancers to other body parts as reported in previous studies among advanced cancer patients (Jordan et al., 2013; Ngamkham et al., 2011). Moreover, the association between the type and site of cancer and the location of the pain in the current study may be due to the destruction and/or compression of nearby tissues by the increasing size of the cancer as established in previous studies (Bredal et al., 2014b; Guerreiro Godoy Mde et al., 2014; Jordan et al., 2013). As health professionals caring for advanced cancer patients, these findings therefore illuminates the importance of assessing these patients thoroughly in order to understand their pain for effective management including adjustment in the type and dosage of analgesic (Chapman, 2011; De Groef et al., 2017; Govender, 2014).

The quality of pain among advanced cancer patients can be explored during the assessment of the patient. This may inform the clinician about the type of pain and the appropriate management to use (Chapman, 2011). In the current study, participants described the quality of their pain as: ‘burning’, ‘shooting’, ‘sharp’, ‘piercing’, ‘tingling’ and ‘pulling’. Consistent with some of the pain descriptors in this study are: burning and pulling (L. Aziato & O. Adejumo, 2015). Similarly, burning, shooting, sharp, and tingling were identified in previous studies among advanced cancer patients (L. R. Gauthier et al., 2014; Rustoen et al., 2009; Schaller et al., 2015). Though the current study did not specifically identified the type/category of pain (nociceptive/neuropathic) participants were experiencing, reference could be made to pain descriptors and their corresponding
type of pain in line with previous studies (Ripamonti et al., 2012; Sun et al., 2008).

According to these studies, nociceptive pain is identified with descriptors such as aching, throbbling, pressure, cramping, gnawing and sharp while neuropathic pain is associated with descriptors such as shooting, sharp, stabbing, tingling, ringing (Ripamonti et al., 2012; Sun et al., 2008). In this regard, participants are likely to have experienced nociceptive and/or neuropathic pain.

Some of the participants were unable to describe the quality of their chronic pain in terms of the pain descriptors in this current study. Instead, they likened the quality of their pain to other pain phenomena including being cut with sharp object; child birth and hitting their leg on a stone. This finding concords with the work of Rustoen and the colleagues (2009), who also identified that cancer patients experiencing pain described their pain using pain related phenomena such as: like giving birth, like a claw, icy cold, hot, toothache in the lower back, heat, pressure, like a clamp, beaten with an iron stake and electric shock. The use of analogies by participants in describing their pain is likely to be due to poor understanding of the meaning of the pain descriptors (Bender et al., 2008). Though participants described their pain using other pain phenomena, this study provides further depth to the pain phenomena. For instance, despite the association of pain during child birth and cancer pain, participants were able to further describe their pain to be continuous without intervals of relief in contrast to that of child birth which is purported to be intermittent (Karlsdottir, Halldorsdottir, & Lundgren, 2014). This delineation could probably be due to female participants’ experience of both pain associated with child birth and cancer disease process. This finding therefore suggest the need for clinicians caring for advanced cancer patients to pay much attention to descriptions made by these patients during assessment as they may give clues to understand the sort of pain they are experiencing.
Assessing the severity of pain is crucial in pain management especially among cancer patients. This may assist the caregiver or the clinician to determine the urgency of care and/or the choice of analgesics to use as well as the frequency of reassessment of the pain (Okimasa et al., 2016). The intensity of chronic pain among the participants in this study was described as very severe, very, very painful, terrible and unbearable. Others also rated their pain on a scale of 0 to 10 where 0 indicated the absence of pain and 10 referred to the most severe form of pain. The vast majority who identified their pain intensity to be 10 on a scale of 0 to 10 supports previous studies whose findings identified high intensity of pain among advanced cancer patients (Alexopoulos et al., 2011; van den Beuken-van Everdingen et al., 2016) which may probably be due to extensive destruction of tissues with subsequent nociceptive and neuropathic responses (Babos, Grady, Wisnoff, & McGhee, 2013; Chapman, 2011).

Participants in this study had time variations in their pain intensity. They had the highest intensity of pain at midnight which gradually reduced during the day. Consistent with this finding are those from previous studies among the elderly with musculoskeletal pain and post-operative patients in Ghana which suggested time variation in pain intensity among participants with the highest intensity occurring at night (Aziato & Adejumo, 2015; Aziato, Ohene, Norman, et al., 2016). The presence of severe pain usually at night raises a question as to why this was happening. Wright and colleagues suggested an interrupted sleep among patients consequently aggravates the severity of their pain (Wright et al., 2009). This may have probably accounted for participants’ severe pain experienced during the night as they reported interrupted sleep during their pain experience. Additionally, there is a likelihood of participants focusing on their pain at night since they may not be engaged in other activities to divert their attention during that period. Consequently, this
could also intensify their pain psychologically. However, there is the need for further studies among advanced cancer patients to focus on this phenomenon.

Chemotherapy and surgery are cancer treatments identified to have worsened participants’ pain. Congruent with this finding, several studies have identified chemotherapy, radiotherapy and surgery to cause and/or increase the severity of pain among cancer patients (Guerreiro Godoy Mde et al., 2014). Though none of the participants in this study underwent radiotherapy, each of the therapy is likely to have independently accounted for the severity of pain participants experienced. In view of this, cancer patients undergoing treatment (chemotherapy, radiotherapy and surgery) should frequently be assessed for the presence of pain for prompt treatment to prevent them from becoming chronic (Burton et al., 2012).

The aggravation in pain severity caused by activities such as exercising, changing body positions, overworking, talking and extremes of temperature in this study is in accordance with findings from other studies which also enumerated the engagement of activities and weather (cold and hot) to have worsened the severity of pain among cancer patients (Andersson et al., 2017; Brown et al., 2013; Guerreiro Godoy Mde et al., 2014; Lowery et al., 2013). Participants are therefore likely to avoid such activities including activities of daily living to prevent their pain from being worsened and this may consequently affect their quality of life negatively.

However, contrary to this finding is the assertion that the engagement in such activities rather reduces pain among patients (Jebakani et al., 2015; McPherson et al., 2014). The contrary views suggest the subjective nature of pain among individual patients. The onus therefore lies on the caregiver or the clinician to assess and reassess each and every patient thoroughly to identify the best management plan for them as an individual (Aziato & Adejumo, 2015). Pain and its severity were some of the prominent reasons that
accounted for the participants’ willingness to seek for help or treatment for their ailments in this study. This finding is also consistent with other studies which reported similar finding (Boni & Afrane, 2016; Lam et al., 2009; Zaki & Hairi, 2014). Due to the distressing nature of pain to advanced cancer patients’ quality of life, these patients may want to seek for relief in order to maintain or improve their quality of life (Bender et al., 2008).

5.3 Cognitive dimension of pain experiences

Patients’ knowledge on their pain may to a large extent influence their belief as well as their attitude and consequently the management of the pain. Findings from this study revealed participants were knowledgeable on their chronic pain as most of them were able to identify the cause of their pain. Prior to their severe pain experience, participants were counselled on the experience of chronic pain during the cancer process. This may have probably accounted for participants’ knowledge on their chronic pain (Baker et al., 2014; Geneen et al., 2015; Luckett et al., 2013). Eventually, participants indicated they were able to prepare and cope with their chronic pain. Additionally, the high literacy level (participants with formal education and high educational level) among participants is likely to have accounted for participants’ adequate knowledge on their chronic pain without which they might have hinged on their traditional beliefs and misconceptions about the pain (Baker et al., 2014; Luckett et al., 2013; Turner et al., 2017). However, the lack or inadequate knowledge on chronic pain among some of the participants could be attributed to the lack of education/counselling on the possibility of pain by the physicians or caregivers of the participants. This could also lead to ill preparation and management of the pain (Kwon, 2014; Luckett et al., 2013; Yu et al., 2016). It is therefore essential for clinicians or caregivers to counsel/educate cancer patients on chronic pain which are likely to positively influence their knowledge and
management of their pain and eventually improving their quality of life (Bender et al., 2008).

Patients’ belief regarding the cause of their pain being experienced may greatly influence their intervention and subsequently their adherence to the management plan as well as coping with the pain (Babadag et al., 2015; Bostick et al., 2013; McPherson et al., 2014). Patients’ belief about the cause of their pain could either be organic (diseased body part or injury) or psychological and these beliefs have significant impact on patients’ pain management (Babadag et al., 2015). In line with these studies, majority of the participants in the current study believed their pain was caused by their cancer and only a participant associated the pain to other causes such as curse/charm. Participants who earlier believed their pain was from other causes other than organic cause later refuted that belief having pursued further to manage it spiritually. All the participants were hopeful of relieving their pain over time. However, participants’ hopes were mostly tied to the intervention from God. Invariably, they appeared to be helpless in relieving their pain and were therefore relying on God for intervention (Babadag et al., 2015). The religious orientations of participants (Christian and Muslim) is also likely to have contributed to participants over reliance on God to intervene in their pain relief (Buck & Meghani, 2012).

The presence of pain among patients may create diverse meaning in the minds of such patients regarding the pain. This may ardently influence the patients’ ability to manage and cope with the pain and eventually their quality of life. Participants in this study interpreted their chronic pain and its severity as a progression or persistence of their cancer. Others also associated their pain with an end to their lives. Consistent with these findings are that of several studies among cancer and/or advanced cancer patients who perceived the meaning of their pain as a progression of their cancer and the emergence of death (Bender et al., 2008; Coyle, 2004; Flemming, 2010; Gibbins et al., 2014; Kwok &
Bhuvanakrishna, 2014; McPherson et al., 2014). In furtherance to these meanings, participants in this study perceived ineffectiveness or inappropriateness of their cancer treatment as a contributory factor to their pain experience. A participant in the study revealed that, the pain signalled her of depletion of her blood by the cancer leading to an extreme weakness and subsequent collapse. While there seem to be no documented literature to substantiate this claim, it is imperative for clinicians to assess meanings cancer patients assign to their pain. This may enhance subsequent education or intervention for acceptance of their pain and its management (Gauthier et al., 2009; Hackett et al., 2016).

One’s ability to make an informed decision, pay attention to relevant issues to the betterment of his health and that of others may influence his/her quality of life. The presence of pain has been widely documented to impact negatively on the thought processes of patients including cancer patients. Cancer patients experiencing pain are reported to have impaired concentration and are burdened with several thoughts, beliefs and wishes including: death wish, suicidal ideas, suicidal wish or plans (Calati et al., 2015; Nuhu et al., 2009; Ohnsorge et al., 2014; Stubbs, 2016; Torresan et al., 2015). While these thoughts, beliefs and wishes seem to be unhealthy and could negatively impact on the quality of life of such patients, findings from the current study corroborates these literature. Participants in describing their experience with chronic pain alluded to the fact that chronic pain impeded their reasoning as well as understanding. They were preoccupied with several thoughts regarding their pain. Due to the unbearable nature of the pain participants were experiencing, they bargained to die to end their suffering. Others were preoccupied with cutting off the pain affected body part for relief and committing suicide. Participants’ intension in this study (cutting off the pain affected body part for relief) obviously suggest the influence of chronic pain on the thought processes of
advanced cancer patients and consequently their quality of life (Calati et al., 2015; Nuhu et al., 2009; Ohnsorge et al., 2014; Stubbs, 2016). These unhealthy thoughts and wishes are also likely to have stemmed from frustrations on the part of the participants owing to inadequate treatment of their pain (Abdulla et al., 2013; Wilson, 2007; Zhu & Weingart, 2012). However, this study also suggested that, participants made away these unhealthy thoughts and ideas when they received encouragement from family members coupled with renewed faith in God. This presupposes that encouragement, family involvement as well as religious/spiritual involvement in the care of advanced cancer patients experiencing pain is crucial in their management (Luckett et al., 2013).

**Responses to chronic pain**

Patients experiencing pain may respond to the pain differently. In this study, the participants’ responses to pain were categorised under behavioural dimension and affective dimension.

**5.4 Behavioural dimension of chronic pain experiences**

Under this dimension, the researcher discusses the pain related behaviours exhibited by the participants, verbal communication of pain by participants and pain related symptoms identified among the participants. Participants in this study exhibited variety of observable behaviours such as: crying, shouting/screaming, groaning and moaning during their pain experience. Others squatted, changed their facial expressions, rubbed their thumb on their middle finger swiftly; rubbed and held the affected part of the body. Some participants also exhibited a change in their breathing pattern, had high body temperature and used an aggressive tone in answering questions when in pain. These findings are in commonality with previous studies which also suggested these pain related behaviours among patients experiencing pain. Essentially, all these behaviours were put up
by the participants either consciously or unconsciously to communicate the presence of their pain (Aziato & Adejumo, 2015; Chen et al., 2011; Franck et al., 2010; Jacobson et al., 2015; Rahu et al., 2013; Romano et al., 2016; Roulin & Ramelet, 2014). Though these studies identified variety of pain related behaviours, their sample population were not specifically limited to advanced cancer patients. However, consistency has again been found between findings of the current study and that of McPherson and colleagues, (2014) who identified: facial expression, moaning, whimpering, holding and rubbing or massaging painful sites as pain related behaviours among advanced cancer patients. In this regard, a thorough assessment of advanced cancer patients by clinician and care givers for these pain related behaviours is therefore essential as they are likely to communicate the intensity (Rogers & Todd, 2010; Romano et al., 2016; Shen et al., 2014), location (Roulin & Ramelet, 2014), frequency and in some cases the quality (Rowbotham et al., 2014) of the pain for effective management (McPherson et al., 2014).

Due to the subjective nature of pain, clinicians may largely depend on the expression or communication of pain to enhance pain control and evaluation (Aziato & Adejumo, 2015). The expression or communication of pain including: its’ presence, intensity, frequency, location and quality by patients during assessment and reassessment may therefore be significant if maximum pain control/management is to be achieved. Some of the participants in this study were willing to communicate the presence of pain whereas others were not. Participants who were willing to disclose or had disclosed their pain indicated they did so when their clinician inquired from them about the presence of pain. Others reported their pain when it became severe and unbearable. In some perspectives, participants only communicated their pain to only individuals who they trusted to be capable in assisting them relief their pain or towards their care. Putting this in context, it is worth noting that: trusting relationship between patient and clinician or
caregiver; issue of concern to the patient (in this regard, the severity of the pain or its debilitating effect on the patient) and the willingness and/or expertise of the clinician/caregiver to assess and relief the patient of pain are significant motivating factors which are likely to promote pain disclosure among advanced cancer patients (Collins et al., 2008; Larsson & Wijk, 2007; McPherson et al., 2014; Rogers & Todd, 2010). Furthermore, interactive coaching of patients on communication of pain related concerns is also likely to improve patients’ communication of pain (Street et al., 2010).

Conversely, participants who were unwilling to disclose or could not disclose their pain highlighted on reasons such as: fear of gossip about their cancer state; unwillingness to answer a lot of questions and the perception regarding nurses as professionals and are aware of their pain. Others suggested that, they did not want to disclose their pain to their families in order to maintain the happiness in the family as well as not to worsen their pain. Similarly, the inability of clinicians to attend to the calls of patients or non-pain relief intervention when they were in pain created dissatisfaction among participants and prevented them from further reporting of their pain. In accordance with these findings, previous studies identified the unwillingness of cancer patients to report their pain (Carr, 2007; Champman, 2012; Christo & Mazloomdoost, 2008; Rustoen et al., 2009). They suggested the unfavourable consequences on their families and themselves if they get to know (Larsson & Wijk, 2007) and their regard for nurses to be knowledgeable as they are professionals and are aware of their pain (Carr, 2007) as their reasons for not reporting the presence of pain.

In a typical Ghanaian family or community, communal living is mostly upheld (Acheampong, 2016). Each and every individual is expected to be a “brothers’ keeper” suggesting that information about each individual is likely to be shared through conversations. Others in the quest to show solidarity or willingness to assist during
difficult situation may subject victims of those difficulties through lengthy interrogation for better understanding. Also, in view of the fact that cancer and cancer related pain are stigmatised in various settings (Booker, 2016; Finney et al., 2015), it may stand to reason that participants were unwilling to disclose their pain in order to avoid being stigmatised. Furthermore, the inability of clinicians or caregivers to attend and/or relieve participants of their pain could demotivate them from further reporting as suggested by Aziato and Adejumo, (2015).

The experience of pain is accompanied by other symptoms such as: sleep disturbances as well as tiredness/fatigue. These symptoms may equally impact negatively on the quality of life of the patient just as the pain does (Doghramji, 2012). Participants in this study identified disturbed sleep as one of the challenges associated with their pain experience. They described how they were not able to sleep when they were in pain and at times, they were awoken from sleep spontaneously when the pain intensified. This finding is in accordance with previous studies who also associated sleep disturbance with pain experience (Furlani & Ceolim, 2006; Krause & Stanford, 2011; Lavigne et al., 2011; Mercadante et al., 2015). In spite of this, participants’ inability to have an uninterrupted sleep is likely to further worsen/intensify their pain (Brennan & Lieberman, 2009; Doghramji, 2012; Wright et al., 2009) and consequently affect their productivity negatively as well as their overall quality of life (Alsaadi et al., 2014; Astrup et al., 2015; Lavigne et al., 2011). Furthermore, this finding suggest advanced cancer patients in the context of this study experienced high intensity of pain since mild pain intensity is less likely to cause sleep disturbance (Mercadante et al., 2015).

Participants in this study were unable to perform basic life activities such as: sitting upright, walking, bathing and preparing their own meals as a result of extreme form of weakness/tiredness. This is in no doubt an impediment to their quality of life. Though,
the presence of fatigue among cancer patients has been widely documented (Xiao et al., 2016; Yennurajalingam et al., 2013), the existence of pain is likely to have partly contributed to the extreme fatigue among the participants; compromising on their quality of life (Cheng & Lee, 2011; Yennurajalingam et al., 2013; Yennurajalingam et al., 2012).

In Ghanaian culture, sex is christened as a pleasurable event to be enjoyed (Fiaveh, Okyerefo, & Fayorsey, 2015). A revealing finding from this study suggest advanced cancer patients are unable to have sex with their partners due to the presence of pain and/or the pain associated with ejaculation during sex. While there seem not to be enough studies to substantiate this finding, Wang and Packer (2014) in their study identified a patient with lung metastasis presenting with severe non-relieving abdominal pain after sexual intercourse. Similarly, Paterson and the colleagues also identified sexual dysfunction among prostate cancer patients but they could not directly associate it with the presence of pain (Paterson et al., 2015). There is therefore the need for further studies delving into this phenomenon for better understanding and management; looking at the psychological implications it may have on the participants. Additionally, this finding calls for the need for clinicians to assess the sexual ability of advanced cancer patients which may assist him/her during counselling of the patient as well as their partners.

5.5 Affective dimension of chronic pain experiences

The experience of pain among patients is not only restricted to the sensory, cognitive and the behavioural domains as discussed above. It may extend to influence the emotional aspect of the patient (Silkman, 2008). Participants in this study reported emotional changes which were precipitated by the chronic pain they were experiencing. They were unhappy, depressed, and were filled with anxiety and fear. This findings are consistent with previous studies which also associated the experience of chronic pain among cancer patients with depression and anxiety (Delgado-Guay et al., 2011; Hong et
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al., 2014; Kyranou et al., 2013; Laird et al., 2011; Miaskowski et al., 2012; Miaskowski et al., 2014; Petkova et al., 2010) and fear (Crombez et al., 2012; Dunham et al., 2013; Jain et al., 2015; Nilmanat et al., 2010). However it contradicts the findings from Honerlaw et al., (2016) and that of Williams et al., (2012) who although identified an association between pain, depression and anxiety but pointed out that depression and anxiety rather intensify pain and its symptoms (Honerlaw et al., 2016; Williams et al., 2012). Notwithstanding this, participants in this study revealed that, they became sad and depressed when they realised they could not perform those activities they used to because of the pain as well as the absence of caregivers to rescue them from the pain. It may therefore not be far from right to suggest that, the presence of depression and anxiety among participants may further worsen their incapacitation with consequential drop in their quality of life (Cheng & Lee, 2011; Miaskowski et al., 2012; Miaskowski et al., 2014; Williams et al., 2012).

With regards to fear, participants’ fear were hinged on anticipation of the the next episode of severe pain especially at night and when travelling. Additionally, the perceived side effects of the pain killers including renal problem and the fear of dying out of the pain were also expressed by the participants. This findings corroborates previous studies which also identified fears relating to the pain and the side effects of the pain killers (Dunham et al., 2013; King et al., 2011). However, participants’ fear pertaining to the anticipation of the pain may be due to the devastating nature of chronic pain among cancer patients (Hackett et al., 2016). Individualised assessment of advanced cancer patients’ emotional state including depression, anxiety and fear is therefore significant if treatment adherence, effective pain management and an overall improvement in their quality of life is to be achieved (Honerlaw et al., 2016; Williams et al., 2012).
5.6 Sociocultural dimension of chronic pain experiences

The relationship and interaction between individuals and their family members as well as other significant people in the society is very crucial when the need to support one another emerge (Sjolander & Ahlstrom, 2012). Participants in this study received resounding support mostly from their families as well as the church, prayer camps and other individuals. These supports were rendered physically, emotionally and spiritually. According to the participants in this study, they were enthused about these supports they gained. On the contrary, some of the participants hardly received support during their pain and the cancer process owing to the non-availability of individuals capable of assisting them. Consistent with previous studies, patients including cancer patients in distressing moments rallied support from various supporting networks including the family, church, friends, co-workers and other significant people (Craft et al., 2016; Doku et al., 2015; Torres et al., 2016; Yamaguchi et al., 2016) and others rarely got support (Reavley et al., 2009). The presence of these supports are likely to enhance participants’ pain management and their overall quality of life (Craft et al., 2016; Paterson et al., 2015; Sjolander & Ahlstrom, 2012; Torres et al., 2016).

Essentially these support networks are mostly available based on the patients’ relatedness or interactions with them; which may perhaps account for the participants’ support mostly coming from their family members and the church which they are closely associated with (Aziato, Ohene, Norman, et al., 2016; Craft et al., 2016; Doku et al., 2015; Torres et al., 2016; Yamaguchi et al., 2016). Similarly, family members and close relatives’ keen interest to support their relatives in the context of this study may suggest a call to duty or responsibility haven’t benefited from these patients prior to their pain experience/cancer as enshrined in other cultures (Aziato, Ohene, Norman, et al., 2016; Im et al., 2009; Yamaguchi et al., 2016). Notwithstanding the presence of a close relative for
support, the issue of financial capability as well as physical well-being of the said relative are crucial. Participants’ lack of support may not be limited to only the non-availability of a close relative; but may extend further to include these relatives’ financial capability and physical well-being to meet up with the supporting role (Park et al., 2015).

The upbringing, culture and belief system among advanced cancer patients in the context of this study were identified to influence their pain experience. Participants who said they were stubborn and secretive during their early stages in life were reported to be stoic and exhibited great sense of endurance with their pain. This findings is in line with previous studies who also suggested a relationship between upbringing and perception and management of pain (Aziato & Adejumo, 2015; Pillay et al., 2014). Similarly, the male gender in this study was perceived to be strong and enduring. Consequently, an elderly man is not expected to cry in front of his wife and children during painful situation due to its disgraceful and unrespectable responses they may elicit. This finding opposes the finding from Im and colleagues (2009) who rather reported high pain tolerance among women. However, some of the participants in this study were of the view that, the perception of pain are the same regardless of the gender on condition that the causalities of the pain are the same. The differing stands of participants in this study suggest the possibility of cultural, ethnic and belief system variations among the participants as previously reported in other studies (Aziato & Adejumo, 2015; Ham et al., 2016; Im et al., 2008; Kwok & Bhuvanakrishna, 2014; Pillay et al., 2014). Cognisant of the above findings, clinicians taking care of advanced cancer patients’ stand to effectively manage chronic pain among these patients if they individualise the care putting into consideration the upbringing, cultural and belief system pertaining to each of them (Im et al., 2009). Furthermore, regular education to enhance patients’ knowledge on the pain and its management as well as demystifying any misconception regarding the pain may also help
to improve patients understanding, cooperation and adherence to the management course as well as improved quality of life (Rustoen et al., 2012; Vargas-Schaffer & Cogan, 2014).

5.7 Pain coping strategies

Participants in this study employed varied strategies to cope with their pain. Findings from the current study suggest participants were engaged in diverse cognitive and behavioural coping strategies in minimising and tolerating their pain. They employed cognitive strategies such as: hoping, enduring, diverting attention, ignoring/not thinking about the pain as well as positively thinking about their pain. Behavioural measures participants in this study used to cope with their pain included: praying, isolating themselves, engaging in activities, taking pain medications and inactivity. Consistent with previous studies, participants in this study employed a diversity of both cognitive and behavioural coping strategies to reduce or tolerate their pain (Booker, 2016; Guerreiro Godoy Mde et al., 2014; Paterson et al., 2015; Syrjala et al., 2014). Similarly, several other studies have documented the use of variety of coping strategies in cancer related pain (Dunn et al., 2015; Khalili et al., 2013; Meints et al., 2016; Somers et al., 2015). Cognisance of the fact that participants in this study utilised diverse strategies with some uniquely engaging in practices that seemed to be unusual; for instance, drinking lots of water to reduce their pain suggest the subjectivity of pain experience among the participants (Aziato & Adejumo, 2015). Hence, the need for individualised care to ensure maximum benefit to the patient. However, the researcher recommends further studies to ascertain the efficacy of drinking copious water for pain relief to inform practice.

The frequent use of hoping and praying to cope with pain among the participants suggest the ethnic/racial and cultural influence on choice of coping strategies (Meints et al., 2016). The engagement in hoping/faith in God and praying as coping mechanisms among advanced cancer patients in this study may be due to their religious orientation (de-
Graft Aikins, 2005). Almost all of the participants being Christians were more likely to believe in God and the power of prayers in changing situations in their lives (Buck & Meghani, 2012; Delgado-Guay et al., 2011; Torres et al., 2016). This finding further suggests the wealth of religious beliefs in participants’ pain and cancer experiences. Clinicians and caregivers caring for advanced cancer patients should consider their religious beliefs during their care as they are significant in creating hope and a source of comfort to the patient (Ellis et al., 2015).

Additionally, participants engaged in activities such as exercising, changing body position, massaging the affected part of the body and adhering to pain treatment which may seem to be positive/adaptive coping measures and are likely to reduce participants’ pain and improve upon their quality of life (Khalili et al., 2013; Prasertsri et al., 2011; Price et al., 2013; Torresan et al., 2015). However, the seemingly maladaptive measures such as disengaging in all sort of activity and total isolation among the participants are likely to yield depression with consequential increase in pain intensity (Honerlaw et al., 2016; Williams et al., 2012) and a decline in quality of life (Andrew, Derry, Taylor, Straube, & Phillips, 2014; Prasertsri et al., 2011). With evidence suggesting the readiness to learn adaptive coping measures among cancer patients experiencing pain for them to be less victimised (Bender et al., 2008), the findings of this study makes it imperative for clinicians to educate these patients on individual basis; adaptive coping measures to improve their quality of life.

5.8 Pain management

Though this theme is not consistent with the constructs of the Multidimensional Model of cancer Pain, the researcher suggest it is essential for clinicians/caregivers to be conversant with how advanced cancer patients access intervention for their pain and the bottle necks associated with them. Pain management was of importance to the participants
in this study. The experience of pain was one of the main driving forces for participants to seek treatment for both the pain and their cancer. This finding corroborates other studies which also identified the presence of pain to have triggered patients to seek help (Boni & Afrane, 2016; Lam et al., 2009; Zaki & Hairi, 2014). This could probably be due to the distressing nature of the pain and the threat it had on participants’ quality of life (Butow & Sharpe, 2013; Edrington et al., 2010; O’Brien & Breivik, 2012) as well as the fear associated with it (Dunham et al., 2013; Jain et al., 2015; Nilmanat et al., 2010). In this study, participants sought for treatment for their pain and cancer from diverse settings. Apart from the orthodox medicine, participants were engaged in complementary and alternative medicine including traditional/herbal medicine, spiritual interventions and other non-pharmacological treatments such as: massage, warm and cold compresses. Participants’ quest to access variety of treatment modes for their pain may suggest the unrelieved nature or the under treatment of their pain (Abdulla et al., 2013; Wilson, 2007; Zhu & Weingart, 2012). Also, participants in this study may be learning from the experiences of other patients in Ghana with chronic diseases such as diabetes who also engage in healer shopping in managing their condition (de-Graft Aikins, 2005). However, the multimodal approach to chronic pain management among cancer patients is known to be of high benefit to these patients as it enhances their functionality and quality of life (Aziato, Ohene, Norman, et al., 2016; Binczak et al., 2014; Champman, 2012).

Though participants in this study largely used variety of prescribed pharmacological agent (analgesics) for their pain management, not all were able to identify the names of the drugs they were taking. This could be due to inadequate education on these medications by their clinicians and may have accounted for the non-adherence to treatment among some of the participants in the study (Champman, 2012). Participants’ choice to use over the counter drugs for their pain management is likely to be
due to accessibility and availability of these drugs as previously suggested by Booker, (2016). This study again revealed that, some participants who requested for injection pethedine (opioid analgesic) and were denied due to its untimeliness wrongly injected the preferred drug without the knowledge of the nurses on duty. Giving the intensity of chronic pain among advanced cancer patients, it is not surprising for the patient to get to an extent of injecting himself with opioids secretly. The possibility of overreliance on opioids by these participants cannot be left out (Banta-Green, Merrill, Doyle, Boudreau, & Calsyn, 2009). Additionally, it could also be due to nurses’ unwillingness to provide analgesia with opioids for fear of preconceived dangers associated with it and addiction as suggested in previous studies (Bernardi, Catania, Lambert, Tridello, & Luzzani, 2007; Eid, Manias, Bucknall, & Almazrooa, 2014). Furthermore, participants in this study were relieved of their pain for a short duration and others denied the efficacy of the analgesics. Consequently, the later resulted in participants’ reluctance to continue taking the analgesics and to procure newly prescribed ones. Invariably, these findings are consistent with previous studies (Booker, 2016; P. S. Davies, 2013; Good et al., 2014; Naveh et al., 2011). It is therefore imperative for clinicians caring for advanced cancer patients to educate these patients on their medications to encourage maximum adherence and effective pain management. Similarly, regular pain management training is required for nurses to demystify fears associated with opioids analgesics administration and handling to enhance pain management and unwarranted access by patients (Choi et al., 2014).

Participants in this study also utilised traditional herbal medicine especially at the initial stages of their pain and cancer. They believed the herbal preparations which were in the form of mixtures for oral administration and topical application could dissolve their cancer and relief their pain but to no avail. However, a participant visited several herbal clinics after visiting the hospital for fear of mastectomy (breast amputation) but also to no
Others complemented the orthodox treatment with herbal medicine. They took the orthodox medicine in the morning and the traditional herbal medicine in the evening which also yielded no positive result. These findings corroborate previous studies which also posited the use of herbal medicine among cancer patients and those experiencing pain (Lee et al., 2015; Okello et al., 2010; Sait et al., 2014; Seraj et al., 2012). However, contrary to the findings from Lee et al., (2015) who suggested high efficacy of the herbal medicine among patients experiencing pain, participants in this study were not relieved of their pain when they used the herbal medications either solitarily or together with the orthodox medicine. Participants’ fear for mastectomy and financial challenges which accounted for their preference for herbal medicine is also consistent with the work of Booker, (2016).

Furthermore, participants in this study had variety of spiritual encounters during their active search for relief of their pain and cancer. They visited prayer camps and churches and in some situations men of God come to pray with them in their houses. Others were lured by friends to visit traditional priests or spiritualist for intervention to their pain and cancer. At these settings, participants saw mysterious occurrence and artefacts such as Florida water and oil were used on them but they hardly got positive results. The findings of this study concord with other studies which also suggested the prevalence of spirituality as an intervention for pain relief among cancer patients (Broom, 2009; Buck & Meghani, 2012; Craft et al., 2016: de-Graft Aikins, 2005). Participants’ choice for spiritual intervention in this study could be based on their cultural and belief system and the quest to transcend cancer to achieve inner peace and comfort as suggested by Buck and Meghani, (2012) and Broom (2009).

Though participants in this study utilised other non-pharmacological interventions such as massage, cold and warm complex, exercise to cope with their pain, the findings
seem to suggest there was no structured integration of these interventions in managing participants’ pain. As a result, pain management seemed to be centred on administration of pharmacological agents (analgesics) which may probably not be the only absolute measure in pain management among cancer patients. Clinicians aiming to achieve effective pain management and improved quality of life among cancer patients should therefore endeavour to integrate other non-pharmacological intervention into the classical pharmacological management (Aziato, Ohene, Norman, et al., 2016; Binczak et al., 2014; Champman, 2012).

Economically, most of the participants in this study experienced challenges. Due to participants’ financial difficulties, they delayed unduly in the house before seeking for help. Others resorted to traditional treatment for lack of money. The high cost of investigations and treatment/medications for participants’ pain and cancer coupled with their inability to engage in any financially rewarding activity further worsened the financial plight of the participants in the study. More so, the non-inclusion of cancer treatment in the National Health Insurance Scheme (NHIS) benefit package in Ghana may have also contributed to deepening participants’ financial constraints as all the investigations and treatment were paid out of packet. As a result, participants in the study wallowed in severe pain as they could not purchase their pain medications and others were unable to cater for their dependants. In line with previous studies, one significant reason leading to over delay in presentation of cancer and its distressing symptoms among patients in low and middle income countries including Ghana is financial constraint (Ekortarl et al., 2007; Gueye et al., 2017; Mwaka et al., 2016). Additionally, participants resorting to traditional treatment for lack of money is consistent with the work of Park and colleagues (Park et al., 2015). Similarly several other studies have reported the financial hardship and difficulty that cancer patients experiencing pain go through with their
treatment (Aziato & Adejumo, 2015; Martinez et al., 2014; Nuhu et al., 2009). Furthermore, participants’ inability to purchase their pain medications hence experiencing severe pain concords with previous studies which associated high socioeconomic status with reporting of lower pain intensity and vice versa (Ham et al., 2016; Martinez et al., 2014). Consequently, this may also impact negatively on participants’ quality of life (Ham et al., 2016). In view of this, clinicians managing chronic pain among advanced cancer patients should take cognisance of their patients’ economic status as well as other needs in selecting their intervention to optimise their pain management (Schellack & Annor, 2016; Vargas-Schaffer & Cogan, 2014). Additionally, gradual enrolment of cancer treatment including pain management on the NHIS benefit package may help to reduce participants’ financial constraint as well as enhancing early presentation among patients (Aziato & Adejumo, 2015).

In this current study, the findings acknowledged the influence of health professionals’ attitude on participants’ pain experiences. Participants perceived health professionals as helpful and empathetic whereas others were seen as unhelpful and unaffectionate. Participants described health professionals as helpful and empathetic because they responded to their calls, served their due medications, were educated on the pain and their cancer and frequently checked on them to know how they were fairing as well as reassuring them during their pain experience. Conversely, those who were unhelpful and unaffectionate insulted them and ignored them during their pain experience especially when they needed them for assistance. Others were unwilling to serve them with their analgesics even when the time was due and were uncompromising in terms of advocating for patients. Findings of this study suggested that, helpful and empathetic attitudes on the part of health professional improved the participants’ experience whereas the unhelpful and unaffectionate attitudes impacted negatively on their emotions and
prevented them from communicating their pain. These findings corroborates other studies where health professionals were perceived to be caring and empathetic and consequently improving patients’ pain (Aziato & Adejumo, 2015; Craft et al., 2016; Rustoen et al., 2009; Torres et al., 2016).

However, the poor attitude of health professionals with its negative impact on pain management in this study which is congruent with other studies (Moceri & Drevdahl, 2014; Schreiber et al., 2014; Torres et al., 2016; Tse & Ho, 2014) may be due to inadequate knowledge and professional skills on cancer pain and its management (Rustoen, Geerling, Pappa, Rundstrom, Weisse, Williams, Zavratnik, Kongsgaard, et al., 2013; Schreiber et al., 2014; Tse & Ho, 2014). While this study did not interview health professionals to confirm participants’ negative views about the attitude of some of the health professionals, the imperativeness of health professionals caring for advanced cancer patients to undergo regular training on cancer pain and management as well as professional coaching to improve upon their professionalism and effective pain management (Rustoen, Geerling, Pappa, Rundstrom, Weisse, Williams, Zavratnik, Kongsgaard, et al., 2013; Schellack & Annor, 2016; Schreiber et al., 2014; Tse & Ho, 2014). However, further studies focusing of health professionals’ attitude on cancer related pain and its management may enhance better understanding in the context of the researchers’ setting.

5.9 Summary of the discussion

The experience of chronic pain among advanced cancer patients is multidimensional and these dimensions are interrelated. Chronic pain among advanced cancer patients is experienced at several locations of the body and may be dependent on the type of cancer and the stage of advancement. Chronic pain among advanced cancer patients varied in terms of pain quality and could be categorised into nociceptive and
neuropathic pain. It is generally perceived to be severe. However, the intensity varies with time with the most severe intensity occurring at night which may probably be due to disturbed sleep and inactivity.

Knowledge on pain and its management is influenced by the patients’ literacy/educational status and level as well as pre-counselling on pain. It enhances coping and adherence to pain management. Attitude and beliefs regarding chronic pain and its management and the meaning patients associate with their pain as well as how the pain influence their thought are significant in effective pain management and improved quality of life among cancer patients. The health professionals’ choice of education/counselling and the level of vigilance as well as the pain management approach may take cognisance of the patients’ knowledge, attitude and beliefs regarding the pain and its management as well as the interpretation the patient give to the pain and the influence of the pain on his/her thoughts.

Advanced cancer patients respond to their pain behaviourally and affectively. The expression of pain is done non-verbally using pain related behaviours and verbally by reporting the presence of pain. However, some patients may exhibit stoicism for reasons including fear of stigmatisation, misconception of nurses being aware of their pain and the quest to maintain family happiness. Pain related symptoms such as sleeplessness, fatigue and sexual challenges together with emotional responses such as depression, anxiety; anger and fear may negatively impact on patients’ pain management as well as their overall quality of life. The support system, upbringing, cultural and belief system also play a role in chronic pain experience and management.

Several measures such as hoping, praying, enduring, ignoring, diverting attention, taking analgesics, engaging in activities, isolating self are used by advanced cancer patients to cope with their pain. Similarly, they are likely to seek treatment for their pain
and cancer from complementary and alternative medicine sources mainly because of financial difficulty, accessibility, search for inner peace and comfort. Chronic pain management is apparently based on pharmacologic agents as against a combination of both pharmacologic and non-pharmacologic which is regarded to be effective; suggesting inadequate interdisciplinary engagement in the management of the participants’ pain.

5.10 Evaluation of model used

The multidimensional Model of Cancer Pain (Ahles & Martin, 1992) was used as a conceptual framework for this study. Five out of the six main constructs of the model were supported in this study. The objectives of the study were developed based on the constructs of the model used in the study: sensory, cognitive, behavioural, affective and sociocultural dimensions. The sixth construct of the model: physiological dimension was not explored in this study because physiological factors were not investigated. The model was found to be very useful in exploring and describing chronic pain experiences among advanced cancer patients.

The sensory dimension of pain was described in terms of the location, quality and intensity of the pain in the model. This was consistent with the current study which also described chronic pain among advanced cancer patients as being multi-sited. The pain was described in terms of known pain quality descriptors such as burning, sharp, tingling, piercing and pulling. Additionally, participants described the intensity of their chronic pain to be severe. Therefore, the sensory dimension of chronic pain experience in the study supports the model.

The cognitive dimension of the model describes the knowledge of the patient about the pain, cognitive level, attitude and beliefs, meaning of the pain, the coping style as well as the influence of the pain on thought processes. In support of the model by the current study, chronic pain experience was influenced by participants’ knowledge about the pain,
their attitude and beliefs about the pain, the meaning associated with the pain and the influence of the pain on the patient's thoughts. However, the cognitive level reported in the model was described in the same way as knowledge about the pain in this study. Subsequently, it was perceived to be synonymous to knowledge by the participants. Furthermore, coping strategies which was both cognitive and behavioural emerged from the data in this study as opposed to coping style in the model and therefore was categorised as a separate theme in the study.

The behavioural dimension of the model describes the pain behaviours exhibited by the patient, communication of the pain and pain associated symptoms including sleep and fatigue. In the current study, the behavioural dimension identified supported the model. Chronic pain was expressed in terms of pain related behaviours such as crying, moaning, groaning, holding and rubbing the affected body part. Others reported their pain verbally whereas some exhibited stoicism. The pain was also associated with other symptoms such as disturbed sleep fatigue and sexual challenges.

The Multidimensional Model of Cancer Pain describes the affective dimension of pain experience as the emotional responses to the pain and includes mood, depression, anxiety, fear and suffering. In support of the model, the current study identified depression, anger, anxiety and fear as affective dimension of chronic pain experiences among advanced cancer patients.

The sociocultural dimension of pain experience in the model describes the influence of the patients’ cultural background, the family dynamics and the caregiver perspective. The current study also identified sociocultural dimension of chronic pain experience among advanced cancer patients. Participants’ support networks were mainly the family members and the church and they played significant roles in the chronic pain experiences. The study also identified that, participants’ culture and belief system, gender
and the upbringing influenced their perception, expression and management of the pain. For instance, the male gender was perceived to be strong and enduring and was not expected to cry while in pain as compared to their opposite gender. Invariably, the sociocultural dimension of the model is supported by the findings in this study. Though this study did not interview the caregivers, participants in the study gave their perception of the caregivers which according to them influenced their chronic pain experiences.

However, other themes emerged from the data which were not consistent with the model. While the model made mention of coping style of the participant under cognitive dimension, the present study identified pain coping strategies that advanced cancer patients adopted to deal with their chronic pain. The study identified coping strategies which were both cognitive and behavioural in nature and could not unilaterally categorize them under cognitive dimension of pain experience.

Additionally, participants’ approach to managing chronic pain: orthodox and complementary and alternative medicine as well as the challenges they encountered such as economic challenges and health professionals’ attitude influenced chronic pain experiences among the participants in this study. The MMCP in the state as it was adopted could hardly explore the management approaches and the challenges encountered among cancer patients.

5.10.1 Suggestions for model modification

The researcher therefore recommends that, the model should be modified to include pain coping strategies as a major construct to the model which also influences the pain experiences among advanced cancer patients.

Finally, there is the need to include pain management approaches as well as challenges encountered by patients in the model for an expansive and in-depth
understanding of pain experience among cancer patients which may be of much significance in improving cancer patients’ quality of life.
CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSIONS AND RECOMMENDATIONS

6.0 Introduction

This chapter focuses on the summary of the study including the key findings, its implications on nursing practice, management, education, policy and further research. The chapter further discusses the limitations to the study and conclusions drawn from the study. Finally, this chapter proffers recommendations based on the study.

6.1 Summary of the study

This study sought to explore and describe chronic pain experiences among ACP in the Accra Metropolis with specific interest in describing the characteristics of the pain, exploring the cognitive influence on CP experiences, exploring how these patients respond to their CP. Additionally, to describe the sociocultural influence on CP experiences and to investigate the coping measures adopted by ACP when in pain. The Multidimensional Model of Cancer Pain by Ahles and Martin, (1992) was used as the conceptual framework to guide the study. Literature was reviewed based on the objectives of the study as well as the domains of the model guiding the study (MMCP). The researcher employed a qualitative approach with exploratory-descriptive design for the study. Participants were recruited purposively and a semi-structured interview guide developed based on the objectives of the study was used to elicit data on CP experiences among the participants. Data collection and analysis were done concurrently until the thirteenth participant where in-depth understanding of CP experiences among ACP was achieved and the interviews for the study ended after the thirteenth participant. All interviews were audio recorded and transcribed. Interviews conducted in English were transcribed verbatim whereas those
conducted in Twi (local dialect) were transcribe based on meaning in English and was given to an expert in the language for its accuracy. The data were analysed using thematic content analysis.

Participants’ chronic pain experiences were categorised into seven (7) themes: sensory dimension, cognitive dimension, behavioural dimension, affective dimension, sociocultural dimension, pain coping strategies and pain management. Each theme had sub-themes ranging between 2 to 4. Two of the themes: pain coping strategies and pain management were not consistent with the main constructs of the MMCP which guided the study. The findings suggest chronic pain was multi-sited among ACP and the number of pain locations increased with the cancer process. The quality of pain varied among participants and was described in terms of pain descriptors as well as other pain related phenomena. Participants rated their pain to be of high intensity with majority (8 out of 13 participants) rating it at 10 on a scale of 0 to 10. The intensity varied over time with the highest intensity mostly felt at night. The severity of participants’ pain was associated with factors such as: changing of participants’ body positions, engaging in activities such as exercising, working and talking and extremes of temperatures.

Participants were knowledgeable about their CP. They believed and hoped in God for a better outcome and they interpreted their pain as: a progression/persistence of their cancer, emergence of death and ineffective medication. Furthermore, CP impeded participants’ concentration and they became preoccupied with death wish, suicidal ideations and/or suicidal tendencies.

Chronic pain was expressed non-verbally using pain behaviours such as crying, moaning, groaning, holding/rubbing affected parts. Conversely, CP was verbally communicated when it became severe and was reported to individuals participants perceived to be capable of assisting them with their pain. Participants’ reluctance to report
pain was due to fear of gossip, perception that nurses are aware of their pain and to maintain family happiness. They exhibited pain related symptoms such as disturbed sleep, fatigue and others were affected sexually.

Emotionally, participants were depressed mainly because they were unable to perform those activities they used to perform due to the pain. Others were engulfed with anxiety and fear which were associated with the anticipation of pain especially at night and when travelling as well as the side effects of the analgesics they were taking.

Participants’ support networks including the family, church, friends and other significant people and their upbringing influenced their CP experiences. Similarly, their culture and belief system also influenced the pain experience. The male gender was perceived to be strong and enduring and they were mostly expected to endure pain without crying.

Participants employed varieties of cognitive, behavioural and spiritual measures to cope with their CP. Coping strategies such as hoping/faith in God, not thinking about pain, diverting attention and positive thinking praying and taking analgesics were employed by participants. Other coping strategies participants used to cope with their pain were: drinking a lot of water, engaging in activities such as exercising, adjusting position, massaging affected parts as well as activity disengagement and self-isolation.

Participants used a variety of analgesics to manage their pain; most of which were prescribed and others from ‘over the counter’ sources. The analgesics relieved participants’ pain to an extent but for a shorter duration. Some of the participants took either an over dose or under dose of prescribed analgesics for purposes of maximum analgesia or fear of side effects respectively. Participants were also engaged in complementary and alternative medicine (CAM) such as herbal medicine, spiritual intervention and other non-pharmacological interventions. Financial challenges among the
participants and health professionals’ attitude also influenced the CP experience among the participants.

6.2 Implications

The findings from this study had implications which need to be addressed to ensure an improved quality of life of advanced cancer patients in Ghana. These implications have been categorised into nursing practice, management, education, and research as well as health policy.

6.2.1 Implications on nursing practice

Findings of this study identified the characteristics of CP among ACP to be multiple sited, varied in quality suggesting different types of pain (nociceptive and neuropathic) which may demand different strategies in their management and varied intensity in terms of time as well as worsening factors. Additionally, the cognitive influence, how ACP respond to their CP and the sociocultural influence on CP experiences were also revealed in this study. Finally, the coping strategies and the pain management approaches as well as challenges ACP encountered during their CP experiences have also been identified.

In view of these findings, the onus lies on the caregiver essentially the nurse to carry out thorough assessment and reassessment of the patients’ pain at regular interval to understand the pain on individual patient basis for effective management. Additionally, because nurses are perceived to spend more time with patients than any other health professional group, they are best placed to coordinate patients’ pain management between other health professionals to ensure multimodal and interdisciplinary pain management which seem to be lacking in this study. Similarly, integration of the family and the church and other significant individuals in the care of ACP is essential since they play significant role in the CP and cancer experience. More so, close monitoring and counselling sessions
for ACP experiencing CP are required to prevent them from committing suicide. Furthermore, education of ACP should take cognisance of the patients’ educational level, cultural and believe system to enhance patients’ knowledge on the pain, its management and the utilization of coping strategies. Finally, nurses at all times are expected to put up the best of professional attitude to enhance patients’ pain communication and management.

6.2.2 Implication on nursing management

Nurse Managers at facilities caring for ACP needs to strengthen their supervisory role to ensure the highest standard of professional discipline and attitude to ensure adequate assessment and reassessment of the patients’ pain for effective pain management. Additionally, regular pain assessment and management training should be organised to refresh and update nurses’ knowledge and skills on pain management.

6.2.3 Implication on nursing education

The high prevalence of severe pain among ACP coupled with the negative attitude of nurses identified in this study suggest nurses’ inadequate knowledge on CP among ACP; hence the need for nurses to be prepared adequately on pain management especially regarding cancer patients as well as those with advanced cancers for effective pain management. Additionally, there is the need to strengthen professional adjustment training for nurses before they are graduated from their training institutions to improve their professional attitude towards patients. Furthermore, the training of nurses should give equal attention to palliative care in order for nurses caring for advanced cancer patients to be well equipped to improve their patients’ quality of life.
6.2.4 Implication on nursing research

Though this study revealed the influence of health professionals’ attitude on CP management and experience among ACP, the findings are from ACP’s perspective. There is therefore the need for further studies into this phenomenon from the perspective of the health professionals to better inform practice. Additionally, the small sample size of this study due to its qualitative nature makes it difficult to generalise the findings among all ACP. Further studies with either mixed or quantitative approach may be required to determine the generalizability of these findings in the Ghanaian context.

6.2.5 Implication on policy

The findings of this study showed ACP experiencing pain encountered financial challenges with their pain management as well as that of the cancer which impacted negatively on their quality of life. These findings therefore suggest the need for policy direction toward other means of financing CP management among ACP including their inclusion in the NHIS.

6.3 Limitations

Even though the researcher confirmed the accuracy of the direct translation of interviews conducted in Twi into English based on meaning by an expert, the researchers’ inability to do a back translation may have a limitation on this study in terms of accurate description of participants’ CP experiences. Additionally, this study focused on a single geographical area in Ghana, Accra metropolis amid several other metropolises at different geographical locations in Ghana. There is therefore the need for further studies considering metropolis/regions at different geographical areas to be able to elicit data from diverse cultural and ethnic orientation for stronger generalizable findings. Furthermore, this study explored chronic pain experiences among advanced cancer patients in general and may not be able to describe chronic pain experiences among patients with specific
advanced cancer types. There is therefore the opportunity for further studies into chronic pain experiences among patients with specific advanced cancer types.

6.4 Conclusion

Chronic pain among advanced cancer patients has devastating effect on the quality of life of these patients. This study sought to explore and describe chronic pain experiences among advanced cancer patients in the Accra metropolis. The study established that, chronic pain experience among advanced cancer patients was multidimensional including sensory, cognitive, behavioural, affective and sociocultural dimension. Furthermore, the coping strategies and the pain management approaches employed by the participants as well as the challenges they encountered influenced their chronic pain experience.

Regular assessment and reassessment of the pain, multimodal and multidisciplinary approach towards chronic management and integration of available patients’ support networks including alternate care financing mode are imperative in ensuring effective chronic pain management and improved quality of life for advanced cancer patients.

The multidimensional model of cancer pain was therefore helpful in exploring and describing the various facets of CP experiences among ACP in this study. However, the researcher suggests that, a critical look should be taken for the inclusion of pain management and coping strategies adopted by cancer patients to the model.

6.5 Recommendations

Following the study, the researcher proffers the following recommendations to the Ministry of Health (MoH), Nursing and Midwifery Council of Ghana (NMC),
Management of Ridge Hospital and KBTH to help manage CP effectively and improve the quality of life of ACP.

6.5.1 Recommendations to MoH

- Ensure the training of health professionals (Clinicians) such as nurses include pain management for various chronic ailments such as cancer to improve clinicians’ knowledge and skills in pain management.
- Lobby government to include cancer related symptom treatment such as pain management in the NHIS benefit package and gradually include cancer treatment to moderate the financial burden on cancer patients and improve their quality of life.

6.5.2 Recommendations to NMC-Ghana

- Pain management should be integrated in the current training curriculum for nurses and midwives to enhance their knowledge and skills on effective pain management.
- Enforce the teaching of professional adjustment in nursing and midwifery training institutions as well as refresher training of practicing nurses and midwives to enhance the right professional attitude towards patients.
- Include human resource management in the training curriculum for nurses and midwives and enforce its teaching to enhance the capacity of nurses in coordinating pain management between the various professionals in the pain management team.
6.5.3 Recommendations to management of Ridge Hospital

- Regular (quarterly) in-service training should be organised for the clinical staff on pain management including assessment of pain to update the staff’s knowledge and skills for effective pain assessment and management.

- Establishment of pain clinics to prioritise pain management among cancer patients for an improved quality of life among the patients.

- Adopt multidisciplinary approach to pain management among cancer patients.

- Provision of resources (human and infrastructural) necessary for multidisciplinary management of pain in the facilities with emphasis on palliative care for those with advanced cancers.

- Improve health professional-patient interaction through customer care workshops to enhance health professionals’ attitude and pain communication among patients.

- Develop protocol for pain assessment and management putting into consideration the sociocultural and religious beliefs as well as the non-verbal pain expression behaviours.
Chronic Pain Experiences in Advanced Cancer

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Chronic Pain Experiences in Advanced Cancer


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APPENDICES

APPENDIX A: Information sheet and Consent form

NMIMR-IRB CONSENT FORM TEMPLATE

Title: Chronic pain experiences among advanced cancer patients in the Accra Metropolis

Principal Investigator: Frank Delasi Amenorpe

Address: School of Nursing, College of Health Sciences, University of Ghana,
P. O. Box LG 43, Legon - Ghana.

General Information about Research

Majority of patients who suffer from cancer during the late stages of the disease go through pain. This pain affects them in several ways. This study is therefore seeking to describe persistent pain experiences among patients with advanced cancer in the Accra metropolis. Your views will be sought on the nature of pain you are going through, the meaning you attach to the pain, how the pain affect your daily living as well as how you cope with it. This will be done through an interview that will last between 45 to 60 minutes in English, Twi or Ewe. There is no right or wrong answer and therefore you are free to share your views on questions asked. Your views will help understand what advanced cancer patients with pain go through. You will be required to sign or thumbprint a consent form following your acceptance to be part of the study. The interview will be audio recorded.

Possible Risks and Discomforts

The researcher does not anticipate any harm on you for taking part in this study. However, you may be emotional about telling your story. When that occurs, the session will be rescheduled at your convenience and you will be referred to a clinical psychologist, Bridget Amoako-Atta, Tel: 02419119001, email: b.amoakoatta@gmail.com who can talk to you and relieve you of your emotions without any financial implications to you.

VALID UNTIL
01 NOV 2017

APPROVED DOCUMENT

University of Ghana  http://ugspace.ug.edu.gh
Possible Benefits

You may not have any direct benefit at the moment; however, your involvement in this study will give the researcher a better understanding of pain experiences among advanced cancer patients in Ghana. Consequently, this will improve pain management and shape health policies to the benefit of advanced cancer patients experiencing pain.

Confidentiality

Any information that will show your identity will be protected to the best of the researcher’s ability. However, a false name will be attached to your information for this interview to ensure you are not known by others. Information from other participants will be put together as a report without separating them. In addition to the researcher, the supervisors may have access to the data collected during the research process but will be used solely for academic purposes. The data will also be used for teaching and publication and will be kept for a maximum of five (5) years under lock and key at the School of Nursing, University of Ghana following the completion of the study.

Compensation

There will not be any compensation for your participation in the study. However, you will only benefit from the cost of transport if the interview is conducted outside your home and snacks to refresh you after the interview.

Voluntary Participation and Right to Leave the Research

Your participation in this study is voluntary. You therefore have the right at any point in the course of the study to withdraw your participation without any explanation.

Contacts for Additional Information

In case of any challenges, questions or clarification, you may contact any of the following:

Frank Delasi Amenpor
School of Nursing, University of Ghana, Legon, Accra.

Email: fdelasiamenorge@yahoo.com

Phone number: 0243779761

Dr. Lydia Aziato (Senior Lecturer)

School of Nursing, University of Ghana, Legon, Accra.

Email: aziatol@yahoo.com

Phone number: 0244719686

Prof. Ama de-Graft Aikins

University of Ghana, Legon, Accra.

Email: adajkins@ug.edu.gh

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh
VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title: Chronic pain experiences among advanced cancer patients in the Accra Metropolis has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date

Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date

Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date

Name Signature of Person Who Obtained Consent
APPENDIX B: Interview guide

Data Collection Instrument (interview guide)
Research Topic: Chronic pain experiences among advanced cancer patients in the Accra Metropolis

A. Background Information Form

1. Age (years): 18 - 29 [ ]; 30 - 49 [ ]; 50 - 69 [ ]; 70 and above [ ]
2. Place of residence ..........................................
3. Nationality ....................................................
4. Marital Status ................................................
5. Number of children ..........................................
6. Occupation ...................................................
7. Level of education .........................................
8. Languages spoken ..........................................  
9. Religion .......................................................  
10. What type of cancer have you been diagnosed of? ..........................................
11. How long have you been diagnosed of this cancer? .................................
12. Which type of cancer treatment are you receiving? ...................................
13. How long have you been experiencing the pain? ....................................
B. Guiding questions

**Main question:** please can you share with me how the pain started?

Sub-questions (Probe as needed).

1. Can you please share with me the nature/characteristics of the pain?
   
   **Probe:**
   
   - Severity
   - Location
   - Quality/describing words
   - Worsening/relieving

2. Please tell me what you think about the pain
   
   **Probe:**
   
   - Meaning
   - Beliefs
   - Strength and weaknesses (coping)
   - Impact on reasoning

3. Can you please describe how you feel with the persistence of the pain?
   
   **Probe:**
   
   - Anxiety
   - Depression
   - Suffering
   - Fears

4. Please can you share with me a typical day of your life with pain?
   
   **Probe:**
   
   - Communication of pain
   - Influence on quality of life (fatigue, sleep, work, other activities)
5. Please how has the pain affected your life?

Probe:

• Socialization
• Entertainment/leisure
• Family and societal support
• Finances

6. Please share with me any recommendations to help other patients in the same situation?

7. Is there anything else you would like to tell me?
APPENDIX C: Introductory and Permission letter

UNIVERSITY OF GHANA
SCHOOL OF NURSING

SON/F.11
Ref. No.:.................................................................

October 3, 2016

The Medical Director
Ridges Hospital
Accra.

Dear Sir/Madam,

INTRODUCTORY LETTER

I write to introduce to you Frank Delasi Amenporpe, an M.Phil Year II student of the School of Nursing and Midwifery (formerly School of Nursing), University of Ghana, Legon. He is conducting a research on “Chronic Pain Experiences among Advanced Cancer Patients in the Accra Metropolis”.

I should be most grateful if you could kindly assist him with the information that he may require.

Thank you.

Yours faithfully,

Dr. Lydia Azinto
Senior Lecturer
THE MEDICAL DIRECTOR IN-CHARGE
RIDGE HOSPITAL
ACCRA.

Dear Sir,

PERMISSION TO USE RIDGE HOSPITAL AS PARTICIPANT RECRUITMENT OUTLET.

I am Frank Delasi Amenope, a second year MPhil nursing student at University of Ghana-Legon. I will be very grateful if your high office could grant me the permission to recruit participants from the surgical outpatient department to partake in a study titled: **Chronic pain experiences among advanced cancer patients in the Accra Metropolis**.

The study is aimed at exploring and describing chronic pain experiences among advanced cancer patients in the Accra Metropolis and when completed will inform clinicians about the experiences and concerns of cancer patients for an improved care.

Attached is a mini proposal for the study for your perusal.

A copy of the full protocol has been submitted to GHS-Ethical Review Committee awaiting approval.

I look forward for a favorable response.

Thank you.

Frank Delasi Amenope
(Tel: 0243779761)
APPENDIX D: Ethical clearance from Nuguchi IRB

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Science
University of Ghana

INSTITUTIONAL REVIEW BOARD
Post Office Box 1LG 581
Legon, Accra
Ghana

2nd November, 2016

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824
NMIMR-IRB CPN 013/16-17
IORB 00001276
IORG 0000908

On 2nd November, 2016, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL: Chronic pain experiences among advanced cancer patients in the Accra Metropolis

INVESTIGATOR: Frank Delasi Amenorpe, MPhil Cand.

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 1st November, 2017. You are to submit annual reports for continuing review.

Signature of Chair: ........................................
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)
APPENDIX E: Ethical clearance from Ghana Health Service- ERC

The Ghana Health Service Ethics Review Committee has reviewed and given approval for the implementation of your Study Protocol.

<table>
<thead>
<tr>
<th>GHS-ERC Number</th>
<th>GHS-ERC: 171116</th>
</tr>
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<tr>
<td>Project Title</td>
<td>“Chronic Pain Experiences among Advanced Cancer Patients in the Accra Metropolis”</td>
</tr>
<tr>
<td>Approval Date</td>
<td>3rd January, 2017</td>
</tr>
<tr>
<td>Expiry Date</td>
<td>4th January, 2018</td>
</tr>
<tr>
<td>GHS-ERC Decision</td>
<td>Approved</td>
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This approval does not cover material transfer outside the country.

This approval requires the following from the Principal Investigator:

- Submission of yearly progress report of the study to the Ethics Review Committee (ERC)
- Renewal of ethical approval if the study lasts for more than 32 months,
- Reporting of all serious adverse events related to this study to the ERC within three days verbally and seven days in writing,
- Submission of a final report after completion of the study
- Informing ERC if study cannot be implemented or is discontinued and reasons why
- Informing the ERC and your sponsor (where applicable) before any publication of the research findings.

Please note that any modification of the study without ERC approval of the amendment is invalid.

The ERC may observe or cause to be observed procedures and records of the study during and after implementation.

Kindly quote the protocol identification number in all future correspondence in relation to this approved protocol

SIGNED: CYNTHIA BANNERMAN (GHS-ERC CHAIRPERSON)

Ce: The Director, Research & Development Division, Ghana Health Service, Accra
APPENDIX F: Demographic profile of participants

<table>
<thead>
<tr>
<th>Pseudonym of participant</th>
<th>Age of participant</th>
<th>Place of residence</th>
<th>Marital status</th>
<th>Occupation</th>
<th>Level of education</th>
<th>Language spoken</th>
<th>Religion</th>
<th>Type of cancer</th>
<th>Therapy</th>
<th>Pain duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emefa</td>
<td>36</td>
<td>Abelemkpe</td>
<td>D</td>
<td>Hairdresser</td>
<td>J.H.S</td>
<td>Ewe</td>
<td>C</td>
<td>Breast cancer</td>
<td>Chemotherapy</td>
<td>3 years</td>
</tr>
<tr>
<td>Betty</td>
<td>31</td>
<td>Dansoman</td>
<td>S</td>
<td>teacher</td>
<td>Tertiary</td>
<td>English</td>
<td>C</td>
<td>Breast cancer</td>
<td>Surgery</td>
<td>4 months</td>
</tr>
<tr>
<td>Ken</td>
<td>61</td>
<td>Taifa</td>
<td>M</td>
<td>Plastic waste recycler</td>
<td>Tertiary</td>
<td>English Hausa Twi</td>
<td>Ms</td>
<td>Rectal cancer</td>
<td>Surgery</td>
<td>4 months</td>
</tr>
<tr>
<td>Erica</td>
<td>72</td>
<td>Sowutuo m</td>
<td>W</td>
<td>Unemployed</td>
<td>Elementary</td>
<td>Twi Fante</td>
<td>C</td>
<td>Ovarian cancer Hepatocellular cancer</td>
<td>Surgery</td>
<td>3 months and 3 weeks</td>
</tr>
<tr>
<td>Mary</td>
<td>44</td>
<td>Achimota</td>
<td>W</td>
<td>Trader</td>
<td>Illiterate</td>
<td>Twi Ga Ada</td>
<td>C</td>
<td>Uterine cancer</td>
<td>Surgery</td>
<td>7 months</td>
</tr>
<tr>
<td>Edmund</td>
<td>52</td>
<td>Amasaman</td>
<td>M</td>
<td>Electrician</td>
<td>Tertiary</td>
<td>English Twi</td>
<td>C</td>
<td>Prostate cancer</td>
<td>Surgery</td>
<td>1 year +</td>
</tr>
<tr>
<td>Esi</td>
<td>54</td>
<td>Lashibi</td>
<td>M</td>
<td>Trader</td>
<td>J.H.S</td>
<td>Twi Ewe</td>
<td>C</td>
<td>Breast cancer</td>
<td>Surgery</td>
<td>2 years</td>
</tr>
<tr>
<td>Evelyn</td>
<td>48</td>
<td>Nima</td>
<td>M</td>
<td>Trader</td>
<td>Middle school</td>
<td>English Twi Ga</td>
<td>C</td>
<td>Breast cancer</td>
<td>Surgery Chemotherapy</td>
<td>4 months</td>
</tr>
<tr>
<td>Emmanuel</td>
<td>57</td>
<td>Lapaz</td>
<td>M</td>
<td>Security</td>
<td>Form 4</td>
<td>English Twi Ewe</td>
<td>C</td>
<td>Bladder cancer</td>
<td>Surgery</td>
<td>5 months</td>
</tr>
<tr>
<td>Edem</td>
<td>26</td>
<td>Tabora</td>
<td>S</td>
<td>Student</td>
<td>Tertiary</td>
<td>English Twi Ga</td>
<td>C</td>
<td>Osteosarcoma with lung metastasis</td>
<td>Chemotherapy Surgery</td>
<td>1 year and 3 months</td>
</tr>
<tr>
<td>Elorm</td>
<td>56</td>
<td>Ridge</td>
<td>M</td>
<td>Civil servant</td>
<td>Tertiary</td>
<td>English Hausa</td>
<td>Ms</td>
<td>Prostate cancer</td>
<td>Chemotherapy Surgery</td>
<td>5 months</td>
</tr>
<tr>
<td>Afua</td>
<td>49</td>
<td>Ablekum – Agarpe</td>
<td>M</td>
<td>Evangelist</td>
<td>S.H.S</td>
<td>Twi</td>
<td>C</td>
<td>Vulva cancer</td>
<td>Surgery</td>
<td>8 months</td>
</tr>
<tr>
<td>Edwin</td>
<td>68</td>
<td>Taifa</td>
<td>M</td>
<td>Gold miner</td>
<td>S.H.S</td>
<td>English Twi</td>
<td>C</td>
<td>Prostate cancer</td>
<td>Chemotherapy</td>
<td>4 months</td>
</tr>
</tbody>
</table>

**Keys:** M-Married, S- Single, W- Widowed, D- Divorced, C- Christian, Ms- Muslim