HEALTH-RELATED QUALITY OF LIFE AMONG WOMEN LIVING WITH BREAST CANCER IN GHANA

Submitted in partial fulfilment of the requirements for the Doctor of Philosophy degree in Psychology

By

Nuworza Kugbey

Supervisors:

Prof. Anna Meyer-Weitz (PhD)

Dr. Kwaku Oppong Asante (PhD)

DECLARATION

I certify that the work in this thesis entitled "HEALTH-RELATED QUALITY OF LIFE OF WOMEN WITH BREAST CANCER IN GHANA" has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree to any other university or institution other than the University of KwaZulu-Natal.

I also certify that the thesis is an original piece of research written by me. Any help and assistance that I have received in my research work and the preparation of the thesis have been duly acknowledged.

In addition, I certify that all information sources and literature used in this study are indicated in the thesis.

Nuworza Kugbey (Student Number: 216074750)

December, 2018

DEDICATION

This work is dedicated to the memory of my late mother [Vincentia Adzo Ahiase]. You left too

early without reaping the fruits of your labour. Rest well Mum!

ACKNOWLEDGEMENTS

ABSTRACT

Background: Health-related quality of life has become an important determinant of the effectiveness of medical treatments among persons living with chronic illnesses including breast cancer. Living with breast cancer is associated with several physical, psychosocial and economic challenges that could negatively impact on the health and wellbeing of women receiving treatment for breast cancer. Breast cancer in the second most diagnosed cancer type among women in Ghana and has several implications for the health of these women due to late diagnosis. However, there is lack of comprehensive social science evidence on the health-related quality of life and its associated factors among women living with breast cancer in Ghana. This study examined the predictors of health-related quality of life among women living with breast cancer and further explored the lived experiences of the women with regards to their challenges, illness representation, coping strategies and healthcare satisfactions.

Methods: An explanatory sequential mixed method was employed where quantitative data collection precedes qualitative data collection. For the quantitative phase, a total of 205 women living receiving treatment for breast cancer at a Tertiary Hospital in Ghana were conveniently sampled and administered a set of questionnaires measuring the study variables. For the qualitative phase, a total of 11 women were purposively and conveniently sampled. Individual in-depth interviews were conducted with the participants using a semi-structured interview guide. Descriptive statistics, Pearson Product Moment correlations, multiple regression and mediational analyses using PROCESS were used to analyse the quantitative data whereas the interpretative phenomenological approach was used for the qualitative data analyses.

Results: Quantitative results showed that access to health information, health literacy, shared decision making, doctor-patient relationship, social support, having a fighting spirit, the use of cognitive avoidance and fatalistic attitude were significant protective factors for improved quality of life. On the contrary the depression, anxiety, the use of hopeless-helpless coping and anxious preoccupation were significant risk factors for poor quality of life. These predictors had both direct and indirect effects on quality of life among the women through other variables. Findings from the qualitative analyses showed that bio-psychosocio-economic challenges such as the burden of medical treatment, alternative/herbal medicine use and breast cancer stigma were the major lived experiences of the women. There was general inadequate knowledge and understanding of breast cancer. Spirituality, social support, diversion coping and breast cancer self-care practices were identified as the main coping strategies among the participants. There was a varied perception about the satisfaction with interaction and communication with the healthcare professionals.

Conclusion: The findings from this study suggest that there are several and complex interlinked challenges faced by women living with breast cancer. These challenges could negatively impact on the health and wellbeing of these women if a holistic approach with professionals from different health disciplines to address their needs. The findings underscore the need for cost-effective cognitive-based psychosocial interventions to deal with the psychosocial challenges which affect their emotional states and ultimately their health-related quality of life.

ABBREVIATIONS

APA	American Psychiatric Association
BCAC	Breast Cancer Additional Concerns
DPR	Doctor-Patient Relationship
EWB	Emotional Wellbeing
FWB	Functional Wellbeing
HRQOL	Health-related Quality of Life
PWB	Physical Wellbeing
QOL	Quality of Life
SFWB	Social/Family Wellbeing
SDM	Shared Decision Making
WHO	World Health Organization

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF PUBLICATIONS

The following are papers emanating from this thesis.

Journal Articles

Kugbey, N., Meyer-Weitz, A., & Oppong Asante, K. (Minor Revision_Nov, 2018). Access to health information, health literacy and health-related quality of life among women living with breast cancer: Depression and anxiety as mediators. *Patient Education and Counseling.*

Kugbey, N., Meyer-Weitz, A., & Oppong Asante, K. (2018). Mental adjustment to cancer and quality of life among women living with breast cancer in Ghana. *The International Journal of Psychiatry in Medicine*, 0091217418805087.

Kugbey, N., Oppong Asante, K., & Meyer-Weitz, A. (2018). Doctor–patient relationship mediates the effects of shared decision making on health-related quality of life among women living with breast cancer. *South African Journal of Psychology*, 0081246318801159.

Conference Presentation

Kugbey, N., Oppong Asante, K., & Meyer-Weitz, A. (November, 2018). Breast cancer patients' quality of life: do their involvement in medical decision and relationship with doctors matter? *Paper presented at the College of Humanities Annual Conference*, University of Ghana, Legon-Accra.

CHAPTER ONE

INTRODUCTION

1.1 Background

Cancer morbidity and mortality are significant health challenges that confront both developed and developing countries (Forman, Ferlay, Stewart, & Wild, 2014). There are several cancer types and the most prevalent among women is breast cancer, followed by colorectal, lung, cervix, and stomach cancer (Forman et al., 2014). Evidence suggests that breast cancer diagnosis is common in developing countries with its attendant socioeconomic and psychological problems (Mensah, Yarney, Nokoe, Opoku, & Clegg-Lamptey, 2016; World Health Organization, 2011). Even though breast cancer is diagnosed among both men and women, the prevalence of male breast cancer worldwide is rare, accounting for less than 1% of all breast cancer cases (Anderson, Jatoi, Tse & Rosenberg, 2010; Contractor, Kaur, Rodrigues, Kulkarni, & Singhal, 2008; Korde et al., 2010; Weiss, Moysich & Swede, 2005). Much attention has been dedicated to women living with breast cancer as the prevalence rate of the disease globally is relatively high (Bray et al., 2018).

In sub-Saharan Africa, breast cancer is the most diagnosed cancer among women with approximately a 80% mortality rate (Jiagge, Bensenhaver, Oppong, Awuah, & Newman, 2015), thus, presenting a major public health challenge to these countries. Among women in Ghana, breast cancer is the second leading form of cancer after cervical cancer (Mensah et al., 2016; WHO, 2014) with a high proportion of cases only diagnosed in the later stages of the disease (Atobrah 2013; Jiagge et al., 2015). This late presentation affect the overall prognosis of the disease and lead to increased mortality. However, some researchers have found breast cancer to be the most

1

commonly diagnosed malignancy and a leading cause of death among women in Ghana (Laryea et al., 2014; Ohene-Yeboah & Adjei, 2012). These findings show that there is an urgent need for adequate attention to improve the health and wellbeing of women living with breast cancer

Medical advancements in the treatment options available in the management of breast cancer has resulted in increased chances of survival of cancer patients (Bodai & Tuso, 2014). However, evidence suggests that living with a chronic illness like breast cancer is accompanied by comorbid physical, psychological and social problems (Atobrah, 2013; Clegg-Lamtey, Dakubo, & Attobra 2009a; Opoku, Benwell, & Yarney 2012). Some of these associated challenges include fear, guilt, depression, suicidal thoughts, severe pain, and interpersonal difficulties which are likely to negative influence women's wellbeing.

1.1.1 Risk Factors and Treatment options for Breast Cancer among Women

The high prevalence of breast cancer especially among women have been associated with several risk factors including biological, lifestyle and environmental factors (Bertrand et al., 2015; Castelló et al., 2014; Hystad et al., 2015; Liu et al., 2015). Biological risk factors identified in the breast cancer literature include personal and family history of breast cancer, genetic predispositions, benign breast diseases, ductal/ lobular carcinoma in situ, breast density, endogenous hormone levels, menstrual cycle and age at pregnancy (American Cancer Society, 2015; Anderson, Schwab & Martinez, 2014; Bertrand et al., 2015; Gabai-Kapara et al., 2014; Lopez-Garcia et al., 2010; Santen, Yue, & Wang, 2015; Freer et al., 2015; Turnbull & Rahman, 2008).

Lifestyles that predispose people to breast cancer include smoking, alcohol intake, deodorant use, physical exercise, diet and body weight (Castelló et al., 2014; Chen et al., 2011; Chlebowski, 2013; Hardefeldt, Edirimanne, & Eslick, 2013; Hildebrand, Gapstur, Campbell, Gaudet, & Patel, 2013; La Vecchia, Giordano, Hortobagyi, & Chabner, 2011). It has also been shown that possible environmental risk factors of breast cancer include occupational exposures, radiation, environmental pollutants and diethylstilboestrol exposure (Bhan et al., 2014; Hilakivi-Clarke, de Assis & Warri, 2013; Hystad et al., 2015; Pestana et al., 2015). Even though most of these risks factors are not modifiable, environmental and behavioural factors can be modified by the individual to decrease the chances of being diagnosed with breast cancer (Liu et al., 2015; Moskowitz et al., 2014).

Furthermore, there are several treatments options for breast cancer and some of these main treatment options include surgery, radiotherapy, chemotherapy, hormone therapy and biological treatments (American Cancer Association, 2015). The choice of a particular treatment method(s) depends largely on several factors including the type and stage of breast cancer, size of breast tumour, the grade of the cancer cells, age of the individual, whether cancer cells have receptors for particular cancer drugs and the general health of the individual woman involved (American Cancer Association, 2015). However, some of these treatment methods have severe side effects that could impact on the physical and psychosocial wellbeing of women living with breast cancer. For example, upper extremity issues, fatigue, pain, depression, chemotherapy-induced peripheral neuropathy, and body image disturbances have been noted among women treated for breast cancer (Cantarero-Villanueva, Fernández-Lao, Díaz-Rodríguez, Sanchez-Cantalejo, & Arroyo-Morales, 2011; Ridner, 2005; Sagen, Karesen, Sandvik & Risberg, 2009). Furthermore, these negative side

effects of breast cancer treatments could affect the health and wellbeing of women living with breast cancer, especially their quality of life (Sagen et al., 2009).

1.1.2 Health-Related Quality of Life

Quality of life basically concerns "individuals' appraisal of their lives in relation to goals, expectations, standards and concerns and this appraisal is influenced by the individuals' physical health, psychological state, level of independence, social relationships and their environment" (WHO, 1997, p. 1). For persons living with breast cancer, this is an important domain of their health outcomes, as it determines the overall wellbeing of the patients undergoing treatment. Patients' functional, social, physical and emotional wellbeing constitute important domains of quality of life which are essential in evaluating the effectiveness of the healthcare treatment.

Women with breast cancer have reduced quality of life (Almutairi, Mansour &Vinluan, 2016; Gold et al., 2016; Kyei, Oppong, Opoku, Antwi, & Tagoe, 2014; Montazeri et al., 2008) and therefore, there is the need to examine the predictors of breast cancer patients' quality of life as decreased quality of life suggests poor health and wellbeing. Thus, identification of these factors linked to the quality of life of women living with breast cancer will help in planning interventions aimed at minimizing the risk factors and maximizing the protective factors of better quality of life which is likely to affect treatment adherence and overall illness outcomes.

Furthermore, research evidence suggests that social, contextual/environmental factors, personal characteristics and clinical variables of the patients significantly affect their quality of life (Al-Naggar, Nagi, Ali, & Almuasli, 2011; Clever, Jin, Levinson & Meltzer, 2008; Gokgoz et al., 2011; Reich, Lesur & Perdrizet-Chevallier, 2008; Venetis, Robinson, Turkiewicz & Allen,

2009). One of the key factors identified to have significant influences on health outcomes of persons living with chronic illness, is their level of health literacy –"an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, 2000, p. ix).

Health literacy is seen as crucial in the management of chronic illnesses such as cancer as living with cancer predisposes the patients to both emotional, social and physical challenges (Katz, Belkora & Elwyn, 2014; Thorne, Oliffe & Stajduhar, 2013). For instance, limited health literacy among persons living with chronic illnesses have been associated with negative health outcomes such as poor functional status (Serper et al., 2014; Smith et al., 2013), increased mortality (Baker, Wolf, Feinglass, & Thompson, 2008; Bostock, & Steptoe, 2012), poor health task performance (Smith et al., 2015), unsafe use of medication (Wolf et al., 2012) and decreased quality of life (Halverson et al., 2015). The important role of health literacy in patients' health outcomes have been found among cancer and diabetes patients (Bains & Egede, 2011; Koay, Schofield & Jefford, 2012; Song et al., 2012; Wallace, Carlson, Malone, Joyner, & DeWalt, 2010),

For instance, Song et al. (2012) observed from their study that high levels of health literacy predicted better mental and physical well-being among men living with prostate cancer. On the other hand, some research evidence suggested that the influence of health literacy on health outcomes among persons living with chronic illnesses is not direct (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2012) and that there are other psychosocial mechanisms that explain this association. However, the role of health literacy on health and wellbeing outcomes including quality of life remains unexplored.

The availability of social support to persons living with chronic illnesses like breast cancer have been associated with reduced prevalence of psychological problems and improved health-related quality of life (Bozo, Tathan, & Yılmaz, 2014; Kroenke et al., 2013; Leung, Pachana, & McLaughlin, 2014; Matsuda, Yamaoka, Tango, Matsuda, & Nishimoto, 2014). This is because social support from family, friends and significant others such as the medical/healthcare team serves as a buffer against the negative consequences of living with a chronic illness.

Related to social support, is doctor-patient relationship/communication which has been found to be very important in influencing the health outcomes of patients (Levinson, Lesser, & Epstein, 2010; Zhou et al., 2014). The quality and depth of doctor-patient relationships plays significant roles in the health outcomes of persons living with chronic medical conditions (Kelley, Kraft-Todd, Schapira, Kossowsky, & Riess, 2014; Zhou, Chen, Xu, & Wu, 2014). These findings emphasized the important influence of doctor-patient relationships on the health outcomes of patients through mutual trust and respect. However, in Ghana, little evidence exists regarding how doctor-patient relationships affect breast cancer patients' quality of life, especially, within the context of cancer healthcare delivery.

In addition to the above, depression and anxiety, the two most common comorbid mental health problems have been found to be associated with reduced quality of life in persons living with breast cancer (Brunault et al., 2016; Colby & Shifren, 2013; Gold et al., 2016; Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012). This is due to the fact that the presence of mental health problems interferes with illness management as some of the symptoms may include a loss of interest, lack of concentration, loss of appetite, restlessness, hopelessness and in some cases, suicidal ideation.

In a study among women living with breast cancer, comorbid combined anxiety and depressive symptoms predicted decreased total as well as domain-specific quality of life (Gold et al., 2016). Similar outcomes were also observed by Reyes-Gibby et al. (2012) that depression among women diagnosed with breast cancer significantly predicted a decrease in domain specific and overall quality of life. These findings suggest that there is a need for psychological screening of women with breast cancer to provide the needed psychosocial interventions to improve their quality of life.

Furthermore, religion and spirituality constitute significant resources in the lives of persons living with chronic illnesses, that is, religiosity/spirituality have positive impacts on the wellbeing and overall quality of life of persons living with chronic medical conditions like cancer (Holt, Oster, Clay, Urmie, & Fouad, 2011; Jang et al., 2013; Rippentrop, Altmaier, & Burns, 2006; Tarakeshwar et al., 2006; Vallurupalli et al., 2012). For instance Levine, Yoo and Aviv (2016) found among survivors of breast cancer that spirituality had a significant positive impact on their quality of life. In the same vein, Zamanian et al. (2014) found from their study among women living with breast cancer that positive religious coping predicted better quality of life whereas negative religious coping predicted decreased quality of life. However, how religiosity, which is a central part of the Ghanaian lifestyle, influences the quality of life of women living with breast cancer remains underexplored.

1.3 Rationale of the study/problem statement

The prevalence of breast cancer and its associated health and socioeconomic cost to developing countries like Ghana requires a holistic approach to healthcare, calling on the expertise of several professionals concerned with healthcare within the Ghanaian socio-cultural setting. This is because, there is an increasing rate in detection of breast cancers in Ghana with the survival rate low due to late detection and reporting at health facilities (Atobrah, 2012). Despite efforts at the biomedical level in dealing with breast cancer, one area that has not received much interest and attention by the healthcare system and healthcare researchers is their quality of life. This calls for urgent research attention as quality of life in breast cancer patients is likely to be influenced by the psychosocial and economic challenges that the women with breast cancer experience.

Evidence within the Ghanaian context suggests that the patients' experiences of breast cancer are deeply rooted in the socio-cultural milieu in terms of causal attributions and treatment seeking behaviours (Clegg-Lamptey et al., 2009a). For instance, it has been noted that breast cancer patients in Ghana tend to rely on herbal and traditional medicines which are influenced by their cultural conceptions of the illness (Clegg-Lamptey et al., 2009a). Thus, understanding the socio-cultural influences on the women's perceptions of their breast cancer will enhance knowledge in providing culturally appropriate recommendation for healthcare delivery, particularly pertaining to health education, treatment and support to these women.

Furthermore there is sparse social science research pertaining to breast cancer (Atobrah, 2013) and the few studies conducted, have focused mainly on beliefs and knowledge about breast cancer (e.g. Clegg-Lamptey et al., 2009a, 2009b) without adequate research on women living with breast cancer's psychological health and quality of life. This lack of in-depth examination of the

8

psychosocial challenges faced by persons living breast cancer deprives the patients of the much needed focused psychosocial interventions that they need to deal with their psychosocial challenges associated with living with breast cancer. This study therefore seeks to explore this much needed social science perspective of living with breast cancer to inform psychosocial interventions aimed at reducing the psychosocial challenges and improving the quality of life of the women living with breast cancer.

The review of pertinent literature on breast cancer within the Ghanaian setting revealed that no studies were conducted that explored the lived experiences of women living with breast cancer in terms of their illness representations, coping strategies employed, doctor-patient relationships and shared decision making as well as reasons for the late presentation to the hospital which are all crucial in meaningful intervention endeavours to lessen the burden of breast cancer among women in Ghana. Although some studies have provided insight into reasons for delayed health care seeking and defaulting on treatment (e.g. Clegg-Lamptey et al, 2009a), much attention should be given to improved understanding of breast cancer screening practices of women prior to their diagnosis.

This study therefore seeks to provide the much needed social science perspective of living with breast cancer to inform psychosocial interventions aimed at reducing the psychosocial burdens and improving the quality of life of the women living with breast cancer. This study will further provide suggestions for the needed changes in healthcare delivery with regard to the communication of health information by the health officials to the patients. The study will serve to provide the foundation for future social science research among women living with breast cancer in Ghana and in the African context.

1.4 Research Objectives

The main objectives of this study are to examine the predictors of health-related quality of life among women living with breast cancer and to explore their lived experiences. Specifically, the study investigated the direct and indirect predictive effects of psychosocial factors (social support, doctor-patient relationship, spirituality, coping, anxiety and depression) on the health-related quality of life of women living with breast cancer. Finally, this study explored the lived experiences of women living with breast cancer in terms of their illness representation, coping strategies and the impacts of breast cancer within the Ghanaian context using an explanatory mixed method research design.

1.5 Research Questions

The following are the key research questions that shaped the focus of this thesis.

1.5.1 Quantitative Research Questions:

1. Do health literacy and access to information influence the health-related quality of life among women living with breast cancer in Ghana?
2. Do psychosocial factors (spirituality, doctor-patient relationship, coping, depression, anxiety, and social support) significantly predict health-related quality of life of women living with breast cancer in Ghana?

1.5.2 Qualitative Research Questions

1. What are the lived experiences of women in Ghana living with breast cancer?
2. What are the women's illness presentations of breast cancer?

3. What are the main coping strategies used by women living with breast cancer?

4. How do patients perceive shared decision making in their treatment process?

1.6 Theoretical/ Conceptual Framework

Two theoretical models informed this study: the Revised Wilson and Cleary Model of Quality of Life (Ferrans, Zerwic, Wilbur & Larson, 2005) and the Stress and Coping Theory (Lazarus & Folkman, 1984, 1987). These models present several ways in which socio-demographic, clinical, psychological, social and environmental factors influence the ultimate health outcome which is quality of life in varied groups of people.

1.2.2 The Revised Wilson and Cleary Model of Quality of Life (Ferrans et al., 2005)

The original quality of life model to be adapted for this study was developed by Wilson and Cleary (1995). This model was later revised by Ferrans et al. (2005) to account for some of the shortfalls of the original model of quality of life. The model assumes that overall quality of life of an individual is determined by four key factors, namely; biological function, symptoms, functional status, and general health perceptions (Ferrans et al., 2005). The model further assumed that the key four determinants of an individual's overall quality of life are influenced by the characteristics of the individual as well as the characteristics of the environment (Ferrans et al, 2005). Thus, in any attempt to comprehend the determinants of an individual's overall quality of life, it is important to examine variables from a multifaceted perspective.

Biological factors-The biological determinant of quality of life relates to the physiological processes that support an individual's life and is seen as the most basic factor in the general health status of an individual (Ferrans et al., 2005; Wilson & Cleary, 1995). This is because the biological

function is capable of influencing the other three determinants of an individual's overall quality of life and therefore, becomes the focus of the medical intervention (Kring, 2008).

Symptoms-The next determinant which is the symptoms relate to any abnormalities perceived by an individual within her physical, cognitive and emotional states. These symptoms are usually subjective and unique to an individual and some of the identified symptoms include depression, anxiety, and pain among others (Ferrans et al., 2005; Wilson & Cleary, 1995).

Functional status- Functional status relates to an individual's functioning in terms of his/her ability to perform tasks of daily living effectively (Ferrans et al., 2005; Wilson & Cleary, 1995).

General health perception – This relates to an individual's representation of all health concepts in the model and outside the model (Wilson & Cleary, 1995). This perception could be influenced by all the other variables of constructs in the model ranging from the biological factors, symptoms, functional status, the characteristics of the environment and the characteristics of the individual (Ferrans et al., 2005; Kring & Crane, 2009).

Environmental characteristics- these are social or physical characteristics that could influence the health outcomes of an individual (Eyler et al., 2002; Ferrans et al., 2005). It has been argued by McLeroy et al. (1988) that interpersonal factors such as the influence of healthcare providers, family and friends constitute the social environmental characteristics of the individual which are shaped by the culture of the individual (Ferrans et al., 2005). These influences could be seen in the form of social support received by individuals from their families, friends and significant others as well as doctor-patient relationship which could have significant effects on the health and wellbeing of patients. On the other hand, "Physical environment characteristics are those settings

such as the home, neighbourhood, and workplace that influence health outcomes either positively or negatively" (Ferrans et al., 2005, pp.338).

Individual characteristics- In the revised quality of life model, individual characteristics are multifaceted and these include an individual's demographic, developmental, psychological, and biological factors that influence health outcomes (Eyler et al., 2002; Ferrans et al., 2005). Some of the factors that could be characterised as individual characteristics in this revised quality of life model include sex, age, marital status, type of treatment, ethnicity, religion, body mass index, skin colour, knowledge, beliefs, and attitudes toward an illness, treatment, or behaviour as well as the socioeconomic status, employment and level of education of the individual (Cox, 2003; Eyler et al., 2002; Ferrans et al., 2005).

The variables in the conceptual model suggest several complex relationships of the predictors in influencing quality of life of the individual. Thus, the use of this model as the main theoretical framework would allow for the examination of several direct and mediational effects of the identified variable in the breast cancer literature. It is important to note that the focus of this study is on psychological aspects of living with breast cancer and therefore, detailed attention was not paid to the biological functioning in the conceptualization of the study. This model has been applied in varied patient populations with most of the studies confirming the utility of the model in holistically explaining the factors that influence health-related quality of life (Cramarossa et al., 2013; McCabe, Grutsch, Braun, & Nutakki, 2015; Rodriguez, Mayo, & Gagnon, 2013).

However, this model has been criticised for placing too much emphasis on the medical treatment as the central determinant of health-related quality of life as psychological responses to the medical treatment and disease contribute significantly to patients' reported quality of life

(Kring & Crane, 2008). The unidirectional nature of the determinants of quality of life have also been critiqued as living with chronic illness and treatment involves interrelationships among several medical, psychological, social and environmental variables as well as individual characteristics. For instance, a study among haemodialysis patients found psychological variables such as anxiety, depression, and general health perception significant predictors of quality of life (Kring & Crane, 2008). This model influenced the selection of predictor and mediating variables that are likely to influence the health-related quality of life among women living with breast cancer in Ghana.

In this study, the selection of depression, anxiety, social support, coping strategies, religiosity, shared decision making and doctor-patient relationship as predictor and mediating variables were informed by the key psychosocial variables espoused by the quality of life model. Thus, this study focused on key psychosocial factors that could influence the quality of life among women living with breast cancer in Ghana. Based on the assumptions of the quality of life model, it was hypothesized that depression and anxiety are hypothesized to predict decreased quality of life among women living with breast cancer. However, social support, religiosity, shared decision making and doctor-patient relationships are hypothesized to predict increased quality of life among women living with breast cancer.
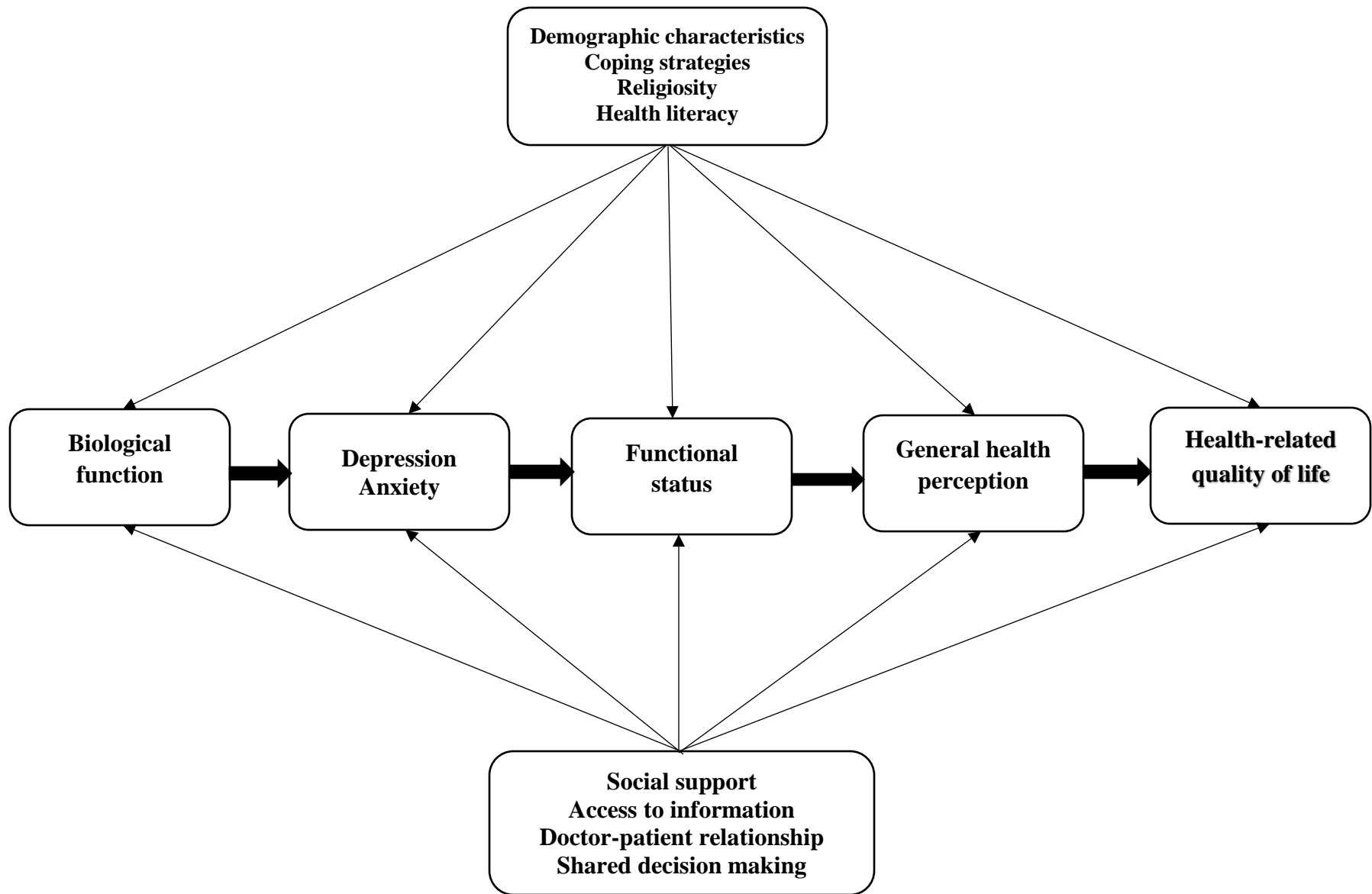
Fig. 1: Conceptual model adapted from the Revised Wilson and Cleary Model of Quality of Life (Ferrans et al., 2005)

15

1.2.3 Stress-and-Coping Theory (Lazarus & Folkman, 1984, 1987)

The stress-and-coping theory (Lazarus & Folkman, 1984, 1987) guided the study of the influence of the various cancer-specific coping strategies on the quality of life among women living with breast cancer. One of the basic assumptions of this theory is that, the coping strategies adopted by an individual in managing his/her chronic illness is likely to influence the immediate and long-term outcomes such as anxiety, depression and quality of life. This is because these coping strategies represent the ways which people cognitively and emotionally adjust to their illnesses. The theory further posits that the effects of the coping strategies on short-term outcomes such as depression and anxiety tend to influence the long–term disease outcomes including the health-related quality of life among persons living with chronic medical conditions (Lazarus & Folkman, 1984, 1987).

The extant literature confirms the applicability of this stress-and-coping theory among several chronic medical condition populations. Studies have confirmed both the direct and mediational effects of coping strategies on the quality of life among patients with chronic medical conditions (Pereira, Baia, & Machado, 2016; Shen, McCreary, & Myers, 2004; Shen, Myers, & McCreary, 2006). In these studies, copping strategies have been linked with short term outcomes such as depression and anxiety which in turn influence the level of health related quality of life among patients. For example, a study among hypertensive patients to predict the mediation effect of depression on the links between coping strategies and quality of life showed that depression significantly mediated the influence of coping strategies on their quality of life (Rueda & Pérez-García, 2013). Based on the assumptions of the stress-and-coping theory and previous empirical literature, it was hypothesized that negative coping strategies such as the use of helpless-hopeless

and anxious preoccupation would predict decreased quality of life whereas positive coping strategies such as having a fighting spirit, the use of cognitive avoidance and fatalism would predict improved quality of life.

1.7 Outline of the Thesis

Chapter One: Introduction - This chapter presents the background of the study by highlighting the prevalence of cancer and specifically breast cancer in the world, Africa and Ghana. The risk factors of breast cancer and quality of life issues of persons living with breast cancer were also discussed as well as a brief overview of the psychosocial factors that affect the health-related quality of life of persons living with breast cancer. The background of the study is followed by the theoretical model underpinning this work. The rationale/problem statement which highlighted the key issues that necessitated this investigation is presented. This is followed by the main research objectives and questions that shaped the focus of the thesis. The outline for the entire thesis concludes this chapter. It should be noted that a more detailed and focused literature review will be integrated into the different focus areas of the chapters as outlined below.

Chapter Two: Methodology - This chapter presents the methods employed in this study. The broad research design and its rationale are discussed. These are followed by detailed description of the two phases of the study (quantitative followed by qualitative). The research setting, sampling, measures/research instruments, data collection procedures and data analysis techniques are also extensively discussed.

Chapter Three: This chapter examined breast cancer patients' access to health information, health literacy and health-related quality of life. The study further examined whether the influences of

access to health information and health literacy on the health-related quality of life among the participants were mediated by levels of reported depression and anxiety. The results of the direct and indirect influences of patients' access to health information and level of health literacy through depression and anxiety are presented. The findings from the study were discussed and the implications of the findings for clinical practice and health psychology research were also highlighted.

Chapter Four: This chapter examined the mediational effects of social support and religiosity on the influences of depression and anxiety on the quality of quality of life among women living with breast cancer in Ghana. The chapter presents the empirical direct and indirect effects of depression and anxiety on quality of life through social support and religiosity as these psychosocial variables have been documented to play significant roles in the breast cancer trajectory. The findings were discussed and implications for psycho-oncological practice and research espoused.

Chapter Five: This chapter examined whether cancer-specific strategies have any significant influence on the health-related quality of life among women living with breast cancer in Ghana. In addition, the possible mechanisms (depression and anxiety) through which these cancer-specific coping strategies influence the health-related quality of life among the participants were also examined. These findings were discussed and recommendations for psychosocial interventions and future research among breast cancer patients suggested.

Chapter Six: This chapter presented the direct and indirect effects of shared decision making/patients' involvement in medical treatment on their health-related quality of life through improved doctor-patient relationship. The findings from the analyses are discussed and practical, scientific and educational implications of the findings suggested.

Chapter Seven: This chapter presented the qualitative findings of the study. Four key research questions were addressed by this chapter. Findings from the study have been presented according to the key research questions. The first part presented the lived experiences of women living with breast cancer and this is followed by the illness representation, coping strategies and healthcare perception among women living with breast cancer. The key themes and sub-themes from the narratives have been presented in the results sections and the findings have been extensively discussed in relation with previous literature on the health and wellbeing among women living with breast cancer.

Chapter Eight: Integrative Discussions and Conclusion

This final chapter presents an integrated discussions of the quantitative results derived from the cross-sectional survey and the qualitative results derived from the in-depth interviews among the participants. The findings are discussed within the quality of life framework and pertinent literature. The contributions of this study to academic scholarship, healthcare provision and health research are highlighted. The chapter concludes by presenting the limitations of the study as well as recommendations for future studies.

CHAPTER TWO

METHODOLOGY

2.1 Introduction

This chapter presents the methodology of this thesis by providing detailed information on the research setting, research design with justification and participants with the sampling rationale. Furthermore, details of the two main phases of the study (quantitative and qualitative) is presented. The individual study phases provide information of the study instruments, data collection procedures and the statistical/analysis techniques that were employed in the data analysis.

2.2 Research Setting

The population for this study consisted of all women diagnosed with breast cancer and receiving treatment at the Radiotherapy and Nuclear Medicine Department of the Korle-Bu Teaching Hospital (KBTH) in Ghana, West Africa. The Ministry of Health in Ghana is responsible for healthcare provision in Ghana with the Ghana Health Service being the mandated government body responsible for implementing government's health policies. According to the Ghana Health Service (2013), the Ministry of Health categorizes healthcare delivery at the levels of the community health post, health centres and clinics, the district/municipal hospital, the regional and tertiary hospital. The Korle-Bu Teaching Hospital is one of the Tertiary Hospitals and the oldest in terms of healthcare provision in Ghana. Patients who access healthcare at the KBTH are usually referred from the smaller health facilities. This hospital caters for all patient groups regardless of socio-economic status. The National Health Insurance Scheme covers part of the cancer treatment but patients still bear some cost not covered by the scheme. Ethical clearance for this study has

been obtained from the Scientific and Technical Committee of the Korle-Bu Teaching Hospital, Ghana.

2.3 Research Design

Every research endeavour requires a research design which is influenced by the aims and objectives of the study. Two main philosophical approaches that underpin this research are post-positivism and social-constructivism (Bartholomew & Brown, 2012). Post-positivistic approach to research assumes that social issues or phenomena can be objectively measured using tools that are appropriate in gathering the needed information about the phenomena (Crook & Garrat, 2011; Hennink, Hutter, & Bailey, 2011). The main objective of the post-positivist approach (quantitative) approach is hypothesis testing. The social-constructivist approach to research assumes that the essential purpose of research is understanding people's subjective meanings of personal experiences (Creswell, 2009). In essence, this approach relies heavily on participants' own subjective experiences regarding the phenomenon under investigation. However, the use of either approach in any scientific investigation has its own limitations. For instance, not all human or social phenomena can be studied objectively as espoused by post-positivists. In the same vein, the social constructivist approach is inadequate in dealing with examining the causal paths between variables.

Due to the inadequacies of the two main research approaches, a mixed-method approach is adopted in this study, specifically, the explanatory mixed methods design was used for this study. This involves conducting a quantitative study followed by a qualitative exploration in order to gain a deeper perspective of the quantitative findings by offering explanations. The combination of the two approaches provide a more comprehensive understanding of the phenomenon under

investigation (Johnson & Onwuegbuzie, 2004). In this study a holistic approach is needed to obtain information from multiple perspectives to derive a more complete understanding of living with breast cancer as well confirm and explain the quantitative measures with the insights gained from the qualitative experiences of patients (Creswell & Plano-Clark, 2017). Therefore, the explanatory mixed method was the best suited to this current study.

2.4 Phase I: Quantitative Study

2.4.1 Sampling and Sampling Procedure

A total of 205 women diagnosed with breast cancer were sampled from the Cancer Centre of the Korle-Bu Teaching Hospital in Ghana. This sample size was chosen based on the minimum sample size requirement for multiple regression with a medium effect and a statistical power of .80 (Field, 2009). Field (2009) suggested that for a medium effect size and a statistical power of .80 (high power) with 10 predictors, a minimum of 150 participants was required. Thus, the 205 participants were adequate to obtain adequate statistical power. Participants recruited into the study met the following inclusion criteria or were otherwise excluded: 1) being diagnosed with breast cancer for the first time at any stage and living with breast cancer for more than six months, 2) be between 20years and 80years of age and 3) receiving care for only breast cancer at the Radiotherapy Department at the Korle-Bu Teaching Hospital.

2.4.2 Measures

The quantitative data was collected by using questionnaires/inventories. The questionnaires used in the data collection include the *Health Literacy Scale* (Ishikawa, Takeuchi, & Yano, 2008), *Functional Assessment of Cancer Therapy-Breast Cancer* (FACT-B; Brady et al.,

1997), *Doctor-Patient Relationship Questionnaire* (van der Feltz-Cornelis et al., 2004), *Multidimensional Perceived Social Support Scale* (Zimet, Dahlem, Zimet, & Farley, 1988), *Santa Clara Strength of Religious Faith Questionnaire* (Plante & Boccaccini, 1997), *Adjustment-MINIMAC* (Watson et al., 1994) and the *Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983). A demographic questionnaire was also administered to gather information about the participant's age, marital status, employment, education, stage of cancer, duration of cancer, and type of treatment. The descriptive statistics of the questionnaires used are summarized in Table 1.

Health Literacy Scale

The Health Literacy Scale developed by Ishikawa, Takeuchi and Yano (2008) was adapted to measure the level of health literacy**.** This scale consists of 14-items which measure all the three (Functional-5items, Communicative-5items, and Critical-4items) components of health literacy as proposed by Nutbeam (2000). Some of the items on the scale include; In reading instructions or leaflets from hospitals/pharmacies, you . . . "found that the content was too difficult" (Functional), since being diagnosed with breast cancer, you have … "understood the obtained information" (Communicative) and since being diagnosed with breast cancer, you have . . . "checked whether the information was valid and reliable" (Critical). The scale has a 4-point Likert response format ranging from 1 (never) to 4 (often). The scores for the items in a scale will be summed and divided by the number of items in the scale to give a scale score. The items on the Functional components will be reverse scored so that higher scores indicate higher Health Literacy. The scale has reliability values ranging between .65 and .84 (Ishikawa, Takeuchi &Yano, 2008). The adapted 6-item scale used in this study has a Cronbach alpha of .80.

Functional Assessment of Cancer Therapy-Breast Cancer (FACT-B)

Functional Assessment of Cancer Therapy-Breast Cancer (Brady et al, 1997) was used to measure quality of life. This scale consists of 37 items with 27 measuring quality of life from four domains (emotional wellbeing-6items, social/family wellbeing-7, physical wellbeing-7, and functional wellbeing-7) and 10 items measuring other breast cancer-related concerns. A 5-point Likert response format was used with responses ranging from 0= Not at all to 4 = Very much. The participants were asked to indicate their responses to the all the items on the scale as they applied to the past 7 days. Some examples of the items on the scale include; "Because of my physical condition, I have trouble meeting the needs of my family" (physical wellbeing domain), "I am satisfied with family communication about my illness" (social/family wellbeing domain), "I worry that my condition will get worse" (emotional wellbeing domain), "I am able to work (include work at home)" (functional wellbeing domain) and "I have certain parts of my body where I experience pain" (breast cancer-related concerns). The scale has reliability value of .90. (Brady et al., 1997). Some studies conducted in Africa have found the scale to be reliable with domain specific values ranging between .65 and .82 (Mullin et al., 2000). In this study, the internal consistency values of the scale were .83, .76, .82, .91 and .65 for physical, social/family, emotional, functional and additional concerns respectively.

Doctor-Patient Relationship Questionnaire

The Doctor-Patient Relationship Questionnaire (van der Feltz-Corneliset al, 2004) was used to measure the depth of doctor-patient relationships: This is a nine-item scale developed to measure the depth of physician-patient relationship. It is a brief measure of the therapeutic aspects of the patient-doctor relationship in the primary care setting (van der Feltz-Cornelis et al, 2004).

A 5-point Likert response format was used as follow: 1= not at all appropriate, 2 = somewhat appropriate, 3 = appropriate, 4 = mostly appropriate and 5 = totally appropriate. Some of the items on the questionnaire include; "My primary care physician/doctor helps me" and "My primary care physician/doctor has enough time for me". A total score was computed with higher scores reflecting good relationship and vice versa. The scale has an internal consistency value of .94 (van der Feltz-Cornelis et al, 2004). In this study, the scale has an internal consistency value of .96.

Multidimensional Perceived Social Support Scale (MPSSS)

The Multidimensional Perceived Social Support Scale (Zimet, Dahlem, Zimet, & Farley, 1988) was used to measure social support: This scale contains twelve items rated on a five-point Likert-type scale with scores ranging from 'strongly disagree' (1) to 'strongly agree' (5). It measures social support from three sources; the family, friends and significant others. Some of the items on the scale include "There is a special person who is around when I am in need", "My family really tries to help me" and "My friends really try to help me". The scale has reliability values ranging between α= 0.92 and 0.94 (Zimet et al., 1988). In this study, the scale has reliability values of .95, .96, .95 and .91 for significant others, friends, family and overall social support respectively.

Santa Clara Strength of Religious Faith Questionnaire

The Santa Clara Strength of Religious Faith Questionnaire (Plante & Boccaccini, 1997) was used to measure the level of religiosity of women living with breast cancer. This is a 10-item scale that assesses strength of religious faith regardless of religious affiliation or denomination. The items were scored on a 4-point scale ranging from 1 = 'Strongly disagree' to 4 = 'Strongly

agree'. Scores can range between 10 and 40. Some examples of items on the questionnaire include "My religious faith is extremely important to me", "My relationship with God is extremely important to me" and "I enjoy being around others who share my faith". The scale has an internal consistency value of .95 (Plante & Boccaccini, 1997). In this study, the questionnaire has an internal consistency value of .94.

Mini Mental Adjustment to Cancer Scale

The Mini Mental Adjustment to Cancer Scale (Watson et al., 1994) was used to measure coping strategies. This questionnaire measures cancer patients' adjustment to their illness. The questionnaire has 29 items which measure five sub-domains [helplessness-hopelessness (8 items), anxious preoccupation (8 items), fighting spirit (4 items), cognitive avoidance (4 items), and fatalism (5 items)]. Some of the items on the scale include; 'I feel life is hopeless.' 'I am upset about having cancer' 'I am determined to beat this disease.' 'I make a positive effort not to think about my illness.' and 'I have put myself in the hands of God'. The questionnaire has a 4-point Likert response format ranging from 1='Definitely does not apply to me' to 4='Definitely applies to me'. The Cronbach alphas of the scale ranges from 0.62 to 0.88 (Watson et al., 1994). A higher score on each of the subscales indicates higher usage of that particular coping strategy by the participant. In this study, the internal consistency values were .93, .88, .76, .91 and .66 for helpless-hopeless, anxious-preoccupation, fighting-spirit, cognitive-avoidance and fatalism respectively.

Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) was used to assess the level of depression and anxiety experienced by women living with breast cancer. This scale consists of 14 items which measure depression and anxiety in patients. Each domain has 7 items measured on a 4-point Likert scale scored from 0 (not at all) to 3 (very often indeed). The total score on any subscale can range between 0 and 21 for either anxiety or depression. Some examples of items in the Anxiety domain include 'I feel tense or wound up', 'I get a sort of frightened feeling as if something bad is about to happen', 'Worrying thoughts go through my mind' and 'I can sit at ease and feel relaxed'. Some examples of the Depression items include 'I still enjoy the things I used to enjoy', 'I can laugh and see the funny side of things', 'I have lost interest in my appearance' and 'I look forward with enjoyment to things'. The scale has inter-item reliability values of .83 for the Anxiety subscale and .82 for the Depression subscale (Bjelland, et al. 2002). In this study, the scale has internal consistency (inter-item reliability) values of .90 and .82 for anxiety and depression subscales respectively.

Shared-decision making

Two items were developed by the researcher to measure patients' involvement in decision making regarding their treatment. The two items used in the study include; "Do you feel that you have been involved by your doctors/nurses in your treatment decision making?" and "Do you wish to be more involved in your treatment decision than your current involvement?" A two-point response format (Yes/No) was used and the analysis used the categorical variables as such.

2.4.3 Pre-Testing of Questionnaires

The questionnaires were piloted using a total of 19 women living with breast cancer to assess the suitability and appropriateness of the questionnaires to the sample. Since most of this questionnaire were developed in Western countries, there was the need to pre-test them to ensure their applicability in the Ghanaian context. Results from the pilot study showed that most of the questionnaires had appreciable inter-item reliability values in exception of the *functional health literacy* component of the Health literacy scale (Ishikawa, Takeuchi &Yano, 2008). It was also observed that majority of the participants could not read nor write and therefore, some modifications were implemented to ensure the accuracy and reliability of the entire research process.

The following modifications and decisions were made based on the findings of the pilot study:

- Items on the Health literacy scale with high response rates (70%) from the pilot study were maintained and some were rephrased for easy understanding. In all, 6 items were retained and used in this study to measure overall health literacy. Items on the scale were "You have…1) *understood all the information you obtained, 2) shared your thoughts about your health with someone, 3) considered the credibility of the information, 4) checked whether the information was correct, 5) collected information to make decisions about your health and 6) used the information obtained in your daily life*". A 4-point Likert response format ranging from 1 (never) to 4 (often) was used as in the original scale with higher scores indicating high level of health literacy and lower scores indicating limited health literacy. The total scores on the scale ranged between 6 and 24. In this study, the health literacy scale had a good internal consistency value ($\alpha = .80$).

28

- To make up for the items that were deleted, additional items on the patients' access to information on breast cancer from both health and non-health professionals where added to the questionnaire to examine patients' access to information about breast cancer which is a critical component of health literacy. A set of questions were developed to measure the main sources of information on breast cancer (What are your main sources of information about breast cancer?), a single item questions each to measure satisfaction with quantity (How satisfied are you with the amount of information about breast cancer from your healthcare provider(s)?), quality (How satisfied are you with the quality of information about breast cancer from your healthcare provider(s)?), whether concerns are addressed (Do you feel that your concerns are adequately addressed by healthcare providers?), rating of overall access to information (How will you rate your access to information about breast cancer?), the use of information from non-healthcare professionals (Have you ever sought information from other sources (not health professionals) about breast cancer?) and type of information (What kind of information did you seek about breast cancer?). Thus, an *Information Satisfaction Index* was created using the three main questions which assessed women's satisfaction with the quantity of information, quality of information and whether their concerns are adequately addressed. A 4-point Likert response format was used and total scores could range between 3 and 12 with higher scores reflecting better satisfaction with information from healthcare providers. Internal consistency value of the Index of .87 was obtained in this study.

- Since the level of education of the participants is relatively low and the questionnaires were interviewer-administered, the 7-point Likert response on the Multidimensional Scale Perceived Social Support (MSPSS) was reduced to a 5-point response scale. This afforded

29

the participants a better understanding as it has been found that the reduction in scale response options are better suited to participants with relatively lower levels of education (Oppong Asante, 2015). The detail of the quantitative questionnaires can be found in Appendix 4.

2.4.5 Procedure

Ethical approval was obtained from the Humanities and Social Sciences Ethical Committee of the University of KwaZulu-Natal, South Africa and clearance was also obtained from Scientific and Technical Committee as well as Institutional Review Board of the Korle-Bu Teaching Hospital in Ghana to collect the data from the facility. Permission was sought from the head of the Nuclear Medicine and Radiotherapy Department of the Korle-Bu Teaching Hospital. The researcher and his two research assistants collaborated with the physicians and other healthcare staff at the Radiotherapy Unit of the hospital in recruiting the participants for the study. These two research assistants were recruited based on their fluency in English as well as the common local languages spoken in Accra (Ga, Twi and Ewe) and trained appropriately for the study. The training for the two research assistants included how to administer the questionnaires and also the ethical issues involved in dealing with such vulnerable populations. The research assistants were selected based on their prior experience in data collection at hospital settings and they both have postgraduate qualifications in Clinical Psychology. However, the researcher conducted all the qualitative interviews himself.

On the days of the data collection, the aims and objectives of the study were explained to the prospective participants, the confidentiality of their responses and anonymity of data collected were assured. The participants were made aware that their participation in the study was voluntary

and that they have the right to withdraw from the study at any point of the study without any negative consequences. Those who voluntarily agreed to participate were made to sign or thumbprint the consent form that we provided them. The questionnaires were all interviewer-administered and one questionnaire administration was between 30 to 45minutes. The completed questionnaires were screened, coded and analysed. The entire data collection lasted for five months.

2.4.6 Statistical Analysis

Cronbach alpha coefficients (α) were used to examine the internal consistencies of the research instruments to be used in the current study. Descriptive statistics (such as means, standard deviations and percentages) were used to summarize the data and describe the nature of the data. Kurtosis and Skewness were computed to test the normality of the data to determine whether parametric or non-parametric tests should be used in testing the stated hypotheses. The normality of the data was based on the recommendation that the values of skewness should range from -2 to +2, whilst those of kurtosis should range from -7 to +7 (West, Finch, & Curran, 1995). Pearson Product-moment correlation coefficient were used to examine possible relationships among the study variables. Independent sample *t*-test and One-Way ANOVA were used to explore possible effects of demographic characteristics on the health-related quality of life of women living with breast cancer. Mediational analyses with the aid of PROCESS Macro (Hayes, 2017) were conducted to determine the direct and indirect predictive effects of health literacy, access to information and other psychosocial variables on health-related quality of life among women living with breast cancer. All analyses were two-tailed, and a p-value of < 0.05 or less was considered statistically significant.

Table 1

Descriptive statistics of the measures used in the study

Variable	Measure	Items	Scale range	Mean	SD	Skewness	Kurtosis	Cronbach alpha (α)
Health Literacy	Health Literacy Scale	6	6-24	18.30	3.94	-.44	-.31	.80
Access to information	Questions developed by researcher	7	N/A	N/A	N/A	N/A	N/A	N/A
Social Support	Multidimensional Perceived Social Support Scale	12	12-60	44.63	9.89	-.56	.14	.91
Religiosity	Santa Clara Strength of Religious Faith Questionnaire	10	28-40	37.22	3.85	1.08	-.43	.94
Anxiety	Hospital Anxiety and Depression Scale	7	0-21	7.61	5.50	.34	-.89	.90
Depression	Hospital Anxiety and Depression Scale	7	0-19	5.91	4.65	.48	-.43	.82
Physical wellbeing	FACT-B	7	0-28	17.30	7.36	-.15	-.93	.83
Social/Family wellbeing	FACT-B	7	0-28	16.76	6.59	-.28	-.38	.76
Emotional wellbeing	FACT-B	6	0-24	17.09	5.62	-.61	-.15	.82
Functional wellbeing	FACT-B	7	0-28	18.81	7.42	-.54	-.63	.91
Breast cancer additional con	FACT-B	10	7-36	23.40	6.30	-.14	-.42	.65
Helplessness-Hopelessness	Mini Mental Adjustment to Cancer Scale	8	8-26	10.51	4.31	1.92	2.78	.92
Anxious Preoccupation	Mini Mental Adjustment to Cancer Scale	8	8-29	15.19	5.64	.44	-.81	.88
Fighting Spirit	Mini Mental Adjustment to Cancer Scale	4	4-16	14.13	2.15	1.40	2.88	.76
Cognitive Avoidance	Mini Mental Adjustment to Cancer Scale	4	4-16	13.15	2.77	-.84	.48	.91
Fatalism	Mini Mental Adjustment to Cancer Scale	5	8-20	17.18	2.86	-1.19	.77	.66
Doctor-Patient Relationship	Doctor-Patient Relationship Questionnaire	9	16-45	37.01	6.52	-.56	.06	.96
Shared Decision Making	Questions developed by researcher	2	N/A	N/A	N/A	N/A	N/A	N/A

2.5 Phase II: Qualitative Study

2.5.1 Sample and Sampling Procedure

A total of eleven (11) women were purposively and conveniently sampled from the total respondents from the quantitative study. The saturation method was used to determine the total sample size for this qualitative study. This is because analysis of the interview data from the 11 participants showed similar patterns and therefore, did not warrant sampling of more women living with breast cancer. The choice of sample size in qualitative studies are dependent mainly on the issues being explored and in most cases data saturation, where no new information are emerging from the participants, determines the sample size (Guest, Bunce, & Johnson, 2006; Kumar, 2014, O'Reilly & Parker, 2013; Walker, 2012). Information from the analysis of the quantitative data did not reveal any significant age differences in the quality of life reported by the women sampled. This sample therefore, cut across the various age categories including young, middle aged and elderly women living with breast cancer and receiving care at the Nuclear Medicine and Radiology Department of the Korle-Bu Teaching Hospital in Accra, Ghana.

2.5.2 Interview Schedule

An interview guide was used to conduct in-depth individual interviews with the women living with breast cancer to explore the lived experiences of women living with breast cancer within the Ghanaian context as culture influences perceptions causal attributions and experience of illness (Clegg-Lamptey et al., 2009). The interview guide focused on four key topics: the lived experiences, illness perception, coping strategies and healthcare satisfaction among the participants. The responses from the participants were used to generate further probing questions

for clarifications. The interview guide was structured in line with pertinent literature within the breast cancer domain and served to inform conversations between the researcher and participants. However, the interview guide was not prescriptive as efforts were made at gaining rich data from the participants. The interview guide is presented in Appendix 5.

2.5.3 Data collection Procedure

The researcher sent a letter of introduction to the director of the oncology depart of the teaching hospital to be used. This was followed by obtaining ethical clearance from the Humanities and Social Sciences Ethical Committee of the University of KwaZulu-Natal, South Africa, the Scientific and Technical Committee and the Institutional Review Board of the Korle-Bu Teaching Hospital in Ghana. The contact list of the women who participated in the quantitative phase was consulted and the prospective participants were contacted. Those who voluntarily agreed to participate in the qualitative phase of the study were visited in their homes. The aims and objectives of the study were explained to the women. Their roles in the qualitative study was also explained to them. All the ethical guidelines regarding the use of human participants were adhered to strictly in the data collection process. The confidentiality of their responses and anonymity of data collected were assured. The participants were made aware that their participation in the study is voluntary and that they had the right to withdraw from the study at any point of the study without any negative consequences. Permission was also sought from the participants to audio-tape the interview. Those who voluntarily agreed to participate in the study signed the consent form provided them during the interaction. The individual interviews lasted between 30 and 60minutes.

2.5.4 Data Analysis

The audio tapes from the field were transcribed verbatim to reflect the views of the participants. All the interviews were conducted in English with local language interjections as and when necessary to throw more lights on a particular issues. These interjections were appropriately translated as the researcher understands the predominant language which in Twi. The data analysis was informed by the Interpretative Phenomenological Approach (IPA) which involves exploration of participants' own subjective real life experiences with no attempts at measuring the objectiveness of the experiences (Smith & Osborn, 2007).

Storey (2007) outlines some key principles and guidelines which informed qualitative analysis. These are;

- Gaining an understanding of the transcribed interview by reading and re-reading of the data and identifying points of interest
- Linking identified and harmonized quotes together to form themes
- Making connections with identified themes
- Summarizing main themes together with their sub-themes with their appropriate quotations

In following the guidelines stated above, the research read and re-read the transcribed data which allowed for an in-depth understanding of the views of the participants. The researcher proceeded to make meaning of the data and developed themes to encapsulate the views expressed by the participants. Sub-themes were developed to elaborate on the dimensions of the major themes that emerged from the data. The sub-themes were supported with direct quotes from the narratives of the participants for emphasis.

2.5.5 Trustworthiness and credibility in qualitative research

Trustworthiness and credibility of qualitative data have become a major issue as these issues may affect the validity of the interpretations drawn from the study (Nieuwenhuis, 2007). To ensure the validity and reliability of the data, the researcher gave the transcribed data to two other experts in qualitative data analysis for the generation of themes and sub-themes. The outcomes of the analysis of the two experts and the researcher were compared and points of divergence were addressed. The observed themes and sub-themes were discussed with thesis supervisors to ensure the validity and reliability of the interpretations. Additionally, the researcher ensured communicative validity throughout the data collection by using rephrasing and summaries to be sure that the accurate views of the participants were vividly captured. All these were done to ensure that meanings as expressed by the participants are not lost during the transcription and interpretation of the results.

CHAPTER THREE

ACCESS TO HEALTH INFORMATION, HEALTH LITERACY AND HEALTH-RELATED QUALITY OF LIFE AMONG WOMEN LIVING WITH BREAST CANCER: DEPRESSION AND ANXIETY AS MEDIATORS

3.1 INTRODUCTION

The information needs of persons living with chronic medical conditions such as breast cancer cannot be underestimated as quality and accurate information is critical for the optimal management of these conditions and improved quality of life (Raupach & Hiller, 2002; Rees & Bath, 2001; Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Shea–Budgell, Kostaras, Myhill, & Hagen, 2014). The need for patients to be actively involved in their treatment decisions have resulted in high information needs among patients in developed countries where a relatively small power distance exists between patients and healthcare providers (Mekuria, Erku, & Belachew, 2016; Rees & Bath, 2001; Rutten et al., 2005). However, the case may not be same in developing countries with greater power distance between the patients and healthcare providers. Power distance refers to the level of expected and accepted inequalities in society which influence the nature of interaction among people (Winterich & Zhang, 2014).

Cancer patients have been found to rely on varied sources of health information which influence their health outcomes and treatment decisions (Blanch-Hartigan & Viswanath, 2015; Colledge, Car, Donnelly, & Majeed, 2008; Halbach et al., 2016). Personal doctors, oncologists, family and friends, mass media and the internet are some of the most commonly used information sources among cancer patients (Tucker, Martin, & Jones, 2017; Walsh et al., 2010; Zaid, Egberongbe, & Adekanye, 2016). Unlike Western countries, evidence in some African countries including Nigeria suggest that little or no use of information from the internet and support groups regarding breast cancer is utilized (Sambanje & Mafuvadze, 2012; Zaid et al., 2016). However, there is no available published literature on the sources of information accessed by women with

breast cancer in Ghana to better inform health care delivery with regard to the information needs of patients.

Apart from patients' access to healthcare information, the level of satisfaction with the information received is equally crucial. The satisfaction with healthcare information has been found to be associated with increased quality of life and decreased levels of psychological distress (Husson, Mols, & Van de Poll-Franse, 2010; Ong, Visser, Lammes, & De Haes, 2000). However, inconsistent findings in this regard have been reported with some studies showing negative relationships between access to and satisfaction with healthcare information and patients' health outcomes (Essen, Larsson, Öberg, & Sjödén, 2002; Fröjd, Lampic, Larsson, & Essen, 2009) or, no significant influence of healthcare information on patients' health outcomes such as depression, anxiety and quality of life (Häggmark et al., 2001).

Access to healthcare information is linked to improved health literacy among patients (Benjamin, 2010; Wills, 2009; Wynia & Osborn, 2010). Health literacy has been conceptualized as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Ratzan, 2000). The *Health Outcome Model* conceptualized health literacy as an outcome of health education and consists of three facets (Nutbeam, 2000). These are functional (basic skills in reading and writing deemed sufficient to function effectively in everyday life), communicative (advanced cognitive, literacy and social skills necessary to extract and derive meaning from varied communications for effective health action) and critical (critical analysis and application of information to exert control over life activities due to more advanced cognitive and social skills) health literacies (Ishikawa, Takeuchi, & Yano, 2008; Nutbeam, 2000). Thus, in implementing health educational programmes aimed at

improving health literacy, there is the need to address the various facets of health literacy to achieve optimal outcomes.

Health literacy has been shown to have significant influences on several health outcomes such as physical functioning, emotional functioning and self-care management (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Busch, Martin, DeWalt, & Sandler, 2015; Smith et al., 2015). However, the mechanisms linking health literacy to these health outcomes have not been fully understood. Some researchers have suggested that three plausible mechanisms connect health literacy to health outcomes in patients: access and utilization of health care, patient-provider relationships and self-care (Paasche-Orlow & Wolf, 2007). These mechanisms could help understand the role of health literacy in health-related quality of life among women living with breast cancer. Health literacy affects disease management, healthcare utilization and key decision-making outcomes in patients (Cavanaugh, 2011; Jordan et al., 2013; McCaffery et al., 2013; Williams, Davis, Parker, & Weiss, 2002). Poor or limited health literacy among patients have been associated with several negative outcomes such as poor patient-physician communication, poorer use of health care, poor adherence and relapse (Berkman et al., 2011; Lillie et al., 2007; Williams et al., 2002; Wu, Moser, DeWalt, Rayens, & Dracup, 2016) although some evidence suggest weak associations or mixed findings (Geboers et al., 2015).

Some specific studies on health literacy and its impacts among cancer patients suggest that higher health literacy is linked to improved mental and physical health, but only predicted physical quality of life after other factors such as age, marital status, race, income, education, types of cancer treatment, tumor aggressiveness, and comorbidities were controlled (Song et al., 2012). This lack of significant predictive effect of health literacy after controlling for patients-related

variables suggest both direct and indirect links between health literacy and health-related quality of life (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013). In contrast, a study among adults, newly diagnosed with lung, breast, colorectal, or prostate cancer found that higher health literacy was associated with greater health-related quality of life; and after controlling for covariates, significant differences were found between those in the highest and lowest health literacy categories in the physical, functional, emotional and social well-being subscales (Halverson et al., 2015). Due to this lack of consistent evidence in the health literacy literature, this study examined the influence of overall health literacy of women living with breast cancer on their quality of life.

Patient education in the Ghanaian context is impacted by patriarchy with most physicians being males, as reflected in the relatively large power distances which can be seen between patients and their healthcare providers (Morrow, Rothwell, Burford, & Illing, 2013). This power distance is likely to impact on information sharing and therefore, it is important to understand the information needs of women living with breast cancer to better address their needs and thus improve health care delivery. Studies reviewed showed inconsistent findings with regards to the direct influences of access to information and health literacy on quality of life. Specifically, the mechanisms that explain the influence of access to health information and health literacy are poorly understood. Examination of possible mechanisms could further our understanding of the influence of these factors on quality of life among women living with breast cancer. There are no studies in the Ghanaian setting addressing these issues despite the rising number of breast cancer cases and associated problems (Ferlay et al., 2015). Therefore, this study examined 1) the main sources of breast cancer information among the women, their access and satisfaction with healthcare information and 2) the direct and indirect effects of health literacy and access to health information

on quality of life among women living with breast cancer through depression and anxiety (which are significant risk factors for poor quality of life). Quality of life in the context of this study refers to the overall functioning of the women in their physical, emotional, social, environmental and disease-specific domains.

3.2 RESULTS

3.2.1 Sources, Satisfaction and Access to health information by women living with breast cancer

Results from Table 2 showed that women living with breast cancer relied on information about their illness from health workers (80%), television (66.8%), radio (53.7%), newspapers (13.2%), Mosque/Church (13.2%), community meetings (7.8%) and schools (3.4%). However, 33.2% of the women indicated that they sought information from non-health professionals and the information were mainly on treatment (83.6%), alternative therapy (65.7%), self-care (65.7%), symptoms (50.7%) and diagnosis/prognosis (46.3%). It was further observed that 93.9% of the women found the information from non-health professionals very useful for their illness. The result further showed that 89.8% of the participants were satisfied with the amount of information received, from health care professionals 91.7% were satisfied with the quality of health care information and 79% indicated that their concerns had been adequately addressed. Responses on access to health care information showed that only 7.3% of the participants rated their access to healthcare information to be poor.

Table 2

Access to health information among women living with breast cancer

Variables	Frequency	Percentage
Main sources of information[1]		
Television	137	66.8
Radio	110	53.7
Newspapers	27	13.2
Hospital (Doctors & Nurses)	164	80.0
School	7	3.4
Church/Mosque	27	13.2
Community Meetings	16	7.8
Satisfaction with the amount of information from health workers		
Very dissatisfied	5	2.4
Dissatisfied	16	7.8
Satisfied	156	76.1
Very satisfied	28	13.7
Satisfaction with the quality of information from health workers		
Very dissatisfied	3	1.5
Dissatisfied	14	6.8
Satisfied	166	81.0
Very satisfied	22	10.7
Concerns adequately addressed by health workers		
Not at all	7	3.4
Somehow	36	17.6
Very well	136	66.7
Absolutely	25	12.3
Sought information from non-health professionals		
Yes	66	32.2
Type of information sought information from non-health professionals		
Diagnosis/prognosis	31	46.3
Symptoms	34	50.7
Treatment	53	83.6
Self-care	44	65.7
Alternative therapy	44	65.7
Usefulness of information from non-health professionals		
Yes	62	93.9
Overall access to health information on breast cancer		
Poor	15	7.3
Good	107	52.2
Very good	68	33.2
Excellent	15	7.3

[1] Percentage does not add up to 100 due to multiple responses

3.2.2 Bivariate relationships among the study variables

As can be seen in Table 3, health literacy was negatively correlated with depression ($r = -.32$, $p < .01$) and anxiety ($r = -.26$, $p < .01$) but positively correlated with overall quality of life ($r = .17$, $p < .05$) and some dimensions of quality of life. Access to health information was negatively correlated with depression ($r = -.22$, $p < .01$) and anxiety ($r = -.23$, $p < .01$) but positively correlated with overall quality of life ($r = .19$, $p < .01$) and some dimensions of quality of life. Anxiety ($r = -.67$, $p < .01$) and depression ($r = -.77$, $p < .01$) negatively correlated with overall quality of life and all the dimensions of quality of life. Satisfaction with information only correlated significantly with anxiety ($r = -.16$, $p < .05$).

3.2.3 Direct and indirect pathways from access to information and health literacy to quality of life

Results from the mediation analysis using ordinary least squares (OLS) path analysis, showed that access to health information had an indirect influence on quality of life through both depression and anxiety after controlling for health literacy. Increased access to health information predicted decreased depression ($b = -1.186$, $t = -2.743$, $p < .01$) and anxiety ($b = -1.572$, $t = -2.994$, $p < .01$) (See Figure 1). Higher levels of depression ($b = -3.581$, $t = -9.929$, $p < .001$) and anxiety ($b = -1.155$, $t = -3.887$, $p < .001$) predicted decreased quality of life. A percentile bootstrap confidence interval for the indirect effect through depression ($b = 4.247$) based on 10,000 bootstrap samples was entirely above zero (1.575 to 7.186) and the indirect effect through anxiety ($b = 1.815$) based on 10,000 bootstrap samples was entirely above zero (.519 to 3.562). However, there was no evidence for a direct influence of access to health information on quality of life ($b = .151$, $t = .092$, $p = .927$).

Table 3

Correlation matrix of the relationship between the study variables

Variables	1	2	3	4	5	6	7	8	9	10	11
1. Health Lit.	1										
2. Access	.14*	1									
3. Info_Sat	.01	.45**	1								
4. Anxiety	-.26**	-.23**	-.16*	1							
5. Depression	-.32**	-.22**	-.10	.72**	1						
6. QOL	.17*	.19**	.12	-.67**	-.77**	1					
7. PWB	.11	.15*	.07	-.61**	-.67**	.88**	1				
8. SFWB	.15*	.07	.10	-.15*	-.30**	.49**	.22**	1			
9. EWB	.13	.08	.08	-.723*	-.68**	.78**	.66**	.16*	1		
10. FWB	.18*	.32**	.16*	-.60**	-.76**	.82**	.72**	.25**	.58**	1	
11. BCAC	.09	.08	.03	-.51**	-.55**	.85**	.75**	.27**	.66**	.57**	1

Info-Sat= Satisfaction with information, Access=Rating of access to health information, Health Lit=Health Literacy, QOL= Quality of life, PWB=Physical Wellbeing, SFWB=Social/Family Wellbeing, EWB=Emotional Wellbeing, FWB=Functional Wellbeing, BCAC=Breast Cancer Additional Concerns.

$*= p < .05$, $**= p < .01$

Health literacy had an indirect influence on quality of life through both depression and anxiety after controlling for access to information. As can be seen in Figure 1, increased health literacy predicted decreased depression ($b = -.349$, $t = -4.384$, $p < .001$) and anxiety ($b = -.328$, $t = -3.394$, $p < .001$). Higher depression ($b = -3.581$, $t = -9.929$, $p < .001$) and anxiety levels ($b = -1.155$, $t = -3.887$, $p < .001$) predicted decreased quality of life. A percentile bootstrap confidence interval for the indirect effect through depression ($b = 1.250$) based on 10,000 bootstrap samples was entirely above zero (.700 to 1.878) and the indirect effect through anxiety ($b = .379$) based on 10,000 bootstrap samples was entirely above zero (.120 to .703). There was evidence for a direct negative influence of health literacy on quality of life ($b = -.631$, $t = -2.027$, $p < .05$).
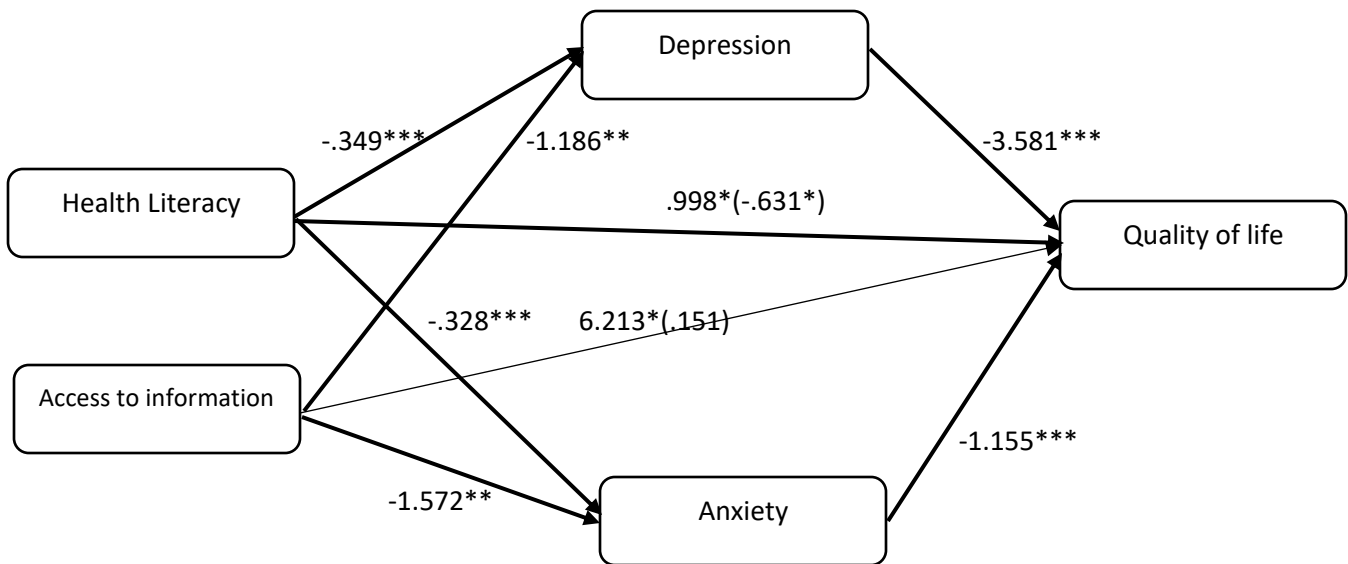
Figure 1: Observed model showing the direct and indirect influence of health literacy and access to health information on the quality of life.

Note: Direct effects of health literacy and access to health information on quality of life are in parentheses

3.3 DISCUSSION AND CONCLUSION

3.3.1 Discussion

Health literacy plays an important role in healthcare utilization and health outcomes of persons living with chronic medical conditions. In addition, patients' ability to access healthcare information is also important in manoeuvring the healthcare system and making informed decisions regarding their health. This study examined the direct and indirect effects of access to information by women living with breast cancer and health literacy on their quality of life through depression and anxiety.

3.3.1.1 Access to information by women living with breast cancer

It was observed that health workers (doctors and nurses), television and radio were the main sources of information about breast cancer among the women. Most of the women were satisfied with the amount and quality of information provided by healthcare professionals and also reported that their concerns were adequately addressed. A third of the women reported seeking information from non-health professionals which were mainly concerned with treatment, alternative therapy and self-care. The majority of the women who sought information from non-health professionals found the information they received as useful. The majority of the women living with breast cancer rated their overall access to information on breast cancer as good. This finding is consistent with previous studies that reported personal doctors, oncologists, family and friends, mass media as the main sources of health information among cancer patients (Nelson, O'Brien, Ashikaga, & Bosompra, 1999; Rees & Bath, 2001; Zaid et al., 2016). This result also corroborates the findings from a systematic review and empirical research on information sources

among cancer patients which found that the most frequent information source utilized was health professionals (Rutten et al., 2005; Shea–Budgell et al., 2014).

Since healthcare professionals play major roles in the lives of women living with breast cancer, it is not surprising that healthcare professionals were the major source of information as personal communication with some healthcare professionals revealed that breast cancer patients are mostly provided with verbal information as the majority of them have low literacy levels. However, the use of television and radio as the second and third most utilized sources of information about breast cancer in this study, contradicts a recent study which found both radio and television to be the least used sources of information on breast cancer (Shea–Budgell et al., 2014). These could be due to differences in socio-demographics as some evidence suggest that the preference for health information sources differed for cancer patients according to some personal characteristics such as age, sex, race and level of education (Blanch-Hartigan & Viswanath, 2015; Galarce et al., 2011; Nagler et al., 2010).

One significant finding in this study is that a third of all the women sampled reported to have sought information from non-health professionals pertaining to treatment, alternative therapy and self-care. This percentage of patients seeking information from sources other than health professionals, may suggest unmet health information needs and therefore, would explore other avenues for information about their illness (Mills & Davidson, 2002; Raupach & Hiller, 2002). It is also possible that their health care providers do not readily provide this kind of information, and they might not easily ask due to the existence of power differentials. The key challenge in patients seeking information from non-health professionals is the credibility of the information provided by these non-health professional sources. The emphasis on treatment and alternative therapy by

48

the patients as the main reasons for seeking information from non-health professional sources may likely be due to their non-belief in the medical treatment or that they feel the treatment is not effective and therefore seek better treatment. These findings could also be related to the kind of side-effects of the medical treatment and as such, people with lower levels of health literacy might not understand the negative side effects and possibly do not make sense when they expect to become better. Thus, providing health information to women living with breast cannot be underestimated as evidence suggests that cancer patients rely extensively on alternative sources for health information (Rutten et al., 2005; Walsh et al., 2010).

3.3.1.2 Access to health information and health-related quality of life

The findings suggest that increasing access to health information enhance the chances of better health outcomes including quality of life. The findings regarding the impact of access to healthcare information on depression, anxiety and quality of life could be attributed to uncertainties that characterize patients' perceptions about treatment outcomes and prognosis. Thus, increased access to health information may serve to alleviate the levels of depression and anxiety associated with living with breast cancer which in turn result in improved quality of life.

These findings highlight the importance of information needs of breast cancer patients as evidence suggest that access to health information leads to better mental and physical health outcomes (Husson et al., 2010; Ong et al., 2000). However, access to health information did not have any significant direct influence on the quality of life among the participants. This finding suggests that access to information has direct impacts on short term health outcomes such as depression and anxiety which subsequently affect quality of life. This finding is consistent with

previous studies which did not find any significant direct influence of access to health information on the quality of life among cancer patients (Häggmark et al., 2001).

Access to health information plays an important role in the lives of persons living with chronic medical conditions as the uncertainties surrounding the medical treatments due to the negative side effects can only be resolved with accurate and relevant information from both health and non-health professional sources. This becomes even more importance taking into cognizance the multiple medical treatments being received by the women sampled in this study. Therefore, their access to information on prognosis and alternative therapy could help lessen their psychological burdens such as depression and anxiety (Husson et al., 2010; Zaid et al., 2016).

3.3.1.3 Health literacy and health-related quality of life

The results indicating that health literacy led to decreased depression and levels which result in improved quality of life are congruent with previous works which found significant associations between higher health literacy and improved health outcomes such as health-related quality of life (Halverson et al., 2015; Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015). Evidence has linked limited or poor health literacy to several negative short and long term health outcomes including increased depression and anxiety levels, and poor quality of life (Berkman et al., 2011; Geboers et al., 2015; Halverson et al., 2015; Wu et al., 2016).The indirect positive effect of health literacy on quality of life has also been highlighted by some studies among persons living with diabetes (Al Sayah et al., 2013) though mechanisms such as diabetes knowledge. These findings could be due to the demanding nature of the treatment process which requires individuals to have information about the potential benefits and possible side effects.

Those with limited health literacy may find it difficult in obtaining the needed information which could heighten their depression and anxiety levels.

Surprisingly, after controlling for other study variables such as access to information, depression and anxiety, health literacy had a significant direct but weak negative influence on the quality of life among the participants. This suggests that higher health literacy is associated with decreased quality of life. This could be due to the fact that health literacy alone may not be enough in influencing patients' wellbeing as more information from different sources which is one of the key attributes of health literacy could be detrimental to the quality of life of the women. This is because some negative information about breast cancer on prognosis and complications of the medical treatments could negatively impact on the wellbeing of the women. This contradicts what was found in others studies that health literacy is associated with improved health outcomes (Berkman et al., 2011; Busch et al., 2015; Smith et al., 2015). It is worth noting that some cross-sectional studies did not find evidence of a direct influence of health literacy on health-related quality of life among cancer patients (Geboers et al., 2015; Halverson et al., 2015). Thus, the possible mechanisms of the impact of health literacy on health outcomes of women living with breast cancer should be the focus of future studies.

This study has some limitations which need to be considered in the interpretation and application of these results. The use of cross-sectional design could not account for other transient factors that may have impacted the responses of the participants. It is also worth noting that no causal relations can be assumed between the study variables. Since the healthcare staff do not provide participants with leaflets containing information about their condition and its management, the health literacy scale used did not include the functional aspect (patients' ability to read hospital

leaflets), which needs to be taken into account. Despite these limitations, this study provides a comprehensive evidence on information seeking patterns, the possible mechanisms that could explain the links between access to health information, health literacy and quality of life which have been sparsely researched.

3.3.2 Practice Implications

The findings of this study have some practical implications. First, the use of various information sources by the women living with breast cancer implies that healthcare providers should constantly assess patients' knowledge to be sure that the correct and relevant information are being processed. This could also help in identifying patients who have limited health literacy as higher literacy in this study correlated positively with increased health-related quality of life domains. Since access to information has been found to have both direct and indirect effects on the quality of life among the participants, the information needs of the patients should be a priority area in oncology practice especially to patients who desire more information about their condition. Secondly, healthcare providers should encourage patients to ask questions and seek clarifications as these may help in reducing the level of depression and anxiety associated with diagnosis and treatment as well as treatment side effects. There is the need for timely screening and care for common mental health problems such as depression and anxiety among women living with breast cancer as these present significant challenges to their quality of life.

3.3.3 Conclusion

The results from the study showed that women living with breast cancer resort to varied sources for information about their condition with the three most prominent ones being health workers (doctors and nurses), television and radio. However, the reliance on the television and radio suggests that there is the need for consented effort to streamline the quality of information on breast cancer provided by these media outlets. It was also found that a substantial number of women utilize non-health professional sources of information regarding treatment and alternative therapy which suggests a need for improvement in the unmet information needs regarding treatment in general and health outcomes. The mechanisms through which access to health information and health literacy influenced quality of life among women living with breast cancer were through mental distress such as depression and anxiety.

CHAPTER FOUR

DEPRESSION, ANXIETY AND QUALITY OF LIFE AMONG WOMEN LIVING WITH BREAST CANCER IN GHANA: MEDIATING ROLES OF SOCIAL SUPPORT AND RELIGIOSITY

4.1 INTRODUCTION

Breast cancer is one of the commonly diagnosed tumours among women (Stewart & Wild, 2014). In sub-Saharan Africa, breast cancer is reported to be one the most diagnosed cancer among women with high mortality rates attributed to late diagnosis (Atobrah, 2013; Ferlay et al., 2014; Naku Ghartey Jnr, Anyanful, Eliason, Mohammed Adamu, & Debrah, 2016). Recent advances in treatment methods and breast cancer awareness have led to early detection and treatment seeking which increase the chances of survival (Narod, Iqbal, & Miller, 2015). However, being diagnosed with breast cancer and the various treatment approaches present several challenges to the women which impact on their overall health and wellbeing.

Evidence suggests the prevalence of comorbid mental health problems such as anxiety and depression which are linked to decreased quality of life of breast cancer patients (Brunault et al., 2016; Colby & Shifren, 2013; Gold et al., 2016; Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012). These common mental health problems exacerbate the health outcomes of the patients due to their interference with illness management as some of the symptoms may include a loss of interest, lack of concentration, loss of appetite, restlessness, hopelessness and in some cases, suicidal ideation (Association, 2013).

4.1.1 Depression, Anxiety and Quality of Life

There is a high prevalence of mental health problems among women living with breast cancer with prevalence rates of anxiety and depression as high as 40% (Fatiregun et al., 2016; Kyranou et al., 2013; Maass, Roorda, Berendsen, Verhaak, & de Bock, 2015; Mitchell, Ferguson, Gill, Paul, & Symonds, 2013; Reece, Chan, Herbert, Gralow, & Fann, 2013). For instance, a study

conducted among breast cancer patients in South Africa reported prevalence rates of 36.6% and 34.3% for depression and general psychological distress respectively (Kagee, Roomaney, & Knoll, 2018). These findings underscore the need for routine psychological assessment of breast cancer patients as the presence of these common mental health problems could interfere with treatment regimen and adherence.

The presence of depression and anxiety are significant risk factors for decreased quality of life among breast cancer patients (Gold et al., 2016; Reyes-Gibby et al., 2012; So et al., 2010). For example, breast cancer patients reported reduced quality of life due to the comorbid combined anxiety and depressive symptoms (Gold et al., 2016) Similarly, So et al. (2010) reported that more than half of their studied sample had either depression or anxiety with about 16% of the total sample reporting both clinically significant depressive and anxiety symptoms. The same study further indicated that higher levels of depressive and anxiety symptoms were significantly associated with decreased overall quality of life and domain specific quality of life. The implication of these findings is that the presence of comorbid mental health problems like depression and anxiety poses a significant challenge to the health and wellbeing of women living with breast cancer.

However, a study conducted among breast cancer patents in Malaysia found that their participants reported relatively better health-related quality of life, with lower levels of anxiety and depressive symptoms (Ng et al., 2015). The findings by Ng et al. (2015) clearly contradicts other studies which found decreased quality of life and heightened anxiety and depression levels (e.g. Gold et al., 2016; Huang & Hsu, 2013), suggesting some inconsistency in the literature regarding the impact of breast cancer on the lives on women. Some authors have argued that the

impact of depression and anxiety may differ in influencing patients' health and wellbeing if the element of distress which underline depression and anxiety is controlled for, which may result in anxiety influencing more coping strategies and ultimately better quality of life (Xie et al., 2012). Thus, in examining the effects of depression and anxiety on quality of life, it is important to determine the unique contribution of each condition on the quality of life among breast cancer patients.

4.1.2 Social Support, religiosity and quality of life

Social support and religiosity play significant roles in the lives of individuals with or without chronic illnesses. The importance of social ties and their benefits have been emphasized in the social science as well as health literature. Shumaker and Brownell (Shumaker & Brownell, 1984) defined social support as "an exchange of resources that the provider or recipient perceives to enhance the recipient's well-being". This definition encapsulates the essence of social support to the individual at the receiving end. Two main mechanisms of how social support impacts the lives of individuals are the direct effect hypothesis and the buffer-hypothesis (Cohen & Wills, 1985). That is, social support can influence the health and wellbeing of an individual as well as serve as a buffer against the impact of stressful events on the wellbeing of individuals (Cohen & Wills, 1985). Social support comes from various sources including family, friends and significant others and in the case of persons living with chronic conditions, support from their healthcare team plays a significant role in their recovery and adjustment to their illness (Salonen et al., 2013).

Further, persons living with chronic illnesses like breast cancer require support in the management of their illness as evidence suggests that social support plays a significant role in their health outcomes including their health-related quality of life (Haugland, Wahl, Hofoss, & DeVon,

2016; Michael, Berkman, Colditz, Holmes, & Kawachi, 2002). This is because support received or perceived by the patients may help them to cope with the negative consequences of their illness and thereby, promoting their wellbeing. For instance, in a study among female breast cancer patients in Malaysia, lower levels of psychological distress and improved health-related quality of life were due to social support among the participants (Ng et al., 2015). The outcomes of these studies support earlier findings which found social support connections as predictive of the quality of life of breast cancer patients (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Lim & Zebrack, 2008; Matthews & Cook, 2009; Sammarco & Konecny, 2008).

In addition to social support religiosity and spirituality play important roles in the lives of individuals especially persons living with chronic illness conditions. In the context of this study religiosity and spirituality is used interchangeably as it is difficult to delineate spirituality and religiosity within the Ghanaian context. The significant role of religiosity in the lives of both healthy individual and persons living with some form sickness have been documented in the health and social science literature (Gesselman et al., 2017; Trevino, Balboni, Zollfrank, Balboni, & Prigerson, 2014; Wilson, Forchheimer, Heinemann, Warren, & McCullumsmith, 2017; Zamanian et al., 2015). In a study among cancer patients, Rippentrop, Altmaier and Burns (2006) found spirituality and religiosity to be predictive of quality of life of cancer patients with spirituality being more predictive of higher quality of life than religiosity. Levine, Yoo and Aviv (2017) found among survivors of breast cancer that spirituality had a significant positive impact on their overall as well as specific domains of quality of life. Similar findings were reported by Holt, Oster, Clay, Urmie and Fouad (2011) that religiosity was significantly and positively associated with better mental health and negatively associated with depression.

Furthermore, some studies that specifically examined the influence of religiosity on the health and wellbeing of breast cancer patients have found a significant association between religiosity and wellbeing among the patients with higher religiosity being associated with better health outcomes such as quality of life (Jang et al., 2013; Vallurupalli et al., 2012; Zamanian et al., 2015). For instance, Jang et al. (2013) found a significant positive relationship between religiosity and quality of life among women living with breast cancer.

However, McLaughlin et al. (2013) found among breast cancer patients that religiosity can be both a positive or negative resource for these patients as patients who resorted to passive coping and deferring all responsibilities to God, risks lower health outcomes. On the other hand, patients who rely on God but still actively involved in the disease coping process are likely to report better health outcomes including quality of life (McLaughlin et al., 2013). In the same vein, Zamanian et al. (2015) found among women living with breast cancer that positive religious coping was significantly and positively associated with better quality of life while negative religious coping was associated with decreased quality of life. These findings suggest that although religiosity may be helpful to persons living with chronic illness, it is important to examine the nature of the religiosity as negative religiosity has been found to be detrimental to the health and wellbeing of patients (Ng, Mohamed, Sulaiman, & Zainal, 2016; Trevino et al., 2014) or has no effect at all (Meisenhelder, Schaeffer, Younger, & Lauria, 2013). From the studies reviewed above, it was hypothesized that: religiosity is likely to significantly predict quality of life.

4.1.3 Social support and religiosity as mediators

In addition to the significant direct impact of social support and religiosity on the quality of life among women living with breast cancer, some evidence exists that social support and religiosity may play mediating roles in the effect of some predictors on quality of life. For instance, social support was found to significantly mediate the relationship between HIV stigma and depression, as well as stigma and quality of life (Rao et al., 2012), resilience and quality of life among breast cancer patients (Zhang, Zhao, Cao, & Ren, 2017), loneliness and depression in elderly people (Liu, Gou, & Zuo, 2016). Manning-Walsh (2005) found in a study among breast cancer patients that social support was positively related to quality of life and partially mediated the effects of distress on quality of life. However, religious support did not mediate distress - quality of life relationship and was not directly related to quality of life. There is a lack of evidence on the indirect effects of depression and anxiety on quality of life through social support and religiosity of women living with breast cancer. This study seeks to fill this gap in the health psychology literature. Thus, it was hypothesized that depression and anxiety are likely to have both direct and indirect influence on quality of life through social support and religiosity.

4.2 RESULTS

4.2.1 Demographic profile of the study participants

The participants sampled for the study had a mean age of 52.49years ($SD = 11.14$months) and a mean duration since diagnosis of 29.64months ($SD = 38.75$months). The majority of the participants were married (67.8%) and about 89.3 %. Approximately 90% of the participants self-reported themselves as Christians and about 61% were currently employed; with 27.5% and 11.3%

had unemployed and retired respectively. In terms of the current treatment being received by the participants, 41.8% of the participants received Surgery + Chemotherapy + Radiotherapy, 20.5%, 9.3% and 5.5% received Chemotherapy only, Radiotherapy only and Surgery only respectively whereas 10.4%, 5.5% and 6.5% of the participants received Surgery + Chemotherapy, Surgery + Radiotherapy and Chemotherapy + Radiotherapy respectively.

4.2.2 Relationship among depression, anxiety, social support, religiosity and quality of life

It was observed in Table 4 that level of depression among the participants in the study correlated significantly and negatively with the level of social support ($r = -.155$, $p < .05$) and quality of life ($r = -.773$, $p < .01$). However, level of depression among the participants in the study did not correlate significantly with the level of religiosity ($r = -.130$, $p > .05$). These findings means that high level of depression is related with lower levels of social support and quality of life.

The findings also showed that level of anxiety among the participant was not statistically and significantly correlated with their levels of social support ($r = -.010$, $p > .05$) and religiosity ($r = -.030$, $p > .05$). However, the level of anxiety among the participants was significantly and negatively associated with their quality of life ($r = -.671$, $p < .01$) which suggests that high anxiety level is related with low quality of life. It was further observed that depression and anxiety were significantly and positively related ($r = .721$, $p < .01$) which suggests that higher depression level is related to higher anxiety levels.

Table 4

Descriptive statistics and bivariate relationships among depression, anxiety, social support, religiousity and quality of life

Variables	Mean	SD	1	2	3	4
1. Depression	5.921	4.606	-	-	-	-
2. Anxiety	7.510	5.508	.721**	-	-	-
3. Social support	44.653	9.779	-.155*	-.010	-	-
4. Religiosity	37.218	3.851	-.130	-.030	.274**	
5. Quality of life	95.393	26.294	-.773**	-.671**	.215**	.057

Note: *$p < 0.5$; **$p < .01$

4.2.3 Testing for indirect effects (Mediation analysis)

Mediation analysis conducted using ordinary least squares (OLS) path analysis showed that depression indirectly influenced quality of life through social support among breast cancer patients after controlling for anxiety. As can be seen in Figure 2 and Table 5, higher depression level was related with lower social support among the participants ($b = -.653$, $t = -3.100$, $p = .002$) and higher level of social support was related with higher level of quality of life among participants ($b = .378$, $t = 3.152$, $p = .002$). A bootstrap confidence interval for the indirect effect ($b = -.247$) based on 10,000 bootstrap samples was entirely below zero (-.482 to -.071). There was evidence for significant direct effect of depression on quality of life with higher depression level predictive of lower quality of life among the participants ($b = -3.275$, $t = -9.157$, $p < .001$).

However, depression did not indirectly influenced quality of life through religiosity among breast cancer patients after controlling for anxiety. As can be seen in Figure 2 and Table 5, higher

depression level was related with lower religiosity among the participants (b = -.188, t = -2.247, p = .026). However, religiosity did not have a significant effect on quality of life (b = -.436, t = -1.447, p = .149). A bootstrap confidence interval for the indirect effect (b = .082) based on 10,000 bootstrap samples included zero (-.028 to .240). There was evidence for significant direct effect of depression on quality of life with higher depression level predictive of lower quality of life among the participants (b = -3.275, t = -9.157, p <.001).

For anxiety, the results showed that anxiety indirectly influenced quality of life through social support among breast cancer patients after controlling for their level of depression. As can be seen in Figure 2 and Table 5, higher anxiety level was associated with higher social support among the participants (b = .376, t = 2.134, p = .034) and higher level of social support was related with higher level of quality of life among participants (b = .378, t = 3.152, p = .002). A bootstrap confidence interval for the indirect effect (b = .142) based on 10,000 bootstrap samples was entirely above zero (.011 to .324). There was evidence for significant direct effect of anxiety on quality of life with higher anxiety level predictive of lower quality of life among the participants (b = -1.233, t = -4.188, p <.001).

However, anxiety did not indirectly influenced quality of life through religiosity among breast cancer patients after controlling for level of depression. As can be seen in Figure 2 and Table 5, anxiety level was not significantly related with religiosity among the participants (b = .093, t = 1.321, p = .188). Religiosity did not have any significant effect on quality of life (b = -.436, t = -1.447, p = .149). A bootstrap confidence interval for the indirect effect (b = -.040) based on 10,000 bootstrap samples included zero (-.147 to .027). However, there was evidence for significant direct

effect of anxiety on quality of life with higher anxiety level predictive of lower quality of life among the participants ($b = -1.233$, $t = -4.188$, $p < .001$).
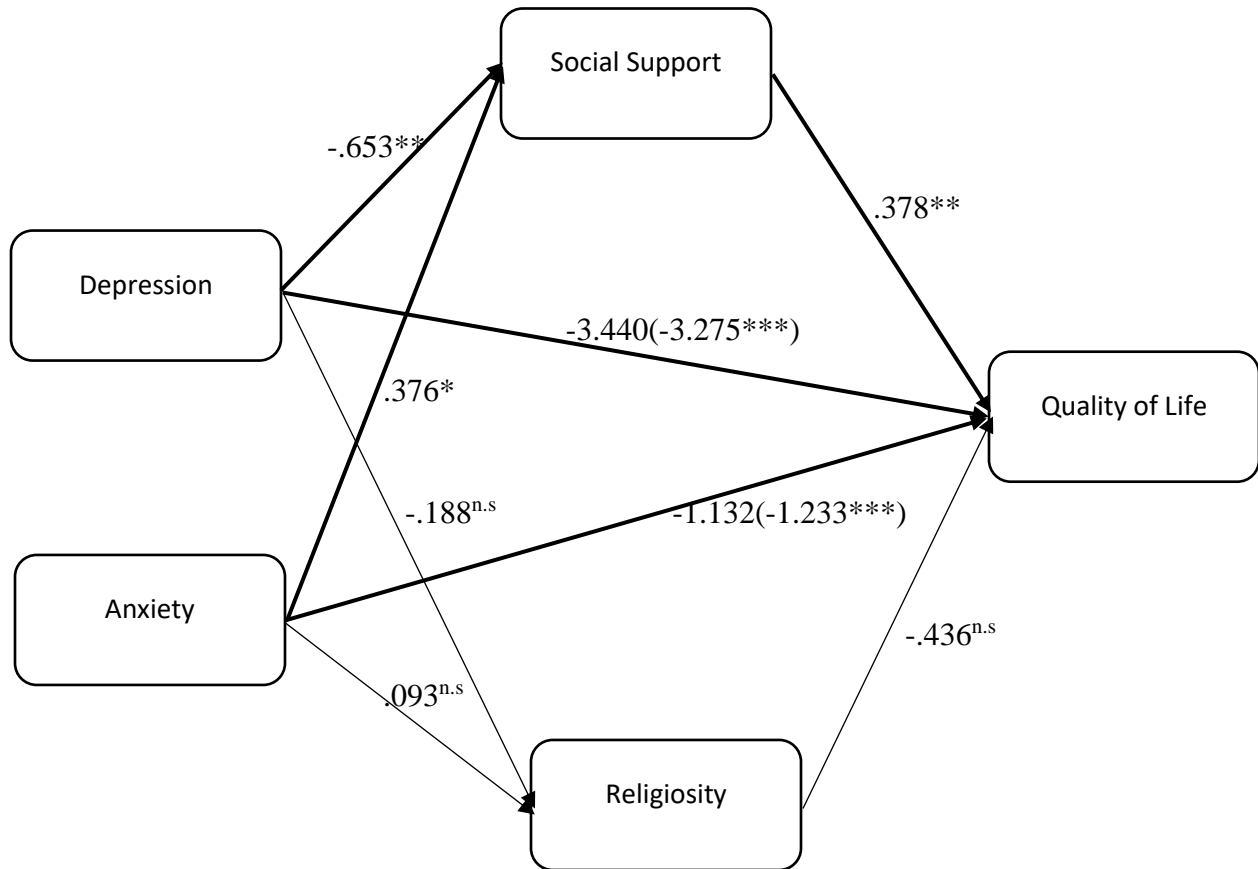
Figure 2: The observed path models

The beta values in parenthesis indicate the direct effects of the predictors on quality of life. Path coefficients are unstandardized estimates. $^*p < 0.05$; $^{**}p < 0.01$ level; $^{***}p < 0.001$ and n.s = not significant at the .05 level.

Table 5

Direct and indirect effects and 95% confidence intervals for the models

Model pathways	b-values	t-values	p-values	95% Confidence Interval	
				Lower bounds	Upper bounds
Direct effects (Model 1)					
Depression ⟶ Social Support	-.653	-3.100	.002	-1.068	-.238
Depression ⟶ Quality of life	-3.275	-9.157	<.001	-3.981	-2.570
Social support ⟶ Quality of life	.378	3.152	.002	.142	.615
Depression ⟶ Religiosity	-.188	-2.247	.026	-.354	-.023
Religiosity ⟶ Quality of life	-.436	-1.447	.149	-1.031	.158
Indirect effects (Model 1)					
Depression ⟶ social support ⟶ quality of life	-.247	-	-	-.482	-.071
Depression ⟶ religiosity ⟶ quality of life	.082	-	-	-.028	.240
Direct effects (Model 2)					
Anxiety ⟶ Social support	.376	2.134	.034	.029	.723
Anxiety ⟶ Quality of life	-1.233	-4.188	<.001	-1.814	-.653
Social support ⟶ Quality of life	.378	3.152	.002	.142	.615
Anxiety ⟶ Religiosity	.093	1.321	.188	-.046	.231
Religiosity ⟶ Quality of life	-.436	-1.447	.149	-1.031	.158
Indirect effects (Model 2)					
Anxiety ⟶ social support ⟶ quality of life	.142	-	-	.011	.324
Anxiety ⟶ religiosity ⟶ quality of life	-.040	-	-	-.147	.027

4.3 DISCUSSION

4.3.1 Depression, Anxiety and Quality of Life

In this section, the findings from the bivariate correlations showed significant positive relationship between anxiety and depression as reported in previous literature where high comorbidity between depression and anxiety was found (Gold et al., 2016; Ng et al., 2015; Reece et al., 2013; So et al., 2010). Levels of depression and anxiety among the participants correlated significantly and negatively with their overall quality of life. These results were also confirmed by the path analysis which found both depression and anxiety to have significant effects on participants' quality of life. Findings revealed that elevated levels of depression and anxiety resulted in decreased quality of life among the women living with breast cancer which are consistent with previous findings among breast cancer patients (Gold et al., 2016; Reyes-Gibby et al., 2012; So et al., 2010).

The presence of comorbid mental health problems have detrimental effects on health and wellbeing of persons living with chronic illnesses including breast cancer. Symptoms of these common mental health problems may affect treatment adherence and coping strategies employed by the patients. Therefore, it is possible that depression and anxiety among the participants in this study decreased the overall health and wellbeing as reflected by their decreased quality of life. For instance, a depressed individual may lose interest in treatment outcomes as depression is character sized by sadness, hopelessness, helplessness and general poor outlook on life which could negatively impact quality of life. It is worth noting that the findings concord with recent evidence in South Africa which suggest that breast cancer has comorbid mental complications such as

psychological distress and major depression which could negatively impact on the quality of life of the patients (Kagee et al., 2018).

4.3.2 Social support, religiosity and quality of life

Social support was found to be significantly and positively related with the overall quality of life among the participants, whereas religiosity did not have any statistically significant relationship with overall quality of life among the participants. The path analysis supported the findings from the bivariate correlations as increased social support significantly predicted concomitant increase in overall quality of life of the participants. The effect of social support on the health outcomes of persons living with chronic illnesses have been documented in the literature as social support serves as an important resource in times of distress (Haugland et al., 2016; Lim & Zebrack, 2008; Matthews & Cook, 2009; Ng et al., 2015; Sammarco & Konecny, 2008). This finding support the direct hypothesis that perceived or actual social support has direct benefits to the patients (Cohen & Wills, 1985). Therefore, it is important to recognize the social support needs of women living with breast cancer to promote their health and wellbeing which will affect their evaluation and satisfaction with the quality of their lives.

There was no evidence of a significant influence of religiosity on the overall quality of life of the participants which suggests that personal religious faith is not a significant factor when other variables (e.g. social support) are controlled for among the patients. One of the possible reasons for this finding may be the religious nature of the Ghanaian population which is widespread as almost all the participants reported very high religiosity levels. Thus, there is the need to start differentiating between religiosity and spirituality in the Ghanaian context to provide a clearer picture of which component of the two (religiosity/spirituality) is more beneficial to the health and

wellbeing of persons living with chronic illnesses. This finding is inconsistent with previous works which found that religiosity promotes good health outcomes including improved quality of life (Jang et al., 2013; Vallurupalli et al., 2012; Wilson et al., 2017; Zamanian et al., 2015). On the other hand, some studies (McLaughlin et al., 2013; Zamanian et al., 2015) have reported that religiosity may actually have a detrimental effect on quality of life of patients as people are likely to defer responsibility to a higher supreme being and not play any active role (passive religious coping) in their recovery and this seems to be the case as there was a weak negative effect of personal religiosity on quality of life in this study, albeit not statistically significant.

4.3.3 Social support and religiosity as mediators

Mediation analysis revealed that depression had a significant indirect effect on quality of life through social support. That is, the presence of depression among the participants resulted in lower perceived social support which led to decreased quality of life among the participants. This finding could be attributed to the fact the when people are depressed they are less likely to seek and receive support to deal with their challenges as the pertinent symptoms of depression which include loss of interest, low energy, sadness, helplessness and hopelessness may prevent the women from seeking and receiving social support (Drageset & Lindstrøm, 2003; Kagee et al., 2018; Ng et al., 2015). Since social support is found in this study to have significant direct effect on quality of life, it can be concluded that the mechanism linking depression to poor quality of life is decreased social support. However, it is important to note that depression remained a significant direct predictor of quality of life which suggests that social support may be a partial mediator as there may be other variables that play a role that are not accounted for in this study.

This finding confirms the study results of Manning-Walsh (2005) who found that social support from family and friends partially mediated the effects of symptom distress on quality of life among breast cancer patients. The significant mediation role of social support has been reported in other studies using different populations (Rao et al., 2012; Zhang et al., 2017). In contrast to the significant mediation effect of social support on the link between depression and quality of life, religiousity did not significantly mediate the link between depression and quality of life. This could be due to the fact the religiosity did not have any significant direct relationship with both depression and quality of life which confirms results from other previous studies (Manning-Walsh, 2005; Meisenhelder et al., 2013) Since there is scant literature in this direction, the findings may serve to stimulate further research to examine the specific aspects of religiosity which influence health outcomes in breast cancer patients.

An interesting finding was observed in this study. That is, after controlling for the effect of depression, anxiety had a direct positive influence on social support and an indirect positive influence on quality of life through social support. That is, social support partially mediated the influence of anxiety on quality of life. This finding suggests that in the absence of depression, anxiety leads to increased perceived social support which intend results in improved quality of life among the participants in the study. This may suggests that although anxiety and depression are positively related, they differ on some specific elements which influence the increased social support. For instance, evidence suggests that depression and anxiety have one general underlying element which psychological distress and if distress is controlled, anxiety and depression are negatively related (Simms, Grös, Watson, & O'Hara, 2008; Xie et al., 2012) which may account for this positive impact of anxiety on quality of life through social support. Further, as stated by (Xie et al., 2012) "…anxiety motivates action, and may sometimes encourage people to work

toward solving their problems. Depression, on the other hand, features behavioural inhibition, and tends to undermine action". Thus, this finding contribute to the literature on the unique effect of anxiety on quality of life through social support which require more investigations. However, anxiety did not have any significant indirect effect on quality of life through religiosity. This could also be attributed to the lack of significant direct relationship between religiosity and quality of life as well as anxiety. With no existing studies in this area, this could be another opportunity to explore aspects of religiosity that may influence quality of life significantly.

The findings of this study has some implication for psycho-oncological care as it was evidenced from this study that common mental health problems decrease the reported quality of life among women living with breast cancer. Thus, it is recommended that mental health screening should form part of the overall healthcare delivery for this group of women. The findings also underscore the need to provide and strengthen the social support systems of the women living with breast cancer to mitigate the negative consequences of the diagnosis as it was evidenced in this study that social support mediates the link between the common mental health problems and women's reported overall quality of life. The study also has some implication for clinical research among women living with breast cancer. Firstly, there is the need to examine both religiosity and spirituality to determine the unique effects of each of them on the health outcomes among the women. In addition to the above, there is the need to conduct a longitudinal study to examine the mental health trajectories of the women and how these influence their health and wellbeing from diagnosis through to recovery. This would enable researchers to unravel both stable and transient predictors of health and wellbeing among the women living with breast cancer.

4.3.4 Conclusion

It is concluded that women living with breast cancer experience significant anxiety and depression which is associated with decreased quality of life. The presence of the comorbid mental health challenges influence the levels of perceived social support and religiosity which are significant resources for coping with breast cancer. Therefore, mental health screening should form an integral part of routine physical examination and care for women diagnosed with breast cancer.

CHAPTER FIVE

DEPRESSION AND ANXIETY AS MEDIATORS OF THE INFLUENCE OF COPING STRATEGIES ON QUALITY OF LIFE AMONG GHANAIAN WOMEN LIVING WITH BREAST CANCER

5.1 INTRODUCTION

The prevalence of breast cancer sub-Saharan Africa is relatively low. However, compared to developed countries, the mortality rates are higher in sub-Saharan Africa (Ferlay et al., 2010; Ferlay et al., 2015; Ginsburg, 2013; Jedy-Agba, McCormack, Adebamowo, & dos-Santos-Silva, 2016). This has made breast cancer a growing health problem as it has surpassed cervical cancer and is diagnosed in every one out four cancer cases (Ferlay et al., 2010; Jemal et al., 2013). Despite lack of national statistics, breast cancer among women is identified as one of the most prevalent forms of cancer after cervical cancer with a high proportion of cases only diagnosed in the later stages of the disease in Ghana (Atobrah, 2013; Laryea et al., 2014; Mensah, Yarney, Nokoe, Opoku, & Clegg-Lamptey, 2016; Ohene-Yeboah, 2012). Medical advancements in the treatment options available in the management of breast cancer have led to increased chances of survival in cancer patients (Bodai & Tuso, 2015). Notwithstanding this, research evidence suggests that living with a chronic illness like breast cancer is accompanied by comorbid physical, mental health and social problems such as hypertension, depression, anxiety and loss of social contacts due to stigma (Atobrah, 2013; Clegg-Lamptey, Dakubo, & Attobra, 2009; Opoku, Benwell, & Yarney, 2012). In dealing with diagnosis and treatment, patients adopt several coping mechanisms which have been found to significantly influence their health and wellbeing (Khalili, Farajzadegan, Mokarian, & Bahrami, 2013).

5.1.1 Coping strategies and health-related quality of life

Coping with chronic illnesses such as breast cancer can be either adaptive or maladaptive or both as some evidence suggests that breast cancer patients rely on both coping strategies (Manne et al., 1994; Nipp et al., 2016; Paek, Ip, Levine, & Avis, 2016). In adaptive coping, patients accept

73

and actively engage in ways to deal with their challenges whereas in maladaptive coping, patients avoid dealing with problems through distancing of themselves from the problems both cognitively and physically (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004). However, these coping strategies have different effects on the quality of life the breast cancer as studies have reported that adaptive coping strategies are associated with better mental health outcomes and improved quality of life while maladaptive coping strategies are significantly associated with poor mental health outcomes and decreased quality of life (Kershaw et al., 2004; Petersen et al., 2008; Sarenmalm, Öhlén, Jonsson, & Gaston-Johansson, 2007; Silva, Crespo, & Canavarro, 2012; Stanton et al., 2000).

In spite of the influence of coping strategies on mental health outcomes and quality of life of women diagnosed with breast cancer, some specific coping strategies have been found to have varied influences on several aspects of quality of life of the women. For instance, whereas helplessness coping and anxious preoccupation predicted decreased health-related quality of life, religious coping, optimistic coping and problem focused coping positively predicted increased health-related quality of life among women living breast cancer (Filazoglu & Griva, 2008; Johansson, Rydén, & Finizia, 2011a; Kulpa, Ziętalewicz, Kosowicz, Stypuła-Ciuba, & Ziółkowska, 2016). Similarly, having a fighting spirit which involves individual's determination to significantly deal with their illness, is linked to improved health-related quality of life whilst fatalism predicted decreased health-related quality of life among the patients (Yeung & Lu, 2014). These findings point to the fact that maladaptive coping is detrimental to the health and wellbeing of cancer patients (Brunault et al., 2016; Nipp et al., 2016; Paek et al., 2016).

It is evidenced from the studies reviewed above that while the majority of the studies found adaptive coping strategies to be associated with better health and wellbeing outcomes and maladaptive coping strategies to be associated with poor health and wellbeing outcomes, there are some inconsistencies in the influence of some of the cancer-specific coping strategies. For instance while some researchers found fatalism to be beneficial to the wellbeing of patients (Anagnostopoulos, Kolokotroni, Spanea, & Chryssochoou, 2006; Kang et al., 2008), others have reported its detrimental effect on the quality of life among cancer patients (Bustillo et al., 2017; Gonzales, Hurtado-de-Mendoza, Santoyo-Olsson, & Nápoles, 2016). In addition, some of the previous studies did not use cancer specific coping measures and therefore, did not provide much information that are unique to coping with cancer.

5.1.2 Anxiety, depression and health-related quality of life

Anxiety and depression are the two of the most common mental health comorbidities of chronic medical conditions such as breast cancer (Brunault et al., 2016; Gold et al., 2016; Kagee, Roomaney, & Knoll, 2018). Studies have reported that substantial percentages of women living with breast cancer experience common mental health problems including depression, anxiety and general psychological distress. For instance, a study among women living with breast in South Africa showed that over a third of the total sample reported elevated depressive symptoms (Kagee et al., 2018). Similar findings were also reported in systematic and epidemiological reviews with prevalence of depression and anxiety among women living with breast cancer to be between 9% and 67% (Fann et al., 2008; Kyranou et al., 2013; Maass, Roorda, Berendsen, Verhaak, & de Bock, 2015). The presence of these common mental health problems among women living with breast

cancer could impact negatively on their treatment adherence as evidenced in other chronic disease populations (Elderon, Smolderen, Na, & Whooley, 2011; Hoen et al., 2010).

One of the key measures of treatment outcomes is health-related quality of life as reported by patients. However, evidence suggests that there are several psychosocial, medical and individual characteristics of the patients which could impact on the health-related quality of life among the patients. Presence of comorbid anxiety and depression have been linked with decreased health-related quality of life among women living with breast cancer (Colby & Shifren, 2013; Huang & Hsu, 2013; Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012). The negative impacts of anxiety and depression on the health-related quality of life among breast cancer patients may be due to depressive and anxiety symptoms' interference with medical treatment. This is most especially because key symptoms of depression such as extreme sadness, loss of interest, lack of concentration, loss of appetite, restlessness, sleep problems and in some cases, suicidal ideations (APA, 2013) could affect patients' active participation in treatment. Therefore, it is important to examine the influence of anxiety and depression on the health-related quality of life among women living with breast cancer in the Ghanaian context since there are no published literature to that effect.

5.1.3 Coping strategies, anxiety, and depression

Cancer-specific coping strategies such as the use of helpless-hopeless, anxious preoccupation, presence of fighting spirit, cognitive avoidance and fatalism have been found to influence several domains of health outcomes among persons living with chronic medical conditions including cancers. The use of helpless-hopeless and anxious preoccupation have been associated with elevated psychological distress, anxiety and depression among cancer patients

(Johansson, Rydén, & Finizia, 2011b; Kulpa, Kosowicz, Stypuła-Ciuba, & Kazalska, 2014). On the other hand, decreased mental health problems are linked with the presence of a fighting spirit, the use of cognitive avoidance and fatalism among cancer patients (Kulpa et al., 2014; Saita, Acquati, & Kayser, 2015). These coping strategies could be classified as maladaptive (helpless-hopeless and anxious preoccupation) and adaptive (fighting spirit, cognitive avoidance and fatalism) with studies showing that the use of maladaptive coping strategies result in increased anxiety and depression levels whilst the use of adaptive coping strategies results in decreased anxiety and depression levels (Kershaw et al., 2004; Sarenmalm et al., 2007; Silva et al., 2012; Yeung & Lu, 2014).

5.1.4 Anxiety and depression as mediators between coping strategies and health-related quality of life

The importance of coping strategies in influencing both short and long-term outcomes in chronic disease patients has been theoretically grounded in one of the most well cited stress-and-coping theory (Lazarus & Folkman, 1984, 1987). One of the basic assumptions of this theory is the fact that the coping strategies adopted by an individual in managing his/her chronic illness is likely to influence short-term outcomes such as anxiety and depression. The theory further posits that the effects of the coping strategies on these short-term outcomes could influence the long–term disease outcomes including the health-related quality of life among persons living with chronic medical conditions (Lazarus & Folkman, 1984, 1987). Thus, among women living with breast cancer, is it possible that the various cancer-specific coping strategies could influence short-term outcomes such as anxiety and depression which would eventually influence the reported health-related quality of life among women living with breast cancer?

Evidence in the cancer literature suggests that coping strategies directly influence the health-related quality of life among persons living with various types of cancers (Kershaw et al., 2004; Petersen et al., 2008; Sarenmalm et al., 2007; Silva et al., 2012; Stanton et al., 2000), anxiety and depression (Kulpa et al., 2014; Saita et al., 2015). However, there is lack of evidence on the potential mediational roles of anxiety and depression in the links between cancer-specific coping strategies and health-related quality of life among women living with breast cancer. Findings among other chronic disease conditions such as coronary heart disease and hypertensive patients found that depression significantly mediated the effects of coping strategies on quality of life, life satisfaction and psychological hypertension and wellbeing (Rueda & Pérez-García, 2013; Shen, McCreary, & Myers, 2004; Shen, Myers, & McCreary, 2006). The outcomes from these studies suggest mental health comorbidities could explain the impact of coping strategies on the health-related quality of life among persons living with chronic medical conditions.

Although some studies (e.g. Clegg-Lamptey et al., 2009; Opoku et al., 2012) have been conducted among women living with breast cancer within the Ghanaian setting, the majority of these few studies have focused on the emotional and psychosocial challenges for women living with breast cancer (Bonsu, Aziato, & Clegg-Lamptey, 2014). Thus, little studies have been conducted with regards to the quality of life of women living with breast, and how specific cancer coping strategies influence their quality of life. The mechanisms linking the various cancer-specific coping strategies have not been fully established in the psycho-oncological literature. This study therefore, sought to 1) determine whether cancer specific coping strategies predict quality of life in Ghanaian women living with breast cancer, and 2) examine the mediating roles of anxiety and depression in the influence of the five cancer-specific coping strategies on the health-related quality of life among women living with breast cancer. The findings of this study may inform

policies that would address the psychosocial needs of breast cancer patients such as the inclusion of routine psychological assessment to examine the various coping strategies being utilized by the patients to shape the overall healthcare delivery. The findings may inform cognitive-based interventions to address the use of coping strategies and their impacts on reducing anxiety and depression leading to improved health-related quality of life.

5.2 RESULTS

5.2.1 Demographic profile of participants

Results from the demographic Table 6 showed that most of the participants were relatively old with a mean age of 52.49years and a mean duration of illness since first diagnosis being 32.28months. Most of the participants were married (67.8%) with only 19.6% reported to have tertiary education. The majority of the women sampled (89.7%) were Christians, 61.2% were employed, 88.2% have an average monthly income of less than GHC1500 ($338) with over half of the participants with an average income of GHC500 ($113) and below which suggests very low levels of income in comparison to Ghana' per capital income of $ 1,513.46 in 2016. Nearly half (41.8%) of the participants reported to have received Surgical, Chemotherapy and Radiotherapy treatments for their breast cancer. The details of the participant's socio-demographic characteristics are presented in Table 6.

Table 6

Summary of the Demographic profile of the participants

Characteristics	Frequency (N)	Percentage (%)
Age	Mean=52.49years	SD=11.14
Duration in months since diagnosis	Mean=29.64months	SD=38.75months
Marital status		
Never married	16	7.8
Married	139	67.8
Separated/divorced	24	11.7
Widowed	26	12.7
Educational level		
No formal education	22	10.7
Primary/JSS/MSLC	73	35.6
Secondary	70	34.1
Tertiary	40	19.6
Religion		
Christianity	184	89.7
Islam	18	8.8
Others	3	1.5
Employment status		
Unemployed	56	27.5
Employed	125	61.2
Retired	23	11.3
Average monthly income (GHC)		
Less than GH500	99	53.2
From Gh500 to less than GH1000	37	19.9
From Gh1000 to less than Gh1500	28	15.1
From Gh1500 to less than Gh2000	12	6.4
Gh2000 and above	10	5.4
Type of treatment		
Surgery	11	5.5
Chemotherapy	42	20.9
Radiotherapy	19	9.5
Surgery + Chemotherapy	21	10.4
Surgery + Radiotherapy	11	5.5
Chemotherapy + Radiotherapy	13	6.5
Surgery + Chemotherapy + Radiotherapy	84	41.8

5.2.2 Relationships among the study variables (Coping strategies, anxiety, depression and health-related quality of life)

To examine whether significant relationships exist among the study variables, the Pearson Product Moment correlation was computed and the summary of results are presented in Table 7. As can be seen from Table 7, the use of a helpless-hopeless coping strategy was significantly and positively correlated with anxiety ($r = .55$, $p < .001$) and depression ($r = .54$, $p < .001$), but negatively correlated with health-related quality of life ($r = -.53$, $p < .001$). An anxious preoccupation was significantly and positively correlated with anxiety ($r = .65$, $p < .001$) and depression ($r = .63$, $p < .001$), and also negatively correlated with health-related quality of life ($r = -.68$, $p < .001$). However, the presence of a fighting spirit was significantly and negatively correlated with anxiety ($r = -.28$, $p < .001$) and depression ($r = -.27$, $p < .001$), but positively correlated with health-related quality of life ($r = .13$, $p < .05$). On the other hand, cognitive avoidance as a coping strategy was significantly and negatively correlated with only anxiety ($r = -.15$, $p < .05$) and depression ($r = -.27$, $p < .001$), whereas fatalism was significantly and negatively correlated with depression ($r = -.24$, $p < .001$) and positively correlated with health-related quality of life ($r = .18$, $p < .05$).

It was further observed from Table 7 that levels of anxiety and depression among the women living with breast cancer were significantly and negatively correlated with their health-related quality of life ($r = -.67$, $p < .001$; $r = -.77$, $p < .001$ respectively). These findings mean that higher anxiety and depression among the women living with breast cancer are associated with decreased health-related quality of life.

Table 7

Correlation matrix of the relationship among the study variables

Variables	1	2	3	4	5	6	7
1. HH	1						
2. AP	.63***	1					
3. FS	-.38***	-.15*	1				
4. CA	-.15*	-.16*	.41***	1			
5. FA	-.20**	-.32***	.06	.14*	1		
6. Anxiety	.55***	.65***	-.28***	-.15*	-.03	1	
7. Depression	.54***	.63***	-.27***	-.27***	-.24***	.72***	1
8. HQOL	-.53***	-.68***	.13*	.11	.18*	-.67***	-.77***

HH = Helplessness-Hopelessness, AP = Anxious Preoccupation, FS = Fighting Spirit, CA= Cognitive Avoidance, FA = Fatalism and HQOL = Health-related quality of life.

*= $p < .05$, **= $p < .01$, ***= $p < .001$

5.2.3 Mediation effects of anxiety and depression on the relationship between coping strategies and health-related quality of life

5.2.3.1 Helplessness-hopelessness and health-related quality of life

The entire model including the predictor and the mediators explained 63.56% of variance in the health-related quality of life among the participants (R^2 = .6356, $F(3,193) = 112.1942$, $p < .0001$). The use of a helplessness-hopelessness coping strategy had an indirect negative effect on

health-related quality of life through anxiety ($b = -.6443$, $SE = .2372$, 95%CI = -1.1378 to -.2090).

As can be seen in Fig. 3, a helplessness-hopelessness coping strategy resulted in increased anxiety ($b = .7005$, $p < .0001$) and increased anxiety resulted in decreased health-related quality of life ($b = -.9197$, $p < .001$). Similarly, hopelessness-helplessness coping had a significant indirect negative effect on the health-related quality of life ($b = -1.8597$, $SE = .3067$, 96%CI = -2.5007 to -1.3041). As can be seen in Fig. 3, the use of a helplessness-hopelessness coping strategy resulted in increased depression ($b = .5688$, $p < .0001$) and increased depression resulted in decreased health-related quality of life ($b = -3.2695$, $p < .0001$). Therefore, anxiety and depression mediated the link between the use of a helplessness-hopelessness coping strategy and health-related quality of life. There was evidence of a significant negative direct effect of the use of a helplessness-hopelessness coping on health-related quality of life among the participants ($b = -.7063$, $p < .05$).
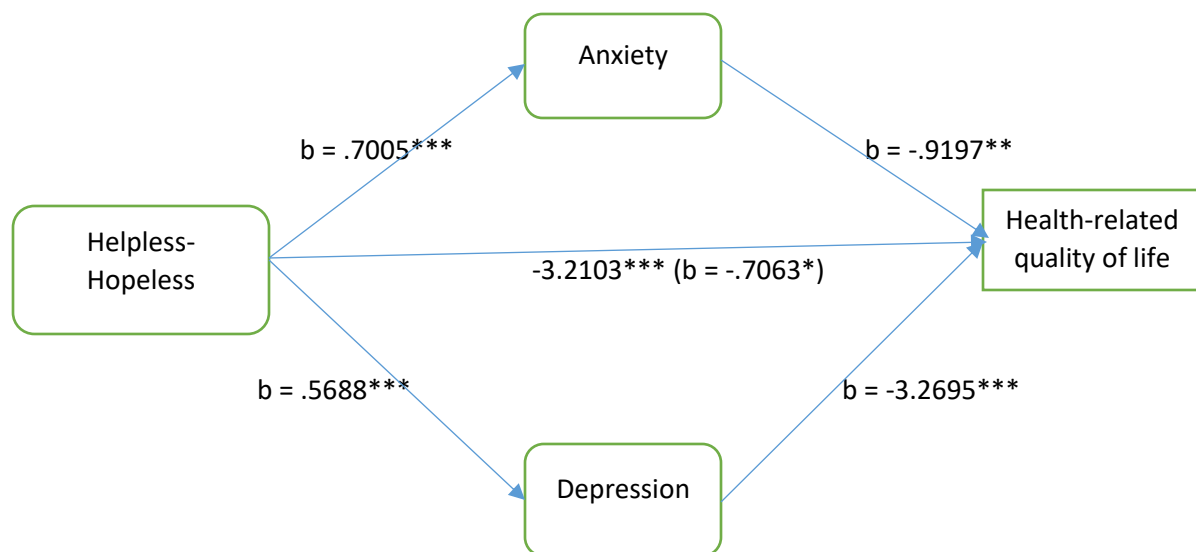
NB: Direct effect of helpless-hopeless on health-related quality of life in parenthesis.

Figure 3: A model showing the mediating effects of anxiety and depression on the relationship between helpless-hopeless coping and health-related quality of life.

5.2.3.2 Anxious preoccupation and health-related quality of life

The entire model including anxious preoccupation, anxiety and depression explained 65.91% of variance in the health-related quality of life among the participants (R^2 = .6591, $F(3,194) = 125.0463$, $p < .0001$. Anxious preoccupation did not have any significant indirect effect on the health-related quality of life ($b = -.3459$, 95% CI = $-.7197$ to .0406). As can be seen in Fig.4, anxious preoccupation predicted increased anxiety, but anxiety did not significantly predict health-related quality of life ($b = -.5509$, $p > .05$). However, anxious preoccupation had a significant indirect effect on health-related quality of life ($b = -1.4685$, $SE = .2207$, 95% CI = -1.9149 to -1.0565). As can be seen in Fig. 4, anxious preoccupation predicted increased depression ($b = .5113$, $p < .0001$) and increased depression predicted decreased health-related quality of life ($b = -2.8720$, $p < .0001$). Therefore, only depression significantly mediated the link between anxious preoccupation and health-related quality of life among the participants. There was evidence for a direct significant negative effect of anxious preoccupation on health-related quality of life ($b = -1.3571$, $p < .0001$).
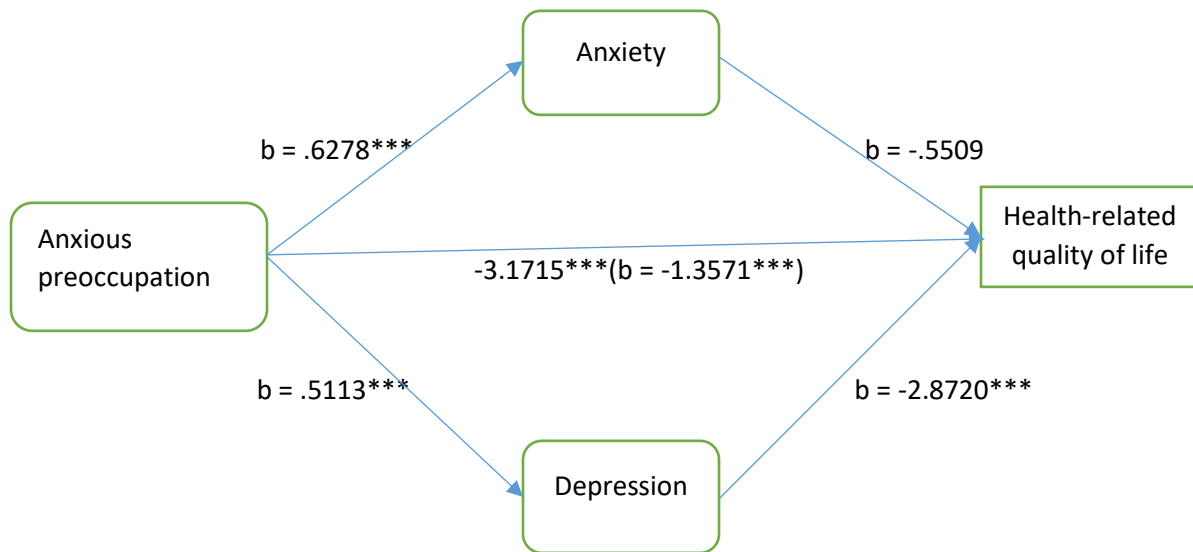
NB: Direct effect of anxious preoccupation on health-related quality of life in parenthesis.
Figure 4: A model showing the mediating effects of anxiety and depression on the relationship between anxious preoccupation coping and health-related quality of life.

5.2.3.3 Fighting spirit and health-related quality of life

The overall model explained 63.53% of variance in the health-related quality of life among the participants ($R^2 = .6353$, $F(3,199) = 115.5457$, $p < .0001$). The presence of a fighting spirit had significant indirect positive effect on health-related quality of life through anxiety ($b = .8366$, $SE = .3284$, 95%CI $= .2809$ to 1.5537). As can be observed from Fig. 5, fighting spirit predicted decreased anxiety ($b = -.7079$, $p < .0001$) and anxiety predicted decreased health-related quality of life ($b = -1.1818$, $p < .0001$). Similarly, the presence of a fighting spirit had a significant positive indirect effect on health-related quality of life through depression ($b = 2.0467$, $SE = .5953$, 95%CI $= 1.0234$ to 3.3701). As can be seen in Fig. 5, fighting spirit predicted decreased depression ($b = -.5755$, $p < .0001$) and depression predicted decreased health-related quality of life ($b = -3.5565$, $p < .0001$). Thus, anxiety and depression significantly mediated the influence of fighting spirit on health-related quality of life among the participants. There was evidence for a direct effect of the

presence of fighting spirit on health-related quality of life among the participants (b = -1.3160, p < .05).
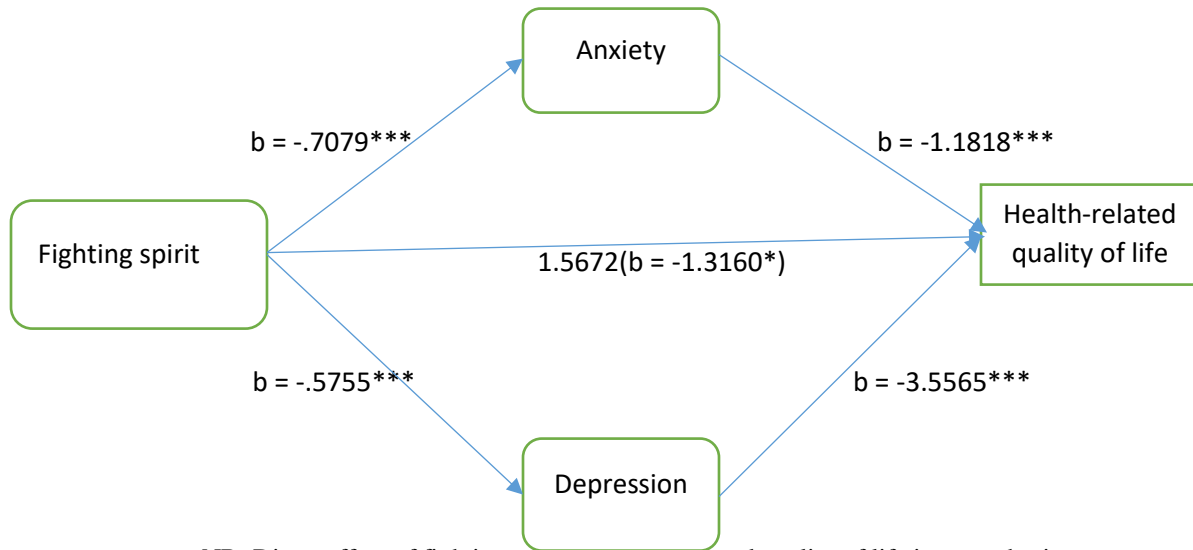
NB: Direct effect of fighting spirit on health-related quality of life in parenthesis.
Figure 5: A model showing the mediating effects of anxiety and depression on the relationship between fighting spirit and health-related quality of life.

5.2.3.4 Cognitive avoidance and health-related quality of life

The entire model explained 63.22% of variance in the health-related quality of life among the participants (R^2 = .6322, $F(3,199)$ = 114.0324, p < .0001). The use of cognitive avoidance had a significant positive indirect effect on health-related quality of life through anxiety (b = .3270, SE = .1912, 95%CI = .0073 to .7442). Fig. 6 below shows that cognitive avoidance predicted decreased anxiety (b = -.2971, p < .05) and anxiety predicted decreased health-related quality of life (b = -1.1006, p < .0001). Similarly, cognitive avoidance had a significant positive indirect effect on health-related quality of life through depression (b = 1.6360, SE = .5188, 95%CI = .6770 to 2.7178). As can be seen in Fig 6, the use of cognitive avoidance predicted decreased depression (b = -.4529, p < .0001) and depression predicted decreased health-related quality of life (b = -

3.6121, $p < .0001$). Thus, anxiety and depression significantly mediated the influence of the use of cognitive avoidance on health-related quality of life among the participants. There was evidence for a significant direct effect of cognitive avoidance on the health-related quality of life among the participants.
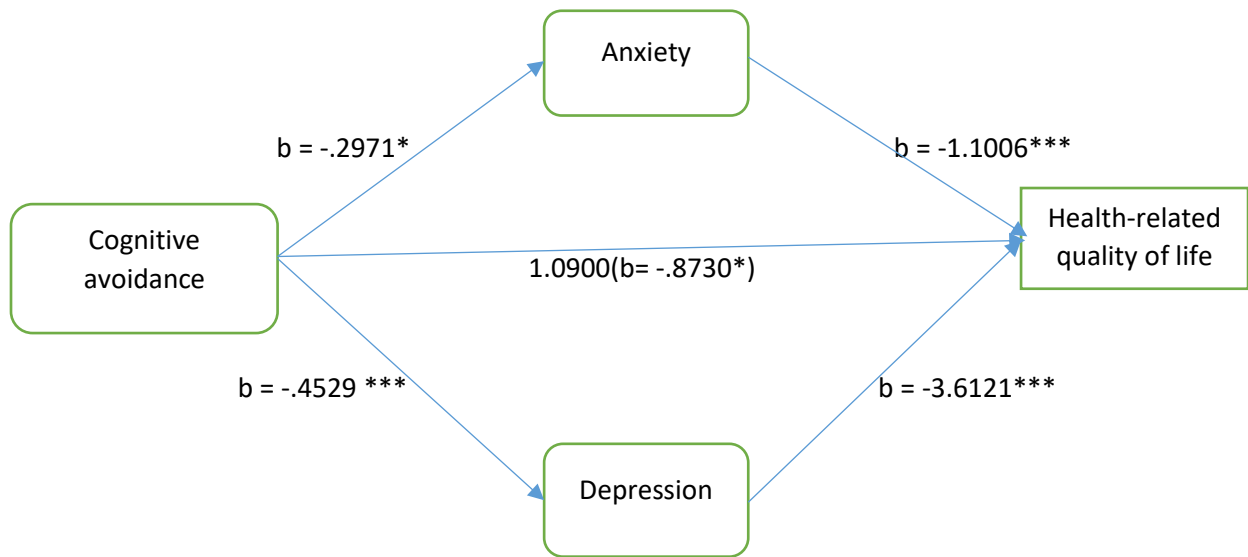

NB: Direct effect of cognitive avoidance on health-related quality of life in parenthesis.
Figure 6: A model showing the mediating effects of anxiety and depression on the relationship between cognitive avoidance coping and health-related quality of life.

5.2.3.5 Fatalism and health-related quality of life

The entire regression model explained 62.51% of the variance in the health-related quality of life among the participants ($R^2 = .6251$, $F(3,199) = 110.5977$, $p < .0001$). Fatalism did not have any significant indirect effect on health-related quality of life through anxiety ($b = .0723$, $SE = .1638$, 95%CI = -.2134 to .4334). As can be seen from Fig. 7, fatalism did not significantly predict anxiety ($b = -.0619$, $p > .05$), but anxiety predicted decreased health-related quality of life ($b = -1.1674$, $p < .0001$). However, fatalism had a significant positive indirect effect on health-related quality of life through depression ($b = 1.3232$, $SE = .4371$, 95%CI = .5723 to 2.2842). As can be observed from Fig. 7, fatalism significantly predicted decreased depression ($b = -.3906$, $p < .0001$)

87

and depression significantly predicted decreased health-related quality of life (b = -3.3878, $p <$ .0001). Therefore, only depression significantly mediated the influence of the use of fatalism on the health-related quality of life among the participants. There was no evidence for a significant direct effect of the use of fatalism on the health-related quality of life among the participants.
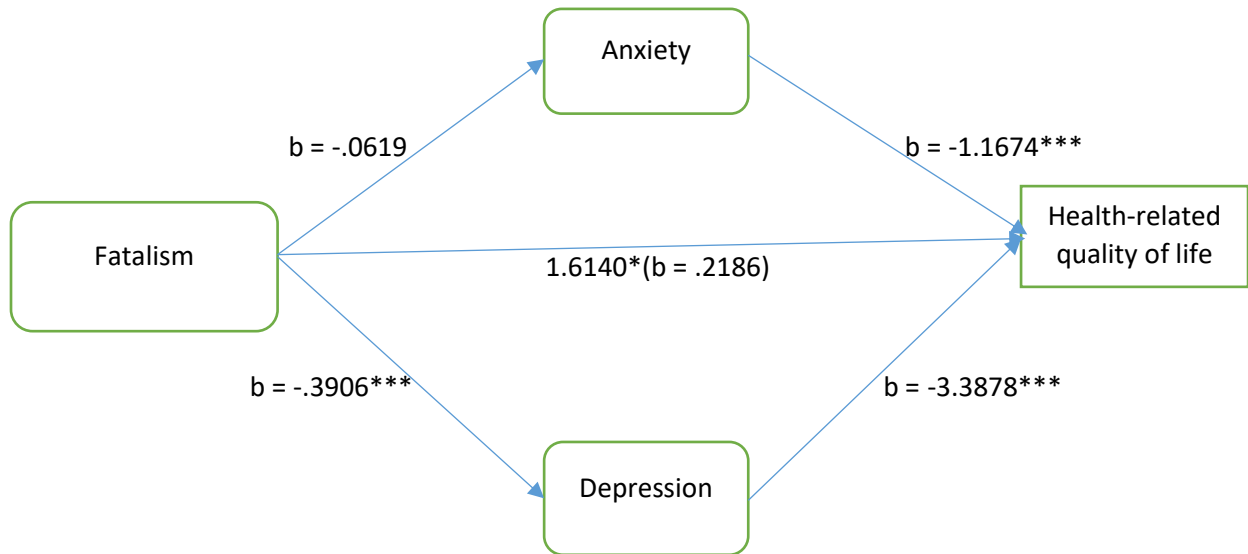
NB: Direct effect of fatalism on health-related quality of life in parenthesis.
Figure 7: A model showing the mediating effects of anxiety and depression on the relationship between fatalism and health-related quality of life.

5.3 DISCUSSION

The purpose of this study was to investigate the influence of cancer-specific coping strategies on the health-related quality of life of women living with breast cancer. This study also examined whether anxiety and depression significantly mediated the influence of the cancer specific coping strategies on the health-related quality of life among the women. Findings from the analyses are discussed in the subsequent sub-sections.

5.3.1 Coping strategies and health-related quality of life

Findings from the study showed that participants' use of a helplessness-hopelessness coping strategy and an anxious preoccupation were significantly and negatively correlated with their health-related quality of life. This means that the more hopeless views and anxious thoughts that are held by the participants about their breast cancer, the lower their health related quality of life. This pattern of relationship between the use of negative coping strategies and health-related quality of life has been demonstrated in the extant literature. For example, negative coping strategies such as hopelessness-helplessness and anxious preoccupation have been found to be associated with decreased quality of life in breast cancer patients (Brunault et al., 2016; Ferrero, Barreto, & Toledo, 1994; Nipp et al., 2016; Paek et al., 2016).

Anxious preoccupation as a cancer-specific coping mechanism may be detrimental to the health and wellbeing of women living with breast cancer in this study due to effects of anxiety as an emotion on quality of life. Thus, the more anxious views and attitudes the women have towards dealing with their illness, the lesser they enjoy their lives and appreciate the positive aspects of their existence. Their anxious preoccupation may predispose them to other negative emotions and thought patterns that result in poorer quality of life. The literature is replete with studies which highlight the detrimental influence of the use of anxious preoccupation as a cancer-specific coping strategy across varied cancer populations (Johansson et al., 2011b; Kulpa et al., 2014; Yeung & Lu, 2014).

However, the presence of a fighting spirit, the use of cognitive avoidance and fatalism were significantly and positively correlated with health-related quality of life among the women living with breast cancer. Fighting spirit and cognitive avoidance have been shown to be associated with

89

improved quality of life (Anagnostopoulos et al., 2006; Ferrero et al., 1994; Rottmann, Dalton, Christensen, Frederiksen, & Johansen, 2010; Schou, Ekeberg, Sandvik, Hjermstad, & Ruland, 2005). The use of denial or cognitive avoidance may help the women carryout their day-to-day activities with little attention to their predicament. Some evidence in the literature suggests that the use of denial or cognitive avoidance could protect people against the negative emotions and feelings associated with living with a chronic illness like breast cancer (Khalili et al., 2013) as they tend not to be preoccupied with thoughts about the existence of their disease..

Unlike other studies which found fatalism to be detrimental to quality of life in breast cancer patients (Ferrero et al., 1994; Schou et al., 2005; Whitford, Olver, & Peterson, 2008), a positive relationship between fatalism and health-related quality of life was found in this study. This could be due to the meaning ascribed to the items which measured fatalism as they could have implied positivity to the patients as observed among a sample of Chinese cancer patients (R. T. Ho, Chan, & Ho, 2004; S. Ho, Kam Fung, Chan, Watson, & Tsui, 2003). Similarly, fatalism was found to be negatively related to hopeless-helpless and positively correlated with religiosity and external locus of control (Grassi, Rosti, Lasalvia, & Marangolo, 1993; Kang et al., 2008). It is plausible that the use of fatalism by the women living with breast cancer within the Ghanaian context may serve to protect them against the negative emotions and feelings associated with living with breast cancer.

5.3.2 Anxiety, depression and health-related quality of life

Levels of anxiety and depression among the women living with breast cancer were significantly and negatively correlated with their health-related quality of life. These findings mean that higher anxiety and depression among the women living with breast cancer are associated with

90

decreased health-related quality of life. In the regression models, depression and anxiety were significant predictors of decreased health-related quality of life among the participants. These findings suggests that the negative emotional experiences associated with living with a chronic medical condition like breast cancer is detrimental to the overall health outcomes of patients. These effects could be due to the impacts of the presence of anxiety and depression on disease prognosis, adherence to medical treatments (Elderon et al., 2011; Hoen et al., 2010). Since breast cancer treatment requires strict adherence and commitment to medical treatments, the symptoms of anxiety and depression may interfere with the treatment process resulting in poor outcomes.

The negative impacts of anxiety and depression on the health-related quality of life among women living with breast cancer have been reported by some previous studies. For instance, the presence of comorbid anxiety and depression among breast cancer patients was found to be predictive of decreased quality of life in the samples studied (Colby & Shifren, 2013; Huang & Hsu, 2013; Reyes-Gibby et al., 2012). These findings suggest that there is that need for psychosocial interventions targeted at reducing the burdens of anxiety and depression among women receiving treatment for breast cancer to improve their long term health outcomes such as life satisfaction and quality of life. For instance, screening for common mental health problems as part of the routine medical assessment could help in providing holistic care to the patients.

5.3.3 Coping strategies, anxiety, and depression

Findings from the study showed that participants' use of a helpless-hopeless coping strategy was significantly and positively correlated with anxiety and depression. An anxious preoccupation was significantly and positively correlated with anxiety and depression. These findings mean that patients' use of helpless-hopeless coping strategy and being preoccupied with

91

anxiety about their disease contribute to their increased emotional problems. These linkages are not surprising as the key characteristic of the use of hopeless-helpless coping strategy is low level of control over the disease and the individual easily gives up and the key characteristic of the anxious preoccupation is excessive worry about cancer and the possibility of its recurrence (Saita et al., 2015; Watson et al., 1994). The findings of elevated anxiety and depression among the participants due to the use of hopeless-helpless coping and an anxious preoccupation are consistent with previous studies (Johansson et al., 2011b; Kulpa et al., 2014).

However, the presence of a fighting spirit and use of cognitive avoidance as a coping strategy were significantly and negatively correlated with anxiety and depression, whereas fatalism was significantly and negatively correlated only with depression. Evidence in the coping literature suggests that the use of adaptive coping strategies such as having a fighting spirit characterized by seeing the disease as a challenge, the use of cognitive avoidance characterized by refraining from actively processing information related cancer and adopting a fatalistic approach characterized by deferring responsibility to supreme being or fate have been found to protect individuals against experiencing severe negative emotional states such as depression and anxiety (Saita et al., 2015).

The findings are consistent with previous works which found these the use of these three coping strategies to predictive of decreased anxiety and depression (Kershaw et al., 2004; Petersen et al., 2008; Sarenmalm et al., 2007). However, fatalism proved to be a positive strategy among the participants as it was associated with decreased depression which is inconsistent with some previous findings which reported that patients' adoption of a fatalistic approach to their illness contributed to increased negative emotional states and poor quality of life or no relationship (Johansson et al., 2011b; Whitford et al., 2008; Yeung & Lu, 2014). It is worth noting that the

items measuring fatalism could be positive in the Ghanaian context as deferment of the illness outcome to fate or external forces including a supernatural being may serve to protect the patients against negative emotional experiences.

5.3.4 Anxiety and depression as mediators between coping strategies and health-related quality of life

Findings from the mediation analysis revealed that anxiety and depression significantly mediated the link between the use of a helpless-hopeless coping strategy and health-related quality of life. However, only depression significantly mediated the link between anxious preoccupation and health-related quality of life among the participants. That is, helpless-hopeless coping strategy was related with increased anxiety and depression which resulted in decreased health-related quality of life which suggests that anxiety and depression serve as important mechanisms through which the use of negative coping mechanism such as helpless-hopeless negative influences health-related quality of life among women living with breast cancer. The result also mean that being preoccupied with anxious thoughts about breast cancer results in increased depression which in turn lead to decreased health-related quality of life. These findings are consistent with previous studies among cancer patients from Western developed countries which found the use of helpless-hopeless coping and anxious preoccupation to be positively related with increased anxiety and depression (Johansson et al., 2011b; Kulpa et al., 2014; Whitford et al., 2008; Yeung & Lu, 2014) which in turn predicted decreased health-related quality of life (Kulpa et al., 2016). However, the finding of significant mediation effects of both anxiety and depression on the links between helpless-hopeless coping, anxious preoccupation and health-related quality of life have not been

documented and these results present new insights into the mechanisms linking negative coping strategies to decreased health-related quality of life among breast cancer patients.

Furthermore, having a fighting spirit, the use of cognitive avoidance and fatalism had significant indirect positive effects on health-related quality of life among the women living with breast cancer through depression and both anxiety and depression. That is, anxiety and depression significantly mediated the influence of fighting spirit on health-related quality of life among the participants as well as the influence of the use of cognitive avoidance on health-related quality of life. However, only depression significantly mediated the influence of the use of fatalism on the health-related quality of life among the participants. These findings suggest that the use of these groups of coping strategies result in decreased anxiety and depression which in turn resulted in increased health-related quality of life among the participants.

These findings are consistent with previous works which found having a fighting spirit, the use of cognitive avoidance and fatalism are associated with decreased anxiety and depression levels (Kulpa et al., 2016; Saita et al., 2015). For instance, in a study among cancer patients to determine the mediating role of affect in the relationship between coping strategies and health-related quality of life among cancer patients, it was observed that whereas having a fighting spirit was associated with more positive affect which in turn resulted in improved quality of life, fatalism was associated with more negative affect and decreased quality of life (Yeung & Lu, 2014). However, the authors acknowledged that the fatalism scale used did not include two key items which were important positive coping resources (Yeung & Lu, 2014). Studies conducted among breast cancer patients in some Asian countries have reported significant positive impact of the use of fatalism as a coping strategy on the health and wellbeing of breast cancer patients (R. T. Ho et

al., 2004; S. Ho et al., 2003; Kang et al., 2008). It is not surprising that the use of fatalism in this study seems to be protective against negative emotional experiences as the majority of the study participants reported being Christians with strong religiosity and faith in God. This could be one of the key reasons why fatalism is protective against negative experiences in this study compared to previous works which found fatalism to be a maladaptive coping strategy (Schou et al., 2005; Whitford et al., 2008; Yeung & Lu, 2014). These findings from this have contributed to the breast cancer literature by shedding light on the mechanisms linking adaptive coping strategy to improved health-related quality of life.

5.3.5 Implications for clinical practice and research

The findings of this study have some implications for clinical practice and research. The first implication of the findings is that women living with breast cancer adopt several cancer-specific coping strategies which influence their health-related quality of life in diverse ways and therefore, it is imperative for oncology providers to explore these coping strategies and provide guidance and counselling on which coping strategies need to be discouraged and which ones need to be encouraged. The findings also imply that mindfulness-based interventions aimed at helping patients adjust cognitively to their illness are necessary to decrease the levels of anxiety and depression experienced by the women living with breast cancer which will in turn improve the overall rating of their health-related quality of life.

In this study, the use of fatalism which borders on leaving everything to a supreme being may serve to reinforce the spiritual beliefs of the women and therefore, must not be discounted as a maladaptive cancer-specific coping mechanism as reported by some previous studies (Schou et al., 2005; Whitford et al., 2008; Yeung & Lu, 2014). This therefore, requires regular in-service

training of oncology nurses and physicians in counselling techniques which would enable them examine patterns of coping and its impact on the health outcomes of women living with breast cancer. This implication is relevance in the face of relatively longer duration of the disease (Mean = 29.64months, SD=38.75months) which indicates high chances of survival among the women. In addition to the above, the findings imply that there is the need for research to determine factors that influence the use of specific coping strategies by women living with breast cancer. These would also help to obtain a holistic overview about factors that influence the use specific coping mechanisms and how these affect the health outcomes of the women living with breast cancer.

5.3.6 Limitations

The study has some limitations that need to be taken into consideration in interpreting the results. Data was collected from participants at only one point in time which did not take into consideration temporal influences on their health and wellbeing. It is also possible that the women in this study might be using other coping strategies (e.g. use religious coping) that were not captured by the MINI-MAC as it was found in this study that fatalism which connotes some religiosity was found be positively correlated with improved quality of life. Thus, there is the need for a qualitative studies to explore coping strategies used by the women living with breast cancer aside the cancer-specific coping strategies and how these impacts their health and wellbeing. Despite the limitations of this study highlighted above, this study highlighted the importance of cancer-specific coping strategies on the various domains of quality of life among women living with breast cancer within the Ghanaian setting as little research exist in that regard. That is, while some coping strategies in the western world are detrimental to the health and wellbeing of persons living with cancer, the findings may not be applicable as some of these negative coping styles serve to protect women against the negative consequences of living with breast cancer, especially,

the use of fatalism as a coping mechanism which has religious connotations. The findings also contribute significantly to the understanding of some key mechanisms linking coping strategies to health-related quality of life among women living with breast cancer which was hitherto, lacking in the literature.

5.3.7 Conclusion

This study was conducted to examine the direct and indirect effects of cancer specific coping strategies on the health-related quality of life of women living with breast cancer through anxiety and depression. The findings suggest that cancer-specific coping strategies have significant influences on the health-related quality of life of women living with breast cancer which underscore the need to address psychosocial issues among breast cancer patients. Anxiety and depression were significant mediators in the links between coping strategies and health-related quality of life among the participants. One key finding that needs attention is the positive impact of the use of fatalism on health outcomes of patients. This suggests that the context of the women should be taken into consideration as strong religious beliefs could have influenced such outcomes.

CHAPTER SIX

DOCTOR-PATIENT RELATIONSHIP MEDIATES THE EFFECTS OF SHARED DECISION MAKING ON HEALTH-RELATED QUALITY OF LIFE AMONG WOMEN LIVING WITH BREAST CANCER

6.1 INTRODUCTION

Quality of life has become an important outcome measure of persons living with chronic illness including breast cancer (Paraskevi, 2012; Perry, Kowalski, & Chang, 2007). Due to increased survival chances of women diagnosed with breast cancer, efforts are made by clinicians and researchers to identify ways to enhance the health and well-being of these women. Quality of life refers to individuals' appraisal of their lives in relation to goals, expectations, standards, and concerns and this appraisal is influenced by the individuals' physical health, psychological state, level of independence, social relationships, and their environment (World Health Organization [WHO], 1998). Quality of life domains such as physical, social/family, emotional, and functioning well-being are essential in evaluating the effectiveness of the healthcare treatment.

Several factors have been found to have significant effects on the quality of life of women living with breast cancer. For instance, socio-demographic factors such as age (Brunault et al., 2016; Howard-Anderson, Ganz, Bower, & Stanton, 2012), duration of illness, level of education, type of treatment, body mass index, stage of cancer, and other comorbidities (Farin & Nagl, 2013; Klein et al., 2016) are found to be associated with quality of life among breast cancer patients. Mental health problems such as depression and anxiety (Colby & Shifren, 2013; Reyes-Gibby, Anderson, Morrow, Shete, & Hassan, 2012) influence the overall quality of life and the various domains of quality of life. On the other hand, factors such as social support (Kroenke et al., 2013; Leung, Pachana, & McLaughlin, 2014), patients' involvement in decision making (Vogel, Leonhart, & Helmes, 2009), and doctor–patient relationship and communication (Maly, Liu, Liang, & Ganz, 2015; Street, Makoul, Arora, & Epstein, 2009; Trudel, Leduc, & Dumont, 2014) are found to improve quality of life among women living with breast cancer.

6.1.1 Doctor–patient relationship and quality of life

One of the important contextual factors that influence the health outcomes of persons living with chronic illnesses like breast cancer is doctor–patient relationship (Farin & Nagl, 2013). The quality of doctor–patient relationship has been viewed as an underlying principle in patient-centred care as most decisions regarding accurate diagnosis, effective treatment, and health outcomes are inextricably dependent on quality of this doctor–patient relationship (Kaba & Sooriakumaran, 2007; Zhou et al., 2014). This makes the doctor–patient relationship an important variable especially in the oncology practice as it involves a complex process of decision making with regard to treatment options and other critical health decisions (Kerr, Engel, Schlesinger-Raab, Sauer, & Hölzel, 2003; Vogel et al., 2009).

Studies have shown that good doctor–patient relationships are associated with improved quality of life among breast cancer patients (Farin & Meder, 2010; Zhang, Nilsson, & Prigerson, 2012). A key component of the doctor–patient relationship is effective communication, as several studies have found it to be significantly associated with positive health outcomes among cancer patients (Maly et al., 2015; Street et al., 2009; Trudel et al., 2014). However, the mechanisms linking effective doctor– patient communication to positive health outcomes are poorly understood (Street et al., 2009). Increased access to care, greater patient knowledge and shared understanding, higher quality medical decisions, enhanced therapeutic alliances, increased social support, patient agency and empowerment, and better management of emotions are suggested as key mechanisms linking doctor–patient communication to positive health outcomes (Street et al., 2009). These findings highlight the importance of doctor–patient relationship in influencing the health outcomes of breast cancer patients.

6.1.2 Shared decision making and quality of life

Closely related to the doctor–patient relationship is the concept of shared decision making which has been advocated as critical in the care and treatment of persons living with chronic illnesses (Step, Rose, Albert, Cheruvu, & Siminoff, 2009; Street & Voigt, 1997). For instance, in the study by Vogel et al. (2009), the influence of physician–patient communication and shared decision making on patients' depression and quality of life were investigated and it was found that high level of information and active participation in decision making were associated with lower levels of depression and improved health-related quality of life. Evidence also exists for the positive impact of shared decision making on health outcomes in the long term (Davies, Kinman, Thomas, & Bailey, 2008; Griggs et al., 2007).

However, some systematic reviews did not find any strong evidence of shared decision making influencing clinical outcomes (Arora, 2003; Joosten et al., 2008). It was reported that some patients do not want to assume responsibility for their treatment decisions which impact their extent of involvement in shared decision making (Arora, 2003; Deadman, Leinster, Owens, Dewey, & Slade, 2001). The lack of consistency in the findings suggests that there is a need for further research to examine the influence of shared decision making and doctor–patient relationship on the health outcomes of breast cancer patients. It is evident from the studies reviewed that little attention is paid to the mechanism linking shared decision making to health outcomes especially quality of life among breast cancer patients.

In addition, the majority of the studies were conducted in western countries with relatively different orientations to healthcare and patterns of doctor–patient relations, for example, power–distance/ orientations (Hofstede, 2001, 2011) than that of the African context. It is believed that

power differentials have significant influence on doctor–patient communication and the expectations that patients may have from their healthcare providers (Charles, Gafni, Whelan, & O'Brien, 2006; Nápoles-Springer, Santoyo, Houston, Pérez-Stable, & Stewart, 2005). That is, patients from cultures with low power distance are more likely to be actively involved in their medical decisions, whereas patients from cultures with high power distances accept authoritative recommendations from their healthcare providers without questioning (Gao, Burke, Somkin, & Pasick, 2009; Hofstede, 2011). In Hofstede's insight on country comparisons in cultural dimensions, Ghana had a score of 80% on power distance which suggests that people accept a hierarchical order in which everybody has a place and which needs no further justification. Thus, there is a need for a study in the Ghanaian context to examine how doctor–patient relationships and shared decision making influence the quality of life among breast cancer patients with consideration of the impact of culture on doctor–patient interactions and patients' involvement in medical decision making. Therefore, this study seeks to examine (1) the direct influence of shared decision making and doctor–patient relationship on the overall quality of life and its various domains, and (2) the indirect influence of shared decision making on the overall quality of life, as well as the various domains of quality of life through doctor–patient relationship.

6.2 RESULTS

6.2.1 Bivariate relationships among the variables in the study

Results from Table 8 showed that level of education ($r = .31$, $p < .01$), duration of illness ($r = .19$, $p < .01$), and current treatment ($r = .33$, $p < 01$) were significantly correlated with overall quality of life. As can be seen in Table 8, all the participants' demographic variables in exception of age were significantly associated with the various dimensions of quality of life. Doctor–patient relationship was significantly and positively correlated with overall quality of life ($r = .29$, $p < .01$) and all the dimensions of quality of life, physical well-being ($r = .16$, $p < .01$), social/family well-being ($r = .17$, $p < .01$), emotional well-being ($r = .31$, $p < .01$), functional well-being ($r = .21$, $p < .01$), and breast cancer additional concerns ($r = .29$, $p < .01$). Shared decision making was significantly and positively correlated with the overall quality of life ($r = .24$, $p < .01$) and four dimensions of quality of life, that is, physical well-being ($r = .12$, $p < .05$), emotional well-being ($r = .24$, $p < .01$), functional well-being ($r = .22$, $p < .01$), and breast cancer additional concerns ($r = .20$, $p < .01$). Shared decision making was correlated with an improved doctor– patient relationship ($r = .51$, $p < .01$).

Table 8

Bivariate correlation among the variables in the study

VARIABLES	1	2	3	4	5	6	7	8	9	10	11	12
1. Age	1											
2. Education	-.19**	1										
3. Duration	.37**	.10	1									
4. Treatment	.15*	.06	.31**	1								
5. DPR	.15*	.21**	.14*	.27**	1							
6. SDM	.12*	.15*	.14*	.29**	.51**	1						
7. PWB	.04	.21**	.09	.26**	.16*	.12*	1					
8. SFWB	-.06	.27**	.02	.06	.17**	.06	.22**	1				
9. EWB	.10	.21**	.13*	.31**	.31**	.24**	.65**	.15*	1			
10. FWB	-.06	.33**	.14*	.32**	.21**	.22**	.72**	.28**	.58**	1		
11. BCAC	.03	.17**	.09	.33**	.29**	.20**	.77**	.27**	.68**	.62**	1	
12. QOL-Total	.02	.31**	.19**	.33**	.29**	.24**	.88**	.49**	.78**	.82**	.85**	1

*$p < .05$, **$p < .01$.

DPR= Doctor-patient relationship, SDM= Shared decision making, PWB=Physical Wellbeing, SFWB=Social/Family Wellbeing, EWB=Emotional Wellbeing, FWB=Functional Wellbeing, BCAC=Breast Cancer Additional Concerns, QOL-Total= Overall quality of life.

6.2.2 Mediation effect of doctor–patient relationship on the effect of shared decision making in quality of life

The entire model explained 23.66% of the variance in overall quality of life ($F(5,195) = 12.088$, $p < .001$). After controlling for education, duration, and treatment, shared decision making was noted to have a significant indirect effect on overall quality of life through doctor–patient relationship. As can be seen from Table 9, shared decision making had a significant positive effect on doctor–patient relationship among the patients ($b = 7.633$, $t = 6.762$, $p < .001$) and a higher level of doctor–patient relationship was associated with increased overall quality of life among the patients ($b = 0.614$, $t = 2.021$, $p < .05$). A bias-corrected bootstrap CI for the indirect effect ($b = 4.688$) based on 10,000 bootstrap samples was entirely above zero [0.006, 9.555]. However, there was no evidence of a direct effect of shared decision making on overall quality of life among the patients ($b = 2.720$, $t = 0.510$, $p = .611$).

Table 9

Direct and indirect effects and 95% confidence intervals for the models

Model pathways	*b*-values	*t*-values	*p*-values	95% CI	
				LL	UL
Direct effects (Total Quality of life)					
SDM————▶DPR	7.633	6.762	<.001	5.4067	9.859
SDM————▶Quality of life	2.720	.510	.611	-7.797	13.238
DPR————▶Quality of life	.614	2.021	.045	.015	1.213
Indirect effects (Total quality of life)					
SDM——▶DPR——▶Quality of life	4.688*	-	-	.006	9.555

*= significant as the confidence interval did not include zero. Controlled variables: *Education, Duration and Treatment.* LL = Lower limit, UL = Upper limit.

Since there was a statistically significant indirect effect of shared decision making on overall quality of life among the patients, the indirect effects of shared decision making on the various dimensions of quality of life were also tested. As can be seen in Figure 8, shared decision making had a significant indirect effect on emotional well-being through the doctor–patient relationship ($b = 1.198$) and the 10,000 biased-bootstrap CI was entirely above zero (0.185, 2.315). However, there was no evidence of a direct effect of shared decision making on emotional well-being among the patients (Figure 8). Shared decision making had a significant indirect effect on the breast cancer additional concerns dimension, through the doctor–patient relationship ($b = 1.456$) and the 10,000 biased-bootstrap CI was entirely above zero (0.151, 2.808). However, there was no evidence of a direct effect of shared decision making on the breast cancer additional concerns dimension among the patients (Figure 1). Details of the direct and indirect effects of shared decision making on the various dimensions of quality of life through doctor–patient relationship are depicted in Figure 8.

6.3 DISCUSSION

Quality of life among women living with breast cancer has attracted research interest with evidence suggesting that the women experience decreased quality of life due to the challenges associated with the illness. However, some factors have also been identified to have led to improved quality of life among breast cancer patients. This study examined whether shared decision making and doctor–patient relationship have any significant influence on quality of life among women living with breast cancer in Ghana. The study also examined whether the effect of shared decision making on quality of life among the women is mediated by doctor–patient

relationship. Findings showed that shared decision making and doctor–patient relationships have positive impacts on the quality of life among women living with breast cancer.
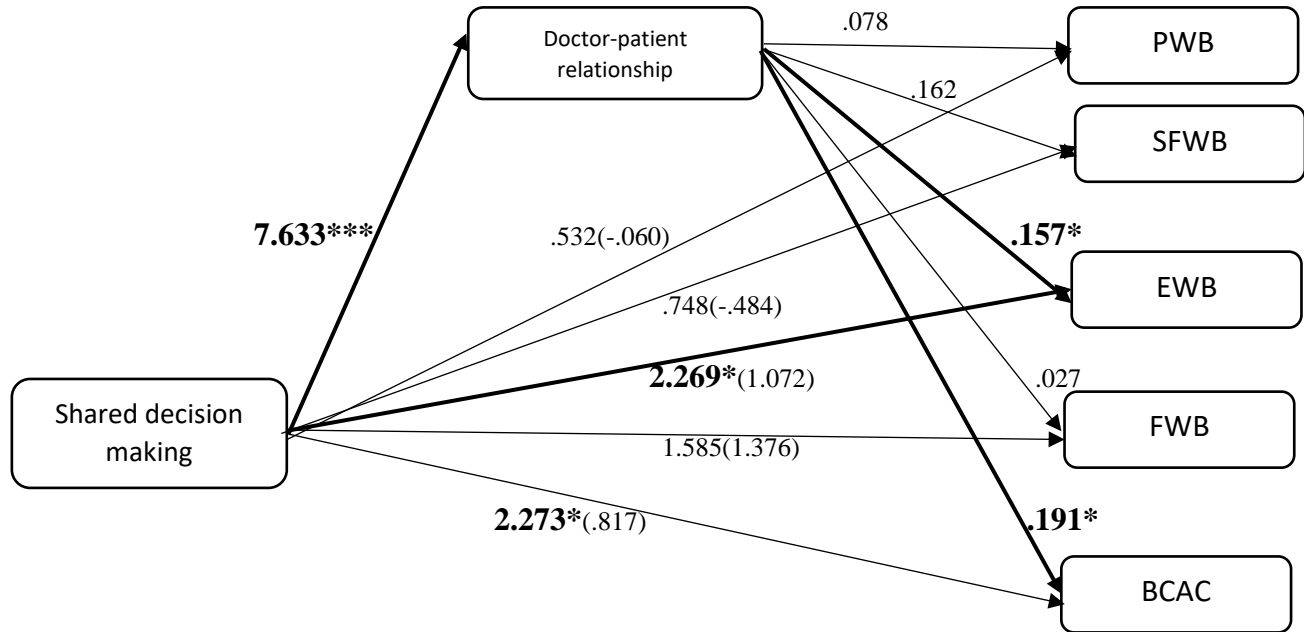
Figure 8: Observed Model showing the indirect effects of shared decision making on the domains of quality of life through doctor-patient-relationship

6.3.1 Shared decision making and quality of life

The findings of the study showed that shared decision making was associated with higher overall quality of life and all the dimensions of quality of life, except social/family well-being. These findings suggest that women living with breast cancer who reported being involved in their treatment decision making were more likely to report an improved quality of life. The findings are consistent with previous studies which showed that shared decision making has significant positive impacts on the health outcomes of women living with breast cancer (Davies et al., 2008; Griggs et al., 2007; Vogel et al., 2009). This significant relationship between shared decision making and quality of life suggests that involvement of patients in the breast cancer decision making process

107

may empower the women to take charge of their lives, clear doubts, and uncertainties that surround breast cancer. This may lessen their fears and negative emotional reactions to the illness as some evidence suggests that patients' involvement in decision making results in decreased depression and anxiety levels as well as greater satisfaction with healthcare (Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007; Vogel et al., 2009).

6.3.2 Doctor-patient relationship and quality of life

Doctor–patient relationship was found to be significantly correlated with overall quality of life such that a better relationship was associated in improved overall quality of life and all the dimensions of quality of life. This result is consistent with previous literature which established the positive impact of doctor–patient relationship on several health outcomes including quality of life (Farin & Meder, 2010; Zhang et al., 2012). This result was confirmed with the path analysis which showed that doctor–patient relationship significantly influence overall quality of life as well as emotional well-being and breast cancer concerns. An interesting finding is that doctor– patient relationship was only significant in predicting the emotional aspects of quality of life among women living with breast cancer after controlling for demographic characteristics. This finding suggests that the interaction with the physicians and nurses could help the patients in dealing with their negative emotions as copious evidence have suggested that breast cancer diagnosis is associated with negative emotional experiences such as sadness, shock, and anxiety (Bonsu, Aziato, & Clegg-Lamptey, 2014).

6.3.3 Doctor-patient relationship as a mediator between shared decision making and quality of life

The mediation analysis showed that shared decision making was significantly and positively associated with better doctor–patient relationships. That is, participants who reported to have been involved in the treatment decisions by their doctors/nurses reported better relationships with their doctors/nurses. This is consistent with other previous findings (Hamann, Leucht, & Kissling, 2003; Vogel et al., 2009). The doctor–patient relationship was found to fully mediate the link between shared decision making and overall quality of life among women living with breast cancer. That is, women with breast cancer who reported being involved by doctors/nurses in their treatment decision making experience good relationships with their doctors which result in improved overall quality of life. No evidence was found for the direct effect of shared decision making on overall quality of life when doctor–patient relationship was controlled for, and this suggests that improved doctor–patient relationship may explain the influence of shared decision making on quality of life. Similarly, shared decision making had indirect effects on only the emotional well-being and breast cancer additional concerns domain of quality of life through doctor–patient relationship which suggests that the impact of shared decision making is most probably important in emotional concerns among women living with breast cancer (Gattellari, Butow, & Tattersall, 2001).

These findings are in line with previous systematic reviews which found weak direct association between shared decision making and health outcomes (Arora, 2003; Joosten et al., 2008). Therefore, this study provides some evidence for the lack of a significant association between shared decision making and health outcomes possibly due to its influence on other

variables which lead to improved health outcomes in the long term. The extant literature on shared decision making and quality of life did not provide any information on the possible mediators of this link. It is possible that in our African context, the involvement of patients in decision making may foster better quality interpersonal relationships with health workers despite the commonly accepted high power differentials between patients and their healthcare providers. As such, this study provides the basis for further research to augment the health communication and patient education literature in Africa.

There are some limitations in this study that need to be considered in the interpretation of the results. First, causality cannot be assumed with regard to the significant effects found among the study variables. Second, shared decision making was measured with a single item and conceptualized to mean 'patients' perceived involvement by doctors/nurses in their treatment decision'. This single-item measure may not capture all the various facets of the concept of shared decision making, thus limiting the interpretation of the results. However, as the literature suggests that the use of single items to measure constructs is permitted provided they capture that essence of the variable of interest (Bergkvist & Rossiter, 2007). Despite these shortfalls, this study is the first to have examined both the direct and indirect influences of shared decision making on quality of life through the doctor–patient relationship among women living with breast cancer in Ghana. Studies conducted across the different phases of illness are recommended to provide a more holistic overview of the influence of shared decision making and quality of doctor–patient relationships on patients' health outcomes.

6.3.4 Clinical implications

The findings from this study that shared decision making results in better quality of life especially the emotional dimensions suggest that there is a need for a shift in perspective and orientation with regard to how physicians deal with their patients. That is, there is a need for greater involvement of patients in the decision-making process and that they are given adequate information to make informed decisions in collaboration with their healthcare providers and thus be more empowered in the management of their illness. This would reduce the patriarchal nature of healthcare delivery which characterizes the African context and especially the Ghanaian healthcare delivery system (Haskins, Phakathi, Grant, & Horwood, 2014). This implies that shared decision making is the very foundation of patient-centred care. The study also emphasizes the importance of the doctor–patient relationship in the health outcomes of women living with breast cancer in Ghana as this therapeutic relationship may serve to protect patients against negative emotional experiences and thus ultimately their health. Evidence suggests that accurate diagnosis, effective treatment, and health outcomes are inextricably dependent on the quality of the doctor–patient relationship (Kaba & Sooriakumaran, 2007; Zhou et al., 2014). Thus, doctors' communication, attitudes, and interactions with their patients should be guided by mutual respect and good clinical practices. In addition, the findings suggest that research on shared decision making would immensely benefit from studying other possible mechanisms that link shared decision making to health outcomes such as quality of life. For instance, studies should examine whether shared decision making influence the coping strategies that are employed by patients in dealing with their illness. It is also important that studies be conducted among physicians to explore their views and attitudes towards shared decision making.

6.3.5 Conclusion

In conclusion, this study found shared decision making and doctor–patient relationship to be significant protective factors of overall quality of life and domain-specific quality of life among women living with breast cancer. This study contributes to the health literature with regard to the need to involve patients in their treatment decision process to lessen their emotional burdens and uncertainties associated with diagnosis of breast cancer. The findings will serve to generate more interest in this area of patients' involvement and its impact on the health outcomes such as mental and social health issues.

CHAPTER SEVEN

LIVED EXPERIENCES OF WOMEN RECEIVING TREATMENT FOR BREAST CANCER IN GHANA: A QUALITATIVE STUDY

7.1 INTRODUCTION

Living with breast cancer presents women with significant challenges that they must deal with as the illness interferes with their physical, social, psychological, economic and spiritual lives (Aziato & Clegg-Lamptey 2015; Bringmann et al., 2008; Kagee, Roomaney, & Knoll, 2018; Zelle et al., 2012). These challenges have been found to be the major contributing factors to decreased health-related quality of life among women living with breast cancer (Almutairi, Mansour & Vinluan 2016; Gold et al, 2016; Montazeri et al, 2008). Evidence suggests that women diagnosed with breast cancer differ in their reaction to the illness and that these reactions in turn influence their coping strategies and disease management (Kaptein et al., 2015).

However, the specific socio-cultural and economic contexts may influence patients' perception and understanding of their illness which are inextricably linked with their lived experiences. The interrelationships among the entire experiences of the women suggest that the socio-economic and cultural factors may impact on how patients make meaning of their illness and these illness representations may influence the lived experiences of the patients. Thus, the relationships among these factors are multidimensional and may sometimes revolves in a cycle as the lived experiences may also influence the socio-economic status and illness perception of the patients. These interrelationships are illustrated in the Fig. 9 below.
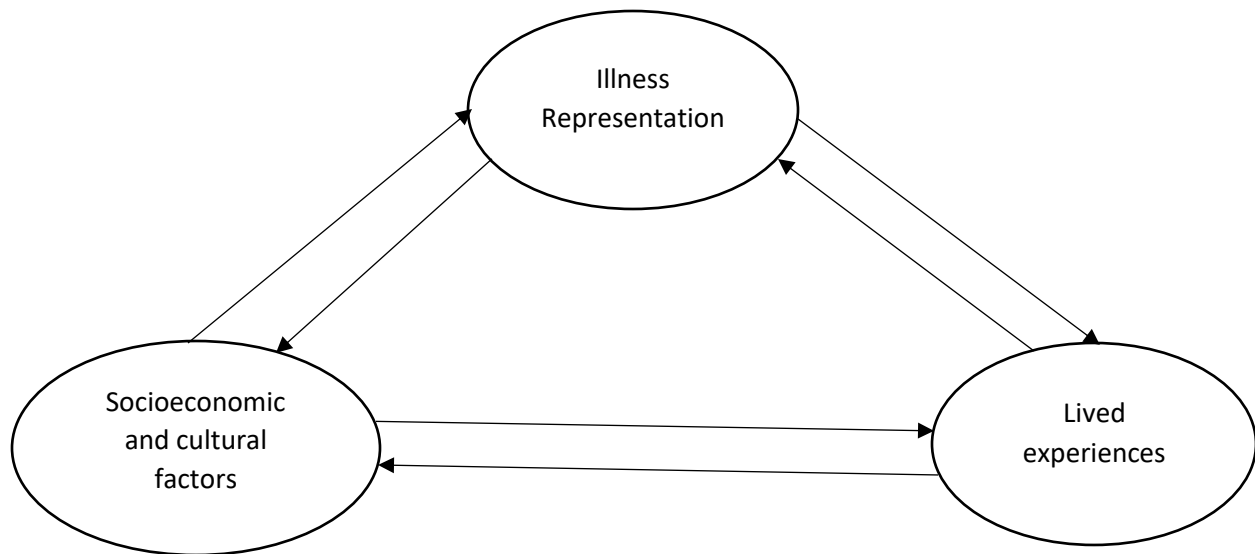
Fig. 9: The interrelationships among socioeconomic/cultural factors, illness representation and lived experiences

Breast cancer patients' cognitive and emotional representations of their illness becomes a critical aspect of the healthcare delivery process which cannot be overlooked. This is because patient-centred care requires health professionals to take the needs and views of patients into consideration to ensure satisfaction and thus improved health outcomes (Shay & Lafata, 2015). Illness perceptions among breast cancer patients have been linked to several health outcomes including depression, anxiety, physical and mental quality of life (Fanakidou et al., 2018; Hopman & Rijken, 2015; Tang et al., 2017). However, there are no documented empirical studies in Ghana which explored illness representation among women with breast cancer per se despite a few studies among persons living with diabetes which found varied illness representations and their subsequent impact on health outcomes such as self-care practices and mental health of persons living with diabetes (de-Graft Aikins, 2003; Kugbey, Oppong Asante, & Adulai, 2017; Nyarko, Kugbey, & Atindanbila, 2014). There is thus a need to explore the illness perceptions among women living with breast cancer as their perceptions are likely to influence the overall lived

experiences of women living with breast cancer as well as their involvement in and adherence to the required medical treatments.

Some empirical evidence of women living with breast cancer within the Ghanaian setting reported on their emotional and psychosocial challenges for instance, sadness, fear, guilt and anxiety, severe pain and suicidal ideation (Bonsu, Aziato & Clegg-Lamptey, 2014; Clegg-Lamptey, Dakubo, & Attobra, 2009; Opoku, Benwell, & Yarney, 2012). Stigma, an important psychosocial challenge has been reported among breast cancer patients in some countries (Maree & Mulonda, 2015; Wong-Kim, Sun, Merighi & Chow, 2005) while research findings from other contexts revealed little or no stigma attached to breast cancer (Lebel & Devins, 2008). Since the socio-cultural contexts of patients may influence peoples' attitudes and beliefs about breast cancer, there is the need for studies to explore stigma among women living with breast cancer in Ghana particularly in the absence of any published literature in this regard.

Another important challenge faced by women living with breast cancer is the economic burden of the illness. Poverty among Ghanaian women living with breast cancer has been found to be a major concern to their treatment adherence as well as healthcare utilization (Clegg-Lamptey et al., 2009; Opoku et al., 2012). This is because within the Ghanaian healthcare system, the national health insurance does not cover all the treatments for breast cancer patients and such patients are expected to bear the remaining cost which is relatively expensive (Opoku et al., 2012). The enormous economic and financial burdens of breast cancer treatment and care in the face of poverty among the populace could compound the challenges women face and impact their health seeking behaviour patterns which may affect their overall health and wellbeing.

In dealing with the multitude of challenges various coping strategies are employed. It has been argued that coping plays a major role in the lives of persons diagnosed with chronic medical conditions including breast cancer (Kugbey, Meyer-Weitz, & Oppong Asante, 2018). As noted earlier, the illness representations of the women are likely to influence the type of coping strategies they adopt in trying to adjust with the burden of the medical treatment and living with the disease. Evidence suggests that spirituality, social support, acceptance, cognitive restricting and avoidance are common coping strategies among women living with breast cancer (Anagnostopoulos, Vaslamatzis, & Markidis, 2004; Hajian, Mehrabi, Simbar, & Houshyari, 2017; Mehrabi, Hajian, Simbar, Hoshyari, & Zayeri, 2015). These coping strategies among breast cancer patients significantly influence their health outcomes (Kvillemo & Bränström, 2014).

However, contextual and cultural differences may influence the illness representation and coping strategies that are employed by women living with breast cancer in a low-resourced healthcare setting like Ghana. Studies among Ghanaian women diagnosed with various cancer types have showed that surrendering to God, illness acceptance, the will to live and self-care practices are key coping strategies (Binka, Nyarko, Awusabo-Asare, & Doku, 2018; Bonsu, Aziato, & Clegg-Lamptey, 2014). These studies were conducted outside the capital of Ghana and may not reveal the entire picture of the coping strategies used as the economic and psychosocial pressures of living in the capital city could impact on the choice of coping strategies employed.

Since breast cancer treatment involves several complex decisions and interactions with healthcare professionals which may have an impact on the overall health satisfactions. These interactions relate to how the health workers relate and communicate with the patients in their healthcare delivery. Evidence in the western literature suggests that effective communication and

117

good interpersonal relationship between health professionals and their patients result in several positive health outcomes such as improved adherence to medical treatment, life satisfaction, improved quality of life, and decreased negative emotional states such as depression and anxiety (Epstein et al., 2017; Janz et al., 2017; Street Jr, Makoul, Arora, & Epstein, 2009). Patients' interactions with their health providers become an important issue as there is copious evidence of unmet information needs among breast cancer patients (Halbach et al., 2016; Kowalski, Lee, Ansmann, Wesselmann, & Pfaff, 2014; Miyashita et al., 2015) which can be lessened by good interaction with the health professionals. However, a thorough literature search did not reveal any empirical studies within the Ghanaian context which explored the perspectives of women living with breast cancer on their satisfaction with healthcare in terms of their communication and interactions with health professionals.

Despite complexities of living with breast cancer and its treatment, there is a lack of substantial evidence in the Ghanaian setting on the lived experiences of breast cancer with regard to the socio-economic, psychological, spiritual and healthcare burdens of women diagnosed with breast cancer to inform large scale research, psychosocial and policy interventions. For instance, the lived experiences of women with regards to the healthcare delivery system and communication with their healthcare providers have not been explored even though studies have found doctor-patient communication and relationship as well as access to healthcare information to be important in oncology care (Blödt et al., 2018; Faller et al., 2016; Husson et al., 2013). This study seeks to explore the lived experiences of women living with breast cancer by taking into consideration the important domains that have received little psychological research attention within the Ghanaian setting.

7.2 RESULTS

7.2.1 Demographic profile of the participants

The demographic characteristics of the participants are summarized in Table 10. As can be seen from Table 10, most of the participants were younger than 60years and all of the participants except one reported to be a Christian. The details of the distribution in terms of marital status, years of marriage, number of children, employment status, educational level, duration of illness and the types of treatment received are presented in Table 10.

Table 10

Demographic profiles of the respondents in the qualitative study

Participants	Age	Marital status	Years of marriage	Number of Children	Employment	Education	Religion	Duration of illness	Treatment
Participant 1	63	Married	30years	3	Retired	A-Level	Christianity	2.5years	More than one
Participant 2	50	Married	35years	5	Self-employed	MSLC	Islam	2.5years	More than one
Participant 3	46	Unmarried	-	1	Self-employed	Vocational	Christianity	2years	More than one
Participant 4	57	Married	28years	1	Unemployed*	Secondary	Christianity	2.5years	More than one
Participant 5	55	Widowed	15years	4	Unemployed	MSLC	Christianity	1.5years	More than one
Participant 6	67	Married	40years	4	Retired	Technical	Christianity	12years	More than one
Participant 7	57	Married	30years	6	Unemployed	Primary	Christianity	4years	More than one
Participant 8	71	Widowed	-	4	Retired	MSLC	Christianity	< 1year	More than one
Participant 9	57	Married	29years	-	Employed	Tertiary	Christianity	1year	More than one
Participant 10	48	Unmarried	-	0	Self-employed	MSLC	Christianity	7years	More than one
Participant 11	50	Remarried	18years	3	Employed	Tertiary	Christianity	1year	More than one

Findings from the study showed that living with breast cancer is associated with several interrelated challenges. One of the key issues that was prominent among women living with breast cancer was the burden of medical treatments. These include physical changes, economic and social challenges which have negative consequences on the emotional wellbeing of the women living with breast cancer. In terms of the physical challenges, women have reported changes in their appearance, loss of breast and weakness which prevent them from engaging in their normal day-to-day activities. For the economic challenges, the cost of breast cancer treatment which is not covered by the national health insurance scheme placed enormous financial burden on the patients and relatives. Socially, breast cancer has placed role limitations on the women as most of them could not engaged in their usual work and social activities. These challenges have significant negative emotional impacts on the lives of women living with breast cancer.

7.2.2 Illness representation

Participants' cognitive and emotional representations of their illness were explored. This was important because women's understanding and meanings of breast cancer are likely to influence their lived experiences. Three main themes were derived from the interviews and these are breast cancer knowledge, perceived causes of breast and duration/curability of breast cancer. Results from these transcribed data are presented in details under the three major overarching themes.

7.2.2.1 Knowledge of breast cancer

Factual and accurate knowledge about breast cancer is likely to help patients in their adjustment to their illness as it may minimize the uncertainties surrounding breast cancer. Two key sub-themes emerged from participants' view on what they think breast cancer is. That is, those who have no factual knowledge and those who have some factual knowledge about breast cancer. Most of the participants do not have any factual knowledge about breast cancer as illustrated by the following quotes from the interviews:

> *"as a matter of fact, if you ask me, I wouldn't know even before the thing (breast cancer) happened, I had not heard of the name before and in my family, I had not heard that anyone has had that disease before" (P6).*

> *"Breast cancer is a disease that kills hahahaa (laughs)… yeah and claims life. That is what I think about breast cancer" (P2).*

> *"...breast cancer... I don't know what breast cancer is ooo…" (P5)*

> *"Hmmm...they say it is a sickness. All that I know is that it is a sickness. Some also say it is a demonic sickness (P7).*

On the other hand, some of the participants had some factual knowledge about what breast cancer is as their knowledge about the disease included the mention of abnormal cell growth in the breast.

> *"Cancer is an abnormal growth which can cause death and that if it is in the breast, they call it breast cancer. If it's somewhere else they add the place to it" (P1)*

"Hmmmm...Breast cancer, I understand is a growth of cells in the breast....abnormal cells... so to say...it shouldn't be there and if it keeps on spreading, you are at a risk of losing your life" (P9).

"It starts with the lump. I think when you go earlier, they can just take the lump out for you. When you don't see it and it spreads, that's when it becomes cancerous…Like I told you, at the initial stages, I thought it was meant for old ladies who'd given birth already, sixty years upwards. That was what was in my mind. That was how I knew breast cancer to be. Nowadays in your thirties and forties, if you're not careful, you'll get it" (P4).

7.2.2.2 Perceived causes of breast cancer

Participants in the study had varied views about their perceived causes of breast cancer. Whereas a substantial number of the women stated that they did not know how their breast cancer came about or they have no ideas as to what might have caused their disease, others mentioned supernatural forces, physiological and stress as the possible causes of their illness.

"I don't know what caused my breast cancer" (P5)

"I don't not know the cause (of my breast cancer) because I do not drink, I do not smoke. What I will say I like is that, I like is fried plantain and pastries because I am a caterer myself so those times when prepare them, I used to consume a lot. They said when you drink, you will get the disease but I do not drink. So as for the cause, I do not know" (P6).

"I do not know my Child. As for me...hmmm...I do not know. Sometimes, they say it is a family sickness or runs through the family but my mother did not experience this, neither

did any member from my father's family experience this.....hmmm...so my child (interviewer)....I don't know ooo" (P8).

Some of the participants perceived their illness to have some underlying supernatural causes and these perceived causes were influenced by what they have heard from people and their own beliefs.

"Ah....as for me...I cannot tell. I do not know if I was shot spiritually or the sickness came on its own. As for me, in all things, I just give it to God. I also told you earlier that I had a dream that I was being shot. Where I had the gunshot in the dream is the same place that I experienced the cancer in the breast" (P7).

"... well my sister was saying as for breast cancer, it is an evil spirit people give it to people and so on. And you see this superstition me I told her that me I don't know o… so she was preventing me not to go for the surgery because she thought if I go for the surgery, I will die so I told her that, sister let me go if I die praise God, I will die with my fine body unlike sitting down this thing (breast cancer) will get worst, spread over my body, I don't know how I will look like when I will die… (P4)".

Another participant emphatically stated that she is convinced that extreme stress from her work might have caused her breast cancer.

"...as for mine (breast cancer), I suspect stress...high level of stress… I am not someone who lives a careless life. By nature, I am the prudent type in all aspects of life...eating...whatever. I have never even taken alcohol before in my whole life. I do not even know how it tastes...and I am not someone who leads reckless life. You see...they said this disease is a lifestyle related problem. My psychologist sat with me trying to find out

my family life and I realized that the only thing that I did that my body kept signalling me that I didn't head to was stress. High levels of stress. Otherwise, my eating level is not bad, my marriage is not bad, my children are grown and it is not like I had little children giving me pressure at home. In fact I realized that it was more work-based. Because at a point in time, I was always having breakdowns. For about 3 years, my white blood cells were not functioning properly so I was on immune boosters and all manner of supplements" (P11).

Another participant also reported physiological basis as the perceived cause of her breast cancer she indicated that her inability to breastfeed her child after delivery might have led to her breast cancer.

"....my belief is that because I did not give my girl (her daughter) the breast milk and I was forcing it to come... They have an extractor that you put at your nipple and it would extract the milk. I used it but it did not work for me. This right breast of mine, I really worked on it. I really forced it. I feel it is caused by the milk that was supposed to come out but did not come. If I had gotten any old lady to tell me. They have a way of doing it, if you don't breastfeed your child, they'll give you some medicine, you'll rub it on your breast and by the time you realise, it will come out by itself. As at that time, I didn't know anything like that and by the time I realised, the thing was hardened" (P3).

7.2.2.3 Duration/Curability of breast cancer

From the analysis, it was not possible to separate illness duration from curability as most of the participants linked duration to curability. A substantial number of the participants were of the view that their breast cancer can be completely cured with the medical treatments and help of God.

However some of the participants were not sure of the curability of the disease. The participants went further to provide reasons for their perceived duration/curability of their breast cancer as illustrated below.

"Yes, I have the full assurance. I have psyched myself up. I have not finished what I came to do on this earth...laughs....I have not finished at all. I have to enjoy the fruits of my labour. My children have now gotten jobs so I have to take care of my grandchildren and all that so I cannot go now. I will not go now" (P11).

"Nothing is too hard for the Lord. God can do a lot of miracles. God also uses doctors to perform his miracles. That is why I always run to doctors when I am sick...as for me...with the treatment I am currently going through....I know of someone who started with it since the year 2000 and the person is still alive and kicking. Nothing has happened to her....So I know that God will also have favour on me so that I can be healed completely" (P10).

"Aww....according to people....For instance, my siblings showed me one woman who has been treated of breast cancer for about 18 years now. A lot of people...even in my church....there are people I know have been cured of the disease....almost about 4 people. They all confessed to have gotten some but now, they have been cured. What I have realized to be the most difficult aspect is the chemotherapy...if i am try my best and go through the process, I know I will be fine. There was one woman who also testified that she had this disease when she was 71 just like me and now she is 82...she is very strong. She told me that if I am able to go through all the processes, I will become stronger than how I am now. However, I don't really know how long my sickness will last" (P8).

However, a participant was of the opinion that she is uncertain about the duration/curability of her sickness since the causes are not even known in the first place.

> *"I don't really know because like we are saying...I don't know the root cause. Sometimes, they say it is from your diet...sometimes but I don't really know. I can't tell because we haven't found the real cause of the disease...so to say it can be done away completely....I am not sure...I believe with the mastectomy and radiation, it will go away very soon...because of the treatment and my faith in God" (P9).*

Another participant had mixed perceptions about the duration/curability of her breast cancer and stated that it all depends on the stage of the disease.

> *"...yes, I think at times. I may say yes or no. And seeing that the thing is now common, I think when you report early, it can help. And I may say that, even the doctors...I mean...those medicines, some are very strong so they have to add some local herbs. I think some herbs can help a lot...than even these orthodox medicine" (P6).*

The results above showed that the participants in the study differ in their perceptions with regards to what breast cancer is all about, their perceived causes and duration/curability of the disease. These differences in their illness representation could influence their lived experiences.

7.2.3 Bio-psychosocial and economic challenges of living with breast cancer

The analysis of the interview data from the participants revealed three major themes along which participants' lived experiences with breast cancer can be understood. These are the burden of medical treatment, alternative medicine and breast cancer stigma. Each of these three major themes have their respective sub-themes which represent the details of the narratives as expressed by the participants.

7.2.3.1 Burdens of medical treatment

Medical treatments seem to have a major impact on the participants' lived experiences. Medical treatments constitute the largest component of breast cancer treatment aimed at dealing with disease progression as well as complete cure. However, patients have expressed concerns with regards to their experiences with the medical treatment regimen. Here three key sub-themes emerged namely physical, economic and social burdens. Each of the three burdens identified from the analysis have emotional impacts on the lives of women living with breast cancer. It is important to note these three sub-themes are not mutually exclusive as the concerns expressed by the patients are inter-related. The three sub-themes are presented with their illustrations.

Physical burden

Most of the participants reported that the medical treatment has significant negative effects on their physical health due to the unpleasant side effects associated with the treatments especially chemotherapy and radiotherapy. The following narratives from the participants illustrate the physical burdens of the medical treatment.

"....it is not easy. Especially with the chemotherapy, when they started with the treatment, the body is not used to that kind of harsh medication and it really breaks you down. The first time I was given, I was down for three weeks. I was in bed for three weeks. I was very weak...vomiting, diarrhoea and all manner of things will happen to you. In fact, it is only the grace of God which will take you through. It is not easy. It is not easy but it is like you see death facing you so you have to go through" (P11).

"You will feel you have neuropathy in your fingers and in your toes… You feel like pins and needles in your fingers. When I started the radiation too, I do not know if it is from the radiation or from the tablets ...but it is becoming worse" (P9).

These narratives from the women suggest that the medical treatments resulted in disruptions in their physical abilities and the treatment tend to present several unpleasant physical side effects. However, the effects transcend only the biological disruption to include loss of energy to carryout daily routine activities and changes in physical appearance. For instance, one participant stated that the treatments have made her slow.

"...my problem is that the strength is not like before, before I used to go round for my daily activities, but our daily bread, you know this education of today… But for now if I go out and once I come back I can't go out again, so everything just became slow" (P2).

Another participant indicated that the treatments resulted in changes in her physical appearance which was very difficult for her;

"The first 'chemo' (chemotherapy) when you see me, you couldn't recognize me. I lost my hair, everything. It was very terrible, vomiting as if I was pregnant but all the same, I went through" (P6).

The above severe physical discomforts and negative experiences with the medical treatments have negative emotional impact on the lives of the participants. These emotional experiences range from worry about the curability of the disease, sadness due to the loss of a breast through a mastectomy and the negative side effects of the medical treatments. Some of these negative emotional experiences reported by the women are presented below;

"Emotionally...obviously ...I mean to be living with such a disease...you will think about it...you know, from time to time, you will be living with one breast for the rest of your life and this affects you emotionally. It does not make you feel less of a woman but you see...you started life with two breasts and now one is no more...so psychologically...it does have an effect on you" (P9).

From this narrative, it was clear that living with the illness itself, has negative emotional consequences for the patients and the fact that one has to live with "*one breast*" also presents another challenge to the psychological wellbeing of the women. Thus, dealing with loss presents a significant negative emotional burden to the participant.

Another participant stated that breast cancer and its treatment regimen are "*very scary*". This participant was focused on short term impact of the treatment especially the negative side effects while not paying attention to the long term benefits of the treat. She perceived her life to be in a circle as she keeps going back and forth in terms of her health. She stated that:

"...it is not easy. It is very scary, very...very scary, honestly because one doesn't know whether you are going forward or backwards. I'm going in circle, I just don't know where I am now" (P2).

It can be seen from the quote above that the participant's anxiety and fear stemmed from the uncertainties surrounding the prognosis of her breast cancer which keeps her in constant fear.

Another participant presented an instance of worry about the negative side effects of the treatment procedure especially chemotherapy, with little attention to the ultimate outcome of the medical treatment. She stated that:

"My worry is about the 'chemo' (chemotherapy). For now, I am only praying about the chemotherapy because I was told when you are doing that therapy, you will lose your hair...feel sick and a whole lot...and that is what I am praying against" (P8).

Economic burden

Almost all the participants interviewed raised concerns about the cost of medical treatment which they see as a major hindrance to their effective participation and adherence to the required medical treatments. These economic burdens have resulted in negative emotional experiences among women living with breast cancer. Examples of quotes from the participants to illustrate the economic burden of breast cancer are as follow:

"... it is a lot of money...hmmm....things are really difficult...it is just like this injection that I am coming to do this morning at the hospital but my problem is with money. For instance the cost of today's injection is GHC1400 ($305). After the injection, I will pay GHC300

($65) for other things. Hmmm...when it happens like that...it is very difficult. If you do not

really spend, you will not live long...Money becomes the major issue.

"....because I even understand that, after this radiation, I have to go through another

infusion and they are saying that for one year, it is going to cost me GHC100, 000

($21,750)" (P9).

These quotes illustrate the significant financial but also emotional costs involved in the medical treatment of breast cancer.

The high cost of the medical treatment has led to non-adherence to the treatment regimen as one participant reported that she had to abandon treatment due to a lack of money. She said:

"I did not go for the remaining treatments because I have not gotten the money, that's one.

Because it's a money intensive thing. And the doctor told me that after this one, there's

another one that costs ten thousand cedis ($2,175) that I have to do. I asked myself...what

is this? So I decided to hold on and see what the Lord will do" (P3).

This clearly showed that some patients may stop treatment not because they do not want to follow the medical treatment regimen but financial constraints could push people to abandon their treatments.

The unaffordable treatment regime of breast cancer treatment were reported to have resulted in an exhaustion of savings. The economic burden of the breast cancer treatment resulted in the collapse of her business as the savings for the business were pumped into the treatment. This participant stated that:

"I had my own money. The money that I was using to trade was the one which I used to take care of myself and foot the other bills. It is now that I know that my financial strength is very low and business has gone down. Due to this, I have sent a letter to my church for financial support" (P10).

This woman's experience shed light on the financial burden posed by breast cancer treatment as she has exhausted her business savings and would now resort to begging for alms from her church and other sources. The challenge here is that, there is no guarantee that she would get the needed support and even if she gets the support, would it suffice for the entire treatment period?

Women's dependence on financial support from others to continue with the medical treatment have led to donor-fatigue and thus social isolation.

When your siblings even see your face, they start to run away because they know that, when they see you, you will bother them with money. Money makes everyone run away from you. Had it not been for the support of my children when it happened that I had to go and do another surgery, I would have died" (P7).

One participant reported that her support usually comes from her friends but due to the huge financial burden of the medical treatment and her previous reliance on the help of her friends, they have started avoiding her. She stated that:

"My friends helped me when the disease started but they are all tired now. If someone helps you today, tomorrow and you come for help the next day too...the person will definitely run away upon seeing you" (P7).

One significant domain of the economic burden of living with breast cancer and its treatment is loss of work due to the illness. One participant recounted that she was relieved of her duties at the workplace when her boss got to know that she had breast cancer and was undergoing treatment. Although she indicated her fitness and readiness to continue working, they managed to get her to leave her job and became unemployed. She narrated how her boss got her to leave her job as follow:

> *"…before then I was working, I was working at a printing press… so after my treatment it's like the boss couldn't put the thing straight but if you are a matured person and someone is talking to you, you know where he is driving towards… so in a nut shell, I opted out voluntarily… he said that this kind of sickness (breast cancer) you need rest, you do not have to exhaust yourself, you do not have to frustrate yourself, a lot of, to the extent that I should even go to SSNIT (Social Security and National Insurance Trust) to tell them am retiring. So I told them that in fact the SSNIT age is 60years or voluntary will be 55years and am not at that age. I'm not invalid so why should you ask me to go to SSNIT? So I opted out voluntarily because if I force my way there he will find ways and means to frustrate me (P4).*

The narrative above showed that breast cancer and its treatment pose a significant threat to the economic survival of patients as poor knowledge among the Ghanaian populace could lead to discriminatory actions as reported by this participant.This raises issues about social protection and labour legislation regarding ill health.

Social burden

One of the participants highlighted the social burden placed on her by the breast cancer treatment. This burden is in the form of role limitation both at church and at home. That is, due to her condition, she could not do a lot of things she used to do including leadership positions in her church and domestic chores. The quote from the participants in presented below;

> *"...I was a leader in church and I have told them to even replace me but they are refusing to do so because they are expecting that I will get well and come and join them but I don't have the strength and I don't want to put so much pressure on myself. So someone is handling the position until I get well" (P11)*

This clearly showed role limitation in her church due to the side effects of her medical treatment. She further continued that:

> *"...and at home, a lot of things that you used to do as a woman and a mother, you realize you do not have much strength to do so ...so you need to cut down on the work that you are doing so that it doesn't affect you too much. Sometimes, you even desire to do it but the strength is not there. Because of the surgery, I am not supposed to use the left hand to lift heavy things so even when you are in the room and wants to bring something down, you have to call someone. It limits you in your duties in the home" (P11).*

The quotes and discussion presented above provide evidence for the burden of medical treatment on the women living with breast cancer which are likely to affect their overall health and wellbeing.

7.2.3.2 Alternative Medicine

Alternative medicine including herbal preparations are very common in the Ghanaian society and persons living with chronic illnesses such as breast cancer are not left out. This emphasises the complexities in the health-seeking patterns of persons living with chronic conditions in Ghana. Under the broad theme of alternative medicine, four sub-themes were identified from the participants' narratives and these include; sources of alternative/herbal medicine, use of alternative/herbal medicine, previous use of alternative/herbal medicine and non-usage of alternative/herbal medicine. It is important to note that the economic burdens associated with the medical treatment seemed to have created a greater necessity to resort to alternative medicines including herbal preparations which may interfere with treatment received or even endanger their lives.

> *"I mean….errrmmm….it is not always that I get the money to buy the hospital drugs so I have to get a solution that will help me" (P6).*

Sources of alternative/herbal medicine

The sources of information on alternative/herbal medicine were explored and two key sources were identified by the participants. One of the participants indicated that she was introduced to alternative/herbal medicines by a health worker, specifically a nurse. She stated that:

> *"A nurse who is a ecclesiastical sister from Indonesia told me that Noni is very effective for cancer and she has planted some and because it's not plenty she has not been able to distribute to many patients so when I came back after the surgery you know we have some in the house so I prepared the Noni and I took it, when its ready I took it" (P1).*

Another participant also reported that he got into the use of alternative/herbal medicine through an herbalist who claims to be an expert in curing breast cancer. Her trust in the use of the herbal products was reinforced by many women who were with the herbalist with testimonies of being cured of breast cancer through the use of the herbalist's medications.

> *"One of these herbalists. He said he is into breast cancer and he can help me. And when I went there, there were people who were testifying that it was good" (P3).*

The use of alternative/herbal medicine

Some of the participants indicated that they have resorted to the use of alternative/herbal medicine. This was either due to the high cost of the medical treatment, the desire for complete cure or both. The following are some of the direct quotes from the participants with regards to their use of herbal medicine and reasons for resorting the alternative/herbal treatment.

> *"...all these herbal things, anything they do I just...hahaha (laughs) go for it, rubbing everything and adding everything and did everything they told me" (P2).*

> *"I could see that it was very tough for me to purchase the medicine. The arimedics...it was very expensive so I had to report to the doctor and he said....errrm...I should go back to the first one. As a matter of fact....things were not moving on well so I started using these vegetables and then some Chinese herbs (P6).*

This participant indicated that she uses all kinds of herbal preparations for her treatment so far as she hears about it.

Another participant stated that:

"...I don't have anything to use but there was some known once (herbs) that I take, you all know this cell apple they say that its good and the leaves I use it for tea…….. but they are all geared towards improving your health and that's why I take them" (P1).

Another participant stated that she resorted to these alternative/herbal medicines due to financial difficulties she faced with the medical treatment. Thus, she uses relatively cheap herbal products to treat her conditions.

"I have been taking these Chinese things. I took noni, I used noni, and I take in some things (herbs). I have even forgotten some of them….I have been taking these herbs because they said they can help cure cancer. It is cancer this thing so…errrm…I was taking them. I took noni for some time and this aloe Vera juice….I was buying some and preparing some myself too. I mean….errrmmm….it is not always that I get the money to buy the hospital drugs so I have to get a solution that will help me" (P6).

The quote from this participant suggests that lack of financial resources could push women living with breast cancer to resort to the use of alternative/herbal medicine.

Previous use of alternative/herbal medicine

Some of the participants in the study indicated that they had previously used alternative/herbal medicines but have ceased using them as the study period. The main reason for them stopping the use of alternative/herbal medicine was due to ineffectiveness of the herbal products and sometimes worsening disease outcomes. The following are some of the quotes from previous alternative/herbal medicine users:

"This year September, I tried using herbal medicine but it didn't work. All the drugs were liquid. I was drinking those concoctions but they didn't work. After about a month, I realized it was even worsening my case, I wasn't able to drink water. In a day, all I could drink was the cover of a cup. I couldn't belch and so I was finding it difficult to eat. When you're eating and you can't belch, it's something else. I was coughing. All those things were happening and so I decided to stop" (P3).

Another woman also recounted her experience with the use of alternative/herbal treatments which did not work and she had to go back to continue her medical treatment. She stated that:

"Initially, when it was detected, I also visited some herbal clinics to get some medicines...it was not easy...it was just some immune boosters and those kinds of things but later on I was not seeing any improvement so I took the decision to stick to the hospital...In fact when the thing was diagnosed and the doctor said the only way out was a surgery, I was not too in for that so I went to see if there could be any alternative help traditionally that could help me to avoid the surgery but after I was on that treatment for a while, I was not seeing any improvement because he said the breast was going to shrink but it had gotten so lean, so the Doctor kept warning me not to shift my attention to such things and lose my life. So when I saw it myself that I was not seeing any improvement, I discussed with the herbal doctor...so he told me that, if I am not seeing any improvement, then I should focus on what the hospital is advising...so I stopped going (P11).

These quotes suggest that the ineffectiveness of alternative/herbal medicines and treatments led to participants' withdrawal from the use of alternative/herbal medicines and treatments.

Non-usage of alternative/herbal medicine

However, some of the participants indicated that they have never used any alternative/herbal medicines for various reasons.

> *"I do not use any other treatments because as for me, it will not help me" (P10).*

> *"...you know the time it started and I saw the lump, one of my friends was a nurse so I discussed it with her and I was referred to the hospital. So when I went to the hospital, I didn't discuss with anybody again so I started the treatment. Because of the hospital treatment, I don't want to use any other form of treatment" (P5).*

One participant indicated that she does not use any alternative/herbal treatment at the moment as her focus is on the medical treatment. However, she intends to try some of the "well-known" herbal medicines after she finishes the hospital treatment. She stated that:

> *"I don't use any….As for me, I don't use anything. I don't use any herbal medicine at all but some people say that the leaves of 'aluguitugui' (Annona muricata leaves) when boiled, is a good remedy but I have never tried it before. Because I am taking the injections now, I do not want to add any herbal medication. However, when I finish, I will give it a try if it really works. I will boil some and try if it works" (P7).*

7.2.3.3 Breast cancer stigma

Stigma is one of the key challenges to health and social support seeking behaviours. Under the broad theme of breast cancer stigma, three sub-themes were identified and these include; Experienced and perceived stigma, no stigma and disclosure of disease status.

Experienced and perceived stigma

Some of the participants in the study had reported experiencing or perceiving some form of stigma as a result of their illness and the negative side effects of their medical treatments.

A participant reported that:

> *"One day I was going to Korle-Bu and I was in this caravan… I was sitting beside this young lady, I was even wearing long sleeves so she saw my hands and she didn't want my body to touch her. I noticed it so I pushed to the door a little so that I wouldn't touch her"* *(P1).*

> *"Two women in our church were acting funny, but I was seated there I was just looking at them. But now when they see me it's like they want to hug but because of what they did, they cannot"* *(P4).*

> *"I will say when I got this disease I had a lot of problems, my siblings didn't want to come close to me, even talking to me was a problem…I don't know why, even when people see me they try to avoid me but I will not keep anything to heart, it is God who has brought me to the world so I will take it like that. I was sad due to the fact that my own siblings did not want to come close to me. So I was asking if they could do this what about those who are not my family? For this reason I avoided social gatherings"* *(P5).*

Another woman recounted her experiences with how people treat her due to her sickness which constitute both experienced and perceived stigma. She said:

*"...people have all manner of myths about it (breast cancer). If you are not a strong person, it affects you because your own people reject you. Everywhere you go, you face some sort of rejection. I realized that because, sometimes, people that are very close to you, who you would have done anything for and they too would have done anything for you in the past **if it was malaria or something**....but this time around they have drawn back and they are being careful getting close to you perhaps they do not know whether you have gone to do something evil and this curse has come upon you. So they need to be careful getting closer. For some too, they feel the monetary aspect is so huge and they don't have money so if they come close and they cannot give you money, they will feel embarrassed so they better don't come. So all them have different reasons for staying back and it is like sometimes, you will feel alone...you will feel alone. So we need a lot of education in Ghana because that is the time that you are in trouble and you need people to stand with you and for whatever their reasons are, most of them will not stand with you. It is not easy...it is not easy. I face all manner of problems at the office and all that" (P11).*

The experiences recounted by these participant showed that the stigma attached to breast cancer could result in feeling of loneliness and loss of social support from family and significant others which are likely to negatively impact on the emotional wellbeing and overall health of the women living with breast cancer.

No stigma

However, some of the women did not report any experiences that could be classified as stigmatization. This may suggest that not every woman living with breast cancer experiences

stigmatization and may be due to several reasons. Some direct quotes from participants with regards to their non-experience or perception of stigma are presented below:

> *"...as for me, no one runs away from me. However, it is only due to finances that someone will run away from me. No one runs away from me because of the disease (breast cancer) per se"* (P7).

> *"Noooo...as for that (being treated differently in a negative way)...It has never happened before"* (P10).

These two participants reported no stigma associated with breast cancer and if people run away from them, it may be due to financial pressure and not the stigma associated with living with breast cancer an issue raised earlier as a result of the financial implications of treatment.

Disclosure of disease status.

One of the key issues that emerged was the willingness of the participants to disclose their breast cancer status to others. Analysis of the interview data showed that whereas some participants have disclosed and are comfortable with disclosing their breast cancer status to other people, some of the women have not disclosed their breast cancer status and will not disclose their status to other people for varied reasons.

The women who have disclosed their disease status to others did it to help create awareness of the existence of 'breast cancer' and inform others to be alert for any warning signs and importantly to seek early diagnosis and treatment. Most of them also indicated that they were not 'shy' of their breast cancer and will therefore feel comfortable disclosing their disease status to others. Some

direct quotes from some of the participants who have disclosed and are comfortable with disclosing their breast cancer status to other people are presented below:

"I am not shy okay. I am not bordered at all. It is just a sickness so there is no need to feel shy about it. It can also happen to anyone. If I tell someone, it is just to let the person know that such a disease exists, so that they can seek early treatment when they find themselves in such situations before matters worsen. And I know God will help them if they seek early treatment because I have been in this for 7 years and I am still alive" (P10).

"I like talking about it to people… I don't feel anything because I like others to realize that there is a disease like breast cancer… in my case I think because I spoke to a nurse about it and started the treatment a bit early that is what favoured me" (P2).

"No problem with taking to people about it at all…I just want people to know that this condition (breast cancer), you can find yourself in a condition like this and one should not panic. We shouldn't hide it, if you realize that you have such a thing you shouldn't hide it. People hide it when they see some strangers they hide it and that's what causes the problems, as soon as there is a sore you know that there is a problem" (P1).

The non-disclosure among some women was due to the perceived negative responses they might get from the public especially those who are not their immediate family members as there are a lot of misconceptions about breast cancer in the Ghanaian context. Below are some of the views expressed by the women:

"I am comfortable with my family. Apart from them...I don't discuss it with outsiders…It is not for the fear of stigmatization but you know, psychologically...when people know that

you have a certain kind of disease, you will not know how people will relate to you… This woman has undergone mastectomy and especially women...they talk a lot. Yes, women talk a lot. I think that will rather affect your emotions when people say all these things about you. So I think it is better to keep it to yourself. Not because of stigmatization per se but the psychological impact it will have on you when people know that you are living with this disease" (P9).

"Initially, it is difficult to let others know about it. Even my family members, the doctor had to advise me to tell them before I told them. I kept it to my Husband and children until the Doctor advised me to tell them. At least they should know. Together with one or two close friends who would support and encourage me so I did that and it has been helpful. But you realize that out of about 10 friends, if you should tell any, just one or two will keep track and monitor and keep getting close to find out what is wrong with you anytime...all the rest will back out. You don't really know what their reasons are. And sometimes, when people see you, they look at you strangely as if they can't even recognize you again. The same people who know you very well will look at you strangely as if something has changed on you or it is like they no longer want to have you as friends. You will be smiling at somebody and the person will not smile back but that was not what the person was doing before. So psychologically and emotionally, if you are not a strong person, it will really weigh you down and that will even create more problems for you than even the sickness. Yes...emotional aspect...because you lament more...you cry more...and that makes your situation even worse but once you are able to overcome it, you begin to recover better" (P11).

From the narratives it is learned that fear of stigma and other unknown reactions from people are the key reasons for non-disclosure of disease status.

7.2.4 Coping with breast cancer

Persons living with chronic medical conditions such as breast make several efforts to adjust to their life circumstances. In their adjustment process, they employ several coping strategies that may influence both their short and long-term health outcomes. Three key coping strategies emerged from the interviews. These include the use of spirituality/religious coping, social support and seeking diversion. However, it is important to note that the participants in the study did not rely on only one form of coping but a myriad of strategies all aimed at helping to adjust to the disease and improve their quality of life. The details of the themes and the sub-themes are presented in the following sections.

7.2.4.1 Spirituality/religious coping

Almost all the participants mentioned that breast cancer and its treatment has drawn them closer to God/Allah. That is, they were of the view that living with breast cancer and undergoing the difficult medical treatments have strengthened their faith in God/Allah and helped them in in dealing with the challenges associated with living with breast cancer. Some of the participants engaged in several religious activities such as daily prayers and rituals to help them cope with their condition i.e. in building of hope, financial provision, healing and acceptance of their health condition as reflected in the quotations below:

> *"It has rather strengthened my faith because...you know....when something happens to you, as a Christian, you trust God that, He is your healer, so it has strengthen my faith in God*

145

that He will heal me...even though the doctors are working on it. He is the ultimate Healer"
(P9).

"...so you see...so if you don't have faith that God will provide for the treatment...I mean what do you do? You just lose hope. But with God...you trust that help will come. So our faith in God should rather strengthen us in this times (of living with breast cancer)" (P4).

"Religion plays a big role. Because without your faith in God, something like this (breast cancer) can just break you down because you go through a lot. Even financially, yes...finances....you go through a lot. So you pray to God that he should provide the finances" (P9).

Apart from religiosity and spirituality providing hope and healing to the participants, reliance on God served to provide companionship to some participants. This helps women to make meaning of their social role limitations and viewed God as their hope and source of comfort:

"... I think it (breast cancer and its treatment) has even made me much stronger because at a point in time, I didn't have anybody apart from God. So it has rather drawn me closer to God...just that some roles that I was playing in church, because I am now not too regular in church, I am not able to play those roles because of the sickness but I am very close to God than before" (P11).

On the other hand, the use of spirituality as a coping mechanism is influenced by the participants' belief that their disease is a test from God which they must pass and therefore, will not give up.

"I think it is just a test from God…hmm because one cannot live His life just like that, if you say you believe in God He will never leave you like that. He tests you to see whether it is true you believe in Him and whether you will divert your faith somewhere. This is what my faith tells me. He has brought it and shown me a way out of it" (P2).

"I took it cool…I believe we get everything from God…so in all things we must give thanks to the Lord so if he is using that condition, if I find myself in that condition, it should be for a purpose so instead of grumbling and blaming him and say why me?... I just have to remain calm" (P1).

These quotes from the participants indicate that God or a supreme being plays an important part in the breast cancer journeys of these women and thus, may subsequently influence their perception of the illness and overall health outcomes through acceptance, hope, companionship and meaning making.

Some of the participants also emphasized the role of their religious faith and spirituality in healing process as they admitted the fallibility of the medical doctors in their treatment:

"…but to my belief I know God is talking the lead in my life. I am hoping that doctors will do what will be better for me that what my belief takes me" (P2)

"When I wake up, I say my prayers…Because my survival depends on God. You know the doctors can heal you but if God is with you, everything will end well" (P7).

"…without God, I would have been gone (dead). You wouldn't have even gotten me to interview me....laughs…It is God" (P11).

The use of religiosity among the participants had led to women accepting their fate and this acceptance serves as a coping strategy. Below are the direct quotes from the some of the participants in the study:

"But I have come to accept the situation, so what is important is to focus on the treatment" (P11).

"Hmm....as for sadness......aaa....even if I become sad or not, it has happened. Excuse me to say...the stage I have gotten to now, I do not have any husband that I will have to expose my breast to… "(P8).

7.2.4.2 Social support

From the narratives, social support in the forms of emotional, financial and instrumental support emerged as key coping strategies. Social support plays significant role in the overall coping with the disease. One thing that run through all the narratives was social support from immediate family most especially, children, spouses and siblings. Below are some direct quotes from participants regarding the value of social support in coping.

"Everything is normal now because my husband is matured and I am also old. I am 50 years. My husband is a matured person and this is not what will make him say 'I don't love you again'. So things are quite normal in my home. He is very supportive. The children too are grown. It is not like little kids that you have to do so much for them. They are also cooperative so I don't really have any serious challenge at home" (P11).

"...they (family and friends) are the ones who have been helping me mostly. As for me, I do not hide it (sickness). I tell people so that if anyone sees some changes in the breast, the person can seek immediate medical attention to save matters. It is not something that I do hide (P10).

"I think I have my family with me...they understand and give me the necessary support so I am okay....I am ok....apart from the few side effects here and there...the family is always there as they used to" (P9).

"They (family) are crying for me. I'm here with my dad, he takes care of me so he sees me. If there's any help, he assists me. Those abroad, especially my mum, she calls me every day. She calls to check up on me and find out how I am doing, because she's not here. She should be here but she also has a problem. She has to have a surgery on her spine. My brothers too support me with money" (P3).

"...they (family) have been very supportive. All my children support me. I also have friends who have been very supportive. When I was on admission, there was this friend who was always visiting me.

"They (family members) support me in terms of finances. When they visit me, they give me money because they have realized that the treatment for cancer is not easy. It is all about money. It needs a lot of money" (P8).

Another woman reported the use of handkerchief to make up for her lost breast as a coping strategy. However, her hope is on the support from her relative for the silicon to use for her breast.

"Now, I've told my sister-in law to bring me silicon. They have this breast silicon, I'll just put it in my brassiere and move about. As I'm sitting down here, I've just used a handkerchief and mad it like cup to cover up for my breast. When I get the silicon, I'll just fix it there" (P3).

7.2.4.3 Diversion coping

A substantial number of the participants in the study also reported the use of diversion coping strategies which include listening to music, or religious sermons and/or watching movies to take their minds off their breast cancer.

For participants who use songs and inspirational messages, one woman reported that;

"I love songs ...so I have a lot of songs on my phone which I listen to. Sometimes on the television too…Mostly, gospel songs. A few friends who are also aware of the situation do send me inspirational messages. When I read them, it encourages me. You are a Christian but sometimes, you get down as a human being. You need to encourage yourself so I like reading them" (P11).

Other participants use either television alone or both as illustrated by the following direct quotes from the participants;

"...oh I watch movies if I am at home, you see once a while you will laugh err if it's emotional too you say aww and I watch movies, I like watching movies not any movie at all but movies that encourage and inspire me or make me laugh… local, foreign. You see some movies… you learn from them, you learn from them maybe like somebody has done

something and you see it you would not want to do it because of the end results "ahaa" so I like watching movies, movies that will educate you. You see, not any movie at all, will educate you, encourage you or teach you lesson. I also like music, I listen to music a lot especially, gospel, even these local music like the ones by Ampofo Adjei (a Ghanaian musician) and co if you listen to the words and lyrics in the song you can see that they inspire you" (P4).

"…what do I have? It is just this television that I watch…When I watch the programmes, I become happy and it takes my mind off the sickness (breast cancer)" (P8).

These quotes from the participants suggest that radio and television may play significant roles in their breast cancer journey as it may serve to help them cope and as a potential source of life lessons that might be meaningful to them.

7.2.5 Patients' perceptions of the healthcare delivery

Patients' overall assessment and perceptions of the healthcare services they received related to their communication with the healthcare workers were assessed. These include communication/interaction with health workers and satisfaction with information from health workers

7.2.5.1 Communication with health workers

The communication with the health workers especially were characterized with mixed feelings. That is, whereas some participants felt satisfied with communication with their healthcare providers, others reported dissatisfaction with their communication with their healthcare providers

and cited instances to substantiate their claims of dissatisfaction with communication with health workers.

Below are some direct quotes from the participants about their communication with healthcare providers which reflected a lack of adequate contact time between the doctors and patients. The short duration of the consultation is seen by the women as hampering their overall healthcare as they are unable to effectively communicate their feelings and concerns to their healthcare providers:

> *"I think those at the radiotherapy are more helpful than the surgical because they could ask you how you feel, especially just after the radiotherapy. I think within 7 or 10 days they will tell you to go for lab test to check your chemical composition first and then they ask you questions and you see the doctor before the next one (doctor) but over there (Chemotherapy), there was nothing like that when you are doing it (chemotherapy), a doctor comes and he will just come to prescribe the medicine for you or what you felt the previously or maybe sitting somewhere at times the nurse will just ask you: any problems? I didn't see it the way I saw it at radiotherapy department. They (radiotherapy health workers) are more professional about it ..." (P1).*

> *"...also, I do not know if it is pressure but sometimes, the doctors are unable to have much interactions with you. Because, sometimes, the numbers are large, so if they should spend more time with you, others are also in a queue suffering. However, a few of them have the tendency of allowing you to tell them all that is bordering you. But for some of them, they want you to move out quickly for someone else to come which sometimes, it is not the best.*

Because if you do not get information from your doctor, you might listen to someone out there which might not help you"(P11).

"...you know doctors with their cases, hahaha (laughs) we patients are scared of the doctors so sometimes it seems like some doctors use to be in a mood to talk and sometimes they are not in that mood. As for me, whenever I see that chance I used to ask doctors questions, and sometimes, I just don't know what to talk about, so I keep quiet, they check me. So when he sees what is wrong with me he just prescribes what he is supposed to prescribe to me and just go away? Sometimes I ask questions sometimes I do not" (P2).

The quotes from these participants showed some problems with the attitudes of some of the health workers and that there are challenges with the nature of communication with the health workers. That is, the medical doctors do not have adequate time for their patients and this seems to undermine patient-centred care. Patients even have to be sensitive to the needs to the health care providers i.e. being able to "read the moods" of their healthcare providers before asking questions to seek clarifications. But these challenges seems to be limited to only some units of the oncology department.

Another participant expressed dissatisfaction with the level of communication and interaction with the health workers and expressed concerns about the adequacy. She recounted her unique experiences at the health facility to illustrate her perceptions about the effectiveness of communication between patients and the health workers;

"...it (communication/interaction with health workers) is not bad. Most of them are nice with the exception of one or two. And for those exceptions, it is normal...in my case, I think

I have problem identifying my veins. I don't know of others. Sometimes, if we are 10 in a room, they will identify everybody's vein and will find mine difficult. So it is like I needed a more experienced hand to handle me but sometimes you are scared that if you asked that a particular person should attend to you, the others might get offended. I feel if you make preferences and you are doing some day and your preference is not around, the others might not mind you. But I think such things should be handled internally so that the patients will not suffer. Because if there is a more experienced hand, why should an inexperienced hand attend to you for you to suffer? But now they have realized that I have a peculiar problem so when I go, they allow specific people to handle me…"(P11).

However, one participant expressed maximum satisfaction with the communication and interaction with the health workers at the facility.

"Oh...I have nothing wrong with it (healthcare). I am happy with it. They treat me well" (P10).

7.2.5.2 Information provision by health workers

Similar to the views expressed by the participants about the communication with their health workers, most of the participants reported inadequate information provision from the health workers which they attributed to the attitudes of the health workers.

"...the information is not enough, because sometimes, I realize that when you ask questions which you might have heard others talk about, all they tell you is that 'do not compare yourself to that person, You are unique, your system is different' but at the end of the day some of the things that happened to the others, end up happening to you. So I think

154

that, if you are rather told, it will reduce tension and when the thing is happening, you will understand it and know that, it is not scary. Because, sometimes, you live far from here, so when the things is happening to you, it puts some fear in you. But if you know and understand it, you are more relaxed. They tell us some...but they also shield some. I don't know if maybe they feel we will get scared and back out of the treatment. Because, sometimes, it is not easy so they want you to get there before they give you the information. When I started with the radio, for about two weeks, I started feeling choked, something had blocked my throat, and I could not even swallow water. It was so painful, so coincidentally, I was eating some fish with bone so I concluded that I had swallowed bone...so I concluded that, if I had swallowed bone, I do not want to bring bone issue to the radiotherapy unit because they will not mind me. So I took it to a private clinic and complained to the doctor that I had swallowed bone. The doctor did an x-ray and could not find any bone so I was told, there was no bone or if there was, it was in a position that could not be seen by the x-ray machine. So in each case, it might create infection for me so he put me on antibiotics. It was later on when I was chatting with a friend in the radiotherapy unit that the friend asked if I was sure I had swallowed a bone because she had a similar painful experience after radiotherapy. I was told it was the radiation so I was given medication to stop it. But according to the lady I interacted with, she was told, but I was not told. So I suffered for a whole week before complaining, and I was given medication so I am fine now. If I had known earlier, I would not have spent money on x-rays which were not necessary. Getting more information prior to the treatment is very important" (P11).

"I asked questions but you know err surgical, I once asked a doctor a question and the way he answered, excuse my language he was been saucy…but as a patient I couldn't do anything because your hand is in their mouths" (P1).

The views expressed by these participants with examples, demonstrate the inadequacy of information provided by the health workers and thus the unmet information needs of participants which are likely to increase the uncertainty surrounding the treatment and prognosis of their illness. This lack of adequate information was reflected in the fact that patients felt that the healthcare providers were unwilling to provide them with complete information and also, reacted to questions in ways that discouraged further information seeking.

On the other hand, some of the participants expressed satisfaction with the information provided by the health workers as this information helped them in in engaging in self-care practices aimed at improving their health:

"Ooh… when I contracted this disease, according to Doctors, they said I should not take in sugar, meat or Alcohol. Myself, I do not take alcohol and I do not also take in too much sugar. They said I should resort to fish, salad and vegetables. That is what I do to help myself" (P8).

"I guess it (information provided) is okay… as for me I would like to hear everything about myself. If you tell me I would take it as it is, I would never be scared even though it's scary but I will appreciate it because once the doctors have seen it, I know the doctors would do something about it. So as for me you know we are all not the same, somebody cannot take some information about yourself but as for me I would like to hear everything. In your

blood you will see this… this and that I would like it. I would be very interested in the

information so that I would know how to handle myself" (P2)

"I am happy with information…I am not afraid of any information they give to me. I am

even happier they are teaching me what to do to be cured. I also obey everything I am told.

I am also able to ask them questions to clear any doubt that I have in my mind" (P10).

7.2.5.3 Perception of healthcare delivery

The participants' perception about the overall healthcare they receive at the health facility

was explored and almost all the participants expressed satisfaction with the care they receive at the

facility. These expressions of satisfaction are linked to their communication with healthcare

professionals and access to health information from the hospital. The participants went further to

give examples to buttress their expression of satisfaction with the overall healthcare that they

receive at the facility.

"It is good…I think the doctors know their work because I am seeing improvement in my

health. Initially, I was so sick but now I am fine and can drive myself here. Initially,

someone had to drive me her. The only problem is that, the numbers are large and this

makes the waiting period long and stressful. I think they are doing their best, but if maybe

the doctors could be more, it can save situations" (P11).

"I am very happy with their work… Ohhhhh...even how the healthcare professional will

even talk to you... will make you feel at home. They also encourage us sometimes" (P8).

However, based on experience, one participant reported that she was not satisfied with the healthcare delivery at the facility.

"I will say I am not so satisfied….like I was saying, the Doctors do not really have much time for us. And even if you have a problem and you come...the other time I remember when my side effects started getting worse, I wanted to see a doctor and I came here and a nurse asked me if it was an emergency. So if it is not an emergency, the doctor will not attend to you. So you see... I think I did not see the doctor that day. I do not know. Even the people who do the radiation...sometimes when you are going to see the Doctor, there is a need to send your folder so that he knows your history but these people will tell you that, when you take it along, the doctors will get annoyed. But if you have your personal doctor, at least you can go and see the person at any time. That person has your information already, so when you go, you just inform him or her that "doctor, this thing is getting worse or you would want to discuss something with him" and the person will have time for you. But here, I think the doctor to patient ratio is so minimal. You really do not get access to the doctors anytime you want. I think it is a big problem" (P9).

The quotes above emphasises the need for a more patient-centred care within the Ghanaian public healthcare delivery system to ensure that patients get the necessary personalized care.

7.3 DISCUSSION

7.3.1 Key findings

This study explored the lived experiences of women living with breast cancer. The major themes and sub-themes under the various areas of focused are discussed within the Ghanaian socio-cultural milieu and related to previous literatures. The discussion of the findings presents a holistic overview of how the women experience their illness in its entirety as the various areas of centration are inextricably linked. That is, the lived experiences associated with the illness influences illness perception and the coping strategies that are employed by the women in dealing with the challenges associated with living breast cancer. The discussion concludes by discussing healthcare satisfaction in terms of patients' communication with healthcare providers and the overall healthcare service delivery at the hospital.

Previous studies among women living with breast cancer have reported several physical and psychosocial burdens with affect the health and overall wellbeing of women (Aziato & Clegg-Lamptey 2015; Bringmann et al., 2008; Kagee et al., 2018). For example, studies conducted among women living with breast cancer in Ghana found that experiences of sadness, fear, guilt, anxiety, severe pain and suicidal ideation are common experiences among women living with breast cancer (Bonsu et al., 2014; Clegg-Lamptey et al., 2009; Opoku et al., 2012). These negative emotional experiences reported by earlier studies could be attributed to the burdens of the medical treatment as found in this study. This suggests that the experiences of negative emotions are not in isolated but inextricably linked with challenges that come with going through the medical treatments and its negative side effects.

One of the key issues that was pervasive among women living with breast cancer is the use of alternative/herbal medicines. This finding was not surprising as alternative and herbal medicine use are very common and acceptable among the Ghanaian population (Aziato & Antwi, 2016; Gyasi, Mensah, & Siaw, 2015; Kretchy et al., 2016; Yarney et al., 2013). Among the participants, three categories of alternative and herbal medicine use emerged, that is, current users, previous users and non-users. However, some of the women who had no experience with the use any alternative and herbal medicines indicated their willingness to try them after their medical treatments. These patterns of alternative medicine use among the women is fuelled by the desire to get completely healed and to reduce the economic burden associated with cancer treatment. For example, some of the participants indicated that they find the herbal products cheaper and accessible. Thus, the high cost of the medical treatment could be an important push factor which drive breast cancer patients towards the use of alternative medicines. These findings have been reported among a sample of Ghanaians who indicated the cost and timely accessibility of alternative medicine as the key reasons for their usage (Kuunibe & Domanban, 2012). The challenge to the healthcare delivery system is whether the healthcare professionals are aware of alternative medicine use and how these can be managed holistically to the benefit of the women living with breast cancer.

Furthermore, stigma emerged as one of the main issues that confront women living with breast cancer. Some of the participants have experienced stigma from strangers and their close friends. These experiences and perceived stigma have resulted in self-stigma among the women living with breast cancer as some of them avoid situations where their disease status and side effects might be apparent to others. These experiences have significant negative impact on the health and wellbeing of the women as stigma prevents from seeking the necessary help and

support. This was evidence in some of the participants' unwillingness to disclose their disease status for fear of rejection and stigmatization. One of the striking things found was the impact of the financial burden on the family members of women living with breast cancer as participants reported that their relatives avoid them, maybe, not necessarily due to the stigma but the huge financial implications of the breast cancer treatment. All these experiences that are interlinked has significant negative emotional consequences on the participants in the form of feeling isolated, depressed and anxious about the future.

These findings mirror some results from previous studies which found stigma to be one of the key issues that confront women living with breast cancer (Maree & Mulonda, 2015; Wong-Kim et al., 2005). This suggests that there is the need for further research into issues of stigma among women living with breast cancer to ascertain the magnitude of this problem as stigma among breast cancer patients has received little attention in the African continent (Maree & Mulonda, 2015). Cancer stigma in Africa has been attributed lack of adequate disease knowledge and superstitious beliefs which put the blame on the patients for having done some wrong. For instance, a quote from a participant vividly illustrated the key reasons for the stigma attached to breast cancer, "*they too would have done anything for you in the past **if it was malaria or something**....but this time around they have drawn back and they are being careful getting close to you perhaps they do not know whether you have gone to do something evil and this curse has come upon you*". However, the internalized stigma which may be brought about by the financial burdens are not surprising as pertinent literature supports the significant financial implications of breast cancer treatment (Clegg-Lamptey et al., 2009).

161

The lived experiences of women living with breast cancer are likely to influence their cognitive and emotional representation of their illness. Findings from the study showed most of the women lacked factual information about breast cancer especially what breast cancer is all about and its potential causes. This lack of inadequate knowledge about breast cancer has consequences for patients' perception of their illness and the treatment outcomes. For example, a participant recounted that she seems to be moving in circle with no apparent difference in her circumstances. That is, her focus was on the short term outcomes such as the side effects of the medical treatment procedures and not the long term health outcomes of the treatment. However, most of the participants believe that their illness can be completely cured and that they believe their illness will not last long so far as they have God and go through the medical treatment. This perception of the curability and duration of the illness is rooted in the personal faith of the participants as reference to God run through all the responses of the participants.

As has been noted earlier, the subjective perceptions of breast cancer by women influenced their coping strategies especially the reliance on their personal spirituality as the key coping strategy. This could be due to lack of inadequate knowledge about the disease and its causes as well as the uncertainties surrounding the outcomes of the medical treatment. Spirituality plays a significant role in the life of the African and for that matter Ghanaians and therefore, served as a major resource for them in coping with the challenges of living with breast cancer (Mbiti, 1990, 2015). This finding is consistent with previous studies which found deferring responsibility to God and personal faith as important resource for coping with breast cancer (Hajian et al., 2017; Mehrabi et al., 2015). It was observed that reliance on God and spirituality has led to disease acceptance among the participants which serves to protect them against the experience of negative emotional

states. Acceptance disease has been reported by other studies among women with different cancer types (Binka et al., 2018; Bonsu et al., 2014).

In addition to the reliance on spirituality, social support from family members and friends served as a key coping resource. Evidence in the psycho-oncology literature revealed that social support plays a pivotal role in the treatment of breast cancer and its aftermath (Anagnostopoulos et al., 2004; Hajian et al., 2017; Mehrabi et al., 2015). Social support from family, friends and significant others have been linked to decreased mental health problems such as depression, anxiety and suicidal behaviours and improved quality of life among women living with breast cancer (Haugland, Wahl, Hofoss, & DeVon, 2016; Lim & Zebrack, 2008; Matthews & Cook, 2009; Ng et al., 2015). This finding underscore the need for improved social networks and support systems for women living with breast cancer to cushion them against the negative consequences of the medical treatment and living with breast cancer.

One of the interesting findings from this study was the use of music and films to divert attention from the breast cancer. Radios and televisions served as the main sources of these music and films which help women avoid thinking about their predicament. The use of this coping strategy may relate to a component of cancer-specific coping strategies called cognitive avoidance which has been linked to decreased depression and anxiety but improved quality of life among women living with breast cancer (Kulpa et al., 2014; Saita, Acquati, & Kayser, 2015). On the other hand, a few of the participants indicated that they rely on self-care practices in the form of adherence to their medical treatments and dietary habits as coping strategies. Although not mentioned frequently by the participants, adherence to medical treatments and other prescribed self-care practices could have significant impact on disease outcome of the women. Evidence in

the cancer literature suggests the use of self-care practices as of the coping strategies employed by patients (Binka et al., 2018; Heinze & Williams, 2015; Norris, Liu, & Bauer-Wu, 2009; Radina, Armer, & Stewart, 2014).

Finally patients' perception about the healthcare delivery with emphasis on the interaction and communication with the health professionals revealed mixed findings in this study. Whereas some participants expressed their satisfaction with the interaction and communication with the health professionals, other also reported being dissatisfied with the healthcare delivery at the facility. Those who reported being dissatisfied expressed unmet information needs as they believed the lack of adequate communication and information has affected them negatively. For example, a participant indicated she had to spend extra money to seek medical care at a private facility due to the side effects of chemotherapy which was not made known to her. These and many other instances have showed that there is an information gap in the healthcare delivery system especially to women who are interested in knowing more about their disease. However, some of the participants blamed the ineffective communication and inadequate information on the healthcare professionals to patients ratio which does not enable for extensive consultations as any delay with one patient may be detriment to others waiting to receive care. Analysis of the backgrounds of participants who expressed unmet information needs showed that these women are highly education and enlightened about some best patient-centred practices around the world.

These findings are consistent with previous works which have found that there is a huge unmet information needs among cancer patients including women living with breast cancer (Halbach et al., 2016; Kowalski et al., 2014; Miyashita et al., 2015). These lack of effective communication and inadequate access to health information might predispose the participants to

negative health outcomes such as depression, anxiety and poor quality of life as pertinent literature demonstrates the importance of effective communication, involvement of patients in treatment and other interpersonal variables in improving the overall health and wellbeing of breast cancer patients (Epstein et al., 2017; Janz et al., 2017; Street Jr et al., 2009). Thus, there is the need for reorientation of healthcare professionals to enable them identify patients who need more information about their disease and outcomes to dispel misconceptions and uncertainties surrounding breast cancer.

7.3.2 Implications and limitations of the findings

The findings from this study have several implications for clinical practice, healthcare policy and psycho-oncology research. Firstly, the findings from this study imply that women living with breast cancer are faced with complex physical and psychosocial problems which requires a holistic approach involving multidisciplinary team of health professionals. For example, oncology physicians, nurses, clinical psychologists, social workers, nutritionists and the clergy should work together to provide care that is tailored to needs of the women. Oncology physicians and nurses have the responsibility to go beyond the routine healthcare and probe for the information and psychosocial needs of the patients. Although this may prove difficult in the face of the apparent lack of both human and financial resources, a little more effort may do the trick in addressing the information and psychosocial needs of the patients. All these are importance in the face of increased alternative and herbal medicine use among the participants which may be counterproductive in conjunction with the medical treatments.   The healthcare professionals should be equipped with the necessary skills in appropriate referral systems to promote a holistic care.

Spirituality and personal faith is pivotal in the breast cancer journey of these women and cannot be overlooked by the medical team in providing optimum healthcare to the women living with breast cancer. Psychologists may help in counselling patients and offering group and individual therapies depending on the needs identified. Social workers may play significant roles in issues concerning the family dynamics as the neglect to financial burdens and other reasons may be brought to the fore for appropriate interventions. Nutritionists may be beneficial in the team by providing nutritional interventions and advise on how to maintain good dietary habits for healthy living.

The policy implications of the findings are that there is the need for more healthcare professionals at the oncology department to cater for the huge number of patients. This is because the overwhelming number of patients being attended to by few health professionals does not ensure optimum healthcare regardless of the extra efforts from the healthcare professionals. In addition, the use of alternative and herbal medicine is largely due to financial reasons as they are cheaper than the orthodox treatment and this trend may endanger the lives of these women as the effectiveness of the herbal preparations cannot be ascertained. Thus, there is the need for the National Health Insurance Scheme to widen its scope to cover parts of the treatment cost of the women living with breast cancer.

Findings from this study have implications for psycho-oncology research as there is the need to examine the magnitude of alternative and herbal medicine use among women living with breast cancer using a large sample. There is also the need to examine the prevalence of stigma and its associated factors among women living with breast cancer to inform appropriate intervention programmes. The role of family members in the breast cancer trajectory cannot be overstated and

therefore, there is the need for studies to explore the experiences of relatives of women living with breast cancer to provide information for possible intervention measures aimed at promoting the health and wellbeing of the participants.

The study has some limitations which are worth highlighting as these limitations would guide the interpretation and utility of these findings. Firstly, the relatively small sample size of eleven women place a significant limitation on the findings as no generalizations can be made beyond this sample. In addition, the study was conducted at only one health facility and the experiences at this health facility may not reflect what pertains in other facilities in Ghana where oncology care is provided. Despite these two major limitations, this study has provided a rich data on the lived experiences of women living with breast cancer from different perspectives and would serve as a major springboard the needed social science research among women living with breast cancer in Ghana.

7.3.3 Conclusion

This study explored the lived experiences of women living with breast cancer in Ghana. In addition to the lived experiences, their illness representation, coping strategies and communication with their healthcare professionals were also explored. Findings from the study showed that the women living with breast cancer experience significant burdens of the medical treatments in the form of physical, economic and social challenges. The use of alternative and herbal medicines was common among the participants and most of the participants reported both experienced stigma and self-stigma. In terms of the illness representation, there is lack of knowledge about the disease and therefore, most of the participants reported no knowledge or belief of what might have caused their

disease. However, most participants believed that their disease can be completely cured and this belief was rooted in their faith in God and on the medical treatments.

In terms of the coping strategies, religious faith and spiritual was prominent but other coping resources such as social support from family and friends proved to be significant in adjusting to living with breast cancer and the negative effects of the medical treatment. Diversion coping and the use of self-care practices were also reported by the participants. It is heart-warming that the participants did not report the use of a lot of maladaptive coping strategies. In addition, patients reported mixed feelings with regards to their satisfaction with healthcare delivery in terms of their interaction with the healthcare professionals and access to information. These findings suggest that dealing with women living with breast cancer requires a multidisciplinary approach as their challenges and needs are multifaceted. Thus, it is important for practitioners to pay attention to the individual and the group needs of women living with breast cancer to ensure improved quality of life which is a core measure of the effectiveness of any treatment. This would provide the patients with the needed reassurance and encouragement in dealing with the challenges associated with living with a chronic medical condition like breast cancer.

CHAPTER EIGHT

INTEGRATED DISCUSSION AND CONCLUSION

8.1 Introduction

Breast cancer constitutes a major disease burden in sub-Saharan Africa. In Ghana, breast cancer in the second most diagnosed tumours among women after cervical cancer. Previous evidence in the SSA and to a large extent, Ghanaian literature suggests high mortality rates among women due to late presentations and diagnosis. However, increasing public education and advancement in treatments strategies have led to increased survival chances. However, living with breast cancer presents several psychosocial challenges to the women. These challenges if not properly addressed, are likely to influence their overall health and wellbeing which include their quality of life. This study therefore, examined the possible factors that impact on the quality of life of women living with breast cancer in Ghana.

This study adopted an explanatory sequential mixed method design which involves quantitative data collection and a follow-up qualitative data to elucidate on the observed associations between the quantitative variables (Creswell, 2013; Johnson & Onwuegbuzie, 2004). The first phase of this thesis used a cross-sectional survey design and interviewer administered survey instruments were conducted to collect information on socio-demographic, medical, psycho-social predictors and health-related quality of life from women living with breast cancer at the Oncology Department of the Korle-Bu Teaching hospital in Ghana. The second phase of this work was a qualitative follow-up study among a selection of the participants in the survey to gain a

deeper understanding of the women's lived experiences, illness representations, coping strategies used and extent of their satisfaction with the healthcare delivery.

The key findings from the study are discussed in relation to relevant theories and pertinent literature on the health-related quality of life among women living with breast cancer and centred are around four broad but overlapping areas. These are; access to health information, health literacy and quality of life, depression, anxiety and quality of life, coping strategies used and its linkages to quality of life and lastly, shared decision making and patients' involvement in their treatment as well as aspect related to the doctor-patient relationship as it pertains to quality of life. The implications of the key findings from this doctoral thesis in regards to psycho-oncological, health communication, clinical practice and research are highlighted. The limitations of the findings from this study and recommendations for future studies are also offered. The final part of this work presents an overall conclusion drawn and the researcher's own personal reflections on the entire research process.

8.2 Access to health information, health literacy and quality of life

Access to health information and health literacy are critical in the effective management of chronic medical conditions including breast cancer. These may in turn influence both short and long term health outcomes among patients. Findings from this study showed that access to health information and health literacy were significantly correlated with perceived improved quality of life. Increased access to health information and improved health literacy were found to be linked to quality of life among the participants. Results further revealed that mental health status i.e. decreased depression and anxiety are possible mechanisms through which increased access to

health information and improved health literacy influence the quality of life among women living with breast cancer.

These findings were corroborated by results from the qualitative findings which revealed unmet critical health information needs of the women living with breast cancer. Patients who reported inadequate health information from the healthcare providers expressed worry and uncertainty regarding their treatment. For instance, inadequate information from healthcare providers have led some of the women to incur avoidable healthcare cost due to the experience of some negative side effects of their medical treatments which were not adequately communicated to them during treatment. This inadequate access to health information from the healthcare professionals may be linked to limited health literacy which heighten the level of uncertainty surrounding their disease. These uncertainties and lack of adequate information in turn may heightened patients' levels of anxiety and increase their chances of being depressed. Thus, depression and anxiety serve as possible mechanisms for the positive impacts of access to health information and health literacy on improved quality of life breast cancer patients.

Pertinent literature in Western countries have documented the importance of access to health information to the health outcomes among breast cancer and other chronic disease patients (Blödt et al., 2018; Faller et al., 2016; Husson, Mols, & Van de Poll-Franse, 2010; Husson et al., 2013; Kent et al., 2012). For instance, a study among a large sample of cancer patients in Germany reported that decreased access to health information was significantly predictive of increased depression and anxiety levels as well as poorer reported quality of life (Faller et al., 2016; Faller, Strahl, Richard, Niehues, & Meng, 2017). This and many other studies have linked inadequate access to health information and unmet information needs to several health outcomes which

suggest that when participants' information needs are not taken into consideration in the medical treatment process, the overall purpose of treatment which is improved functioning in all domains of life, could be defeated.

Health literacy among cancer patients significantly influenced the levels of depression, anxiety and quality of life. Similar results were reported by other studies (Halbach et al., 2016; Halverson et al., 2015; Panagioti et al., 2018). Limited health literacy among cancer patients have been associated increased depression, anxiety and poor quality of life (Couture, Chouinard, Fortin, & Hudon, 2017). The findings in this study are consistent with previous works which reported that limited health literacy among cancer patients may results in poor patient-physician communication, poorer use of health care, poor adherence and relapse (Berkman et al., 2011; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Lillie et al., 2007; Paasche-Orlow & Wolf, 2007; Williams, Davis, Parker, & Weiss, 2002). The findings from this study underscore the need for efforts aimed at improving the level of health literacy among women living with breast cancer to reduce the anxiety and depression associated with breast cancer which intend lead to improved quality of life.

8.3 Depression, anxiety and quality of quality of life

Depression and anxiety are two of the most common mental health comorbidities among persons living with chronic medical conditions such as breast cancer. Comorbid depression and anxiety among cancer patients could influence their adherence to their treatment and healthcare utilization. Therefore, this study examined the impacts of depression and anxiety on the quality of life among women living with breast cancer in Ghana. Findings showed that levels of depression and anxiety were significantly correlated with decreased quality of life. This means that high levels

172

of depression and anxiety is linked to lower quality of life. Further analysis showed that whereas depression had a significant negative indirect effect on quality of life through social support anxiety had a significant positive indirect effect on quality of life through social support. However, religiosity did not significantly mediate the influences of depression and anxiety on quality of life among women living with breast cancer as religiosity may not necessarily imply spirituality. This presents an opportunity to delve into the conceptualization of religiosity and spirituality among Ghanaians to determine whether the two mean the same or different things.

These findings suggest that depressed patients are less likely to perceive social support and therefore, may report poorer quality of life as previous literatures suggest that perceived and received social support is linked to improved quality of life among cancer patients (Haugland, Wahl, Hofoss, & DeVon, 2016; Michael, Berkman, Colditz, Holmes, & Kawachi, 2002; Ng et al., 2015). The positive impact of anxiety on social support leading to improved quality of life could be due to the fact that anxiety may serve to motivate action among these women. That is, anxiety associated with living breast cancer may lead to seeking social support which was evidenced in the qualitative results as the participants sought support from their families, friends and even sent letters to their religious organizations for support. Clinical evidence suggests that depression and anxiety have one general underlying element which psychological distress and if the general element of distress is controlled, anxiety and depression are negatively related (Simms, Grös, Watson, & O'Hara, 2008; Xie et al., 2012) which may account for this positive impact of anxiety on quality of life through social support. Further, as stated by (Xie et al., 2012) "…anxiety motivates action, and may sometimes encourage people to work toward solving their problems. Depression, on the other hand, features behavioural inhibition, and tends to undermine action".

Evidence from the qualitative phase of this thesis showed that participants experience negative emotional states which have an impact on their overall health and wellbeing. These negative emotional experiences are linked with the physical, economic and social burdens of medical treatments. For example, the negative physical impacts of the medical treatment have led to loss of jobs, businesses, friendships, social roles and stigma. All these experiences predispose women to experience depression and anxiety which are likely to negatively impact on their overall health perception and quality of life. Evidence in the breast cancer literature have documented fear, worry, sadness, guilt, suicidal ideation and stigma as some of the key issues that are prevalent among women living with breast cancer (Aziato & Clegg-Lamptey 2015; Bonsu, Aziato & Clegg-Lamptey, 2014; Clegg-Lamptey et al., 2009b; Opoku et al., 2012). These psychosocial issues have been found to negatively influence the health outcomes of the patients (Almutairi, Mansour & Vinluan 2016; Bringmann, Singer, Höckel, Stolzenburg, Krauß & Schwarz, 2008; Gold et al, 2016). Thus, the qualitative findings confirm the impact of psychosocial challenges on the health and wellbeing of women living with breast cancer.

Contrary to expectation, the quantitative result did not show any significant impact of religiosity on the quality of life among women living with breast cancer. This is contrary to the findings from the qualitative study which showed spirituality and faith in God/Allah to play significant roles in adjustment to disease and its treatment. Some of the participants even mentioned the fact that it is their belief in God for healing that is keeping them alive. Others also noted that due to the huge financial burden posed by their breast cancer treatment, they rely on God for His provisions. All these suggests that spirituality is critical to the health and wellbeing of women living with breast cancer. The divergence in the quantitative and qualitative results could be attributed to the measure of religiosity used in the survey which focused on personal religious

faith and also, the very religious/spiritual nature of almost all the study participants. That is, spirituality/religiousity was inherent in the participants as most of them made reference to God/Allah which confirms the religiousness of the African as asserted by previous African scholars (Mbiti, 1990, 2015). This may imply that the conceptualization of religiosity and its impact on health and wellbeing among the women may be different from conceptualization of spirituality.

The significant role of religiosity in the lives of women living with breast cancer have been reported previous studies such that, spirituality and religiosity serve to help patients cope with their illnesses which result in improved health and wellbeing (Gesselman et al., 2017; Trevino, Balboni, Zollfrank, Balboni, & Prigerson, 2014; Wilson, Forchheimer, Heinemann, Warren, & McCullumsmith, 2017; Zamanian et al., 2015). On the other hand, the non-significant result of religiosity in the quantitative study corroborates however with some previous works which found negative religiosity to have a detrimental or to no effect on the health and wellbeing of breast cancer patients (Meisenhelder, Schaeffer, Younger, & Lauria, 2013; Ng, Mohamed, Sulaiman, & Zainal, 2016; Trevino et al., 2014). While it is important to explore quantitatively the role of religiosity in the quality of life among women living with breast cancer it nevertheless seem to play a critical role in improving the health and wellbeing of women living with breast cancer as religiosity and spirituality seems to form an inherent part of their existence.

8.4 Coping strategies and quality of life

Coping with chronic medical conditions like breast cancer influences the overall health outcomes of patients including their quality of life. Findings from the quantitative phase of this thesis showed that whereas helpless-hopeless and anxious preoccupation were significantly and

negatively correlated with quality of life, the presence of fighting spirit, the use of cognitive avoidance and fatalism were significantly and positively correlated with their quality of life. Further analyses showed anxiety and depression as significant mediators between three of the coping strategies (use of a helpless-hopeless coping strategy, presence of fighting spirit, cognitive avoidance) and quality of life. It was noted that only depression significantly mediated between two coping strategies (anxious preoccupation and fatalism) and quality among the women.

Congruent with the stress-and-coping theory of Lazarus and Folkman (1984, 1987), the findings showed that coping strategies influence both the short term (depression and anxiety) and long term (quality of life) health outcomes among women living with breast cancer. The use of negative coping strategies such as helpless-hopeless and anxious pre-occupation led to increased depression and anxiety levels which in turn reduce the quality of life among women living with breast cancer. Anxious-preoccupation and the use of helpless-hopeless coping strategies among cancer patients have been found to be detrimental to their health as these coping strategies are characterised by the loss of hope, feelings of helplessness and anxiety. These experiences may interfere with patients' adherence to treatment and self-care practices which result in poor health outcomes. Evidence in cancer and other chronic disease literature have reported the detrimental effects of the use of helpless-hopeless and anxious-preoccupation on the overall health and wellbeing of patients (Brunault et al., 2016; Ferrero, Barreto, & Toledo, 1994; Nipp et al., 2016; Paek et al., 2016).

The use of cognitive avoidance, having a fighting spirit and fatalism had significant influences on quality of life which are consistent with previous studies (Filazoglu & Griva, 2008; Johansson, Rydén, & Finizia, 2011a; Kulpa, Ziętalewicz, Kosowicz, Stypuła-Ciuba, &

Ziółkowska, 2016; Yeung & Lu, 2014). However, some previous studies found the use of fatalism to be predictive of decreased quality of life (e.g. Schou, Ekeberg, & Ruland, 2005; Whitford, Olver, & Peterson, 2008; Yeung & Lu, 2014). The differences between the finding from this study and previous studies which found the use of fatalism to be detrimental to the quality of life among cancer patients could be due to the measures of fatalism. Some of the previous studies used fatalism measures without two key items that relate to fighting spirit and thus, made the use of fatalism more positive coping strategy. It is also not surprising within the Ghanaian context where religiosity and spirituality are inherent in everyday life experience as most of the women made reference to God in the qualitative phase of this study. Since fatalism connotes fate and deferring responsibility of the illness to God or a higher authority, this may serve to protect the women against the negative emotional burdens that come with living with breast cancer. Various studies support the positive impact of a fatalistic attitude among cancer patients on the health outcomes including quality of life (Anagnostopoulos, Kolokotroni, Spanea, & Chryssochoou, 2006; Anagnostopoulos, Slater, & Fitzsimmons, 2010; Kang et al., 2008; Saita, Acquati, & Kayser, 2015). These authors were of the view that fatalism has items which connote a positive attitude toward a 'supreme being' which serves to lessen the anxiety and negative emotions associated with living with breast cancer.

The qualitative phase of the study provided a deeper insight into the various ways of coping used by the women living with breast cancer apart from the cancer specific coping strategies measured in the quantitative phase. Spirituality was the mostly used coping strategy mentioned by the women as every participant made reference to God in dealing with the burdens of the medical treatments and in everyday living with breast cancer. The use of spirituality has resulted in acceptance of the disease among the women as they have entrusted their care "into the hands" of

177

God. The use of spirituality and subsequent acceptance of the illness are linked to improved wellbeing among the participants as their negative thoughts about the disease seemed contained by the knowledge and conviction of God's power in supporting them through the treatment and healing process. Evidence from the previous literature among cancer patients have reported on the role of spirituality/religiosity and acceptance of the disease through cognitive restructuring (Al-Azri, Al-Awisi, & Al-Moundhri, 2009; Manuel et al., 2007). For instance, the study among Omari breast cancer patients found Islamic beliefs and practices as the most common coping strategies used (Al-Azri, Al-Awisi, Al-Rasbi, & Al-Moundhri, 2014). The use of religiosity as a coping strategy among women in study suggest the inclusion of spiritual or faith-based psychotherapy interventions in efforts to improve the health and wellbeing of these women by reducing the level of distress they experience.

Another coping strategy that emerged from the qualitative data was the use of social support. Social support from family, friends and significant others were reported to have helped the women in dealing with their breast cancer. The support given were in the form of financial, emotional and spiritual support. However, the support is mainly from immediate family as most of the participants have not disclosed their disease status to their friends and other people who are not part of their immediate families. Evidence suggests that the use of social support as a coping strategy is effective in bring about decreased depression and improved health outcomes (Al-Azri et al., 2009; Haugland et al., 2016; Lim & Zebrack, 2008; Manuel et al., 2007; Matthews & Cook, 2009; Ng et al., 2015; Salonen et al., 2013). Thus, social support serve as an important resource for women living with breast cancer in dealing with the various physical, economic and psychosocial challenges associated with breast cancer.

Further, one of the least used coping strategies found among the women living with breast cancer was the use of self-care practices. Self-care practices in the form of adherence to hospital treatments and dietary habits were identified among some of the women. These coping strategies may serve to ensure improved health outcomes in the short and long term. Other qualitative studies among women living with breast also found the use of self-care practices as effective coping strategies (Al-Azri et al., 2009; Manuel et al., 2007). This finding underscore the need for healthcare providers to emphasize the importance of self-care practices in the provision of holistic and comprehensive healthcare.

8.5 Shared decision making/patients' involvement, doctor-patient relationship and quality of life

Breast cancer treatment involves complex decision making processes to ensure effective health outcomes. This decision making process does not only rest on the health professionals but patients who are the recipients of healthcare are expected to be involved. Thus, patients' involvement or shared decision making has become a central issue in health communication research and practice. Findings from the quantitative phase of this study showed that patients who expressed involvement in their medical decision making processes reported improved doctor-patient relationships which in turn led to better quality of life among women living breast cancer. This finding suggests that when patients feel involved in their medical treatment decision making, it helps them to develop a sense of importance and also fosters good relationships with their healthcare providers. Patient empowerment is argued to improve the long term health outcomes of patients such as quality of life as they would experience less uncertainties and anxieties through

their close collaboration and partnership with health care providers in their healthcare (Chen, Pai, & Li, 2008; Moattari, Ebrahimi, Sharifi, & Rouzbeh, 2012).

The qualitative findings shed light on the importance of shared decision making and patients' involvement in medical decision making on the perceived improved health outcomes. For example, women who expressed dissatisfaction with their involvement in the treatment decision making especially with regards to communication and interactions with the healthcare providers reported particular mental health challenges i.e. being anxious and depressed due to a lack or inadequate information about their medical treatment and side effects. The importance of patients' communication and interaction with their healthcare providers are congruent with previous literature which found patients' communication with their healthcare providers to be related to decreased negative emotional experiences, healthcare satisfaction and improved quality of life (Engel et al., 2003; Jiang, 2018; Kimiafar, Sarbaz, Sales, Esmaeili, & Ghazvini, 2016; Zhou et al., 2014). Unmet information needs have been widely reported in the cancer literature as cancer patients seek information from various sources to aid them in coping with their cancer (Faller et al., 2017; Halbach et al., 2016; Kimiafar et al., 2016; Li et al., 2011).

On the other hand, those who felt that they have been involved in their medical decision making reported good interpersonal relationships with their healthcare professionals and expressed satisfaction with the overall healthcare they receive at the health facility. These findings are consistent with previous works which have found shared decision making and patients' involvement to be beneficial to the health outcomes of cancer patients (Davies, Kinman, Thomas, & Bailey, 2008; Griggs et al., 2007; Vogel, Leonhart, & Helmes, 2009). The benefits of involving patients in decision making include decreased levels of depression, anxiety and increased

satisfaction with overall health care (Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007; Vogel et al., 2009). Specifically, other studies have also observed that good doctor-patient relationship result in decreased depression and anxiety levels, and improved quality of life (Farin & Meder, 2010; Li, Matthews, Dossaji, & Fullam, 2017; Zhang, Nilsson & Prigerson, 2012).

It is a concern that some patients reported having to be sensitive to the needs of the health care providers by not seeking information or involvement when health care providers are perceived not to be in the "mood" to engage with their patients. This power play between doctors and patients is pervasive (Bending, 2015), especially in cultures with more power distance like Ghana (Hofstede, 2011). This becomes as major concern as most of the breast cancer patients are marginalized, less informed, poor and have very little options to demand a better service. These findings suggest that health providers' involvement of patients in the treatment decision making, communication and information provision about the disease and its treatment need to be taken seriously in providing holistic healthcare to women living with breast cancer.

8.6 Implications of the findings for interventions, clinical practice and policy

The findings suggests that living with breast cancer in Ghana presents significant bio-psychosocial and economic challenges for the women and their relatives. These challenges contribute to poor health outcomes among the women living with breast cancer. Due to the relatively younger age of the women living with breast cancer in Ghana, there are significant social and economic limitations which are likely to influence their health seeking behaviour and overall health and wellbeing outcomes. The findings from this study have several implications for psychosocial intervention, clinical practice and healthcare service delivery, guidelines and policy as outlined below.

8.6.1 Clinical practice and psychosocial interventions

It was found that women living with breast cancer resort to several sources of information about their disease, medical treatment and its associated problems. This underscores the need for health professionals providing care to provide the women with information about their disease, its management and related issues to address the uncertainties surrounding living with breast cancer and also, allay their fears and anxiety about the disease and the medical treatment options. This also calls for routine assessment of patients' perceptions and knowledge about breast cancer as these may significantly influence their coping strategies and adherence to medical treatment regimens. The assessment of patients' knowledge could also help in identifying patients who have limited health literacy as higher literacy and access to health information were associated with decreased, negative emotional experiences such as depression and anxiety which in turn led to improved quality of life. Healthcare providers should encourage patients to ask questions and seek clarifications as these may help in reduce the uncertainties and fears associated with diagnosis and treatment as well as treatment side effects. These empowerment of the women living with breast cancer may serve to foster good interpersonal relationships with the healthcare providers. Evidence from this study showed that involvement of patients in the healthcare decision making process is linked to improved relationship between healthcare providers and the patients which in turn results in improved quality of life. Findings from the in-depth interviews showed the importance the women attach to good interpersonal relationships with their healthcare providers.

In addition, most of the participants in this study are currently using, have used or have the intention to use alternative health care i.e. herbal medicine as part of their treatment process. This implies a complex health seeking patterns which need to be addressed holistically by healthcare

professionals to ensure optimum health outcomes. That is, healthcare professionals at the oncology unit should ask patients about their alternative medicine use and provide them with the accurate information about treatment.

There seems to be a need for the routine screening for common mental health problems such as depression and anxiety as they pose a significant challenges to the quality of life of the women living with breast cancer as found in this study. There are available mental health screening tools to help healthcare professionals to assess common mental health problem among this population and make appropriate referrals for psychosocial care. The early identification of mental health problems and subsequent treatment and support may serve to lessen their negative impact on the medical treatment as well as the overall health and wellbeing of the women.

In addition to the above, findings from this thesis underscore the need to provide and strengthen the social support systems of the women living with breast cancer to mitigate the negative consequences of the diagnosis and the negative physical and psychosocial effects of the medical treatment. Social support was found to play significant roles in improving both short and long term health outcomes. Participants mentioned social support as one of the key resources for coping with their disease. Linked with social support is the influence of patients' religiosity and spirituality which have important influences on their disease outlook and shape their disease journey. It can therefore be argued that supportive faith-based psychosocial interventions may further strengthen the faith of these women that will assist them in adjusting to their illness.

Furthermore, several coping strategies are employed by women living with breast cancer in their journey with breast cancer. These include both negative and positive strategies. Support to women in this regard may be of critical importance especially in identifying the likely use or the

use of maladaptive strategies. These could lead to the implementation of cost effective psychosocial interventions such as mindfulness-based therapies to help patients focus their thoughts on fighting the disease as well as enjoy the positives of life despite the limitations placed on them by their illness. The implementation of these mindfulness-based strategies might lead to decreased depression and anxiety which will in turn improve the quality of life of the women (Gu, Strauss, Bond, & Cavanagh, 2015; Van Aalderen et al., 2012). This therefore, requires regular in-service training of oncology nurses and physicians in counselling techniques which would enable them examine patterns of coping and its impact on the health outcomes of women living with breast cancer.

8.6.2 Healthcare Guidelines and Policy

One of the key issues that emerged from the findings of this thesis was the huge financial cost of the breast cancer treatment. Itis of great concern that despite their subscription to the National Health Insurance Scheme, the women still have to pay for most of their services since the insurance does not cover the main treatment procedures. There is thus an urgent need for improved funding for special medical conditions such as breast cancer so that the financial burden of treatment can be lessened. This will go a long way to improve the overall health outcomes of the patients and is likely to have positive impacts on the society as the financial cost predispose the women to severe negative emotional health problems and neglect.

In addition to the above, there is the need for increased public education about breast cancer and its associated risk factors. Specifically, the education should target creating awareness about the disease in terms of the risk factors, early warning signs and the need for early screening and treatment seeking to avoid late presentations with a poor prognosis. One of the areas of public

education is breast cancer stigma, as stigma from society was identified as one of the key challenges that are faced by women living with breast cancer e.g. the participants reported their friends avoiding them due to their lack of knowledge about breast cancer and that as some people think that breast cancer is contagious. Thus, public education starting from school might be useful as young girls should also be more aware of the risks of breast cancer and be taught breast self-examination skills that will help them to identify any abnormality throughout their lifespan.

8.7 Contribution to academic knowledge

This PhD thesis makes three major contributions to academic scholarship. First is the confirmation of the revised quality of life model (Ferrans et al., 2005) and expansion on the revised quality of life model to include more complex relationships among the variables in the model. This study found bidirectional relationships among the variables as against the unidimensional relations suggested by Ferrans et al. (2005). While revised quality of life model assumes that the predictors of quality of life among persons living with chronic medical conditions are in a unidimensional sequential pattern, there seem to be more complex patterns of the interrelationships among all the variables in the model in influencing the overall quality of life of persons living with chronic medical conditions. The findings support some earlier studies which reported more complex relationships among predictors of quality of life than those reported in the revised quality of life model (Kring & Crane, 2008).

Secondly, the use of an explanatory mixed method in this doctoral thesis provides a holistic picture of the health and wellbeing of women living with breast cancer in Ghana. That is, the known predictors of quality of life among women living with breast cancer as reported by previous studies in other countries were investigated. The qualitative phase of the work provides an in-depth

understanding of these relationships found in the quantitative phase as the qualitative phase shed light on the quantitative outcomes. In addition, the qualitative phase of this doctoral thesis unearthed several psychical and psychosocial challenges among the women by exploring their lived experiences in terms of medical treatment, illness representations, coping strategies and their relationships and communication with healthcare providers. The findings from both phases of this doctoral thesis present a more holistic and encapsulating overview of living with breast cancer in a low resourced setting.

In addition to the above, one of the unique contributions of this study is the fact that the quantitative phase provides more evidence on the mechanisms explaining the influence of some of the key predictors on quality of life among women living with breast cancer as most of earlier studies reported mainly the direct effects of the predictors on quality of life. That is, both direct and indirect effects of the predictors on quality of life were examined and presented throughout this study. The results provide support for stress-and-coping theory (Lazarus & Folkman, 1984, 1987). These findings provide evidence for the significant mediation roles of some key variables which could be targets for cost-effective psychosocial interventions in a limited resource setting like Ghana. Furthermore, a thorough literature search did not reveal any studies that have comprehensively documented issues about the health and wellbeing of women living with breast cancer in Ghana and Africa as whole. Therefore, this study may serve as a useful academic reference material for future studies on breast cancer-related issues in Ghana and beyond.

8.8 Limitations of the study

This doctoral thesis has made significant contributions to the health psychology and specifically, the psycho-oncology literature but there are some limitations that are worth highlighting. These limitations are important to be given the needed attention in the overall interpretation and application of the results. The first and foremost limitation is the use of a cross-sectional study design for the quantitative phase. This design limits any causal inferences as has been inherent in most cross-sectional survey designs. Since the participants were also contacted at only one point in time, the influences of other transient variables which are likely to have confounded the relationships among the study variables were not accounted for by this design. In addition to the above design, the use of a non-probabilistic sampling approach in identifying respondents for this study is a major limitation that needs to be considered in the interpretation of these findings. Despite these limitations inherent in the use of a cross-sectional survey, it was the only practical design to use considering resource constraints in terms of finances, personnel and time as well as patient fatigue.

Secondly, some of the research instruments were not applicable to the Ghanaian context. For instance, the health literacy measure which measures the three key components of health literacy (functional, communicative and critical) was not applicable and the items had to be adapted to suit the needs or circumstances of the women living with breast cancer in Ghana. Thus, the original 14-item scale was reduced to a 6-item scale which gives a picture of overall health literacy without the examination of the key components. In addition to the above limitation, some single items were also used to tap into some more relevant concepts, but has reliability issues. Despite these limitations, the adapted version of the health literacy scale still provided important information on how aspects of health literacy influences health outcomes among women living

with breast cancer. Previous studies have also suggested that the use of single items to measure constructs are as reliable as using multi-item scales (Bergkvist & Rossiter, 2007; Drolet & Morrison, 2001).

In the qualitative phase, the small number of participants involved in the study may not reflect the entirety of the experiences of women living with breast cancer. In addition to these limitations, the sample was also selected from one treatment facility and may not be generalize to the general population of women living with breast cancer. Despite these limitation, the findings from the qualitative phase of the study have provided a very rich data on the lived experiences of women living with breast cancer which have important implications for clinical practice, psycho-social interventions and psycho-oncology research.

8.9 Recommendations for future research

Based on the findings from this doctoral thesis, several recommendations are proposed for future studies to address the social science research gap in the breast cancer literature. Firstly, there is the need for a longitudinal study to examine the health and wellbeing from diagnosis through to post treatment. This would enable researchers to unravel both stable and transient predictors of health and wellbeing among the women living with breast cancer. It is also likely to reveal the trends in the health outcomes of women which could inform interventions targeted at specific periods in the disease journey. Since the prevalence of common mental health problems serve as significant risk factors for poor health outcomes among women living with breast cancer, there is the need for studies which examine the prevalence and the predictors of these common mental health problems including depression, anxiety and suicidal behaviours.

Secondly, access to health information and health literacy play significant roles in the short and long terms health outcomes among women living with breast cancer and therefore it is important to determine the predictors of patients' access to health information and health literacy. The findings would inform measures to improve women's access to health information and health literacy. Related to this recommendation is the validation studies required within the Ghanaian setting as most of the instruments, though highly reliable, have not been validated in the Ghanaian context.

Thirdly, the findings suggest that research on shared decision making would immensely benefit from studying other possible mechanism that link shared decision making to health outcomes such as quality of life. For instance, studies should examine whether shared decision making would influence the coping strategies that are employed by patients in dealing with their illness. It is also important that studies be conducted among physicians to explore their views and attitude towards shared decision making. Due to the large power difference between healthcare professionals and patients as evidenced in the narratives from women with regards to their communication with their healthcare professionals, studies from the perspectives of health professionals would provide a clearer picture in addressing the unmet information and other care needs of women living with breast cancer.

Future studies among caregivers and relatives of women living with breast cancer are urgently needed to understand their own lived experiences of having a patient and relative living with breast cancer. This has become necessary in the face of significant role changes, financial and social burdens reported by women living with breast cancer. The findings from these studies may

help in understanding the needs of women living with breast cancer, and their relatives to inform holistic psychosocial interventions.

8.10 Conclusion

Based on the findings from this study, it is concluded that women living with breast cancer are entangled in a complex web of issues that affect every aspect of their lives. Bio-psychosocial, economic and spiritual domains of functioning among these women are affected by diagnosis of breast cancer. There is an urgent need for a shift in the focus on treatment which is mainly physical to a more holistic approach involving professionals from both medical and non-medical fields to adequately address the needs of the women living with breast cancer. That is, breast cancer goes beyond the individual patient and any attempt at dealing with the disease should include caregivers as well as relatives to ensure better health and social outcomes.

The findings from this doctoral thesis underscore the need for mindfulness-based psychosocial interventions aimed at helping patients cope with their disease by focusing on the positive aspects of existence in the face of challenges. There is also the need for social support networks which may help women in adjusting to their illness as stigmatization from the public and the huge financial implications of the illness is robbing women of their important social networks. These findings have also set the foundation for more social science research on issues surrounding breast cancer to provoke national debates on how to holistically address the issue of breast cancer prevention and treatments.

8.11 Personal reflection on the data collection process

Having received my academic training in quantitative research approaches and data analyses in my undergraduate and master's degree levels, this PhD journey was an intriguing one where there was the need to shift from purely quantitative to a mixed-method design involving qualitative data collection and analyses. Initial challenges were dealt with and several lessons were learnt during the qualitative phase of the data collection.

Firstly, due to recent issues of investigative journalism and exposure of corrupt practices in Ghana, people are now careful in granting interviews to "strangers". This was also influenced by the fact that am doing my PhD in South Africa where some of them thought I was a foreigner despite telling them of my Ghanaian citizenship. This was exemplified by the inability of some patients who participated in the survey refusing a follow-up interview. For instance, one patient explicitly stated that "… they have been advised not to talk to any journalist or stranger by the healthcare workers". This made it difficult in convincing some of the participants that the entire data collection exercise was for an academic purpose only. However, I was able to gain the trust of some of the patients after explaining the rationale behind a follow-up to them. Being able to overcome this mistrust in the system

Secondly, the qualitative interviews drew me closer to the patients as they narrated their experiences of living with breast cancer. The majority of the participants were interviewed in their homes and did not conceal information regarding how breast cancer has influenced their lives as most of them will make reference to things around them at home as evidences. These encounters at the various homes of the participant was an emotional one as I have had no prior contact with persons living with breast cancer. The narratives of the patients in terms of their challenges in living with breast cancer had a negative emotional impact on me privately. However, I relied on

my professional counselling skills to manage my own emotional shortcomings and offered some counselling after each interview by being empathetic, genuine and supportive.

Thirdly, power distance was pervasive in the entire data collection process especially during the interview process. Even though I explained to the participants at the initial stages that I am a student researching issues surrounding living with breast cancer, some of the participants referred to me as "… as for you doctors…". This presupposes that anyone doing anything pertaining to breast cancer is seen as a doctor or health professional. Even though I assured the participants that I am not a medical practitioner, the responses from them suggest the perceived high power distance between the patients and health workers especially in discussing issues relating to their satisfaction with healthcare they received at the hospital.

Fourthly, there were at least two instances of follow-ups where I was told that the patients had died. These were patients who had agreed to participate in the follow-up interviews but unfortunately pass on before the due dates for the scheduled interviews. This episode taught me a lesson about the transient nature of life on this earth. I sought counselling from a senior colleague to deal with the lost as I have developed some attachment to the study participants. The willingness of the rest of the patients to freely open up about their experiences of living with breast cancer and the encouragement to do more research helped me to overcome some of the initial negative emotional experiences.

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APPENDICES

Appendix 1: Ethical clearance from UKZN

24 March 2017

Mr Nuworza Kugbey 216074750
School of Applied Human Sciences – Psychology
Howard College Campus

Dear Mr Kugbey

Protocol reference number: HSS/1428/016D
Project title: Health-Related Quality of life of Women with Breast Cancer in Ghana.

Full Approval – Full Committee Reviewed Protocol

In response to your application received 1 September 2016, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL.**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

with

take this opportunity of wishing you everything of the best   your study.

I

Yours faithfully

Dr Shamila Naidoo (Deputy Chair)
Humanities & Social Sciences Research Ethics Committee

/pm

cc Supervisor: Prof Anna Meyer-Weitz & Dr Kwaku Oppong Asante
cc Academic Leader Research: Dr Jean Steyn
cc School Administrator: Ms Ayanda Ntuli

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 3587/8350/4557 Facsimile: +27 (0) 31 260 4609 Email:
Website:
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Founding Campuses: Edgewood   Howard College   Medical School   Pietermaritzburg   Westville
www.ukzn.ac.za

Appendix 2: Ethical clearance from Korle-Bu Teaching Hospital

KORLE BU TEACHING HOSPITAL
P. O. BOX KB 77,
KORLE BU, ACCRA.

Tel: +233 302 667759/673034-6
Fax: +233 302 667759
Email: Info@kbth.gov.gh
pr@kbth.gov.gh
Website: www.kbth.gov.gh

23rd January, 2017

MR NUWORZA KUGBEY
SCHOOL OF APPLIED HUMAN SCIENCES
COLLEGE OF HUMANITIES
UNIVERSITY OF KWAZULU-NATAL
SOUTH AFRICA

HEALTH LITERACY AND HEALTH-RELATED QUALITY OF LIFE OF WOMEN WITH BREAST CANCER: A STUDY AT THE KORLE BU TEACHING HOSPITAL

KBTH – IRB /00035/2016

Investigator: Mr Nuworza Kugbey

23rd January, 2017 the Korle-Bu Teaching Hospital Institutional review Board (KBTH IRB) reviewed and granted approval to the study entitled "Health Literacy and Health-Related Quality of Life of Women with Breast Cancer: A study at the Korle Bu Teaching Hospital"

Please note that the Board requires you to submit a final review report on completion of this study to the KBTH-IRB.

Kindly, note that, any modification/amendment to the approved study protocol without approval from KBTH-IRB renders this certificate invalid.

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

This IRB approval is valid till 31st December, 2017. You are to submit annual report for continuing review.

Sincere regards,

OKYERE BOATENG (MR)
CHAIR (KBTH-IRB)

Cc: The Chief Executive Officer
    Korle Bu Teaching Hospital

    The Director of Medical Affairs
    Korle Bu Teaching Hospital

Appendix 3.1: Consent form for individual participants (Quantitative)

CONSENT FORM FOR INDIVIDUAL PARTICIPANTS (SURVEY)

Discipline of Psychology

School of Applied Human Sciences

College of Humanities

University of KwaZulu-Natal

Dear Madam,

My name Nuworza Kugbey, a PhD student at the University of KwaZulu-Natal, Durban, South Africa conducting a study as part of my final research thesis. The purpose of the study is to study the health-related quality of life of women living with breast cancer in the Greater Accra Region of Ghana. Therefore, my research sample consists of women living with breast cancer and receiving care at the Radiotherapy Unit of the Korle-Bu Teaching Hospital, Accra-Ghana. The knowledge gained from this study will extend the existing body of knowledge regarding quality of life among women living with breast cancer in Ghana, provide guidelines for policy development and will also contribute to the development of psychosocial interventions for women living with breast cancer and identify ways to improve the quality of life women living with breast cancer.

This study will require you to answer a few questions about yourself e.g. your age, level of education, marital status, etc. and seven short questionnaires. Complete anonymity of all participants will be ensured. The questionnaire will be kept for five (5) years in accordance with the University regulations and thereafter it will be disposed of by means of shredding. Participation is voluntary and you are completely free to withdraw from this study at any stage for any reason.

Your participation will be highly appreciated and it will not take more than 30 minutes to complete. Please feel free to contact either me or my supervisors for any further clarification regarding this study.

If you have any questions about your rights as a participant please contact PhumeleleXimba in the research office at the University of KwaZulu-Natal on 031-2603587 or email: **ximbap@ukzn.ac.za**.

Yours sincerely,

Researcher: **Nuworza Kugbey**   *Supervisor:* **Prof. Anna Meyer-Weitz**

Tel: +233(0) 249377659 (Ghana)   Tel: +27 (0) 312607618 (South Africa)

Email: nkugbey@gmail.com   Email: meyerweitza@ukzn.ac.za

Co – Supervisor: **Dr. Kwaku Oppong Asante**

Tel: + 27(0) 733 925 332 (South Africa)

Email: kwappong@gmail.com

I …………………………………………………….... (Full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project as discussed with me based on the previous page of

this document, and I give consent to participate in the study. I also grant permission for the survey to be administered and to be used for research purposes only. I fully understand that all the information that I provide will be kept confidential and anonymous.

I understand that:

My participation is voluntary   [   ]

Confidentiality and anonymity have been assured   [   ]

I can withdraw from the study at any time with no negative consequences   [   ]

_____   _____

Signature of participant   Date

_____   _____

Signature of researcher   Date

Appendix 3.2: Consent form for individual participants (Qualitative)

CONSENT FORM FOR   **QUALITATIVE STUDY**

Health-Related Quality of Life of Women Living with Breast Cancer

Good Morning, /afternoon/evening, my name is Nuworza Kugbey. I am a PhD student at the University of KwaZulu-Natal, 4041, Durban, South Africa. I am conducting a study among women living with breast cancer. The purpose of the research is to examine the perceptions, experiences and coping strategies used by women living with breast cancer in the Greater Accra Region in Ghana. The knowledge gained from this study will extend the existing body of knowledge regarding quality of life among women living with breast cancer in Ghana, provide guidelines for policy development and will also contribute to the development of psychosocial interventions for women living with breast cancer and identify ways to improve the quality of life women living with breast cancer. I would like to speak to you only if you agree to speak to me.

This discussion will take a maximum of 50 minutes. I will ask you to talk about the following: your experience with breast cancer in terms of how it affects you and how you cope with the illness, your perceptions about breast cancer in terms of the causes, severity, curability and your satisfaction with your communication with doctors/nurses, satisfaction with the information you receive from your doctors/nurses and your general impressions about the healthcare you receive at the hospital.

All information that you give will be kept confidential and be used for research purposes alone and raw data will be destroyed as soon as the study is completely over. Also, we will not use your actual name or designation in reporting the findings of the study so that no one will be able to link your information to you personally.

You will not be given any monetary payments for participating in the study. Your participation in this study is voluntary and you have the right not to talk to us if you do not want to. If you agree to take part in the study, we will ask you to sign a form as an indication that we did not force you to participate in the study. Please note that you will not be at any disadvantage if you choose not to participate in the study. You may also refuse to answer particular questions if you don't feel comfortable answering them. You may also end the discussion at any time if you feel uncomfortable with the interview. I will also need your permission to use audio-tape recorders to capture our discussion.

Should you have any further questions you may call me in the on +233(0) 249377659. If you have any questions about your rights as a participant please contact PhumeleleXimba in the research office at the University of KwaZulu-Natal on +27 (0) 31-2603587 or email: **ximbap@ukzn.ac.za**.

Thank you.

Researcher: **Nuworza Kugbey**   *Supervisor:* **Prof. Anna Meyer-Weitz**

Tel: +233(0) 249377659 (Ghana)   Tel: +27 (0) 312607618 (South Africa)

Email: nkugbey@gmail.com   Email: meyerweitza@ukzn.ac.za

Co – Supervisor: **Dr. Kwaku Oppong Asante**

Tel: + 27(0) 733 925 332 (South Africa)

Email: kwappong@gmail.com

I …………………………………………………….... (Full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project as discussed with me based on the previous page of this document, and I give consent to participate in the study. I also grant permission for interviews to be audio taped, and for the transcribed interview material to be utilized for research purposes only. I fully understand that all the information that I provide will be kept confidential and anonymous.

I understand that:

My participation is voluntary   [   ]

Confidentiality and anonymity have been assured   [   ]

I can withdraw from the study at any time with no negative consequences   [   ]

I also grant permission for my interview to be audio taped   [   ]

_____   _____

Signature of participant   Date

_____   _____

Signature of researcher   Date

Appendix 4: Quantitative research questionnaire

QUANTITATIVE RESEARCH QUESTIONNAIRE

SECTION 1:SOCIO-DEMOGRAPHIC INFORMATION

Indicate your responses by circling any number that is related to your response to the statements below:

1. **Age** (Please write in years): …………………………………….

2. **Marital Status:**

Never married	1
Married	2
Separated/Divorced	3
Widowed	4

3. **Highest Level of Education:**

No Formal Education	1
Primary/JSS/MSLC	2
Secondary	3
Tertiary	4

4. **Can you read in English**

Yes	1
No	2

5. **How will you rate your English ability to read and understand**

Excellent	5	Very good	4	Good	3	Average	2	Poor	1

6. **Religion:**

Christian	1
Islam	2
Other: Specify	3

7. **Employment Status:**

Unemployed	1
Employed	2
Retired	3

8. **Average monthly income:**

Less than GHC 500	1
From GHC500 to less than 1000	2
From GHC1000 to less than 1500	3
From GHC1500 to less than 2000	4
GHC2000 and above	5

9. How long ago, were you first diagnosed with breast cancer? ....

10. Type of current treatment:(*Tick as many as applicable*)

Surgery	1
Chemotherapy	2
Radiotherapy	3

11. Have you ever had any treatment before this current | Yes | **1** | No | **0** | treatment?

12. Do you have any other medical condition?

Yes: Please specify…………………………...	1
No	2

13. Stage of breast cancer…………………………….. (Interviewer)

SECTION 2: MSPSS

Instruction:
Please rate the extent to which you agree/disagree with the following statements by circling the appropriate number on the 1 to 5 point scale provided. Strongly Disagree = **1**, Disagree = **2**, Uncertain = **3**, Agree = **4** and Strongly Disagree = **5**

Statements	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
1. There is a special person who is around when I am in need	1	2	3	4	5
2. There is a special person with whom I can share my joys and sorrows	1	2	3	4	5
3. My family really tries to help me	1	2	3	4	5
4. I get the emotional help and support I need from my family	1	2	3	4	5
5. I have a special person who is a real source of comfort to me	1	2	3	4	5
6. My friends really try to help me	1	2	3	4	5
7. I can count on my friends when things go wrong	1	2	3	4	5
8. I can talk about my problems with my family	1	2	3	4	5
9. I have friends with whom I can share my joys and sorrows	1	2	3	4	5
10. There is a special person in my life who cares about my feelings	1	2	3	4	5
11. My family is willing to help me make decisions	1	2	3	4	5
12. I can talk about my problems with my friends	1	2	3	4	5

SECTION 3: SCSRFQ

Instructions:
Please answer the following questions about your religious faith in managing your Breast cancer by circling the appropriate number. **1 = Strongly Disagree, 2 = Disagree, 3 = Agree and 4 = Strongly Agree**

Statements	Strongly Disagree	Disagree	Agree	Strongly Agree
1. My religious faith is extremely important to me	1	2	3	4
2. I pray daily	1	2	3	4
3. I look to my faith as a source of inspiration.	1	2	3	4
4. I look to my faith as providing meaning and purpose in my life.	1	2	3	4
5. I consider myself active in my faith or church.	1	2	3	4
6. My faith is an important part of who I am as a person	1	2	3	4
7. My relationship with God is extremely important to me	1	2	3	4
8. I enjoy being around others who share my faith	1	2	3	4
9. I look to my faith as a source of comfort	1	2	3	4
10. My faith impacts many of my decisions	1	2	3	4

SECTION 4: HADS

Instructions:

Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

1. **I feel tense or 'wound up':**		8. **I feel as if I am slowed down:**	
Most of the time	3	Nearly all of the time	3
A lot of the time	2	Very often	2
Time to time, occasionally	1	Sometimes	1
Not at all	0	Not at all	0
2. **I still enjoy the things I used to enjoy:**		9. **I get a sort of frightened feeling like 'butterflies in the stomach':**	
Definitely as much	0	Not at all	0
Not quite so much	1	Occasionally	1
Only a little	2	Quite often	2
Not at all	3	Very often	3
3. **I get a sort of frightened feeling like something awful is about to happen:**		10. **I have lost interest in my appearance:**	
Very definitely and quite badly	3	Definitely	3
Yes, but not too badly	2	I don't take as much care as I should	2
A little, but it doesn't worry me	1	I may not take quite as much care	1
Not at all	0	I take just as much care as ever	0
4. **I can laugh and see the funny side of things:**		11. **I feel restless as if I have to be on the move:**	
As much as I always could	0	Very much indeed	3
Not quite so much now	1	Quite a lot	2
Definitely not so much now	2	Not very much	1
Not at all	3	Not at all	0

5.	**Worrying thoughts go through my mind:**		12.	**I look forward with enjoyment to things:**	
	A great deal of the time	3		As much as I ever did	0
	A lot of the time	2		Rather less than I used to	1
	From time to time but not too often	1		Definitely less than I used to	2
	Only occasionally	0		Hardly at all	3
6.	**I feel cheerful:**		13.	**I get sudden feelings of panic:**	
	Not at all	3		Very often indeed	3
	Not often	2		Quite often	2
	Sometimes	1		Not very often	1
	Most of the time	0		Not at all	0
7.	**I can sit at ease and feel relaxed:**		14.	**I can enjoy a good book or radio or TV programme:**	
	Definitely	0		Often	0
	Usually	1		Sometimes	1
	Not often	2		Not often	2
	Not at all	3		Very seldom	3

SECTION 5: FACT-B

Instruction:

Below is a list of statements that other people with your illness have said are important. Please circle one number to indicate your response as it applies to the past 7 days.

0 = Not at all, 1 = A little bit, 2 = Somewhat, 3= Quite a bit and 4 = Very Much

PWB

Statements	Not at all	A little bit	Some what	Quite a bit	Very Much
1. I have a lack of energy	0	1	2	3	4
2. I have nausea	0	1	2	3	4
3. Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
4. I have pain	0	1	2	3	4
5. I am bothered by side effects of treatment	0	1	2	3	4
6. I feel ill	0	1	2	3	4
7. I am forced to spend time in bed	0	1	2	3	4

SFWB

Statements	Not at all	A little bit	Some what	Quite a bit	Very Much
1. I feel close to my friends	0	1	2	3	4
2. I get emotional support from my family	0	1	2	3	4
3. I get support from my friends	0	1	2	3	4
4. My family has accepted my illness	0	1	2	3	4
5. I am satisfied with family communication about my illness	0	1	2	3	4
6. I feel close to my partner (or the person who is my main support)	0	1	2	3	4
7. I am satisfied with my sex life	0	1	2	3	4

EWB

Statements	Not at all	A little bit	Some what	Quite a bit	Very Much
1. I feel sad	0	1	2	3	4
2. I am satisfied with how I am coping with my illness	0	1	2	3	4
3. I am losing hope in the fight against my illness	0	1	2	3	4
4. I feel nervous	0	1	2	3	4
5. I worry about dying	0	1	2	3	4
6. I worry that my condition will get worse	0	1	2	3	4

FWB

Statements	Not at all	A little bit	Some what	Quite a bit	Very Much
1. I am able to work (include work at home)	0	1	2	3	4
2. My work (include work at home) is fulfilling	0	1	2	3	4
3. I am able to enjoy life	0	1	2	3	4
4. I have accepted my illness	0	1	2	3	4
5. I am sleeping well	0	1	2	3	4
6. I am enjoying the things I usually do for fun	0	1	2	3	4
7. I am content with the quality of my life right now	0	1	2	3	4

Instruction _ BCAC

Please circle one number indicating your response as it applies to the past 7 days by use the following response format: **0= Not at all, 1= A little bit, 2= Somewhat, 3= Quite a bit, and 4= Very Much**

STATEMENTS	Not at all	A little bit	Some what	Quite a bit	Very Much
1. I have been short of breath	0	1	2	3	4
2. I am self-conscious about the way I dress	0	1	2	3	4
3. One or both of my arms are swollen or tender	0	1	2	3	4
4. I feel sexually attractive	0	1	2	3	4
5. I am bothered by hair loss	0	1	2	3	4
6. I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
7. I worry about the effect of stress on my illness	0	1	2	3	4
8. I am bothered by a change in weight	0	1	2	3	4
9. I am able to feel like a woman	0	1	2	3	4
10. I have certain parts of my body where I experience pain	0	1	2	3	4

SECTION 6: MINI-MAC

Instruction:

Read the statements carefully and indicate the extent to which a given statement applies to you at present regarding your illness. **1=Does not apply at all to me, 2= Rarely apply to me, 3= Apply to me sometimes** and **4 = Totally applies to me**

Statements	Not at all	Rarely	Some times	Always
1. I feel that life is hopeless	1	2	3	4
2. I can't handle it	1	2	3	4
3. I can't cope	1	2	3	4
4. I feel there is nothing I can to do to help myself	1	2	3	4
5. I am not very hopeful about the future	1	2	3	4
6. I feel like giving up	1	2	3	4
7. I feel completely at a loss about what to do	1	2	3	4
8. I think it is the end of the world	1	2	3	4
9. I am upset about having cancer	1	2	3	4
10. I worry about the cancer returning or getting worse	1	2	3	4
11. I am a little frightened	1	2	3	4
12. I have difficulty in believing that this is happening to me	1	2	3	4
13. I suffer great anxiety about it	1	2	3	4
14. I feel very angry about what has happened to me	1	2	3	4
15. I am apprehensive	1	2	3	4
16. It is a devastating feeling	1	2	3	4
17. I am determined to beat this disease	1	2	3	4
18. I am very optimistic	1	2	3	4
19. I see my illness as a challenge	1	2	3	4
20. I try to fight the illness	1	2	3	4
21. I make a positive effort not to think about my illness	1	2	3	4
22. I distract myself when thoughts about my illness come into my head	1	2	3	4
23. Not thinking about it helps me cope	1	2	3	4
24. I deliberately push all thoughts of cancer out of my mind	1	2	3	4
25. Since my cancer diagnosis, I now realize how precious life is and I'm making the best of it	1	2	3	4
26. I've put myself in the hands of God	1	2	3	4
27. I've had a good life. What's left is a bonus	1	2	3	4
28. At the moment I take one day at a time	1	2	3	4
29. I count my blessings	1	2	3	4

Instruction:

You will read nine statements that a person can make about his/her doctor. Please choose the appropriateness of each statement for your doctor by marking one number per statement. The meaning of the numbers is as follows:

1 = not at all appropriate, 2 = somewhat appropriate, 3 = appropriate, 4 = mostly appropriate, 5 = totally appropriate

STATEMENTS	Not at all	Rarely	Some times	Mostly	always
1. My doctor helps me	1	2	3	4	5
2. My doctor has enough time for me	1	2	3	4	5
3. I trust my doctor	1	2	3	4	5
4. My doctor understands me	1	2	3	4	5
5. My doctor is dedicated to help me	1	2	3	4	5
6. My doctor and I agree on the nature of my medical symptoms	1	2	3	4	5
7. I can talk to my doctor	1	2	3	4	5
8. I feel content with my doctor's treatment	1	2	3	4	5
9. I find my doctor easily accessible	1	2	3	4	5

SDM

STATEMENTS	Yes	No
1. Do you feel that you have been involved by your doctors/nurses in your treatment decision making?	1	2
2. Do you wish to be more involved in your treatment decision than your current involvement?	1	2

Section 8: HLS

1. What are your main sources of information about breast cancer? ....
   (*Tick as many as applicable*).

Television	1
Radio	2
Newspapers	3
Hospital/Doctors/Nurses	4
School	5
Church/Mosque	6
Community meetings	7

I would like to ask you about information you receive from the doctors and nurses (health care providers):

2. How satisfied are you with the **amount** of information about breast cancer from your healthcare provider(s)?

Very satisfied	4	Satisfied	3	Dissatisfied	2	Very dissatisfied	1

3. How satisfied are you with the **quality** of information about breast cancer from your healthcare provider(s)?

Very satisfied	4	Satisfied	3	Poor	2	Very poor	1

4. Do you feel that your concerns are **adequately** addressed by healthcare providers?

Absolutely	4	Very well	3	Somehow	2	Not at all	1

5. Have you ever sought information from other sources (**not health professionals**) about breast cancer?

Yes	1	No	0

   If yes: Continue with the following questions;

6. What kind of information did you seek about breast cancer?
   (*Tick as many as applicable*).

Diagnosis/Prognosis	1
Symptoms	2
Treatment	3
Self-care	4
Alternative Therapy	5

7. Do you find the information useful to your breast cancer?

Yes	1	No	0

8. How will you rate your access to information about breast cancer?

Excellent	5	Very good	4	Good	3	Poor	2	Very poor	1

Instructions:
Below are some statements of actions one could follow after receiving some of the information about breast cancer issues mentioned above. To what extent did you have the following experiences?

Actions	Never	Rarely	Sometimes	Often
You have…				
1. collected information from other sources as well	1	2	3	4
2. paid attention only to some information	1	2	3	4
3. understood all the information you obtained	1	2	3	4
4. shared your thoughts about your health with someone	1	2	3	4

	Never	Rarely	Sometimes	Often
You have…				
1. considered whether the information was applicable to your situation	1	2	3	4
2. considered the credibility of the information	1	2	3	4
3. checked whether the information was correct	1	2	3	4
4. collected information to make decisions about your health	1	2	3	4
5. use the information obtained in your daily life	1	2	3	4

Thank you

Appendix 5: Qualitative interview guide

A. Demographics

A1: How old are you?
A2: Are you currently married? If yes, for how long?
A3: Do you have children? If Yes, how many?
A4: Are you currently working?
A5: What is your highest level of education?
A6: What is your religion?

B. Experience with breast cancer

B1: How long have you being diagnosed with breast cancer?
B2: What kind of treatments do you receive for your illness?
B3: Do you use any other treatment methods apart from the hospital treatment?
(Probe: From where? Why?)
B4: How do you feel about living with breast cancer?
B5: How does living with breast cancer affect your life?
(Probe: physical, social, emotional and spiritual impacts)
B6: How do you cope with your condition?
(Probe: why this coping strategy)
B7: What role does religion play in your coping with breast cancer?
B8: What role does your family and friends play in your coping with breast cancer?
B9: Do you feel stigmatized by your family, friends and neighborhood?
(Probe: If yes, how do you deal with the stigma?)
B10: How will you rate your general health and wellbeing?

C. Perceptions about Breast Cancer

C1: What do you think is breast cancer?
C2: What do you believe to have caused your breast cancer?
(Probe: Why?)
C3: How did you arrive at this information?
C3: Do you believe breast cancer can be completely cured?
(Probe: Why?)
C4: How long do you believe your breast cancer will last?
(Probe: Why?)
C5: How do you feel talking about your illness to others?
(Probe: why?).

D. Healthcare Satisfaction

D1: How satisfied/dissatisfied are you with your communication with the Doctors/Nurses?
(Probe: Why?)
D2: How satisfied/dissatisfied are you with the information you receive from the Doctors/Nurses?
(Probe: Why?)
D3: How satisfied/dissatisfied are you with the general healthcare you receive from this hospital?
D4: Do you have any other concerns that bother/worry you? (Probe: What are they?).