EXPLORING THE WELLBEING OF FAMILY CAREGIVERS OF WOMEN WITH
ADVANCED BREAST CANCER A STUDY IN THE ACCRA METROPOLIS

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DECLARATION

I, Beulah Alomele do hereby declare that with the exception of references made from other researches and writers which have been duly acknowledged, this thesis is my original research work which has been supervised. This work has neither in whole or part been presented to any institution for the award of any degree.

Beulah Alomele

Date

This thesis presented for examination with our approval as supervisors.

Dr. Lydia Aziato

Date

Ms. Lillian Ohene Akorfa

Date
DEDICATION

This work is dedicated to my husband Mr. Sylvester Hatsu and my children Delali Kojo and Yayra Afua Hatsu.
ACKNOWLEDGEMENTS

The immense contributions received from different people have made this work possible.

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LIST OF ABBREVIATIONS

ABC………………….. Advanced Breast Cancer

QoL…………………..Quality of Life
ABSTRACT

Breast Cancer is the leading cause of death and most commonly diagnosed cancer in women. In the advanced stage of the disease, the involvement of the family is required in the care of the patient at home. Advanced Breast Cancer (ABC) does not affect the woman alone but also the wellbeing of the family caregiver. The purpose of this study was to explore the wellbeing of family caregivers of women with advanced breast cancer in the Accra Metropolis. The Quality of Life Model Applied to Family Caregivers by Betty Ferrell (1991) was the organizing framework for this study. A qualitative exploratory descriptive design was employed. A purposive sampling technique was used and data were saturated with the thirteenth participant. Data were collected with a semi-structured interview guide. All interviews were audio taped and transcribed verbatim. Data were analyzed using thematic content analysis. During the study, anonymity and confidentiality were ensured. The four themes stipulated by the model; the physical, social, psychological and spiritual well-being of family caregivers was identified. Emerging themes were beliefs about breast cancer, other sources of treatment and support. Most of the caregivers experienced body pain, sleep disruption, fatigue, and loss of appetite. They assisted their sick relatives with activities of daily living. Their social wellbeing was affected by Isolation, financial burden, secrecy and employment challenges. Psychologically, they expressed fears, were depressed, lost concentration, were empathetic and were anxious. Spiritually, caregivers sought meaning to sick relatives’ illness by questioning God, became more religious and developed positive attitudes. The caregivers had different beliefs about the cause of breast cancer; sought other forms of treatment for their patients and received support from church and family members. It was recommended that caregivers be counseled and educated.
CHAPTER ONE

1.0 Introduction

This chapter presents the background to the study, the problem statement, the purpose, objectives and the research questions. The significance of the study and the operational definitions of keywords used are also presented.

1.1 Background to the Study

Breast cancer is a menace to society; it has claimed the lives of many women (Ferlay et al., 2015; Leong et al., 2010). Documented evidence indicates that globally, it records the highest incidence among cancer cases in women (Bray, Ren, Masuyer, & Ferlay, 2013; DeSantis, Ma, Bryan, & Jemal, 2014; Torre et al., 2015). Almost 1.7 million newly confirmed cases of female breast cancer, as well as 522,000 deaths from breast cancer have been reported (GLOBOCAN, 2012). It is estimated that, 3.2 million women worldwide will have breast cancer by 2050 (Tao et al., 2015).

In the United States of America (U.S.A), 230,480 new cases of advanced breast cancer (ABC) and 39,520 breast cancer deaths have been reported (DeSantis, Siegel, Bandi, & Jemal, 2011). In Korea, 17,792 new cases of breast cancer and a crude incidence rate of female breast cancer, including advanced breast cancer of 70.7 cases per 100,000 women have been reported (Z. Kim et al., 2015). In Canada, despite regular mammography in elderly women, death from breast cancer is on the increase (Miller et al., 2014). Studies indicate that, women with breast cancer seek medical help late and these accounts for majority of advanced breast cancer deaths (Aziato & Clegg-Lamptey, 2015).
Ghana is no exception to the menace of breast cancer. Among cancer cases in women, breast cancer records the highest with 33.9% of all cancer cases (Laryea et al., 2014). Most of the breast cancer cases progress to the advanced stage of the disease as a result of late reporting. Factors that account for advanced breast cancer include poverty, ignorance and resorting to ineffective alternate medicine such as spiritualists and herbalists. These actions usually result in death from advanced breast cancer (Ohene-Yeboah & Adjei, 2012).

Socio-culturally, the breast is a symbol of womanhood, an organ of reproduction and enhances the image, beauty and attractiveness of a woman to the opposite sex (Mosher et al., 2013). Thus, breast cancer, and advanced breast cancer for that matter, is a threat to a woman’s image and womanhood. It leads to great physical, social and psychological distress in females (Choi et al., 2014; Mosher et al., 2013). The hair loss associated with chemotherapy further compounds the social and psychological health of the woman (Amiri-Kordestani et al., 2014). Her inability to have satisfactory sexual intercourse with her spouse threatens the very core of her marriage (Ussher, Perz, & Gilbert, 2012). Also, the impending death associated with it distresses the woman further (Uchida & Akechi, 2015).

The care of women with advanced breast cancer demands the involvement of family caregivers sometimes in other contexts (Girgis, Lambert, Johnson, Waller, & Currow, 2013). A family is a group of people related by marriage, blood or adoption. When the group comprises of the mother, father and their children, it is termed the nuclear family. However when it includes father mother, children uncles, aunts, cousins and grandparents, then it is referred to as the extended family. In Africa, the extended family system is practiced widely (Nwogugu, 2014). However, it appears be losing its importance in this era and age.
The family has been of immense support to the healthcare delivery system worldwide over the years. Family involvement in the care of a patient is crucial because of the support they render (Stamataki et al., 2014). They play a major role in decisions regarding the care of their sick relatives (Laidsaar-Powell et al). They give emotional, financial and physical support to their sick relations. With increased incidence of chronic diseases such as Advanced Breast Cancer (ABC), early discharge from the hospital coupled with high cost of treatment, the phenomenon of family care giving is on the rise (Henriksson, Årestedt, Benzein, Ternestedt, & Andershed, 2013). Studies have shown that, the human resource base of the healthcare delivery system in most low and middle income countries is woefully inadequate (Gupta et al., 2011). Thus, professional nursing care rendered to patients and clients is of low quality (Douri, 2015). This has led to the involvement of the family in the care of their sick relatives.

In Africa and Ghana in particular, the family, especially females play an immense role in the life of a sick person (Nukunya, 2003). These women have other social and economic commitments, thus, they require a high degree of resilience to combine these commitments with caring for sick relatives (Manderson, Block, & Mkhwanazi, 2016). When a woman is diagnosed with ABC; it has an impact on the wellbeing of family members who take care of the woman. Family caregivers are relatives or friends who give any form of physical, social, spiritual or psychological care to the patient and they do not charge the patient for the care they render (Roth, Fredman, & Haley, 2015). Death from ABC is inevitable be it in the long or short term. The thought of impending bereavement by family caregivers, affects their psychological wellbeing (Kim, Shaffer, Carver, & Cannady, 2015). The high cost of treatment of breast cancer poses financial burden on the family (Mao et al., 2013).
Advanced Breast Cancer is associated with sleeplessness, inability to perform self-care and pain. Family caregivers spend sleepless nights intermittently serving pain medication. They also perform the self-care needs for the patient. The sleeplessness and stress experienced by family caregivers during their care giving duties, compromises their immunity and takes a toll on their physical and psychological wellbeing (Northouse, Williams, Given, & McCorkle, 2012). Family caregivers are involved in running errands, shopping and other social activities on behalf of the patient. The care demand renders them socially isolated compromising their social wellbeing (Williams, 2014). Spiritually family caregivers pray to God for healing for their sick relative (Aziato & Clegg-Lamptey, 2015).

The world health organization asserts that, health encompasses physical, mental, social and spiritual wellbeing (WHO, 1998). The burden of family care giving, challenges the physical, psychological, social and spiritual wellbeing of family caregivers of women with advanced breast cancer (Williams & McCorkle, 2011). Judging from the impact of ABC on the health of family caregivers of women with ABC from the literature above, the quality of life model applied to the family caregiver by Betty Ferrell will underpin this study. This model examines the four dimensions of quality of life. These include the social, physical, spiritual and psychological dimensions (Hinds & King, 2011).

1.2 Statement of the Problem

In Ghana, there has been an increase in the incidence of ABC in recent times which has resulted in the death of many women (Laryea et al., 2014). Over the years, family caregivers have played very important roles in the care of their sick relatives. They still play a major role in the care of patients during and after discharge from the hospital. They provide financial and psychological support for their sick relatives on admission
(Henriksson et al., 2013). But there seems to be a dearth of literature on the wellbeing of family care givers of women with ABC in Ghana.

Studies have shown that, the burden of care giving compromises the health of Family caregivers of women with advanced breast cancer physically, psychologically, socially and spiritually (Leow, Chan, & Chan, 2014) however, the socio-cultural and economic factors that influence the setting where these studies were done are different from the Ghanaian setting. These have necessitated this research.

1.3 Purpose of the Study

The purpose of this study is to explore the wellbeing of family caregivers of women with advanced breast cancer in the Accra Metropolis.

1.4 Objectives of the Study

1- Explore the physical wellbeing of the family caregivers of women with advanced breast cancer

2- Investigate the social wellbeing of the family caregivers of women with advanced breast cancer

3- Identify the psychological wellbeing of the family caregivers of women with advanced breast cancer

4- Explore the spiritual wellbeing of the family caregivers of women with advanced breast cancer
1.5 Research Questions

1-What is the physical wellbeing of the family caregivers of women with advanced breast cancer?

2-What is the social wellbeing of the family caregivers of women with advanced breast cancer?

3-What is the psychological wellbeing of the family caregivers of women with advanced breast cancer?

4-What is the spiritual wellbeing of the family caregivers of women with advanced breast cancer?

1.6 Significance of the Study

The findings from this study will enhance the education of family caregivers of patients with advanced breast cancer to enable them to give better care to their sick relatives. It will serve as an important resource material for counsellors to enhance counselling of family caregivers of patients with advanced breast cancer. It would further add to the existing literature on cancer studies in Ghana. Finally, it would also enhance policy development by the ministry of health on family caregivers. It will also enhance the exploration of family centered care approach in adult healthcare in Ghana.
1.7 Operational Definition of Terms

Wellbeing: The physical, social, spiritual and psychological health status of the relative rendering care to women diagnosed with advanced breast cancer

Family Caregiver: Any member of the family responsible for the care of a sick family member diagnosed with advanced breast cancer.

Advanced Breast Cancer: A condition where breast cancer has spread to other parts of the body; and affected other structures in the body (Stage IV).

Physical Wellbeing: The ability to function well physically

Psychological Wellbeing: The ability to function well emotionally

Social Wellbeing: The ability to interact with patient and society as a whole normally

Spiritual Wellbeing: The ability to perform one’s normal religious duties normally

Family: Any person related by blood or adoption to a woman diagnosed with advanced breast cancer
CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This literature review seeks to discover studies that have been carried out on the wellbeing of family caregivers of women with advanced breast cancer. A comprehensive search was conducted in PubMed, Google Scholar, Science Direct, EBSCOhost, Willey as well as Taylor & Francis Online Libraries. The key words advanced breast cancer, informal caregiver, were used together with psychological, physical, social and spiritual effect on the family, and qualitative study in the literature search. A number of studies were identified. Many of the studies identified focused on the effect of cancer caregiving on family caregivers and the woman. The literature review took into account the justification for the use of the Quality of life (QoL) Model Applied to Family Caregivers. The rest of the chapter reviewed studies on the physical, social, psychological and spiritual wellbeing of family caregivers of women with advanced breast cancer. These comprise the constructs of the Quality of life model which underpins this study. Furthermore, literature was reviewed on the findings from this study. These include beliefs about the cause of breast cancer, other sources of treatment and support.

2.1 Justification for the Quality of Life model Applied to family caregivers

During the conceptualization of the study, the biopsychosocial model developed by Engel (1977) was one of the models considered. Although this model has the biological, psychological and social domains; which could guide the exploration of the wellbeing of family caregivers but it lacked a spiritual domain. Spirituality as a caregiver support is a key concept in the socio-cultural context of Ghana (Aziato, Acheampong & Kitidow, 2017). Thus, the absence of a spiritual domain to guide the exploration of the spiritual wellbeing of the study participants
resulted in the abandonment of this model. Furthermore, the biopsychosocial model focuses on the experiences of an individual diagnosed with a disease. However, the target population for this study was family members caring for a sick relative.

Another framework that was considered was the City of Hope Quality of Life model applied to caregiver communication burden. This model has the physical, social, psychological and spiritual domains. However, these domains were relevant to issues specific to difficulties associated with caregiver communication. On the contrary, this study aims at exploring the wellbeing of family caregivers holistically. Thus, this model could not be used

2.2 The Quality Of Life Model by Betty Ferrell

The Quality of Life model was initially developed to create a theory that defines the domains of quality of life in patients with cancer in order to gain insight into the lived experience of pain and fatigue and its effect on their health. The first model is sometimes referred to as the conceptual model of pain and quality of life (Hinds & King, 2011). In 1985, a theoretical model was developed by Padilla and Grant to explain the relationship between the nursing process and the dimensions of Quality of Life (QoL). Later, Ferrell, Wisdom and Wenz in 1989 created a conceptual framework out of the theoretical model which was used in the development and testing of the QoL instrument which was used in a survey. The QoL survey was designed to measure QoL as an outcome variable in the management of cancer pain (Ferrell, Grant, Borneman, Juarez, & Veer, 1999). Further studies were done in which the instrument was used to gather data about the relationship between pain and QoL (Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991). From these studies a conceptual model normally referred to as the City of Hope Model emerged to illustrate the influence of pain on the dimensions of QoL. The four dimensions of QoL included in this model were physical, social, psychological and spiritual
well-being (King & Hinds, 2011). This first model has generated other models, which includes the QoL Model Applied to Family Caregivers (shown in fig 1) which was developed in 2001. From the model, The Quality of Life (family version) where a thirty-seven item ordinal instrument has been developed to measure the Quality of Life of a family member caring for a patient with cancer.

According to the QoL Model Applied to Family Caregivers, the physical well-being refers to the physical functioning of the caregiver and health problems that may arise are fatigue, sleep disruption, function, nausea, appetite, constipation and aches and pain.

The social well-being involves the interaction of the caregiver with the patient and others. The parameters under the social well-being are isolation, role adjustment, financial burden, roles/relationships, affection/sexual function, leisure activities, burden and employment. The psychological well-being refers to the emotional functioning of the caregiver. The caregiver may experience anxiety, depression, helplessness, difficulty coping, fear, uselessness, loss of concentration, control and distress.

The Spiritual well-being refers to the spiritual impact of caring for a relative with cancer and involves meaning, uncertainty, hope, religiosity, transcendence and positive change.

The physical, social, psychological and spiritual well-being interacts to determine the overall QoL of the family caregiver. Culture has a great influence on the wellbeing of an individual. However, it is not included in the social wellbeing construct of the model.
FIGURE 1: QUALITY OF LIFE MODEL APPLIED TO FAMILY CAREGIVERS
The idea of QoL is essential to cancer nursing (Ferrell et al., 1992). The QoL Model Applied to Family Caregivers was developed specifically for relatives of cancer patients who are involved in one way or the other in the care of their relative. The model has all the domains which are found in other models like Padilla & Grants’ 1985 that sought to explain the relationship between the nursing process and the dimensions of QoL. The model also has all the components in Ferrans’ 1990 model on QoL. The domains in the model has also been used by researchers in studies on the effects of cancer on the QoL of patients and their family (Fujinami, Otis-Green, Klein, Sidhu, & Ferrell, 2012) and (Kim & Given, 2008) Hence, the wellbeing of family caregivers of women with advanced breast cancer will be explored by looking at their physical, social, psychological and spiritual well-being.

The Quality of life normally refers to a general sense of well-being and addresses several areas of life. QoL has different meanings such as: satisfaction, happiness, achievement of goals and personal control (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996). This study views QoL as the interactions of the physical, social, psychological and spiritual well-being of family caregivers of women with advanced breast cancer.

The term family caregiver refers to any person who gives help to another person who is ill. The helper could be a friend or a relative and their services are free. This care can be physical, social, psychological or spiritual (Roth et al., 2015). The family caregivers could also come from the nuclear or extended family. In Africa, the extended family system is widely practiced. However, it is losing its value in this era and age.

A study in China to investigate the QoL and related factors among cancer caregivers, the QoL- Family Version Tool was used to measure the QoL of family caregivers (Lu et al., 2010). In this study, authors omitted two of the items in the spiritual domain because they reported that
most Chinese do not have religious beliefs. Findings indicate that family caregivers gave a wide range of care including bathing of the patient to engage in other activities of daily living like shopping. Family Caregivers were distressed about their patients’ illness.

Thus, the Quality of Life Model Applied to Family Caregivers will be used to guide the research into the wellbeing of family caregivers of women with advanced breast cancer in the Accra Metropolis. There are diverse socio-cultural practices that influence the wellbeing of an individual. However, this is not included in the social domain of the Quality of Life Model Applied to Family Caregivers.

**2.3 Physical Wellbeing of the Family Caregivers**

Family caregivers are second patients with respect to their sick relatives (Obaidi & Al-Atiyyat, 2013). They experience diverse forms of stress in their caregiving activities (Stamataki et al., 2014); They subject themselves to irregular sleep (Lee, Yiin, Lu, & Chao, 2015), are often tired and lose the desire to eat as they provide care for sick relatives; this results in negative health consequences on their health (Bajwah et al., 2013; Sercekus, Besen, Gunusen, & Edeer, 2014; Stajduhar, 2013). On the contrary, some family caregivers in Ghana employ the services of private nurses to care for their sick relatives; thereby reducing the level of physical stress on them.

The task oriented nature of caregiving activities leads to constant exhaustion in caregivers (Peters et al., 2015). In a review to explore family caregiver challenges associated with cancer caregiving, findings indicate that caregivers experience pain, reduction in their weight, tiredness and lose appetite for food in the course of their caregiving activities (Girgis et al., 2013). Also, family caregivers maintain the personal and environmental hygiene of their ill relatives. They
bathe them, change their soiled diapers, wash their clothes, cook for them and accompany them to the hospital for doctors’ appointment (Glajchen, 2012).

Females play a greater role in family caregiving. Thus, the negative physical effects of caregiving is evident in their health (Akpan-Idiok & Anarado, 2014; Rollero, 2016; Jane M Ussher, Sandoval, Perz, Wong, & Butow, 2013), making them vulnerable to sickness (Williams, 2014). Family caregivers experience a feeling of helplessness in the course of their relatives’ sickness (Hashemi-Ghasemabadi, Taleghani, Yousefy, & Kohan, 2015) but others find fulfillment in rendering care (Turner et al., 2016). A study report indicate that, family caregivers performed chores in the home, provided care needs for their sick relatives day and night. They took them to hospital and liaised between healthcare providers and their sick relatives. They run errands and worked to earn income. These activities were overwhelming and resulted in inadequate sleep, exhaustion, poor health (Girgis et al., 2013) and inability to eat (Padmaja, Vanlalhruii, Rana, Tiamongla, & Kopparty, 2016).

Also, caregivers assist their sick and weak relatives to perform self-care needs (Xie et al., 2016). Family caregivers are directly involved in the day-to-day care of their sick relatives. Cooking, feeding and assisting them to have their bath are stressful activities which negatively impacts the health of caregivers (Quesada, Madrigal, Luna, & Perez-Carceles, 2015).

2.4 Social Wellbeing of the Family Caregivers

Family caregiving interferes with ones employment (Wadhwa, 2013). In Advanced breast cancer, the patient becomes dependent on the caregiver. This requires a longer stay with the patient (Badr et al., 2016). Findings from a study report reveal that, Family caregivers used all the money they had saved to care for their sick relatives. Others left their jobs because of the demand of caregiving (Nayak, George, Vidyasagar, & Kamath, 2014). Some absent themselves
from work regularly and in some cases resign completely in order to take care of their sick relatives (Girgis et al., 2013).

The apprehension associated with family caregiving, makes family caregivers unable to enjoy hobbies and recreational activities with their friends (Mosher, Jaynes, Hanna, & Ostroff, 2013). They sacrifice every time to meet a need of their sick relative. A study report indicates that, family caregivers are neither able to visit friends nor honour invitations to social gatherings as a result of the numerous caregiving activities they undertake for their sick relatives (Williams, 2014). Also, family caregivers of women with advanced breast cancer spend most of their time providing care for their sick relatives at the expense of their vacation (Shannon, 2015). In some other cases, leisure is simply nonexistent. (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013).

Sudden isolation from normal daily activities usually accompanies family caregivers of women with advanced breast cancer. A study conducted in Nigeria reveals that, some patients require complete care. Thus family caregivers constantly provide the needed care. This restricted the movement of such caregivers. The sick relatives rely on caregivers take care of their children (Akpan-Idiok & Anarado, 2014). A study in Korea, reports that, family caregivers cancel appointments on certain days because of a sudden change in their patient’s condition (Song et al., 2011).

Advanced breast cancer, has negative consequences on the sexual relationship between family caregivers who are husbands and their sick wives (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012). A study conducted in Australia, to ascertain the extent to which cancer caregiving affected the relationship between male spouses and their sick wives indicates that, there is low or no intimacy. This subsequently, affected communication and negatively impacted
the marital relationship; which made some men contemplate going for other women (Ussher, Wong, & Perz, 2011).

Factors such as culture and religious beliefs influence family caregivers in their caregiving activities. The Islamic religion allows a man to marry up to four women. In a qualitative study in Iran, to explore men’s sexual issues after breast cancer in their wives, findings reveal that, problems exist in the sex lives of spouses. Culture and religion play important role in the sexual adjustment of spouses (Nasiri, Taleghani, & Irajpour, 2012). Another study in Iran which aimed at describing and comparing the marital relationship, sexuality and marital adjustment of Israeli and Chinese husbands of women with breast cancer; involving 50 Israeli men and 50 Chinese men, reveal a lower frequency of sex amongst partners of women with breast cancer in both groups. Also, there was a significant difference between Israeli and Chinese husbands on sexual interest, pleasure and performance. Israeli men reported fewer sexual problems compared to the Chinese men (Woloski-Wruble, Dekeyzer Ganz, Jiang, Qiang, & Kadmon, 2012). However, the use of a convenient sampling method in this study, may not allow the findings of this study to be generalized.

Cancer caregiving is expensive and poverty makes family caregivers seek alternative means of treatment. This results in deaths from advanced breast cancer (Ohene-Yeboah & Adjei, 2012). The high costs of treatment usually deplete family caregiver’s finances. A study report indicates that, some family caregivers used all the money they had in the course of treatment for their sick relative and sometimes solicited for financial help from others (Girgis et al., 2013). In a similar study in Nigeria, findings indicate that, the degree of care received from family caregivers was dependent on the financial status of the sick relative (Akpan-Idiok & Anarado, 2014). Also, the high cost of cancer medications created a great deal of financial burden on some
husbands who are family caregivers (Kavanaugh, Kramer, Walsh, & Trentham-Dietz, 2015). In another study to estimate how much family caregivers spend in the treatment of cancer; and which areas required more financial input, findings reveal that, family caregivers spend more on medication and on meeting the needs of the patient at home (Hanly et al., 2013).

2.5 Psychological Wellbeing of the Family Caregivers

Apprehension is a phenomenon associated with family caregivers of cancer patients (Sklenarova et al., 2015). Advanced breast cancer is associated with distressful symptoms (Hackett, Godfrey, & Bennett, 2016) and has a poor prognosis; family caregivers may be preoccupied with uncertainties about the future of their sick relatives. This creates a state of helplessness in them. One cause of breast cancer is hereditary; this creates great fear in daughters of women with ABC (Ogce, 2013). Family caregivers lack information on specific interventions for sudden onset of symptoms experienced by their sick relatives. This worsens their plight (Tokem, Ozcelik, & Cicik, 2015).

Symptoms such as pain coupled with the poor prognosis of advanced cancer, increases the anxiety levels of family caregivers (Mosher, Ott, Hanna, Jalal, & Champion, 2015). The instability in the manifestation of symptoms as well as impending bereavement and its aftermath, further compounds the degree of fretfulness of family caregivers (Hendriksen et al., 2015). Family caregivers do not plan to become caregivers. The sudden assumption of such roles and the lack of skill for the role often create a lot of worry and emotional maladjustment for family caregivers (Seal, Murray, & Seddon, 2015).

Family caregivers find care giving quite distressful. In a document review to investigate how family caregivers experience distress in their caregiving duties, findings reveal that, the illness of a sick family member in itself results in emotional maladjustments for family
caregivers (Northouse, Katapodi, Schafenacker, & Weiss, 2012). Family caregivers are usually not sure of the outcome of the family member’s illness. In such situation, they become emotionally apprehensive (Mosher et al., 2013). In a related study to ascertain the views of family caregivers on end-of-life care, findings indicate that, it is emotionally distressful to see a relative die a slow and painful death (Hudson, Thomas, Trauer, Remedios, & Clarke, 2011).

Also, lack of information and skill on care, specific to advanced breast cancer makes family caregivers feel helpless. In a related study in Nigeria to investigate the opinion of family caregivers of patients with advanced cancer on caregiving, findings indicate that, family caregivers were bereft of the knowledge and skill in the management of sudden onset of patients’ symptoms at home. This resulted in emotional distress in caregivers (Akpan-Idiok & Anarado, 2014).

There is documented evidence that, family caregivers of cancer patients suffer depression during their caregiving activities and as such, they need treatment (Wood, Gonzalez, & Barden, 2016). The inability to communicate leisurely, just being there to carry out tasks as well as the absence of recreation made family caregivers feel depressed (Lambert, Girgis, Lecathelinais, & Stacey, 2013). The poor prognosis for advanced cancer makes family caregivers depressed (Nipp et al., 2016). Early detection of cancer can result in its cure. However, the possibility of recurrence creates fear in family caregivers of cancer patients (Simard et al., 2013). In a related study, findings indicate that, family caregivers of cancer survivors contemplated the possibility of the recurrence of the disease; and the possibility of going through the distressful caregiver role again. Subsequently, they experienced fear and were uncertain about the future of their relative’s health (Kim et al., 2015).
2.6 Spiritual Wellbeing of the Family Caregivers

Health has a spiritual dimension (Leow et al., 2014). There is increasing evidence of the need to consider spirituality in healthcare delivery (Peteet & Balboni, 2013). Spirituality enhances the coping ability of family caregivers of women with advanced Breast cancer. In a related study, findings indicate that, Family caregivers endure caregiving challenges by expressing faith in God (Sterba et al., 2014).

Also, religiosity is another phenomenon common to family caregivers. A study report reveals that, family caregivers believed that, breast cancer was a punishment for sin so they prayed to God for forgiveness and healing for their sick relatives (Leow et al., 2014). Findings from a related study indicate that, family caregivers become more religious than they were prior to their relative’s illness and they trusted God for healing for their loved ones (Williams, 2014). A study report from Brazil indicates that, the burden of caregiving was overwhelming. This drew family caregivers closer to God. They prayed for the ability to provide the necessary support for their sick relative (Paiva, Carvalho, Lucchetti, Barroso, & Paiva, 2015). Similar studies indicate that, some family caregivers find relief from anxiety when they pray consistently during their caregiving activities (Manning & Radina, 2015).

The conventional orthodox medicine is not the only treatment option available to family caregivers (Gonçalves, Lucchetti, Menezes, & Vallada, 2015). Other treatment options include the use of prayer, music, acupuncture, hypnosis and herbal medicine (James & Bah, 2014; Nworu, Udeogaranya, Okafor, Adikwu, & Akah, 2015). The use of these alternative treatment options, is a common phenomenon among sick individuals and their family members (Mosher et al., 2015). Others use a combination of orthodox medicine and alternative medicine for the treatment of their illnesses (Colvin et al., 2013; Scott, McMahon, Yumkella, Diaz, & George,
Initiation into alternative medicine use is usually based on individual preference, recommendation by friends, relatives or health workers. They believe in a supreme being among people of different cultural background as having the ability to heal diseases cannot be overlooked (Delgado-Guay, 2014). The effectiveness of alternative medicine in the treatment of various diseases is documented (Ried, 2015).

However, it is imperative to emphasize the empirical evidence of the negative impact of alternative medicine on family caregivers of women with advanced breast cancer. Some family caregivers out of ignorance attribute the cause of breast cancer to bewitchment. They therefore encourage their sick relatives to resort to spiritual healers for healing at the early stage of breast cancer at the expense of medical treatment. Thus, medical attention is usually a last resort when the disease has progressed to the advanced stage and death is inevitable (Ohene-Yeboah & Adjei, 2012). On the contrary, atheists who do not believe in the existence of God will not seek spiritual help in times of illness.

Another phenomenon common to family caregivers of cancer patients is, the belief that a closer relationship with God takes predominance over any life’s situation one goes through. A study report to this effect indicates that family caregivers with this belief go through their caregiving experiences with little or no mental or emotional mal adjustments (Wagner, Johns, Brown, Hanna, & Bigatti, 2015). In a study report from Brazil, findings indicate that, family caregivers of cancer patients viewed the caregiving responsibility as an act of expressing love to the care recipient. Love is the basis for devotion to God (Wagner et al., 2015). A limitation of this study is the small sample size used for the study this may compromise the ability to generalize findings.
Cultural beliefs not only play a major role in the life of an individual (Soares, Morgan, Santos, Matozinhos, & de Mattos Penna, 2014) but also influence the health seeking behaviour of a person. Physically, some of these beliefs may be detrimental to health (Wilkinson & Leach, 2015). Some beliefs and practices prevent the use of appropriate medical interventions in the treatment of illnesses (Moorley, Corcoran, & Sanya, 2014). This results in death. Other cultural beliefs affect the physical development of an individual (Ekwochi et al., 2016) which could lead to the deterioration of the health of an individual. The excruciating pain inflicted on an individual as a result of these beliefs is documented (Vogt, Mohmed Zaid, El Fadil Ahmed, Fehr, & Efferson, 2016). Studies indicate that, the belief that spirits are responsible for the cause of diseases exist (Kahissay, Fenta, & Boon, 2017; Lawton, Gerdes, Haack, & Schneider, 2014; Naeem et al., 2016). Although these beliefs influence the treatment seeking decisions of individuals in times of illness (Wilkinson & Leach, 2015), not all cultures believe in the existence of spirits or deities.

2.7 Support

Support is a concept that arises when one has to battle cancer or provide care for someone suffering from cancer. Some studies indicate that support is imperative in caregiving (Cebeci et al., 2012; Fouladi et al., 2013). Support leads to better coping in an individual. Therefore, a reliance on individuals for better adjustment when faced with challenging situations. This concept is frequently referred to in the literature as “dyadic” coping (Brandão, Schulz, & Matos, 2014). Support is not only given by family caregivers but family caregivers also receive support from other members of the family and friends to enable them to give care adequately (Ang, Lang, Ang, & Lopez, 2016). A quantitative study in Finland to investigate the QoL and social
support received by informal caregivers indicate that informal caregivers received support from their family and friends. This support improves their QoL and wellbeing.

Family caregivers receive diverse forms of support from relatives and friends (Mosher et al., 2015). Psychological support for family caregivers enhances their mental wellness (Hou et al., 2014). Emotional support does not only prepare informal caregivers for the caregiver role (P. Hudson & Aranda, 2014) but also reduces caregiver distress and anxiety in the course of caregiving activities (Hudson et al., 2015). Early commencement of emotional support for informal caregivers is imperative for better quality of life (J Nicholas Dionne-Odom et al., 2015). However, preparing an individual for the family caregiver role (Song, Sörensen, & Yan, 2016) is not formalized in Ghana’s socio-cultural context.

Informal caregivers receive physical support from family members and this reduces stress in them (Heller, Gibbons, & Fisher, 2015) and enhances their health (Williamson & Perkins, 2014). Significant others in the family often assist family caregivers by providing direct care for sick relatives. This enables family caregivers to attend to other pressing needs when necessary (Luxardo, Brage, & Alvarado, 2012; Manne, Siegel, Heckman, & Kashy, 2015; Raman, Nicholls, Ritchie, Razee, & Shafiee, 2016).

Financial support from significant others is another form of support family caregivers receive (van Eechoud et al., 2016). This form of support is given to family caregivers voluntarily or upon request (Fennell, Heckel, Wilson, Byrnes, & Livingston, 2016). This is usually seen as an act of love (Lewis et al., 2012; Wagner et al., 2015). Informal caregivers receive financial assistance from other members of the family not only to enable them pay sick relative hospital bills (Nayak et al., 2014), but also to meet the financial needs of the dependants of the sick relative (Kidman & Thurman, 2014).
Another form of support associated with family caregivers of cancer patients is social support (Badr, Smith, Goldstein, Gomez, & Redd, 2015). Psychologically, social support enhances the coping abilities of informal caregivers (Badr et al., 2015). However, this form of support is not developed in the study context. In a randomized control trial to evaluate the effect of a psycho-educational intervention for family caregivers of advanced cancer, findings indicate that, social support assisted family caregivers to cope with high caregiving demands (Leow, Chan, & Chan, 2015).

2.8 Summary Critique of the Literature Review

The literature reviewed so far reveal that caregiving at home can affect the physical, social, psychological and spiritual well-being of family caregivers of women with ABC. A total of 186 literatures were reviewed. One-hundred and seventy-five (175) studies from the high income countries; three studies from sub-Sahara Africa and eight studies from Ghana were reviewed. However, all the studies in Ghana focused on the women diagnosed of breast cancer. Thus, there exists a gap in knowledge about the wellbeing of family caregivers caring for women with ABC at home. In this study, the experiences of Ghanaians will be brought to the fore. It is the researcher’s expectation that, the findings from the study will be used to develop appropriate interventions that will address the needs of family caregivers of women with ABC.
CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter outlines: Research design, Research setting, Target population, Sampling technique and sample size, Procedure for data gathering and Data analysis. Ethical considerations and Methodological rigour were also highlighted.

3.1 Study Design

A qualitative research design was used for the study. A Qualitative study, specifically exploratory descriptive design, deals with a researcher eliciting responses from people on their experiences through interviews and interpreting these responses. The interpretation must reflect the people’s point of view. Interviews must be conducted in the natural settings of the participants (Gergen, Josselson, & Freeman, 2015). The focus of this study was on the wellbeing of family caregivers of women with advanced breast cancer.

3.2 Research Setting

The study was conducted in the Accra metropolis. The Accra Metropolis comprises Okaikoi, Ashiedu Keteke, Ayawaso, Kpeshie, Osu-Klotey and Ablekuma sub metros. It forms part of the Greater Accra Region. The Greater Accra Region has a population of approximately 3,909,764 comprising 2,025,637 females. Its population density is 1,205 people per square kilometer. It accommodates about 16.1% of the total population of Ghana. It has a lot of public and private health facilities. The 37- Military Hospital was used as the outlet for the recruitment of participants. The 37- Military Hospital is specialist hospital located in Accra, on the main road between Kotoka International Airport and central Accra. It is the largest military hospital in the Republic of Ghana after the Korle-Bu Teaching Hospital. (Ghana Statistical Service, 2011)
3.3 Target Population

The target population for this study was any member of the family taking care of a woman diagnosed with advanced breast cancer in the Accra Metropolis.

3.3.1 Inclusion Criteria.

The characteristics for the inclusion criteria were:

- Adult family caregiver male or female,
- Aged 18yrs and above
- Lives in the Accra metropolis
- Can speak English, Twi, Ga, Fante or Ewe
- Has a minimum of six months caregiving experience
- Must have a dependent patient at home
- Will give consent to participate in the study

3.3.2 Exclusion criteria

The characteristics for the exclusion criteria were:

- Family caregiver with a mental disorder
- Resides outside the Accra metropolis,
- Family caregiver with a newly diagnosed patient
- Verbally challenged family caregiver
3.4 Sample size and sampling technique

Qualitative enquiry requires that, responses are elicited from a number of participants to the point where subsequent participants seem to be giving the same responses without the emergence of new information (Bernard, 2011). The sample size for this study was thirteen (13). The study employed purposive sampling technique to recruit the participants who have the specific knowledge and experience in the phenomenon under study (Marshall & Rossman, 2014). Snow ball sampling technique: whereby research participant will direct the researcher to other people with the knowledge and experience in the phenomenon under study (Polit & Beck, 2013) was adopted. Ethical clearance was sought from the Noguchi Memorial Institute for Medical Research and the 37-Military hospital Institutional Review Board with introductory letters from the School of Nursing and Midwifery, University of Ghana. This affirmed the purpose of the study. The Tamakloe ward of the 37-Military Hospital was the recruitment outlet for participants for this study. The ward has a reception, treatment room, six admission wards, a chemotherapy suite, waiting room for out-patients coming for: chemotherapy, dressing of breast cancer wounds and their accompanying family caregivers. The researcher sought permission from the ward in-charge and interacted with the FCGs who were waiting for their sick relatives to either complete their wound dressing or chemotherapy sessions. The researcher briefed the FCGs on the purpose of the study and gave them the information sheet which had the entire information of the study on it. The researcher booked an appointment with FCGs who showed interest in participating in the study based on their convenience, choice of location, day and time; to complete the consent form, and conduct the interview.
3.5 Data collection procedure and tool

A semi-structured interview guide was used to conduct a face-to-face interview with each participant. This enabled participants to recount their experiences in-depth. It also allowed the researcher to redirect participants’ responses when out of context (Creswell, 2014). The interview guide had two sections. Information on the demographic characteristics of participants were captured in section-A. Section-B comprised of questions that were guided by the objectives of the study, the QoL model and the literature reviewed.

The researcher established rapport and explained the purpose of the study to each participant. They were allowed to sign the consent form to indicate their willingness to participate in the study. This made them share information freely on their caregiving experiences with regard to their wellbeing. The interview began with a grand tour question. This enabled research participant to choose a convenient way to provide responses. Also, all unclear responses from the participants were clarified in a follow up question during the interview (Mayan, 2009). Probes were used to explore participants experience and perceptions about changes and adaptations they made in the course of their caregiving activities. The interview was recorded and short notes were written to keep track of ideas for further exploration. Participants were observed for verbal and non-verbal behaviour (Musante & DeWalt, 2010). The interviews were transcribed verbatim (Mayan, 2009). It was conducted in the participant’s place of choice. The language for the interview was determined by the participant and it lasted for forty-five (45) minutes to one (1) hour. The interview questions focused on issues and concepts important to the participant’s experience with regards to their wellbeing. Additionally, important concepts identified prior to starting the study were captured (Mayan, 2009).
3.6 Piloting of the interview guide

Pretesting of a research instrument helps in ensuring the efficacy of the instrument to elicit the expected responses and also helps in modifying the instrument before it is administered to the participants (Khan, 2012). The instrument (semi-structured interview guide) was pretested at the 37-Military hospital with two family caregivers of women with ABC. The pretesting ensured that questions were clear and understandable. Questions that were not clear were restructured. Analysis of the responses obtained improved upon the interview guide. Data obtained from the piloting was not included in the main study.

3.7 Data management

Participants were assigned letters in a chronological manner (A-Z) according to the order of the interview. After each interview, verbatim transcription followed immediately. Each recording was replayed to ensure accurate transcription so as to reduce errors and omissions. The letters allocated to participants were replaced with pseudonyms. Each transcription was saved as a different file in a folder with a unique identification. Hard copies of the interview were securely kept. Furthermore, participant’s demographic characteristics were separated from hard copies. Electronic copies of the transcription were kept in a folder on a computer with a password to ensure the security and safety of the data.

3.8 Data analysis

In qualitative study, data analysis goes with data collection and continues throughout the study (Miles & Huberman, 1994). Data analysis was done together with data collection. Individual interviews were conducted spaced at different time interval. This enhanced data collection and analysis simultaneously. Previous interviews were analyzed before conducting another.
The researcher acquainted herself with the data by listening and reading the transcripts several
times noting down initial ideas after each interview. Thereafter, initial coding was developed by
noting specific ideas, words or concepts. This type of open coding involved labeling sections of
text that was important to the research questions. It involved labeling participants own words
with labels in order to remain close to the data. Categories were formed by merging similar
codes and using encompassing labels. The labels were compared and relationships were
identified between categories. Themes and underlying ideas that seem related to all data were
noted. Research supervisors were involved in the coding and data analysis in order to have a
better data analysis. The transcripts were then exported to the Nvivo software version 11. The
software was used to manage the data

3.9 Methodological Rigour

Rigour is a key factor in a qualitative enquiry (Speziale, Streubert, & Carpenter, 2011).
According to Aroni et al. (1999), rigour is the process of showing reliability and proficiency in a
qualitative study and a demonstration of the validity of the research procedure. Also, a
qualitative study which lacks rigour is not credible and will not generate new knowledge (Morse,
Barrett, Mayan, Olson, & Spiers, 2002). It is therefore imperative that reliability and validity be
adequately employed when conducting research. Thus trustworthiness comprising credibility,
transferability, dependability and confirmability were chosen as the criteria equal to reliability
and validity to ensure rigour in this study. Encompassed in these, were other methodological
strategies such as audit trail, member checks when coding, categorizing or confirming results
with participants and peer debriefing to ensure rigour in this study (Guba & Lincoln, 1982).
These criteria were used to ensure trustworthiness in the study.
Credibility according to Guba and Lincoln (1985) tells how reliable the findings of a study are to reality. To attain this, the researcher purposefully recruited participants who met the inclusion criteria and were able to provide in-depth information on their caregiving experiences with regards to their wellbeing. Iterative questioning and probes to elicit detailed information from participants was employed. Furthermore, member checks in the form of iterative verification to confirm the accuracy of the data was employed (Morse et al., 2002). One interview was transcribed and analyzed before the next one was conducted.

Transferability describes how applicable the findings of a study are in another setting (Guba & Lincoln, 1981). There was an apt description of the study setting, the design that was used for the study, the sample size and the method of data collection. Additionally, there was a description of the inclusion and exclusion criteria, the number and length of data collection sessions that was done and the period within which the data was collected.

Dependability describes whether the study can be replicated by another researcher (Guba & Lincoln, 1981). In order to ensure dependability of this study, the researcher wrote in detail the research process which includes the design and its implementation, data gathering as well as evaluation of the success of the research methodology for future replication by another researcher (Shenton, 2004). This allowed for the examination of the research process so as to establish whether it has been properly applied.

Confirmability in a qualitative study shows how objective the researcher is. It is the process of ensuring that, the findings of the study are the exact experiences and ideas expressed by the participants and not the preferences of the researcher (Patton, 1999). The researcher ensured that, the findings of the study were presented as reflections of the participants’ perspective of caregiving experiences with regards to their wellbeing, and not her preferences by
bracketing her biases and assumptions. She kept an audit trail which shows how data was collected, analyzed and processed to get the findings of this study.

3.10 Ethical Considerations

Ethical clearance was obtained from the Noguchi Memorial Institute for Medical Research, University of Ghana and from the institutional review board of the 37-military hospital with an introductory letter from the School of Nursing, University of Ghana. Potential participants were given the information sheet which outlined the purpose and objective of the study. They were made aware of possible benefits, risks and discomfort involved in the study. They were assured of confidentiality, voluntary participation, the right to leave the study and compensation. The interview was conducted in their preferred location and language. A follow-up was done to find out if they will participate in the study. Potential participants, who agreed to participate in this study, were given consent forms to sign. In the case of participants who could not read or write, the consent form was translated in to their preferred languages in the presence of a witness. Both the participant and the witness signed and thumb printed the consent form to that effect. Furthermore, participants were made aware of the fact that, after signing the consent form, they reserved the right to withdraw from the study without any consequences. They were assured that, all the information they have provided will be kept safe and will not be used against them in any way. Also, participants were assigned alphabets chronologically in order of recruitment, so as to conceal their identity. This ensured anonymity. Thereafter, pseudonyms replaced these alphabets in the findings chapter when participants were being quoted in the thesis. Participants were assured that, the information they have provided, the consent form and the audio-tapes would be in the researcher’s possession for a period of at least five years after the study. Participants’ demographic data have been separated from the hard copies. Soft copies of
the transcriptions have been kept in electronic folders with a unique pass word on the researcher’s hard drive to ensure the security of data. In the course of the recount of life experiences, research participants may express distressing emotions. In the case of such eventualities, the researcher will make arrangements for a counsellor to attend to participants who will require counselling services in the course of data collection.
CHAPTER FOUR

FINDINGS

4.0 INTRODUCTION

This chapter is the presentation of the findings from the analysis of the data collected in the study: exploring the wellbeing of family caregivers of women with advanced breast cancer in the Accra Metropolis. Thirteen participants in the Accra metropolis were interviewed about their wellbeing in the course of caring for their relative with advanced breast cancer. The organizing framework that underpinned this study is the Quality of Life (QoL) Model Applied to Family Caregivers by Betty Ferrell (Hinds & King, 2011). The themes and sub-themes that were generated were based on the constructs of this framework as well as the objectives of the study. Participant’s verbatim quotes corresponding with these themes and subthemes, as well as their pseudonyms were presented. The four main themes according to the framework are: physical, social, psychological and spiritual wellbeing of family caregivers of women with advanced breast cancer. Additionally, new themes that emerged were: believes about advanced breast cancer, Support and other sources of treatment. There were five (5) themes and nineteen (19) Sub-themes in all.

4.1 Demographic characteristics

Thirteen participants (family caregivers of women with advanced breast cancer) were interviewed for the study. They were all Ghanaians and were living within the Accra Metropolis. Saturation was reached at the thirteenth participant. They spoke English, Ga, Twi and Ewe. Ten (10) females and three (3) males were interviewed. The ages of the participants ranged between twenty (20) to sixty (60) years. Six (6) were between the ages of 20 to 29 years, three (3) were between the ages of 30 to 39 years, two (2) were between the ages of 40 to 49 and two (2) were
between the ages of 50-59. Twelve (12) of the participants were Christians and one (1) belong to the Islamic Religion. Six participants gave care for one (1) year. Six (6) gave care for two (2) years and one gave care for seven (7) months. Eight (8) daughters, two (2) mothers, two (2) brothers and one (1) husband participated in the study. Six (6) belonged to the Ga tribe, four (4) were Ewes and three (3) were Akans. Four (4) were married with children, one (1) divorced with children, two (2) were single with a child and six (6) were single. Five (5) participants were students, one (1) was a banker, one (1) a store keeper, one (1) a driver and five (5) traders. Five (5) have had tertiary education Two (2) senior high school (S.H.S) education. Two (2) had Junior High School (J.H.S) education, four (4) had Middle School Leaving Certificate (M.S.L.C) education.

4.2 Physical wellbeing of family caregivers

To answer the first research question “What is the physical wellbeing of family caregivers of women with advanced breast cancer,” the theme physical wellbeing was identified. The data showed that Physical excretions resulted in Caregivers experiencing pain in different body parts. They got tired due to bathing their sick relatives and changing their soiled diapers. Furthermore, they experienced disrupted sleep because their sick relative vomited and were in pain each time they received chemotherapy. Sick relative could not eat due to pain and this resulted in loss of appetite in caregivers. Finally, caregivers assisted their relatives by bathing, cooking, washing their clothes, cutting their hair and changing diapers soiled with faeces. They also accompanied their relatives to the hospital for chemotherapy and wound dressing. The sub-themes found which were consistent with the QoL Model were: Pain, Fatigue, Sleep disruption, loss of appetite and Assistance with activities of daily living. The sub-themes are presented below with verbatim quotes from participants using their pseudonyms.
4.2.1 Pain

Most family caregivers reported pain in different body parts for diverse reasons. Caregivers experienced pain in their thigh and waist due to lifting their sick relatives in the course of bathing them. One caregiver indicated that, she experienced back pain as a result of the nocturnal care she gave. One caregiver indicated that, her body pain was worse in the morning.

“I lift her up to bath her and carry her to the washroom and because of that, I have waist pain and sometimes body pain” (Yawa)

“She is fat, so when I am bathing her, I have to lift her and wash her buttocks. Lifting her made me develop body pain especially in my waist and thighs” (Baaba)

“Her bed is very low and I bend down very often to change the dressing I use in covering the bleeding breast otherwise, the bed will be soaked with blood, so in the mornings I have severe back pain.” (Yaa)

However, a few caregivers did not report aches and pain because they had help from family members. Also, their sick relatives were ambulant.

“Fortunately, I was not the only person taking care of her, my aunties and my sisters also help so I don’t feel any pain in my body”. (Seyram)

“Though she is weak, she is able to walk in the house, bath and eat so I don’t feel any pain in my body because of her”. (Musa)

4.2.2 Fatigue

Family caregivers reported tiredness in the course of their caregiving activities. They indicated that, the tiredness was related to domestic chores and self care activities they performed for their sick relatives because they were weak. Others indicated that, they were tired because they had to accompany sick relatives to the hospital for wound dressing and chemotherapy. The long waiting time at the hospital made them tired.
“Taking care of her is very tiring. You see...now she has become very weak and cannot do anything for herself. I have to wash her clothes, cook and keep the house clean all alone, at the same time, I have to take care of her too. It is not easy combining all that” (Akweley)

“She was wearing diapers, so turning her and lifting her legs to change the diaper when she soiled it with faeces was tiring. I had to change the diaper alone and it was tiring” (Mawuse)

“You see, I was caring for her alone. I had to go to the market to buy food and things that we needed in the house. When her medicine finishes I have to go and buy it. We carry her to the bathroom and bath her because she could not walk and it makes taking care of her very tiring.” (Baaba)

The long waiting time experienced by caregivers who accompanying sick relatives to hospital for chemotherapy and wound dressing made them tired.

“When I take her to the hospital for chemotherapy, the doctors make us wait too long. I feel so worn out when I come home” (Mawunyo)

“We go for wound dressing every three days. Anytime we go, we join a long queue, by the time they finish for us to come back, I become very tired” (seyram)

4.2.3 Sleep disruption

Family caregivers reported sleep disruption as a result of the side effect of chemotherapy. They indicated that their sick relatives vomited and experienced pain at night after receiving chemotherapy, as a result, caregivers kept wake to give them medicine in order to relieve their pain. A caregiver indicated that, her inability to sleep was related to her sick relative’s pain and inability to talk.

“She vomits and complains of pain at night after receiving the medicine (chemotherapy) so I am not able to sleep well, I have to keep wake sometimes to see to it that she is comfortable and give her medicine for the pain”( Manu)

“She complains of pain at her joints at night anytime she receives the chemotherapy and I have a balm I apply to her joints to ease the pain and help her sleep but her sleep is on and off so, I also sleep on and off.”(Musa)
“In fact, each time she receives chemotherapy that night, I do not sleep. I have to be by her and give her medicine because she will be in pain and will be vomiting” (Mawunyo)

Furthermore, one caregiver reported that she could not sleep at night because her sick relative could neither get out of bed nor communicates verbally.

” My mother hardly slept because of the pain she was going through because of that, I could not sleep either. You know how pain is like; her pain is usually very severe at dawn. Sometimes she needs water and she cannot get up. I had to get it for her. Usually, I keep the television on so that I don’t sleep at all. She cannot even call you so sometimes she had to point at what she wants. Even if I sleep, it is for a very short time” (Mawuse)

4.2.4 Loss of Appetite

Most family caregivers reported a loss of appetite. It was attributed to the fact that, their sick relatives could not eat because they were in pain. So they could not eat either. Others could not eat because they were apprehensive.

“Oh! A mother whose daughter is in pain, how can I eat? I don’t even have an appetite for food... Her pain was so much so that she lost appetite for food. When I see her in pain like that, I don’t feel like eating either” (Baaba)

“When I take food to eat and I remember her, I am gripped by fear because I don’t know what will happen next, I just pray that she will not die because the pain is too much. As for the food, I am unable to eat the food” (Ewenam)

“When I give her food she cannot eat because of that me too I cannot eat” (Akweley)

Also, some caregivers indicated that, they lost weight

“I have really lost weight even though I am not too fat and I am not too slim a person. My friends tell me I have lost weight “Mawunyo

“I lost a lot of weight” (Mawuse)
On the contrary, one family caregiver revealed that, he did not experience any loss of appetite because he needed strength to care for his sick relative.

“if I don’t eat, how will I get the strength to be taking care of her? When I get the food, I eat” (Dodzi)

4.2.5 Assistance with activities of daily living

Nine out of thirteen family caregivers reported offering complete care with regards to assistance with activities of daily living. They revealed that, they bathed their sick relatives, cooked their food, fed them, cut their hair, dressed them up, changed menstrual pad and washed their clothes.

”I bathed her in bed, fed her, cooked for her and I had to cut her hair at a point because she was losing the hair. (Mawuse)

“I have to clean her, dress her up, change her menstrual pad, feed her” (Dodzi)

“I have to carry her to the bathroom and bathe her. I wash her dirty clothes, I cook for her and I feed her” (Akweley)

Also, others indicated that, they offered assistance by accompanying their sick relatives to the hospital for chemotherapy and wound dressing

“I take her to the hospital when it is time for her to go for her medicine (chemotherapy) because she feels dizzy and weak after taking it.” (Manu)

“In the morning, I take her to the hospital to dress the wound on the breast. I stay till she is done and I bring her home” (Maame)
4.3 Social Wellbeing of family caregivers

To answer the second research question “What is the social wellbeing of family caregivers of women with advanced breast cancer”, the theme social wellbeing was identified. Analysis of the data revealed that, caregivers could not attend parties, weddings or funerals. They also bought expensive drugs and paid hospital bills covering wound dressing for their sick relatives. Furthermore, these sick relatives could not work thus, caregivers paid school fees, bought clothes and food for the dependants of the sick relative. They used all their savings and even borrowed money to care for them. They also took leave of absence or stopped work to give care. A new finding from the social wellbeing theme was secrecy. Caregivers did not disclose their sick relative’s condition to others for fear of stigmatization and gossip. The sub-themes found which were consistent with the QoL Model were: Isolation, Financial burden and Employment. A new sub-theme which emerged is secrecy. These are presented below with verbatim quotes from participants using their pseudonyms.

4.3.1 Isolation

Eight out of thirteen participants indicated that, they could not attend weddings, funerals, parties or naming ceremonies because their sick relatives depended on them for total care. They revealed that, their lives were isolated and they felt alone.

“My life has become isolated because I need to be around her all the time because she is very weak. I can’t be with my friends, go to parties, weddings or naming ceremonies.” (Mawunyo).

“Since her sickness started she has not been able to do things by herself, because of that I don’t go anywhere. I don’t go to church, I am in the choir but I cannot go for rehearsals. I can’t leave her. I don’t go anywhere because I have to stay and take care of her. It makes me feel alone.” (Akweley)
“I am unable to socialize. I cannot go to weddings, parties or visit friends. I simply do not go anywhere because of the way she is always in pain” (Yaa)

On the contrary, a few caregivers indicated that they could go out because they either had help from other family members or their sick relative could perform self-care activities although they were weak.

“When I am not around; there is someone at home to take care of her. So I could go out and come back as and when necessary”. (Seyram)

“I am able to go out because though she is weak, she is able to walk in the house, bath and eat as necessary” (Musa)

4.3.2 Financial Burden

All the caregivers reported that they bought expensive medicine and paid hospital bills covering wound dressing for their sick relatives. They revealed that,

“Hmm. it is not easy at all. We spend about hundred cedis just for the wound dressing in a week, we will be going for six weeks, this sums up to six hundred cedis. The medicines I buy for her too are also very expensive” (Yaa)

“Her drugs are also very expensive and... So financially, it is not easy” Musa.

“I have single handedly paid my daughter’s medical bills and it has not been easy, the medicines are very expensive” (Ewenam)

Also, some caregivers used all their savings to meet the needs of their sick relatives while others borrowed money to purchase medicine.

“It was just God who helped me go through that because I used all the money in my bank account yet it was not enough” (Mawuse)

“I was working then and I can tell you it was not easy. I had to talk to my grandfather and my aunty to give me money for my mother so that I would pay them at the end of the month”(Seyram)
Furthermore, they indicated that dependents of their sick relatives became their responsibility. They paid their sick relative’s children’s school fees; bore the cost of feeding them and clothed them.

“It is not easy because she is not married but has a son who I am caring for as well... I am responsible for feeding and clothing him” (Musa)

“I am also taking care of her son at the same time. I pay his school fees; I feed him and buy clothes for him” (Ewenam)

4.3.3 Employment

Eight out of thirteen participants either took leave of absence from work or stopped work entirely to care for their sick relatives. Others who were self employed requested friends to take charge of their jobs so as to enable them to give care. A caregiver indicated that he got an additional job.

“I needed to be by her all the time so I had to take leave at work and come and take care of her because she could not do anything for herself” (Yawa)

“I am self employed but I had to stop working to care for her” (Baaba)

“I had to stop the work because I was always asking for days off to take care for my mum. My boss started complaining and I told him that, my mum was sick and there is nobody to take care of her and he also said his job had to go on so I had to stop the work” (Mawuse)

Other caregivers indicated that, they sought the assistance of friends who managed their businesses for them: so as to enable them to give the needed care to their sick relatives.

“I am a commercial driver but as we speak, I have given my vehicle to a colleague driver to drive for me so that I can stay and take care of my wife” (Manu)

“I have given my shop to someone to run for me and by the grace of God I am taking care of my daughter” (Ewenam)
However, one caregiver indicated that, he got an additional job to enable him to meet his financial obligations to his sick relative

“I am usually off duty on Mondays but I do not go out to socialize with friends because I need to go out and work elsewhere to make extra income to sustain us. My monthly salary alone cannot sustain us throughout the month” (Musa)

4.3.4 Secrecy

A sub-theme that emerged from the analysis of the data is secrecy. Caregivers concealed their sick relative’s condition from extended family members and friends for reasons such as fear of stigmatization and gossip. However, a caregiver indicated that, she disclosed her sick relative’s condition to others in anticipation of a cure.

“We live in a compound house but I don’t want people to know that she has breast cancer, I do not want the cotenants to know about her condition otherwise they will stigmatize her” (Yaa)

“We did not tell anybody even her own siblings that she had breast cancer because we know how they are. They gossip too much” (Maame)

“I did not tell anybody. May be that is the reason why I did not hear any rumours about her. I did not tell anybody because people gossip” (Seyram)

However, one caregiver who disclosed her relative’s condition to others was of the view that, disclosing her daughter’s condition to others could help her find a cure for her.

“We did not hide it from anybody. Someone may know a cure for it so it is by telling people about it that you may discover a cure. For us, we did not hide it from anyone” (Baaba).

4.4 Psychological Wellbeing of family caregivers

To answer the third research question “What is the psychological wellbeing of family caregivers of women with advanced breast cancer”, the theme psychological wellbeing was identified. Participants experienced apprehension and could not concentrate at work. The pain
experienced by their sick relatives made them depressed and they feared their sick relative would die. Caregivers who were daughters of women with advanced breast cancer feared they may also develop the disease. Also, while some caregivers wished they could bear their sick relative’s pain in order to offer them some relief, others felt as though they were experiencing the pain their sick relatives were going through. The sub-themes identified which were in conformity with Betty Ferrell’s QoL Model were: anxiety, loss of concentration, depression and fear. A new sub-theme that emerged from the analysis of the data was Empathy.

4.4.1 Anxiety

All the caregivers expressed diverse forms of anxiety. Anxiety was related to uncertainty about the future in the event of death of the sick relative, effect of chemotherapy on the sick relative and financial difficulty.

“I had a lot of anxiety because I was thinking about a lot of things... If she dies, what will become of me and my brother?” (Mawuse)

“I was so anxious because her appearance has changed so much because of the chemotherapy she was receiving that, I could not tell what was going to happen to her next” (Seyram)

“I worry a lot about how to get money to continue taking care of her. I have spent so much on her treatment and I am still spending” (Manu)

4.4.2 Loss of Concentration

Analysis of the data indicates that caregivers lost concentration at work and school and were worried because of their sick relatives. The lack of concentration and worry was attributed to the absence of someone to care for their sick relative in their absence. The lack of concentration resulted in a caregiver stopping school take care of a sick relative.

“I used to sell fruits but each time I go to sell I am not able to concentrate on the selling. I get worried about her and I think about how she is faring in my absence because she is alone in the house” (Yaa)
“I could not sit in the class because I would not be able to concentrate on the lesson. I was always thinking about my mother during class hours so I stop going to classes for about a month just to take care of her” (Mawuse)

“When I go to work I think about her a lot, because of that I can’t concentrate on my work for long. For now we are only two in the house, she does not have the strength to do anything for herself, so when I am at work, I ask myself: what will she do if she needs to get herself water or food?, so leaving her alone in the house gets me worried” (Musa)

4.4.3. Depression

Almost all caregivers experienced depression. Caregivers cried, were sad and felt pity as a result of the suffering, pain and the debilitating effect of advanced breast cancer on their sick relatives.

“Sometimes when I look at her and I see the way she is suffering from the pain in the breast, I sit down and cry...I become lost in my thoughts. I just can’t stand it. I cry for myself and for my Mum” (Yawa)

“When I see her like that, I cry because I know my mum, that is not how she was...When I see how the sickness has made her I just cry” Akweley

“When I see her in pain like that, I go and hide and cry” (Maame)

Other caregivers felt sad upon seeing their sick relatives

“I feel very sad when I see her suffering from the pain in her breast. Everyday things were the same; there was no improvement in her condition. Sometimes I go to my room alone because I am afraid she will see me break down in tears. I was depressed”’. (Mawuse)

“When I look at the pain she is going through and how she bleeds from the breast, I feel very sad. This is not how she used to be, the sickness has changed her a lot” (Dodzi)

“Sometimes when I see her very weak like that, I feel sad. It is as if I am going through what she is experiencing. The pain is just too much for her”. (Musa)

Others indicated that, they felt pity for their sick relatives
“I really feel pity for her when I see her in pain like that… but there is nothing I can do about it”. (Yaa)

“I feel pity for her, I try not to break down in front of her but I need to stay strong. As for her pain, it’s too much, she has become very lean, she has lost her hair and she keeps vomiting….Hmm my prayer is that she will get well soon. When I see all that she is going through, I just feel pity for her” (Mawunyo)

4.4.4 Fear

From the analysis of the data, caregivers anticipated death of their sick relatives and were apprehensive. This produced fear in them.

“Sometimes I fear she will die because of the way she is suffering with pain”. (Musa)

“I was having some fears. When I go to her, she speaks as if she is about to die… Because of that, I was afraid” (Akweley)

“I was afraid she will die, I had heard people say, when you get breast cancer you will surely die” (Ewenam)

Furthermore, caregivers who were daughters indicated that, their fear was based on the fact that, one of the causes of breast cancer was hereditary; so they dreaded the possibility of getting it, because their mothers have had the disease.

“I am afraid of developing breast cancer one day because she is my mother and the possibility of me having it is there” (Mawunyo)

“My fear is that, my mother has had it, my aunty has had it and it is in the family now. It can happen to me so I have to be alert” (Seyram)

“It has not been easy for me because I am her daughter and seeing her with one breast and all the pain and suffering she is going through, I ask myself if I also get breast cancer and I don’t treat it early or am not able to get anybody to help me like this, how am I going to be?. It really scares me “(Maame)

However, one caregiver indicated that he was not afraid to lose his sick relative and that; if she died he would consider it the will of God.

“I am trusting God that she will not die but I am not afraid of her dying either. Whatever happens, I will give it to God” (Dodzi)
4.4.5 Empathy

Some caregivers empathized with their relatives. It was related to the pain the sick person was going through. While some wish they could bear the pain of the sick person, others felt as though they were experiencing the agony of the sick person.

“When I see her in pain like that, I just say in my mind ‘I wish I could bear this pain for my daughter so that she will get some relief’” (Baaba)

“When I see her like that I feel as if I am experiencing the pain.” (Akweley)

“I feel bad; it is as if I am experiencing what she is going through” (Musa)

On the contrary, a caregiver indicated that, she got angry with her sick relative. Her anger was related to the fact that her sick relative refused to eat for fear that she might vomit after eating.

“Sometimes she makes me feel so angry. I feel I am doing my best for her to be well but she does not cooperate with me. For instance, I go through the trouble of cooking for her but she will not eat the food for fear of vomiting” (Mawunyo)

4.5 Spiritual Wellbeing of family caregivers

To answer the fourth research question “What is the spiritual wellbeing of family caregivers of women with advanced breast cancer”, the theme spiritual wellbeing was identified. The pain and suffering experienced by sick relative made caregivers question God as to why their sick relatives should suffer such agony. They concluded that, their sick relative’s condition was a trial of their Christian faith. Caregivers indicated that, they became more prayerful and started going for regular breast examination. One caregiver indicated that, she started educating people on the need for regular breast examination after her daughter died of breast cancer. The sub-themes found which were in line with Betty Farrell’s QoL Model were: Meaning, religiosity and positive change.
4.5.1 Meaning

Family caregivers questioned God as to why their sick relatives should suffer from breast cancer but concluded that the illness was a trial of their faith in God.

“Sometimes when I look at her and I see the way she is really suffering; I as God why us? But I think it is a trial of our faith” (Yawa)

“When she told me she had breast cancer, I was shaking all over. I said, oh God, what is this that has happened to my daughter? But God knows best” (Ewenam)

“When I see her bleeding like that, I ask God, why should this happen to her... but as Christians we go through trials so I see it as such” (Yaa)

However, a participant revealed that, she was angry with God. She felt God was being cruel to her mother because of the way she was suffering from the disease. Her anger was also related to the fact that she lost her father at age six and was raped at age eighteen; she felt she did not deserve that kind of treatment from God.

“I was angry with God; I asked him, what did I ever do to go through this? I was raped when I was eighteen years and my father died when I was young, I was six years. So I felt God was being cruel to my mother because of the way this sickness is making her suffer” (Mawuse)

4.5.2 Religiosity

All the caregivers indicated that, they become more prayerful when the relatives became sick. Some caregivers prayed for healing for their sick relatives and others prayed for money to enable them continue their caregiving activities.

“I did not have any reason to wake up at dawn and pray... Although I pray five times a day like all Muslims, I go to sleep after prayers. When my mother had breast cancer, I realized I had to pray more to God... It made me wake up at dawn and cry out in tears to God so that she will be healed” (Seyram)

“When my mother got sick, I pray more now, sometimes, I sit by her at night and pray for her so that she will get well” (Akweley)

“I have become more prayerful, sometimes I pray all night or fast so that she will be well” (Dodzi)
A caregiver prayed that, his relative will not die

“I pray each day that God will keep her alive. I pray for her before going to work so I trust God to keep her. I am afraid she will die because I have heard people who have had that disease are dead. So I pray that she will not die”. (Musa)

Other caregivers indicated that, their prayers was for God to provide them with money to take care of their sick relatives

“Hmm, madam, this sickness I have spent so much but it is not enough. I keep praying for God to send us divine help. He should touch people’s heart to give us money so that I can continue taking care of her. This has been my prayer day and night”. (Yaa)

“There is nobody to turn to for financial help. Each night, I pray to God to provide me with money the following day for her upkeep. God always provides. It is like he gives me a challenge and then makes a way for me to come out of the challenge”. (Mawuse)

4.5.3 Positive Change

Analysis of the data revealed that, the caregiving activities of family caregivers brought changes in their lives which hitherto were not present. Caregivers who were daughters indicated that, they started going for regular breast examination. Other caregivers started educating people about the disease. One caregiver indicated that, the experience from the caregiving activities has made him show respect to all people.

“I have become very careful in the way I handle my breast... Now I go for regular breast examination. Previously I did not even think about examining my breast” (Seyram)

“My mother’s sickness has brought a change in my life. She has breast cancer and my aunty also has it. It means it is in the family so now, I go to the hospital to have my breast examined regularly” (Mawuse)

“You see my mother was going to the hospital for her breast to be examined after she had a lump removed from her breast yet she still developed advanced breast cancer...because of the suffering she is going through, now I go to the hospital every month to have my breast examined.” (Maame)
One caregiver started talking to people about the disease when her daughter died from breast cancer.

“You see, I am the leader of the women’s fellowship at my church. After my daughter died from breast cancer, now I use that position to educate the women in my church about breast cancer. I tell them to be going for regular breast examination.” (Baaba)

Also, another caregiver indicated that, his sister’s suffering from breast cancer has made him develop respect for all people.

“At first I did not really respect people but my sister's sickness has set me thinking I have realized that, in this world we are nobody and we need to be there for each other because we do not know what will happen to us tomorrow. I don't bear grudge against people anymore. In fact her sickness has made me develop respect for every human being” (Musa)

4. 6 other sources of treatment

A new theme that emerged from the analysis of the data was other sources of treatment. Caregivers indicated that, they sought cure for their sick relatives from spiritualists and prophets at prayer camps. Others also used herbal concoctions they got from herbalists for their sick relatives. This theme was not part of Ferrell’s QoL model.

“I took her to a certain woman who was a spiritualist and she said we should pay four thousand cedis so that she will cure the sickness” (Yawa)

“I took her to a prophet at a prayer camp in our hometown. He has prayed for some women who had breast cancer and they got healed” (Baaba)

“We took her to a prophet at a prayer camp for prayers in the New Year maybe the second week in January” (Akweley)
Other caregivers revealed that, they applied herbal concoctions to their sick relative’s breasts in anticipation of a cure. They got these concoctions from herbalists. They were introduced to the herbalist by friends and family members who attested to the effectiveness of the herbs in curing breast cancer.

“a friend told me about a herbal clinic which has treated a lot of women with this breast sickness. She said their medicine is very good so I took my mother there and they gave us some herbal mixture to apply on the breast” (Seyram)

“My grandmother had a breast sickness sometime ago and she was treated by a herbalist. She said the man’s medicines were very good so when my mother’s own started. We went to the herbalist for some concoctions, so we were applying it to the breast... but she died” (Mawuse)

“a friend told me about a herbalist at Kasoa who has cured a lot of women of this breast cancer. I felt his medicine should be quite effective so I sent my daughter to the herbalist at Kasoa for the herbal treatment but she died in the end”(Baaba)

4.7 Beliefs about the cause of Breast Cancer

Another theme identified from the analysis of the data was beliefs about breast cancer. One caregivers believed that, the physical manifestation of breast cancer in their sick relatives was as a result of a spiritual transfer of the disease to her daughter. Another caregiver was of the view that a person could contract breast cancer by contact with the sick person. A participant further revealed that, breast cancer like any other disease is air borne. Furthermore, other caregivers indicated that they did not know the cause of the disease. This theme was not part of the QoL model.

“My family has a lot of evil spirits... These spirits have followed me to this place to make my daughter suffer from breast cancer” (Ewenam)

“A prophetess told me that, someone bought it spiritually and gave it to my daughter through spiritual means and I believe that”(Baaba)

“Breast cancer has a spiritual cause but medication has its place, it has to be treated with prayers and with medication” (Maame)
One caregiver believed that breast cancer could be contracted through caring for a woman with breast cancer. Another caregiver also believed that it is airborne.

“When you take care of a woman with breast cancer you will also get it”  
(Akweley)

“Breast cancer like every other sickness, is in the air; anybody at all can get it”  
(Enyonam)

Others revealed that, they did not know the cause of the disease

“I don’t know the cause of this sickness but I can say it is a very bad disease. If is full of suffering”  
(Musa)

“Hmm this sickness, some people say it is a curse but as far as I know, nobody has cursed my wife. I don’t believe it is a curse that brings it…I don’t know what brings it”  
(Dodzi)

4.8 Support

Another theme that emerged from the data gathered was support. Family caregivers received assistance from church members in cash and in kind. Church members visited and prayed for their sick relatives; they also gave money and food items to the family. This helped caregivers to cope. Also, other members of the family gave money to pay hospital bills. They were involved in taking sick relatives to hospital for chemotherapy. They bathed and cooked for the sick relatives. Finally, they stayed with the sick person so as to allow caregivers to attend to pressing needs. The sub-themes church support and family support emerged. These were not in the QoL model.

4.8.1 Supports from Church

Church members visited caregivers and their sick relatives and prayed for them. Some gave food items such as fruits, eggs and beverages to the family. Other caregivers indicated that, they received financial and prayer support from the church regularly.
“I thank God her church members, her Christian mothers really showed us love. They came in their numbers, they brought her food stuff, provisions, anytime they passed by... some come and say, “This crate of egg is for your mother, this Milo and milk is for your mother, this pineapple and orange is for your mother... I was encouraged” (Maame)

“Our church members also come and visit us. Our pastor and his wife, the elders and some other members visit us all the time. Anytime they come, they bring rice, provisions and some fruits; it really helped us” (Akweley)

“My church people have done very well. Since this sickness started they have always been there for us. They visit us and bring us food, soap and a whole lot of things. God will really bless them” (Yawa)

Others received prayer and financial support from their church members regularly

“My church members always pray for us. They visit and give us money all the time” (Baaba)

“I am part of the prayer warriors in the church so my ministry members are always praying for my sister to get well. Sickness also involves a lot of money so the church has been helping me with money to take care of her” (Mawunyo)

“My mother is a monthly contributor to the church welfare (monthly welfare dues). So when she fell sick, the church was helping with her hospital bills. They also pray for her”. (Enyonam)

“One church member is single handedly taking care of all of my sister’s medical bills. I always pray that God will continually bless him. The church members come here every Sunday after church to pray for us so that she will get well soon and come back to church” (Dodzi)

4.8.2 Support from family

Close relatives cooked and bathed the sick person. Stayed with the sick relatives in the absence of caregivers. This enabled caregivers to cope and attend to important issues that required their attention. They also assisted in sending the sick relative to hospital for chemotherapy and gave financial help to enable caregiver to provide care.

“My aunty helped in bathing and cooking her food... her presence alone made me feel that I was not alone. She would stay with my mother for me to go and write my exams” (Mawuse)
“If I have to take some documents to my school at cape coast, my sister will cook for her and fetch water for her to bath till I go and return” (Mawunyo)

“If I need to travel to attend to a pressing need, I call her husband to come and take care of her for me to go and return. I will usually cook and put it in the fridge for them. He will only warm the food for her and also fetch water for her to bath”. (Baaba)

Other caregivers received assistance from family members in taking their sick relatives for chemotherapy

“My aunty has a car so comes to pick her to the hospital when we need to see the doctor for chemotherapy” (Akweley)

My sister helps in taking her to the hospital for chemotherapy when I am not able to go because I have to be at work. (Seyram)

Some caregivers indicated that, some close relatives assisted with money for the upkeep of the sick relative and payment for the hospital bills.

“We are three siblings and I am the second born but one is dead, my elder brother is working and supporting us so I am caring for her. We also receive some financial help from my mother’s siblings” (Yaa)

“I have a brother in London who helps me often with money to pay the hospital bills and provide her needs”( Manu)

“My son-in-law provides money all the time so we always had money to pay the hospital bills and for her upkeep” (Baaba)
4.9 Summary

The findings of this study brought out various aspects of the experiences of family caregivers of women with advanced breast cancer in the Accra Metropolis. These were consistent with Betty Ferrell’s QoL model applied to family caregivers. The findings indicated that, family caregivers had health challenges in the course of their caregiving activities. Physically, they experienced fatigue and pain in their bodies. Sleep disruption and loss of appetite were evident, and they offered assistance with activities of daily living to their sick relatives. Socially, they experienced isolation, financial burden and issues with employment. A new sub-theme which emerged under the social wellbeing theme but was not consistent with the QoL model was secrecy. Caregivers did not disclose their sick relative’s condition to others for fear of gossip and stigma. Psychologically, they had anxiety, lost concentration, were depressed and had fears. Empathy was a new theme identified under the psychological wellbeing. Caregivers showed empathy towards their sick relatives, this was not consistent with the QoL model. Spiritually, they sought meaning into their sick relative’s conditions by questioning God, became more religious and experienced positive change in their lives. Additional findings which were not consistent with Ferrell’s QoL model are: other sources of treatment; this includes spiritual and herbal sources of treatment for their sick relatives, beliefs about breast cancer; comprising spiritual and non-spiritual beliefs about the cause of breast cancer. Finally the theme support was identified which includes support from family and church members.
CHAPTER FIVE

Discussion of findings

5.0 Introduction

This study set out to explore the physical, social, psychological and spiritual wellbeing of family caregivers of women with advanced breast cancer. The chapter discusses the findings of the study in relation to existing literature. The discussion is organized on the demographic characteristics, physical, social, psychological and spiritual wellbeing; these themes are consistent with the themes in the Quality of Life Model Applied to Family Caregivers by Betty Ferrell. Thus, the underpinning theoretical framework for this study guided the organization of the chapter. Other sources of treatment, beliefs about breast cancer and support were new themes that emerged from the data and discussed.

5.1 Demographic characteristics

The majority of participants in this study were females who were either mothers or daughters of the sick relative. In the socio-cultural context of this study, the caregiver role is seen as the preserve of females (Nukunya, 2003). The females in this study were physically involved in the care of their sick relatives. This led to the physical effects reported in this study (Akpan-Idiok & Anarado, 2014; Rollero, 2016; Jane M Ussher et al., 2013).

However, this study identified that some caregivers were males who were either a brother or a husband to the sick relative (Kikuzawa, 2016; Nance, May, Padilla, Nava, & Pantoja). This finding may be attributed to the fact that the extended family system is gradually losing its significance; as it is expected that other extended family members will offer to care in the absence of a sister or a mother (Motha, 2017). The practice of male caregivers in the context of this study is limited. However, a study conducted by Shannon (2015) indicate that, males are task
oriented and may usually keep their stress to themselves. Male caregivers may require support and education on effective caregiving with regards to advanced breast cancer.

5.2 Physical wellbeing of family caregivers

The physical wellbeing of the participants in this study; centered on issues concerning pain; fatigue, sleep disruption, loss of appetite and assistance with activities of daily living.

In this study, participants reported pain in different body parts. They reported body pain probably because they underestimated the severity of their own pain as compared to that of their sick cancer relatives. This can often lead to the lack of motivation to seek early treatment. Persistent pain without treatment may lead to a deterioration of the sick relatives’ illness (J. Nicholas Dionne-Odom et al., 2015), restricting sick relatives to bed making them unable to perform self-care needs. The lifting of sick relatives to bathe them in bed or supporting them to the washroom coupled with wound dressing by caregivers aggravated their body pain (Carduff et al., 2014).

Participants perhaps, thought that alleviating the symptom of their sick relatives were of top most priority; and as such, did not take proactive steps in ensuring that their physical health was in good shape. Some sick relatives experienced constant bleeding from the breast due to the advanced nature of the disease. Participants were required to apply new dressing frequently. The low nature of sick relatives’ bed coupled with the frequent bending to dress these wounds resulted in caregivers developing back pain (Darragh et al., 2015; Girgis et al., 2013). It is perceived that participants were ignorant of the application of body mechanics and the use of appropriate lifting techniques that could bring body pain in them to the barest minimum (Washington, Pike, Demiris, & Oliver, 2015). This suggests that participants may require some insight into caregiving and lifting of patients from health professionals. Also, caregivers may
have applied dressing to the bleeding breasts of sick relatives without proper self protective measures (Islam et al., 2014) such as the wearing of disposable gloves. This may have led to infections. Caregivers may require education on infection prevention. In other cultures where the informal caregiving system is formalized and not a family member practice, assistance from close family relatives in the performance of self-care needs for sick relatives was relevant in eliminating body pain in family caregivers (Henriksson et al., 2013). Other participants also revealed that their sick relatives were ambulant and could bath and visit the washroom without assistance. For these patients, participants may have sought early treatment for sick relatives and this may have kept sick relatives condition from deteriorating (J. Nicholas Dionne-Odom et al., 2015).

Another physical effect reported was fatigue. Participants attributed their fatigue to physical exertions they experienced in the course of carrying out domestic activities such as washing, cleaning and cooking for their weak relatives (Bevans & Sternberg, 2012) . Others related their tiredness to long waiting times they experienced when they accompanied sick relatives to the hospital for doctor’s appointments (Ockerby, Livingston, O’Connell, & Gaskin, 2013) . Often, sick relatives were not ambulant, which required that participants run errands to buy needed items for their patient’s upkeep. This made them tired (Peters et al., 2015) . Participants may require counseling to encourage them to request for assistance from other members of the family in providing care for their sick relatives.

Caregivers indicated in this study that they experienced sleep disruption. This finding agrees with Lee et al (2015). Chemotherapy in cancer intervention is normally associated with vomiting (Roila et al., 2016) which may sometimes occur at night (Byun, Lerdal, Gay, & Lee, 2016). Sick relatives vomiting at night require the attention of the caregiver (Morris et al., 2015).
Caregivers woke up to provide vomit bowls for sick relatives. They ensured that sick relatives became comfortable (Cal, Avci, & Cavusoglu, 2017) to continue their sleep. There are other times when caregivers are expected to serve medications (Tjia, Ellington, Clayton, Lemay, & Reblin, 2015) timely. For example, a four to six hourly pain medication may require an interruption of sleep for timely administration. Caregivers woke up at different times at night to serve sick relatives with these pain medications. This made the time interval for caregiver sleep quite short and inadequate (Kotronoulas, Wengström, & Kearney, 2013, 2016). Caregivers may require counselling on adequate sleep to enable them to maintain optimum health and give the required care to their sick relatives.

The loss of appetite was reported in this study. It was related to the inability of the sick relatives to eat (Wittenberg, Saada, & Prosser, 2013). It is perceived that caregivers think about the possibility of their sick relatives dying since cancer is usually associated with death. The thought of losing a loved one made them lose the desire to eat (Shore, Gelber, Koch, & Sower, 2016). The poor appetite and the inability to eat well were characterized by weight loss. Caregivers may be secondary patients. They may require nutritional assessment in the course of their caregiving duties (Ekstedt, Stenberg, Olsson, & Ruland, 2014).

The findings from this study indicated that, Caregivers had sick relatives who were weak, could not do anything for themselves as they were also confined to bed. This required the constant presence of their caregivers by their bed side for the timely needed assistance and care. (Quesada et al., 2015; Wadhwa et al., 2013). Other caregivers had sick relatives who could undertake some movement within the home environment despite the weakness they experienced. They assisted such relatives in the performance of activities outside the home such as accompanying them for reviews (Woźniak & Iżycki, 2014) . Family caregivers may be
counseled to seek help from health professionals when providing physical care for their sick relatives at home.

5.3 Social wellbeing of family caregivers

With regards to the social wellbeing of caregivers, isolation, financial burden, employment and secrecy were reported.

The phenomenon of caregivers’ isolation reported in this study, stemmed from the constant observation and attention they give to their sick cancer patient. Some participants reported that their sick relatives were frail and required a continuous care which they provided. Consequently, participants did not have the pleasure of going out with friends or to parties. They could neither attend naming ceremonies nor honour wedding invitations. Thus, they felt a sense of stagnation in their lives and out of touch with society (Kovaleva, Hepburn, & Spangler, 2015). Participants lamented that their sick cancer relative’s inability to perform basic activities warranted the constant presence of caregivers. Thus, they were unable to effectively play other roles assigned to them. Also, the monotony of caregiving created a sense of loneliness in them (Song et al., 2011). In situations where participants did not report isolation; it was because their sick relatives were ambulant and could perform activities of daily living without assistance. Also family members took turns in the provision of care for sick relatives. This enabled participants to attend to other pressing issues when necessary.

Financial burden was reported in this study. Participants linked the financial burden to the protracted nature of the treatment, expensive drugs and high cost of treatment (Lai, 2012). In the socio-cultural context of this study, the costs of cancer treatments are borne by patients by direct out-of-pocket payment (van Eechoud et al., 2016). In the course of such treatments, participants and family relations are the immediate source of financial support. As such, participants in this
study indicated that they used all their savings and even borrowed money to enable them to pay very high medical bills for sick relatives (Nayak et al., 2014). Another area of the financial burden to participants was the dependents of sick relatives. Participants indicated that their sick relatives had children but were unmarried (Ginter & Braun, 2014). These children became vulnerable because of their mother’s illness. Caregivers thus, paid school fees, clothed and fed these children (Kidman & Thurman, 2014).

The high demand of caregiving underlined the employment challenges in this study (Manne et al., 2015). This made it difficult for participants to combine caregiving with their regular jobs. They took leave of absence from their employers so as to enable them to care for their sick relatives. Others reported that they were either late to work or absented themselves from work as a result of caregiving demands on them. The lateness and absenteeism resulted in contentions between them and their employers making them quit jobs (de Moor et al., 2017). Some participants who were self-employed also stopped work. Others indicated that they requested their friends to run their businesses for them so as to enable them to concentrate on caring for their sick relatives. Contrary to employment challenges, some participants whose relatives were ambulant indicated that, they got an additional job to their current jobs. This enabled them to ease the financial burden on them.

The phenomenon of secrecy in caring for a cancer patient is rooted in the stigmatization associated with the advanced stage of the disease. Participants concealed their sick relative’s condition from extended family members and friends. They indicated that disclosing their sick relative’s condition to extended family members meant exposing them to gossip. Thus, disclosing sick relative’s condition to friends will attract ridicule and mockery of sick relatives from the community (Kenu et al., 2014). The cultural perceptions about an illness influences
ones decisions regarding the illness (Michael, O’Callaghan, Baird, Hiscock, & Clayton, 2014). This could be an indication that Participants considered their sick relative’s advanced breast cancer as a taboo and therefore decided to keep it a secret. However, other caregiver indicated that they revealed their sick relative’s condition to others in anticipation of getting a feedback regarding a cure. This suggests that perhaps participants may have heard testimonies about others having been cured of breast cancer. Thus, they were ready to speak to anyone who could assist them in finding a cure for their sick relatives (Mwangome, Geubbels, Klatser, & Dieleman, 2016).

5.4 Psychological wellbeing

The third objective of this study set out to explore the psychological wellbeing of caregivers. This bothered on issues of anxiety, loss of concentration, depression, fear and empathy.

Family caregivers were anxious for various reasons. Thoughts about impending death of loved ones as a result of cancer were the main causes of anxiety reported in this study. Also, they were unsure of their future in the event of the death of their sick relative (Hendriksen et al., 2015). The thoughts of becoming orphans after losing a cancer sufferer who was a mother was the cause of anxiety specific to young daughters who assumed the caregiver role of their sick mothers. Thus, the socio-cultural impact of becoming orphans coupled with the vulnerabilities associated with orphanhood increased their anxieties (Heath, Donald, Theron, & Lyon, 2014). Treatment with chemotherapy in cancer patients is associated with changes in their physical appearance (Botchkarev & Sharov, 2016). Some participants attributed their anxiety to the physical changes they observed in their sick relatives (Sercekus et al., 2014). This suggests that caregivers perhaps lack information on the effects of chemotherapy. Participants may be
counseled on the effects of chemotherapy on cancer patients. Some caregivers related their anxiety to the financial burden associated with ABC coupled the prolonged treatment of the disease. Caregivers probably resorted to ineffective complementary and alternative medicine for their sick relatives. This perhaps led to the advanced stage of the disease and consequently, prolonged treatment (Laryea et al., 2014). Caregivers may be counseled to seek early treatment for sick relatives.

The loss of concentration was reported in this study. Some participants could not concentrate at school or on their jobs. The loss of concentration stemmed from the absence of caregivers from home leaving sick relatives alone at home. They reported that they thought about how their sick relatives fared alone while they were away. Caregivers may have reported loss of concentration because they did not receive assistance from other members of the family in the provision of care for their sick relatives. (De Roos, De Boer, & Bot, 2017).

Advanced breast cancer is usually associated with pain in the patient. The pain experienced by sick relatives resulted in depression in caregivers which was characterized by frequent crying, feeling of pity and sorrow. Participants may have been depressed probably because despite all efforts to provide a cure for their sick relative, death was imminent (Nipp et al., 2016). Also, caregivers may have thought about the sacrifices made by these sick relatives for them in the past, yet these sick relatives were not in good health to enjoy the fruits of their labour (Park et al., 2013). Probably, caregivers’ inability to adequately relieve sick relatives of their pain resulted in depression in them (Lee et al., 2013).

Findings from this study indicated that majority of participants reported diverse form of fear (Cohen et al.). One of the causes of breast cancer is genetic. This characterized the fear specific to participants who were daughters of the patient. They lamented that, should they
develop advanced breast cancer in future, they were uncertain about who would give them the necessary care within the family. This finding agrees with (Czerwonka et al., 2015), which indicates that family caregivers become apprehensive when they are uncertain about future expectations. Other participants’ fears were rooted in the thoughts about the possibility that their sick relatives may die (Hendriksen et al., 2015). Participants may have reported fear of death of sick relatives probably because they had lost hope. Regular discussion of death by health professionals with caregivers could take away the fear of death (Ray, Brown, & Street, 2014). They may be counselled on how to manage their fears so as to improve their psychological health and to enable them to give better care (Borneman et al., 2015). On the contrary, some participants did not report fear of death. They indicated that if their sick relatives died, they would consider it as the will of God. Participants did not report fear probably because death was a better option compared to the suffering and excruciating pain their sick relatives were experiencing (Ray et al., 2014).

The phenomenon of caregivers’ empathy as reported in this study stemmed from the pain experienced by sick relatives (Aziato & Adejumo, 2014). Some participants reported that they wished they could bear the pain for their sick relatives so as to give them some relief. They may have reported empathy probably because they were mothers caring for sick daughters (Vachon, 2016). Others also indicated that, they felt as though they were experiencing the pain that their sick relatives were going through. Contrary to this finding, some caregivers reported that, they got angry with their sick relatives. The anger was attributed to sick relative’s constant refusal to eat for fear of vomiting. Participants may have expressed anger probably because the caregiving demand was overwhelming which resulted in them becoming frustrated (Pooyania, Lobchuk, Chernomas, & Marrie, 2016).
5.5 Spiritual wellbeing of family caregivers

Issues on spiritual wellbeing of family caregivers in this study revolved around meaning, religiosity and positive change. Participants sought meaning to their sick relatives’ condition as reported in this study. They reported that, in their quest to understand why their sick relatives’ had advanced breast cancer, they question God. Some indicated that they wondered why their loved ones should experience such suffering. This finding is in line with findings from (Mehta, Chan, & Cohen, 2014) which indicate that the distressing physical responses of sick relatives to an illness; has the ability to produce some level of confusion in caregivers. This makes them ask questions. Some participants concluded that, their sick relatives’ ABC was allowed by God. This made them angry with God.

Findings from this study indicated that, religiosity was adopted as a coping mechanism by the participants (Clayton-Jones & Haglund, 2016). Most participants indicated that, their sick relatives’ ABC was a trial of their faith. According to Nukunya (2003), Ghanaians are generally religious. They interpret occurrences they did not make meaning of, to be a divine plan. Religiosity was characterized by increased frequency of prayer and fasting which drew caregivers closer to God. Participants had various requests regarding their sick relatives’ illness. These requests were communicated to God through prayers. Some indicated that, they prayed for healing for their sick relatives. Others also prayed for improvement in their businesses for better income to enable them to give appropriate care. Participants may have become more religious probably because it enabled them to cope with the overwhelming burden of caregiving (Paiva et al., 2015).
The caregiving experience influenced the attitudes of caregivers positively as reported in this study. Some reported that their sick relative experienced bleeding and excruciating pain from ABC; this informed their decision to have regular breast examination. Others indicated that their sick relatives died of ABC. The death experience informed their decision to speak openly to people about the disease (Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015). Participants revealed that respect for a human life characterized the positive attitudes they developed (Mosher et al., 2017).

5.6 Other sources of treatment

A new theme that emerged from this study is other sources of treatment. Participants indicated that, they sought complementary and alternative medicine for their sick relatives prior to conventional orthodox medicine. The cultural belief that the roots of an illness can be traced to supernatural causes (Kahissay et al., 2017), influenced the treatment seeking behaviour of caregivers for their sick relatives (Raman et al., 2016). Some participants indicated that in their quest for a cure, they took their sick relatives to a spiritualist who claimed they could cure breast cancer (Ramakrishnan et al., 2014). Others indicated that they sent their sick relatives to prophets at prayer camps in anticipation of a cure (James & Bah, 2014). Caregivers may have sought cure for their sick relatives from spiritualists and prophets probably because of their religious background (Ching, Zakaria, Paimin, & Jalalian, 2013). They may have seen people healed of diverse illnesses on religious television programmes or on the radio. Also friends and relatives may have testified about receiving healing from such sources of treatment (Ondicho, Ochora, Matu, & Mutai, 2016). Furthermore, perhaps, they probably did not believe that orthodox medicine could cure breast cancer (Silvanathan & Low, 2015); and thus, left sick relative at prayer camps for a prolonged period of time resulting in the cancer spreading to other
tissues in the body (Laryea et al., 2014). Thus making it necessary for sick relatives to undergo both chemotherapy and radiation therapy resulting in an increased financial burden on caregivers.

Findings from this study revealed that, caregivers used herbal medicine as a treatment option for their sick relatives. They revealed that, they purchased these herbal medicines from herbal clinics (Ondicho et al., 2016). Some mentioned that close relatives and friends introduced them to the use of herbal medicine (Nworu et al., 2015; Soner, Sahin, & Sahin, 2013). These relatives and friends attested to the effectiveness of the herbal medicines in curing diseases (Lydia Aziato & Antwi, 2016). It is perceived that, participants may have used complementary and alternative medicine probably because they wanted to avoid the undue delays during visits to the hospital (Ondicho et al., 2016). Easy accessibility to herbal medicine (Gartoulla, Davis, Worsley, & Bell, 2015), availability of herbal medicine (Roy, Gupta, & Ghosh, 2015) and cost effectiveness of herbal medicine as compared to orthodox medicine with regards to chemotherapy and radiation therapy, may have influenced caregivers decision to resort to the use of herbal medicine for their sick relatives. Furthermore, they used herbal medicine probably because they were ignorant of the existence of medical treatment for breast cancer (Ohene-Yeboah & Adjei, 2012). Caregivers may require education tailored towards their needs. They may also be supported by incorporating the treatment of breast cancer fully or partially into the national health insurance scheme.

5.7 Beliefs about the cause of Breast Cancer

Another new theme identified from this study was beliefs about breast cancer. Participants believed that, the physical manifestation of breast cancer in their sick relatives was as a result of a spiritual transfer of the disease to sick relatives by their enemies (Wilkinson &
Leach, 2015). Their socio-cultural background may have influenced attributing the cause of sick relatives’ illness to demonic influences (Damianakis, Wilson, & Marziali, 2016). A participant may have had such beliefs because of their ethnic background. The belief that a family or a person who is cursed will have evil spirits following him or her, wreaking havoc in the form of illness on that individual, exists among different ethnic groups (Padayachee & Laher, 2014). Some participants believed that an unknown human enemy bought breast cancer in the spirit realm and transferred it to their sick relative. Others reported that although breast cancer has a spiritual cause, orthodox medicine has a role to play. Thus, they used a combination of orthodox and spiritual modes of treatment for their sick relatives. This suggests that the belief that breast cancer has a spiritual cause (Meyer et al., 2015), influenced caregivers’ decision to seek the spiritual mode of treatment for their sick relatives. Consequently resulting in a delayed decision to commence early medical treatment (Laryea et al., 2014); hence the development of the advanced form of the disease by sick relatives.

Findings from this study indicated that ignorance influenced the beliefs of some participants about the causes of breast cancer. Some caregivers indicated that they believed that breast cancer was air-borne. Others reported that ABC was a communicable disease. Study participants may be bereft of information on breast cancer probably because education is usually directed at the sick individual and not the family caregiver. Also, the association of breast cancer and cancer in general with death may have resulted in participants deliberately ignoring educational programmes on breast cancer. Sick relatives alone do not experience the ridicule and mockery associated with ABC. It is extended to their family caregivers (Johnson, 2017). Participants may have had these beliefs about the cause of breast cancer but lacked the courage to seek information about the disease for fear of being stigmatized. Caregivers may require
education on breast cancer. Also, study participants may have been aware of breast screening services at hospitals but deliberately ignored patronage of such services; probably because they felt they would never experience breast cancer. They may also have been uncertain about the kind of attitude health professional may exhibit towards them probably because of past experiences with them (Sanders, Sterba, Ford, & Block, 2015).

5.8 Support

Support was a new theme identified from this study with the sub-themes support from church members and support from family members. The phenomenon of church support stemmed from the visitation caregivers received from church members. They reported that church members visited them. These visits encouraged them and gave them a sense of belongingness (Mosher et al., 2015). It is perceived that caregivers may have been emotionally strengthened by church members’ visits. These visits may have enhanced their coping abilities (Newberry et al., 2013).

Additionally, some reported that they received prayer support from church members and their religious leaders. This prayer support gave them the hope that their sick relatives will recover.

The care rendered by participants to sick relatives was facilitated by the food and financial assistance they received from the church. Some participants revealed that church members supported them with food. These foods helped them to save money which they used for other needs. Others reported that the church assisted them to pay their sick relatives’ medical bill. It is perceived that caregivers may require social support interventions to enable them to render appropriate care and also improve their mental and emotional health (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016).
Findings from this study revealed that the phenomenon of family support was rooted in the physical assistance participants received from members of the nuclear family.

Some reported that other members of the family volunteered to stay with the sick relative when caregivers had to attend to pressing needs outside the home (Luxardo et al., 2012). Others indicated that family members helped to convey sick relatives to the hospital with their vehicles for doctors’ appointments.

Reports by some participants indicated that family members assisted them in the performance of domestic activities (Fennell et al., 2016).

Financial assistance characterized the support received from family members to participants as reported in this study. Some indicated that other family members decided to work to provide the income for the care of their sick relative so that they (caregivers) would concentrate directly on providing physical care for the sick relative. Family members may have regarded family caregiving as a situation requiring the division of labour (van Eechoud et al., 2016) and as such each member needed to contribute his or her quota. Also, findings according to Wagner et al (2015) indicates that the blood ties among family members makes it impossible for individuals in the family to overlook the predicament of another member of the same family. Thus, meeting the needs of any member of a family especially in times of sickness is an act of love.

In the socio-cultural context of this study, the extended family system is practiced (Nukunya, 2003). Extended family members are expected to assist members of the family in times of need. Findings from this study revealed that all except two participants received diverse forms of family support from members of the nuclear family. These findings suggest that perhaps the extended family system is losing its significance.
5.9 Evaluation of the QoL model Applied to family caregivers

The quality of life model by Ferrell (1991) was the underpinning framework for this study. It assisted the researcher in exploring the wellbeing of family caregivers of women with advanced breast cancer. The physical, social, psychological and spiritual domains were used to formulate the research objectives. Also, the interview guide was based on the constructs of the model. The physical domain had one major theme as physical wellbeing. A major theme identified from this study was physical wellbeing. This theme was in agreement with the physical domain of the model. Fatigue, Sleep, disruption, function, nausea, appetite, constipation and aches/pain were subthemes that characterized the physical domain in the model. Four subthemes identified from this study were consistent with the model. These were pain, fatigue, sleep disruption and loss of appetite. Nausea and function were not identified in this study. However, a new theme: assistance with activities of daily living emerged, which is associated with the physical domain of the model.

The psychological domain of the model had psychological wellbeing as its main theme. A major theme that identified from this study was psychological wellbeing. This was consistent with the psychological domain of the model. The Psychological domain also had anxiety, depression, helplessness, difficulty coping, fear, useless, concentration, control and distress as subthemes. These subthemes assisted in eliciting responses about the psychological state of health of the participants in this study. However, from the subthemes that were identified in this study, helplessness, difficulty coping, useless and control were not identified. Nevertheless, a new subtheme: empathy emerged which is directly related to the psychological domain.

The model had social wellbeing as its main theme in the social domain. Social wellbeing was identified as a major theme from this study which agrees with the model. The social domain
of the model has a total of eight subthemes namely; isolation, role adjustment, financial burden, roles/relationships, affection/ sexual function, leisure activities, burden and employment. Apart from four of these subthemes comprising isolation, financial burden, leisure activities and employment which were identified as subthemes from the data analyzed from this study; the other concepts were not relevant to this study. However, secrecy was a new theme that emerged from the analysis of the data in this study. This new theme was related to the social domain of the model.

Regarding the spiritual domain of the QoL model, spiritual wellbeing was its major theme. Also, a major theme that was identified from the findings of this study was spiritual wellbeing. This was in agreement with the model. The spiritual domain of the model had concepts such as meaning, uncertainty, hope, religiosity, transcendence and positive change as its subthemes. However, the subthemes that were identified from this study and were consistent with the model were meaning, religiosity and positive change.

In all, seven major themes emerged from the data but only four were consistent with the model. The four themes include physical wellbeing, psychological wellbeing, social wellbeing and spiritual wellbeing. The three additional themes include:

- Beliefs about the causes of breast cancer
- Other sources of treatment with spiritual and herbal sources of treatment as subthemes
- Support also emerged with church support and family support as subthemes

5.10 Suggestions to the model.
The researcher suggests that the QoL model applied to family caregivers should incorporate assistance with activities of daily living into the physical domain of the model, secrecy into the social domain of the model and also empathy into the psychological domain of the model. In addition, the social domain could further be expended to include traditional beliefs and culture as well as support.
Summary, Implication, Limitation, Conclusion and Recommendation

6.0 Introduction

This chapter outlines the summary of the study, the implications of the findings for nursing practice, research, administration and education. The limitation, conclusion and recommendations from the study are also presented.

6.1 Summary of the study

In the Ghanaian context, family caregivers are family members who may have other social and economic commitments. The care of a relative with ABC becomes an additional burden which may predispose family caregivers to health challenges.

This study sets out to explore the wellbeing of family caregivers of women with ABC. The study employed a qualitative exploratory descriptive design. A semi-structured interview guide was designed based on the objectives of the study using the QoL model applied to family caregivers by Betty Ferrell (1991). The study was undertaken within the Accra Metropolis and participants were recruited from the chemotherapy suite of the Tamakloe ward at the 37-Military hospital. Data collection began after ethical approval from the Institutional Review Boards of both the Noguchi Memorial Institute for Medical Research, University of Ghana and the 37-Military Hospital. Participants were purposively sampled and saturation was reached by the 13th participant. The interview guide was pretested at the University hospital to ensure that it was understood and was able to elicit the required responses that would answer the research questions. Participants who agreed to participate in the study signed a consent form. Interviews were audio-taped and verbatim transcription of interviews occurred alongside. Data were analyzed using thematic content analysis.
The key findings revealed that most of the caregivers complained that physically, they experienced pain in different body parts due to lifting sick relatives. They constantly assisted sick relatives with self care needs, domestic chores during the day and at night in addition to running errands for their sick relatives. These resulted in their sleep being disrupted and fatigue. Furthermore, the pains experienced by sick relatives, made caregivers lose appetite for food. One of the caregivers indicated that he did not lose appetite for food; and that he ate because he needed the strength to provide the care.

Most caregivers could not honour invitations to social gatherings because their sick relatives needed to be observed continuously. They were burdened financially as a result of the high cost of treatment for ABC coupled with having to take care of the dependents of sick relatives. The demands of caregiving made majority of caregivers stopped working at a point in time to focus on caring for their sick relatives. A caregiver indicated that, he got an additional job to enable him to offload some of the financial burden brought by his sick relative’s ABC. Also, majority kept their sick relatives’ ABC to themselves for fear of stigmatization.

All the caregivers experienced anxiety as a result of the effect of chemotherapy on the physical appearance of sick relatives. Also, the thoughts about the possibility of their sick relatives dying made them depressed. Caregivers lost concentration at work because there was no one at home to care for sick relatives. The agonizing pain and debilitating effect of ABC made caregivers depressed. They anticipated the death of their sick relatives and sometimes sick relatives’ comments about they not surviving ABC made them afraid. They were empathetic when sick relatives express pain.

Both Christians and Muslims employed spirituality as a coping mechanism in this study. They concluded that, their sick relatives suffered from ABC because it was the will of God. All
caregivers drew closer to God and prayed for the healing of their sick relatives. They exhibited a positive attitude by going for regular breast examination and had a greater value and respect for mankind. A caregiver indicated that she started talking to people about breast cancer.

All caregivers sought complementary and alternative sources of treatment for their sick relatives; in addition to traditional orthodox medicine. Most caregivers sought spiritual healing by taking sick relatives to spiritualists and prophets at prayer camps for prayers for healing. Other caregivers got herbal concoctions from herbalists and applied it on their sick relatives in anticipation of healing for them.

Majority of the caregivers had diverse believes about the cause of breast cancer. Some believed that, breast cancer has a spiritual cause. Others believed breast cancer was air-borne. A caregiver indicated that, breast cancer can be gotten by contact with a person suffering from the disease. Also, other family caregivers were completely ignorant of the cause of breast cancer.

Caregivers received diverse forms of support which helped them to give appropriate care. They were assisted by the church with money and food. They were encouraged by the visits and prayers by church members. Other family members supported caregivers with money and stayed with sick relatives when caregivers had to attend to pressing needs outside the home. They also assisted in maintaining self-care needs of sick relatives and helped to take sick relatives to the hospital for doctors’ appointment.
6.2 Implications for Nursing

The findings from this study have implications that require attention. These implications yield themselves to nursing research, nursing education, nursing administration and nursing practice.

6.2.1 Nursing Research/Avenues for future Research

Caregivers in this study were mostly daughters who were actively involved in the care for their sick relative. While some caregivers believed that their sick relatives would recover, others anticipated their death. Future studies could focus on experiences of survivors of advanced breast cancer, quality of life of family caregivers after the death of a sick cancer relative, experiences of spouses with wives with advanced breast cancer, complementary and alternative treatment use in women with breast cancer and complementary and alternative treatment use in family caregivers of advanced cancer patients; to ascertain the impact of breast cancer on the family

6.2.2 Nursing Education

Oncology nursing curriculum should be developed for the training of oncology nurses’ post basic nursing training. This training will provide nurses with specialized skills to give holistic care to patients with breast cancer and their family members. Causes in medical-surgical nursing and gerontology at the diploma nursing program level should be expanded to include topics on family caregiver wellbeing. Health tutors must teach a comprehensive and holistic approach to cancer management and treatment to include family caregivers of cancer patients. Furthermore, findings from this study revealed that, the physical and social wellbeing of family caregivers were highly compromised. This requires the development of curriculum for palliative nursing programme for the training of palliative care nurses to provide specialized care for patients with advanced cancer. Training of caregivers who may not be family members could be
considered. This will go a long way to improve the physical and social wellbeing of family caregivers. Healthcare for the ABC patient must adopt a family centered care approach, to enable care to be centered on the entire family and not only the sick member.

6.2.3 Nursing Administration.

Findings from this study revealed that, family caregivers not only had superstitious beliefs about breast cancer but were also ignorant about the cause of the disease. This resulted in seeking the inappropriate source of treatment for sick relatives. Therefore, a modification of the policy on public education is required. This will make the education on breast cancer acceptable and easily accessible and further enhance the choice of treatment modalities of family caregivers of breast cancer patients for their sick relatives and the entire population.

6.2.4 Nursing Practice

Findings from this study revealed that, caregivers assisted their sick relatives by accompanying them to the hospital for doctors’ appointments and other procedures such as wound dressing and chemotherapy. However, their psychological wellbeing was highly compromised in the performance of their caregiving activities. Therefore, counselling needs to be provided for caregivers to help them to cope better with their caregiving duties to enable them give better assistance to sick relatives.

6.3 Insight Gained

The researcher noted that, ignorance of the causes of breast cancer was a major problem the research participants had. Caregivers did not receive any form of education from health professionals when they accompanied sick relatives to hospital. Some caregivers combined orthodox medicine with ineffective herbal medicine based on the recommendation of friends and relatives. The psychological health of caregivers was highly compromised.
6.4 Limitation

The study was conducted in the southern part of Ghana. The participants in this study were all Christians except one. The study may be conducted in an Islamic community using Muslims because of differences in the religious beliefs and the findings compared. The small number of male family caregivers in this study may not have adequately represented the experiences of male family caregivers of advanced breast cancer patients.

6.5 Conclusion

Breast cancer is on the ascendency and many patients are progressing to the advanced stage of the disease. Health facilities do not have adequate capacity to nurse these patients. Family members are saddled with the responsibility of caring for these patients who are usually unable to perform any activity by themselves. The care demand on these family members negatively impacts their physical, social, psychological and spiritual health. The stigma associated with the disease is extended to them. It is imperative that policy makers put measures in place to address the health needs of family caregivers of women with advanced breast cancer. Educational materials should be tailored towards the need of caregivers. Health professionals at schools and institutions should intensify general education of The population through health talks to address the stigmatization. The Ministry of Health together with other stakeholders should lobby for the absorption of the cost of treatment for ABC; partially or fully by the national health insurance scheme. This will ease the financial burden on caregivers. With these measures in place, caregivers will be in a better position to give appropriate care to sick relatives.
6.6 Recommendations

Based on the findings of this study, the following recommendations have been made to the Ministry of Health and 37-Military hospital.

6.6.1 Ministry of Health

1-The policy on public education on breast cancer should be modified by the ministry of health and other stakeholders. Health education on breast cancer should be intensified. This will make the education on breast cancer acceptable and easily accessible.

2-The ministry of health and other stakeholders should lobby the government to cover the treatment of breast cancer either partially or completely by the National Health Insurance Scheme.

3-Policy should be made to include breast screening for lumps as a routine investigation for females who come to the hospital for treatment. Also as part of the existing antenatal schedule.

4- The ministry and other stakeholders should develop educational materials tailored to the need of family caregivers of women with ABC.

6.6.2 37-Military Hospital

1-The management of the hospital should prepare educational materials tailored towards the needs of family caregivers and make them available to nurse clinicians for distribution.

2-Opportunity for further education of nurse clinicians as oncology nurses to enhance counselling of family caregivers of women with advanced breast cancer.
REFERENCES


doi:https://doi.org/10.1016/j.soncn.2012.09.005


Lawton, K. E., Gerdes, A. C., Haack, L. M., & Schneider, B. (2014). Acculturation, cultural values, and Latino parental beliefs about the etiology of ADHD. *Administration and Policy in Mental Health and Mental Health Services Research, 41*(2), 189-204.


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


APPENDIX A: BACKGROUND INFORMATION FORM

A. Demographic Information

Code number

1. Age (years)
2. Level of Education
3. Occupation
4. Place of residence
5. Marital status
6. Number of children
7. Nationality
8. Religion
9. Language spoken
10. Relationship
11. Duration of care
APPENDIX B: INTERVIEW GUIDE

B. GUIDING QUESTIONS

1. Share with me what you do for your sick relative on day to day basis

2. Please share with me your caregiving experiences with regards to your physical health

Probes:

- Fatigue
- Aches and pains
- Changes in eating
- Changes in elimination
- Difficulty Sleeping

3. What are some of your experiences with regards to your social health?

Probes:

- Recreational activities
- Social events such as weddings, funerals, naming ceremonies etc
- Work related activities
- Relationship with spouse/family
- Adjustment to caregiver role
- Social isolation
- Any changes in responsibilities
4. What will you say about your psychological health?

**Probes:**

- Fears and worries
- Happy and unhappy moments
- Forgetfulness
- Helplessness
- Depression

5. What can you say about your spiritual life?

**Probes:**

- Closeness to God
- Consultation with prophets/ Mallams/ herbalists
- Use of anointing oil/ concoctions/holy water
- Hope in God

Is there anything else you will like to talk about?
APPENDIX C: INDIVIDUAL CONSENT FORM

CONSENT FORM

Title: Exploring the Wellbeing of Family Caregivers of Women with Advanced Breast Cancer in the Accra Metropolis.

Principal Investigator: Beulah Alomele

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

General Information about Research

Your participation in this research will be valued greatly. The objective of this study is to explore the physical, social, psychological and spiritual wellbeing of family caregivers of women with advanced breast cancer. This study is solely for academic purpose. If you agree to take part in this study, the researcher will meet with you at your convenience and have a conversation with you for about 45 minutes to 1 hour in English, Twi, Ga, Fante or Ewe language. The conversation will be recorded. A second conversation may be arranged if necessary. The conversation will be about the things you go through in caring for your relative with advanced breast cancer. You will be asked to sign a consent form as appropriate.

Possible Risks and Discomforts

It is not expected that being in this study will be harmful to you, however, you may feel emotional about telling your story. If that happens, the researcher will refer you to Miss Bridget Amoako-Atta a clinical psychologist who will talk to you to relieve you of your emotions without any financial cost to you.
Possible Benefits

Sharing your caregiving experiences in this research, will enhance further exploration into family care centered approach in adult health in Ghana.

Confidentiality

The conversation will be recorded on tape and later written in words but your name will not be recorded; neither will it be mentioned in any report. A number and fake names will be given to the conversation. The only people that will know about the conversation will be my supervisors. All written information about you will be kept at a separate place from the recorded information for five years after the study and then destroyed.

Compensation

You will be refreshed with biscuits and coke after the conversation with the researcher. If the conversation takes place outside your home or workplace, you will receive ten Ghana cedis for transportation in addition to the snack.

Voluntary Participation and Right to Leave the Research

Participating in this study is voluntary. You are free to leave the study at any point. Such withdrawal will not affect the quality of healthcare service you or your relative will require from health care providers.
Contacts for Additional Information

If you have any concerns or questions about the research now or later, please contact:

THE RESEARCHER:

Beulah Alomele, M. Phil Nursing (student) Address: Department of Adult Health, School of Nursing and Midwifery, College of Health Sciences, University of Ghana, P. O. Box LG 43, Legon, Accra Ghana. Tel. 0243579331, Email: beulaalomele@gmail.com

SUPERVISORS:

Dr. Lydia Aziato, Department of Adult Health, School of Nursing, College of Health Sciences, University of Ghana, P. O. Box LG 43, Legon, Accra Ghana.
Tel.- 0244719686 /020855271. Email: aziatol@yahoo.com

Lillian Akorfa Ohene, Department of Community Health, School of Nursing, College of Health Sciences, University of Ghana, P. O. Box LG 43, Legon, Accra Ghana Tel. 0246395696. Email- akorfaohene11@yahoo.com

COUNSELLOR:

Bridget Amoako-Atta, Nurses’ Training College- Pantang,
P.O. Box LG 81, Legon, Accra Ghana.
Tel. 0241919901, Email: b.amoakoatta@gmail.com

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.mimcom.org
The above document describing the benefits, risks and procedures for the research title (Exploring the well-being of family caregivers of women with advanced breast cancer 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 D: GENERAL PROFILE OF PARTICIPANTS

#### DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

<table>
<thead>
<tr>
<th>Name</th>
<th>Language</th>
<th>Age</th>
<th>Education</th>
<th>Occupation</th>
<th>Marital Status</th>
<th>Number of Children</th>
<th>Religion</th>
<th>Relationship</th>
<th>Duration of Care</th>
<th>Gender</th>
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<td>student</td>
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<td>none</td>
<td>Christianity</td>
<td>daughter</td>
<td>1 year</td>
<td>F</td>
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<tr>
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<td>trader</td>
<td>Divorced</td>
<td>four</td>
<td>Christianity</td>
<td>mother</td>
<td>1 year</td>
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<td>Ewe</td>
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<tr>
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<td>Akan</td>
<td>40-49</td>
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<td>trader</td>
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<td>four</td>
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<td>M</td>
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<td>1 year</td>
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### APPENDIX E: SUMMARY OF THEMES

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<td>Loss of Appetite</td>
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<td>Assistance with activities of daily living</td>
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<td>Social wellbeing</td>
<td>Isolation</td>
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<td>Financial Burden</td>
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<td>Employment</td>
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<td>Secrecy</td>
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<td>Anxiety</td>
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<td>Loss of Concentration</td>
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<td>Depression</td>
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<td>Fear</td>
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<td>Spiritual Wellbeing</td>
<td>Meaning</td>
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<td>Positive Change</td>
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<td>Other sources of treatment</td>
<td>Spiritual sources</td>
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<td>Herbal sources</td>
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<td>Beliefs about the Causes of Breast Cancer</td>
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<td></td>
<td>Non Spiritual causes</td>
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APPENDIX F: ETHICAL APPROVAL LETTER

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

INSTITUTIONAL REVIEW BOARD

Phone: +233-302-916438 (Direct)
+233-289-522574
Fax: +233-302-502182/513202
E-mail: nirb@noguchi.mimcom.org
Telex No: 2556 UGL GH

My Ref. No: DF.22
Your Ref. No:

2nd November, 2016

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824
 NMIMR-IRB CPN  024/16-17
 IRB 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 : Exploring the wellbeing of family caregivers of women with advanced breast cancer in the Accra Metropolis

INVESTIGATOR : Beulah Alomele, 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 G: INTRODUCTORY LETTER

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

Telephone: 0302-513255 (Dean)
Ext. 6206
0302-513250 (Secretary)
028 9531213
Fax: 513255
E-mail: nursing@ug.edu.gh

SON/A.12
Our Ref:........................................
Your Ref:........................................

The Executive Secretary
NMIMR – IRB
P.O. Box LG 581
Univ. of Ghana
Legon.

Dear Sir/Madam,

DEPARTMENTAL APPROVAL LETTER

This is to introduce to you Beulah Alomele, an M.Phil student of the above School and to inform you Institutional Review Board of the approval of the thesis topic; “Exploring the wellbeing of family caregivers of women with advanced breast cancer” by the department of Adult Health Nursing, School of Nursing.

Thank you.

Yours faithfully,

Dr. Lydia Aziato
SUPERVISOR

October 13, 2016
APPENDIX H: ETHICAL APPROVAL LETTER FROM 37-MILLITARY

Institutional Review Board
37 Military Hospital
Neghelli Barracks
ACCRA

Tel: 0302-769667
Email: irb37milhosp@hotmail.com

26 January 2017

ETHICAL CLEARANCE

37MH-IRB IPN 098/2017

On 24th January 2017 the 37 Military Hospital (37MH) Institutional Review Board (IRB) at a Board meeting reviewed and approved your protocol.

TITLE OF PROTOCOL: Exploring the Wellbeing of Family Caregivers of Women with Advanced Breast Cancer. A study in the Accra Metropolis

PRINCIPAL INVESTIGATOR: Beulah Alomle

Please note that a final review report must be submitted to the Board at the completion of the study.

Please report all serious adverse events related to this study to 37MH-IRB within seven (7) days verbally and fourteen (14) days in writing.

This certificate is valid till 24th January 2018.

DR EDWARD ASUMANU
(37MH-IRB, Vice Chairperson)

37 MILITARY HOSPITAL
INSTITUTIONAL REVIEW BOARD
DATE 26-01-17

Cc: Brig Gen EC Saka Jnr
APPENDIX I: INTRODUCTORY LETTER TO 37-MILLITARY HOSPITAL

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

December 1, 2016

The Administrator
Institutional Review Board
37 Military Hospital
Accra.

Dear Sir/Madam,

INTRODUCTORY LETTER: BEULAH ALOMELE

This is to introduce to you Beulah Aologne, an M.Phil final year student of the above School, Dept of Adult Health Nursing and to inform the Ethical Review Committee of the approval of the thesis topic; "Exploring the well being of Family Caregivers of Women with Advanced Breast Cancer."

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

Thank you.

Yours faithfully,

Dr. Lydia Aziato
SUPERVISOR