

MENTAL HEALTH, QUALITY OF LIFE AND LIFE EXPERIENCES OF GHANAIAI WOMEN
LIVING WITH BREAST CANCER

MENTAL HEALTH, QUALITY OF LIFE AND LIFE EXPERIENCES OF GHANAIAN WOMEN
LIVING WITH BREAST CANCER

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A Thesis submitted to the School of Graduate Studies in Fulfillment of the Requirements for the Degree
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Abstract

Background: The burden of breast cancer may contribute to elevated psychological distress. Conversely, distress may negatively impact the development, recurrence and diagnosis of cancer as it compromises the immune system and adherence to treatment, creating a vicious cycle. With the breast cancer fatality rate significantly higher in Sub-Saharan African women than in women living in higher income countries, further research is needed to limit the devastating impact of chronic diseases on this population.

Purpose: The aim of the study was to determine if Ghanaian breast cancer patients were more susceptible to higher psychological distress and lower quality of life than healthy Ghanaian women and how their lived experiences affect their mental health.

Method: Sixty-four breast cancer patients and 64 healthy participants were recruited to complete the Kessler Psychological Distress Scale and World Health Organization Quality of life-BREF scale. The life experiences of women living with breast cancer were assessed through semi-structured interviews.

Results: Breast cancer patients had higher psychological distress than the healthy women and also scored lower on the quality of life domains of physical health, psychological well-being and environment. The lived experiences of the breast cancer patients followed a similar journey from suspicion of ill-health to difficulty navigating the health system, feeling the effects of breast cancer and lastly, regaining confidence. Breast cancer had affected the women's daily activities, health, female identity, roles and responsibilities. However, financial, emotional and social support, together with

individual coping mechanisms such as religion and physical exercise, mitigated the impact of the breast disease.

Conclusion: Patient centered care approaches could ease the psychological distress of breast cancer patients. Finally, future research should investigate methods of improving the women's psychological well-being, physical health and environment as it may positively impact the prognosis of Ghanaian breast cancer patients.

Keywords: Breast Cancer, Quality of Life, Psychological Distress, Life Experiences, Ghana

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List of Abbreviations and Symbols

B: Regression beta coefficients

CI : Confidence interval

ER: Estrogen receptor

HIC: High Income Countries

K-10: Kessler Psychological Distress scale

LMICs: Low- and Middle-Income countries

NHIS: National Health Insurance Scheme

OR: Odds ratio

PI: Principal investigator

PLH: Peace & Love hospitals

PR: Progesterone receptor

SES: Socioeconomic Status

SSA: Sub-Saharan African

WHOQoL-BREF: World Health Organization Quality of Life BREF

WHO: World Health Organization

M: Mean

MD: Mean Difference

SD: Standard Deviation

χ^2 : Chi-square test

F: F-test for regression

R^2 : coefficient of determination

p: attained level of significance

t: Student's t variable

n: population size

%: Percentage

Exp(B): Odds ratio

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Declaration of Academic Achievement

The following declaration maintains that the content of this manuscript is research that was completed by Rhonda Boateng with contributions from Dr. Harry Shannon and Dr. Allison Williams. Data collection, data analysis and data synthesis for the production of the manuscript were the responsibility of Rhonda Boateng. Dr Harry Shannon assisted in the study design, quantitative data analysis and manuscript review. Dr. Allison Williams contributed to the study design, analysis of the qualitative data and manuscript review.

Mental Health, Quality of Life and Life Experiences of Ghanaian Women Living with Breast Cancer

Chapter 1: Introduction

1.1.Overview

The purpose of this study was to answer the following questions: Are Ghanaian women living with breast cancer more susceptible to psychological distress and do they have a lower quality of life? Also, how do their lived experiences affect their mental health? A mixed methods approach involving qualitative interviews and a quantitative cross-sectional study design was conducted to answer the research questions.

1.2 Breast Cancer in Africa

Researchers have projected that within the next twenty years two-thirds of cancer patients will be in low- and middle-income countries (LMICs) (Pillay, 2002). Cancer is the cause of death for approximately one million Africans each year (Morhason-Bello, Odedina, Rebbeck, Hardford, Dangou, Denny & Adewole, 2013; Sylla & Wild, 2012). With the incidence of cancer expected to rise by more than 85% by 2030 on the African continent, cancer is an increasing health burden that needs to be addressed (Morhason-Bello et al., 2013).

Globally, breast cancer is the most common form of cancer among women (World Health Organization, 2012). In Sub-Saharan Africa (SSA), breast cancer is the second most common form of cancer and a leading cause of death among women in this region, accounting for 16% of cancer-related deaths (Morhason-Bello et al., 2013).

Reports have shown “that breast cancer incidence peaks between 35 and 45 years in West African women, 10-15 years earlier than for western countries” (Brakohiapa, Armah, Clegg-Lamptey & Brakohiapa, 2013). Therefore, the disease is largely affecting premenopausal women who are still within the workforce. Additionally, the majority of cancer patients are diagnosed in late stages of the cancer which decreases likelihood of survival (Ameade, Amalba, Kudjo, Kumah & Mohammed, 2014). Taking

this into consideration, on the smaller scale, breast cancer can impede a woman's ability to provide for her families and on the larger scale, it can affect a country's economy (Igene,2008).

1.2.1. Breast Cancer Risk Factors

Being a woman and being older are the two main risk factors for breast cancer. The risk of developing breast cancer increases with age and as life expectancy increases, it is expected that more people will be diagnosed with cancer (World Health Organization, 2012). However, the incidence of breast cancer is increasing in many LMICs due to other factors such as exogenous hormones, changes to menstrual and reproductive life, obesity, high alcohol consumption, adoption of Western lifestyles and other extraneous factors (Sasco, 2013; Sitas, Parkin, Chirenje, Stein, Abratt & Wabinga, 2008).

Both exogenous and endogenous hormones, especially estrogen, are associated with increased risk of breast cancer. In a meta-analysis performed by Kahlenborn, Modugno, Potter & Severs (2006), the greater risk of developing breast cancer in premenopausal women was linked to intake of oral contraceptives. A South African case control study also found “that combined oral contraceptives can result in a small increase in risk, confined to women below the age of 25 years, but that injectable progesterone contraceptives did not increase risk” (Shapiro, Rosenberg, Hoffman, Truter, Cooper, Rao, ... & Bailie, 2000). Yet, according to an American population-based case-control study involving 4575 breast cancer patients and 4682 controls aged between 35 and 64 years old, the consumption of oral contraceptives did not increase risk of developing the breast disease significantly (Marchbanks, McDonald, Wilson, Folger, Mandel, Daling, ... & Norman, 2002).

Worldwide, women are attaining higher levels of education, increasingly entering the workforce and exercising more control over their reproductive lives. Consequently, they are having fewer children and are older at first full-term pregnancy (Yip, Buccimazza & Hartman, 2015). An additional reproductive change is the shortening of breastfeeding periods. Two-thirds of the difference in breast-cancer incidence between developed and developing countries are thought to be accounted for by

breastfeeding, a hypothesized protective factor against breast cancer. However, this finding has been difficult to confirm in Africa (Sitas et al, 2008).

In the African context, diet has not been highlighted as a significant contributor to the development of breast cancer (Sitas et al, 2008). However, there is evidence that low physical exercise levels can play a role and “obesity in postmenopausal women has been identified as a risk factor when assessed by waist-hip ratio in sub-Saharan Africa” (Sitas et al, 2008).

Other extraneous factors that may be increase the likelihood of developing breast cancer include stress and “exposure to radiation and chemicals” (Sasco, 2013; Igene,2008).

Many of the aforementioned risk factors are associated with economic and urban development. As African women adopt “western lifestyles”, the incidence of breast cancer is expected to continue to increase which adds to the importance of studying the disease (Sitas et al, 2008).

1.2.2. Contributors to high mortality

In West Africa, the estimated incidence of breast cancer is 32 cases per 100,000 people with a mortality rate of 19/100,000 (Ferlay, Shin, Bray, Forman, Mathers & Parkin, 2010). In contrast, there are 77 cases per 100,000 people in North America but mortality rates are 15/100,000. Hence, although high income countries (HIC) have a higher incidence of breast cancer, there is a much higher fatality rate for West African women (Eng, McCormack, dos-Santos-Silva, 2014). It is estimated that one third of breast cancer related deaths globally can be averted with early detection and treatment (World Health Organization, 2012; Dedey, Wu, Ayettey, Sanuade, Akingbola, Hewlett, ... & Adanu, 2016). Survival rates among American breast cancer patients are greater for those with Stage I cancer (96% survival rate over five-year period) than patients with stage IV cancer (as low as 18% five-year survival rate) (Henson, Ries, Freedman & Carriaga, 1991; Rambau, 2011).

There are many contributors to the high mortality rate among SSA women. First, the majority of breast cancer patients present to the hospital in the late stages of cancer. Consequently, these women

have a poor prognosis (Ameade et al., 2014). Second, as is characteristic of LMICs, technology is outdated and there are limited treatment options due to unaffordability and unavailability (Igene, 2008). In addition, SSA women tend to develop triple negative hormone receptor tumors that are more aggressive and difficult to treat. Lastly, of those who do start treatment, many tend to default.

Financial hardships, geographical barriers and ignorance of the disease are all noted factors contributing to late stage diagnosis and, therefore, to mortality. As poverty disproportionately affects SSA, many women are unable to afford medical treatment (Adbulrahman & Rahman, 2012). Not only does this delay patients from presenting to a hospital, it is the leading reason for patients to default on breast cancer treatment (Harding, Selman, Agupio, Dinat, Downing, Gwyther, Mashao, Mmoledi, Sebuyira, Ikin & Higginson, 2010). Additionally, due to the limited resources of LMICs, there are scant medical facilities, obliging many women to travel long distances to receive medical attention (Brakohiapa et al., 2013). Finally, breast cancer awareness programs are generally unavailable preventing women from learning to recognize the signs and symptoms of cancer. Social stigma, fear of mastectomy and preference for alternative/ traditional remedies were also suggested factors for late-stage diagnosis (Scherber, Soliman, Awuah, Osei-Bonsu, Adjei, Abantanga & Merajver, 2014; Clegg-Lamphey, 2009; Aziato & Clegg-Lamphey, 2015).

SSA women tend to have breast cancer types with unfavorable prognostic features that promote high mortality rates including “young age at presentation, large tumor size, high grade histologic subtypes and low rate of hormone receptor positivity” (Ohene-Yeboah & Adjei, 2012). These typical characteristics of African patients may explain some of the discrepancy in breast cancer mortality rates between SSA women and women in HICs as the cancers in SSA women are more difficult to overcome as they are less like to respond to hormone treatment (Ohene-Yeboah et al, 2012). Studies have shown that younger breast cancer patients had more aggressive tumors, higher rate of metastasis, higher clinical stage and lower rates of estrogen receptor (ER) and progesterone receptor (PR) hormone receptor

expression than older cases (Rambau, 2011). The general consensus is that SSA women are more prone to aggressive breast cancer but explanations for this have not been confirmed (Ohene-Yeboah et al., 2012).

Defaulting on treatment is a factor in the high mortality rate in LMICs. Islamic religion, seeking treatment with traditional healers, and lack of awareness about national health insurance coverage of breast cancer treatment were predictors of incomplete medical treatment (Scherber et al., 2014; Clegg-Lamprey, Dakubo & Attobra, 2009). Additionally, a study in Ghana reported that patients at Korle-Bu Teaching Hospital complained about the care they received. They cited lack of sympathy and emotional support, lack of information and communication, lack of counselling and slow processes as care related reasons for defaulting (Clegg-Lamprey, Dakubo, Attobra, 2009). Overall, there are many direct and indirect contributors to the high mortality in SSA.

1.2.3. Breast cancer in Ghana

In Ghana, cancer follows cardiovascular disease and accidents/poisons as the most common cause of hospital admissions (Clegg-Lamprey et al 2009). Breast cancer is the second most common cancer and the number one cause of cancer mortality among Ghanaian women (Clegg-Lamprey, Dakubo & Attobra, 2009). It is estimated that Ghana has an incidence rate of 26 cases per 100,000 people and a mortality rate of 12/100,000 (Scherber et al., 2014; International Agency for Research on Cancer, 2014). The incidence has increased nationwide and is expected to continue to rise due to the many aforesaid factors (Asumanu, Vowotor, & Naaeder, 2000; Dedey et al., 2016; Brakohiapa et al., 2013). It is estimated that 60-70% of women are diagnosed at advanced stages III and IV of the disease with a mean of approximately 10 months of experiencing symptoms at the time of presentation (Dedey et al., 2016; Ohene-Yeboah & Adjei, 2012).

Ghana shares many of the same contributors to high mortality as other SSA countries: unaffordability, defaulting treatment, advanced cancer stage and aggressive cancers (Obrist, Osei-

Bonsu, Ahwah, Watanabe-Galloway, Merajver, Schmid & Soliman, 2014). Likewise, although the risk of breast cancer development increases with age globally, in Ghana similar to neighboring countries, breast cancer affects mostly young pre-menopausal women. The majority of hospitals specializing in breast cancer are located in Accra and Kumasi which presents an additional financial and physical barrier for women who live outside these major city centers (Brakohipa et al 2013). A study at Korle-Bu Teaching hospital in Accra found that nearly thirteen percent of patients default after diagnosis prior to treatment. Approximately 10% of women who start treatment also default. Patients who have defaulted and then return to the hospital often reappear with advanced disease and decreasing curative effect of treatment (Clegg-Lampsey, Dakubo & Attobra, 2009).

1.3. Mental Health

The low priority ascribed to mental health by African governments is evident as 20% of African countries have not implemented mental health policies and funding for mental health treatment are not available in nearly 40% of African states (Bird et al., 2010; WHO,2005; Skeen, Lund, Kleintjes, Flisher & MHaPP Research Programme Consortium, 2010). Consequently, African countries offer limited access to mental health services, a factor to the worldwide mental health treatment gap where less than 10% of individuals in LMICS with mental disorders have access to treatment (Sweetland, Oquendo, Sidat, Santos, Vermund, Duarte, Arbuckle & Wainberg, 2014).

1.3.1 Mental Health & Risk factors

Poverty, gender, education and environment are primary factors that have been associated with poor mental health. Altogether, depression is the most prevalent mental illness in developing countries (Coleman, Morison, Paine, Powell & Walraven, 2006)

Research has shown that individuals with lower socioeconomic status (SES) had poorer mental health (Boyce, Raja, Patranabish, Bekoe, Deme-der & Gallupe, 2009). Similarly, mental illness was more prevalent in the unemployed and in individuals with the lowest incomes who lacked external

economic assistance and who had difficulty paying their bills (Greif & Dodoo, 2015; Bhagwanjee, Parekh, Paruk, Petersen & Subedar, 1998). It is hypothesized that individuals in poverty or with financial trouble are more susceptible to developing a mental health problem “due to factors such as increased levels of stress, malnutrition, exclusion, obstetric risks and exposure to violence” (Patel, 2001).

Women in LMICs have higher rates of depression and anxiety than men, the two most common mental health problems (Prince, Patel, Saxena, Maj, Maselko, Phillips, & Rahman, 2007). It is believed that this results from “gender-specific social factors such as isolation, powerlessness, domestic violence, low education levels and economic dependence” (Moultrie & Kleintjes, 2006). Women’s health can also have a great effect on the family, most notably on children's health. The children of mothers with poor mental health had increased likelihood of “stunting, early cessation of breastfeeding and diarrhoeal disease (Adewuya et al, 2008; Rahman, Iqbal, Bunn, Lovel & Harrington, 2004; Skeen et al 2010).

In LMICS, level of education is a consistent and significant predictor of mental illness with less educated people having higher levels of mental disorder (Greif & Dodoo, 2015; Boyce et al, 2009). Evidence suggests that increased level of education may be a protective factor against mental health problems as it tends to “[improve] one’s social status and [increase] earning capacity. Furthermore, education may promote the brain to develop to its full capacity”. (Skeen et al 2010)

Other factors that have been associated with “indicators of poor mental health [are] poor housing [conditions], food insecurity and exposure to recent and traumatic life events” (Myer, Stein, Grimsrud, Seedat & Williams, 2008; Skeen et al 2010). According to the Life Event schedule of the World Mental Health Survey, illness/injury, loss of employment, major financial troubles and others are classified as recent life events and traumatic life events included “experiences of accidents, illness, loss of loved ones, abuse, crime, war and natural disasters” (Myer et al., 2008).

More priority needs to be placed on mental health as it increases chances of loss of employment due to diminished productivity which can lead to further negative life experiences and consequences such as a decrease in income and increased social stigma (Skeen et al., 2010).

1.2.2 Mental Health in Ghana

Depression and anxiety are the most common mental disorders affecting Ghanaian women. Circumstances that impede Ghanaian women's mental health "include poverty, everyday burdens of paid work, housework and childcare, domestic violence, chronic illness experiences, infertility, and age-related discrimination, in particular witchcraft accusations" (De Menil, Osei, Douptcheva, Hill, Yaro, & Aikins, 2012).

Menil and colleagues' (2012) study highlighted the link between physical and mental health - among the 2814 female participants, women who took medication or vitamins were more likely to have higher levels of psychological distress. Additionally, it adds to arguments that doctors and nurses should screen for mental disorders.

1.4 Mental Health & Breast cancer

Both physical and mental health interacts in a bidirectional manner where the aggravation of one type of condition can deeply impact the other. Psychological disorders are strong predictors of the development of communicable and non-communicable diseases (Prince et al., 2007; Sweetland et al., 2014). Conversely, individuals with physical health conditions - especially chronic illnesses such as HIV, diabetes, heart disease and cancer - are at an increased risk of developing a mental disorder (Patel & Kleinman, 2003; Menil et al., 2012). Left untreated, mental disorder can negatively impact physical health mainly through negative health-related behaviors (Sweetland et al., 2014).

The female breast is intrinsically linked to psychological concepts such as self-esteem, gender identity, femininity and motherhood (Akin-Odanye, Asuzu & Popoola, 2011). Hence, a disease such as breast cancer which affects this organ can be a source of significant stress and may be harmful to a

woman's psychological wellbeing. A study in Malaysia revealed a 51% prevalence of psychological distress and 32% prevalence of depression and anxiety among 168 women with breast cancer undergoing out-patient chemotherapy (Zainal, Hui, Hang & Bustam, 2007).

Breast cancer has emotional implications characterized by deep feelings and fears. The combination of psychological and physical symptoms experienced by breast cancer patients is described as "dual experience trajectory" (Lackey, Gates, and Brown, 2001). Anxiety and depression are the most frequent mental disorders for breast cancer patients and "psychosocial issues associated with breast cancer include concerns about social stigma, body image, or changes in social roles" (Distelhorst, Cleary, Ganz, Bese, Camacho-Rodriguez,... Anderson, 2015; Akin-Odanye et al., 2015). Psychological distress can worsen a patient's outcome.(Greif & Dodoo, 2015; Fann et al, 2008; Badger et al., 2001; Groenvold et al., 2007; Pasacreta, 1997).

Berard, Boermeester & Vilijoen (1998) postulated that levels of psychological distress and predisposition to mental disorder among cancer patients vary according to intrinsic and extrinsic factors. Accordingly, factors related to the breast disease such as type, stage and recurrence as well as cancer complications and treatment side effects are labeled intrinsic factors (Akin-Odanye et al., 2011; Berard, Boermeester & Vilijoen, 1998). Conversely, history of mental disorder, facility of navigating through the healthcare system, personal support and "psychosocial stressors" are the extrinsic factors (Berard, Boermeester & Vilijoen, 1998). Therefore, these vulnerability factors in conjunction with breast cancer can be conducive to the progression of psychological distress and mental illness (Berard, Boermeester & Vilijoen, 1998).

Clegg-Lamprey, Dakubo & Attobra (2009) evaluated the psychosocial and emotional impact of being diagnosed with breast cancer in Ghanaian women. Fear, shock, devastation, weeping and depression were the most common reactions to hearing the diagnosis. The primary concerns of the

patients were fear of death and “mastectomy/deformity, cost of treatment, uncertain future, job security and marriage security” (Clegg-Lampsey, Dakubo & Attobra, 2009)

A study by Akin-Odanye, Chioma and Abiodun (2011) indicated varying degrees of depressive symptoms from minimal to severe depression in Nigerian female breast cancer patients receiving chemotherapy. The results demonstrated that women with breast cancer knowledge and higher education had lower levels of depression. Simultaneously, those with advanced cancer stage had higher risk for developing depression. Average monthly income was proposed to be a significant predictor for depression as those with higher income will be at a reduced likelihood of developing a mental disorder (Akin-Odanye, Chioma and Abiodun, 2011).

In contrast to the two previous studies where the women were in the early stages of the breast cancer treatment, the current study aims to assess the psychological distress and quality of life of women at various stages of breast cancer treatment journey. In all, both physical and mental health issues work in a symbiotic manner and can compromise an individual's quality of life and can interfere with one's daily activities and ability to care for oneself (Berard, Boermeester & Viljoen, 1998; Greif & Doodoo, 2015). Therefore, it is hoped that this preliminary study may lead to more focused research and possible changes to care and management of women in breast cancer in Ghana.

Chapter 2: Method

Design

This study is a sequential explanatory mixed methods study composed of two phases: a quantitative followed by a qualitative study. The qualitative results assist in explaining and interpreting the findings of a quantitative study. The quantitative approach was a cross-sectional design and the primary outcomes were psychological distress and quality of life.

Hermeneutic Phenomenology was the qualitative method applied to the second phase of the project. This section was inspired by Gonzaga (2013) who conducted a qualitative research examining the lived experiences of Ugandan breast cancer patients. In phenomenology, the focus is “targeted toward understanding the meaning of the lived experience in a particular phenomenon” (Richards & Morse, 2007). The study’s objective required understanding how each individual constructs and experiences their everyday lives subjectively. Therefore, the phenomenological method is hermeneutical because it is interpretive and there is an understanding that there is no objective reality (Kafle, 2013; Goble & Yin, 2014). This method was the most appropriate for achieving the objective of furthering our understanding of the lived experiences of breast cancer patients and the disease’s impact on the lives of Ghanaian women. This approach also permitted the modification of interview questions during inquiry as the interviewer deems fit to truly capture each participant’s unique experience (Richards & Morse, 2007). Qualitative data was collected through semi-structured interviews.

Participants

Using a two-sided $\alpha = 0.05$ and power of 0.80 to detect a medium-sized effect between two groups, 64 breast cancer patients and 64 healthy controls were recruited to complete the quality of life and psychological distress scales (Cohen, 1992). The age of the 64 healthy participants ranged from 23 to 68 years old ($M = 52$, $SD = 10.22$) and the 64 women with breast cancer were aged between 24 and 75 years old ($M = 54$, $SD = 11.67$). See descriptive statistics listed in Table 1.

Eligibility Criteria

To be eligible to participate in the study, reading or oral comprehension of English or Twi was required. Twi is spoken as first or second language by 8.3 million Ghanaians principally in the Ashanti region. It is the most common local language (Paul, Simons & Fennig, 2015). Although men can have breast cancer, the disease is almost universally a disease of women. Thus, only women were included in this study. The minimum age of eligibility for the study was 18 years.

The cases must have been diagnosed with breast cancer for the first time in the last five years and had no co-morbidity with any other major illnesses. Participants in the healthy population group were selected carefully to ensure similar age distribution among both groups. The controls must not have been diagnosed with a major illness in the previous year. Major illnesses include cancer, cardiovascular disorders, diabetes, chronic pulmonary diseases, Alzheimer's disease, and dementias. Due to the high prevalence of hypertension in Ghana, women who disclosed having hypertension were still eligible to participate.

Recruitment

Breast cancer patients were recruited from the Peace & Love hospitals (PLH) through referrals by the health care providers and patient counsellors.

Healthy participants were recruited at the hospital and at breast cancer screening events throughout the country so the sample would include women from diverse places of residence similar to the breast cancer patients. At each screening event, the principal investigator (PI) was introduced and the purpose of the study and eligibility criteria was announced. Eligible candidates were then invited to complete the questionnaire at a designated station. All participants received 10 GHC as a token of appreciation. This converts to approximately 3.14 Canadian dollars.

Materials

Demographic questions

The World Health Organization Quality of Life BREF (WHOQoL-BREF) begins with a demographic section (Appendix A). Participants had to indicate their place of residence, level of education, date of birth and marital status. Individuals also disclosed major health issues. Breast cancer patients were asked what type of treatment they were receiving and their cancer stage. Stage 1 and 2 cancers were defined as 'early' while Stage 3 and 4 cancers were considered 'late'.

Kessler Psychological Distress scale

The Kessler Psychological Distress scale (K-10) is a robust measure of non-specific psychological distress (Appendix B; Bougie, Arim, Kohen, & Findlay, 2016). This scale was selected because it had previously been validated in a SSA population (Myer, Stein, Grimsrud, Seedat & Williams, 2008).

The K-10 has a total of six questions. The first question has 10 sub-items asking the participants how often they have experienced different feelings in the past month. Each sub-item is on a 5-point scale where 1 is all of the time and 5 is none of the time. The 10 sub-items were then reverse coded to yield a score between 10 and 50, with fifty representing high psychological distress. Based on normative data on the K-10, individuals who scored under 20 were considered to be doing well. However, a score between 20 and 24 may indicate that an individual has a mild mental disorder and a score between 25 and 29 may point to a moderate mental disorder. Women who scored over 30 were considered to have a severe mental disorder (Andrews & Slade, 2001; Kessler, Andrews, Colpe et al, 2002).

The remaining five questionnaire items sought to understand how feelings of psychological distress had progressed in comparison to previous months, how these feelings had affected the individual's ability to work and how often these feelings were caused by physical health problems.

WHOQOL-BREF

According to the World Health Organization (WHO), quality of life is defined as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and

in relation to their goals, expectations, standards and concerns" (Harper & WHOQOL group, 1996).

Based on this definition, the WHOQOL-BREF was developed as a measure of quality of life consisting of four domains: Physical Health, Psychological, Social relationships and Environment.

The facets incorporated within the physical health domain are activities of daily living, dependence on medicinal substances & medical aids, energy, mobility, pain, sleep and capacity for work.

The psychological domain included bodily image & appearance, negative & positive feelings, self-esteem, spirituality/ religion/personal beliefs and thinking, learning, memory & concentration.

The questions in the social relationships domain related to personal relationships, social support and sexual activity.

The environment domain included questions pertaining to financial resources; physical safety; accessibility to quality health and social care; opportunities for acquiring new information; opportunities for recreation/ leisure activities; physical environment (pollution/ noise/ traffic/ climate/ home) and transport.

A systematic and critical review undertaken by Bowden and Fox-Rushby (2003) found that “the WHOQOL approach [is] more likely to establish reliable conclusions concerning the equivalence of their instrument across countries” when compared to other quality of life scales. Due to the lengthiness of the WHOQOL-100, the WHOQOL-Bref was selected in order to increase the likelihood of completion of the questionnaire by the Ghanaian women. The WHOQOL-Bref has been tested and determined to be a valid measure of quality of life and correlated with the WHOQOL-100 (Harper & WHOQOL group, 1996). Authors of the scale also encouraged the use of the WHOQOL-Bref for cross-sectional studies (Harper & WHOQOL group, 1996).

Each of the 26 question items were on a five-point scale. Using item responses, scores on a 20-point scale were produced for each domain: physical health, psychological well-being, social relationships and environment.

Scores for overall quality of life and satisfaction with health were derived from question items 1 and 2, respectively. There were only 5 score possibilities on these two outcomes: 0, 25, 50, 75 and 100. In order to perform a logistic regression, each score was converted into dichotomous variables (low and high) using a median split. Women who scored 75 or 100 were marked as high overall quality of life and/or satisfaction with health and those who scored 0, 25 or 50 were labeled low for the same factors.

The scores on question items 1 & 2 were then computed to yield a score for overall quality of life & satisfaction with health. The scores ranged from 4 to 20 on a two-point interval. This outcome was also converted into a dichotomous variable. All scores below 16 were considered as having a low overall satisfaction with quality of life and health.

Semi-Structured interview

The interview questions followed the premise of phenomenological inquiry and were also inspired by the interview questions of Gonzaga (2013). The interview schedule, available in Appendix C, was modified based on feedback from hospital staff and patients. The interviews inquired into breast cancer knowledge prior to diagnosis, how breast cancer had affected the women's everyday lives, their female identity and their family and community roles as well as identified coping strategies.

Translation

The questionnaires (demographic component, Kessler K-10 and WHOQOL-BREF) were available in English and in Twi for non-English speakers. The questionnaires were translated to Twi by a journalism student fluent in both languages. It was then reviewed by the PI who reads and understands the language. The questionnaire was back translated to English by another individual, a biology graduate. Then, Twi version was slightly modified to reflect the recommended changes.

Procedure

Quantitative

The potential participants were told the purpose of the study, the risks associated with participating and the compensation. Participants with breast cancer were given the option to complete the scales at home or in an office at the Peace & Love Hospital under the supervision of the PI. Only three breast cancer patients opted to complete the study at home. Due to the difficulty of recuperating the questionnaires, healthy women were not given the option of completing the scales at home.

After providing consent, the participants answered the demographic questions followed by the WHOQoL-Bref and then the Kessler K-10 questionnaire. The questionnaires were completed in one session lasting on average 30 minutes. In most cases, the scales were interviewer-administered or interviewer-assisted. Figure 1 visually presents the procedure in a block diagram.

Quantitative Analysis

Independent Variables

When comparing quality of life and psychological distress between the two groups of women, the independent variables were age, education, marital status and cancer diagnosis. Age was a continuous variable and cancer diagnosis was a dichotomous variable. Dummy variables were created for marital status and education. Marital status had three categories: single, married (reference) and widowed. For marital status, those who were married or living as married were grouped under the “Married” variable. Divorced, single and separated women were grouped. Being widowed was a separate category as these women received more community support and do not have the negative social stigma of being divorced, single or separated. There were four categories of education: no education (reference), elementary, high school, and tertiary.

When analyzing the factors that may influence quality of life and psychological distress within the cancer population, age, marital status, education and cancer treatment were independent variables. The categories of cancer treatment were no treatment (reference), chemotherapy, breast surgery,

radiotherapy and hormone therapy. Due to the many possible combinations, cancer treatments were treated as separate variables.

Multiple Regression

Multiple regressions were run to predict the scores on the Kessler Psychological Distress Scale as well as the physical health, psychological well-being, social relationships and environment domains of the WHOQoL-BREF from cancer diagnosis, age, education and marital status. Additionally, with the breast cancer population, multiple regressions were conducted to identify significant predictors of the score on the four domains of the WHOQoL-BREF scale and the psychological distress scale from cancer treatment, age, education and marital status.

Logistic Regression

Logistic regressions were performed to ascertain the effects of age, marital status, education and cancer diagnosis on the likelihood of self-reporting a high quality of life, high satisfaction with health and receiving a high computed score for both health and quality of life. The outcomes were again assessed using logistic regressions with cancer treatment, age, education and marital status as predictors within the breast cancer population.

Independent-samples t-tests

To compare the responses of breast cancer patients and healthy women on the K-10 and WHOQoL-BREF question items, independent-samples t-tests were conducted. Significant differences in WHOQoL-BREF domain scores between cases and controls were also analyzed with independent-samples t-tests.

Qualitative

A subset of breast cancer patients were interviewed at random but with special consideration for age, marital status and education. To be eligible for the qualitative interview, the breast cancer patients were required to speak English or Twi. Interviews were audio-recorded and transcribed electronically

into Microsoft Word. To capture expressions and subtleties, the interviews conducted in Twi were not translated into English.

The sample of interviewees included women representing diverse demographic factors (marital status, education and age range) to ensure that the life experiences of the selected interviewees reflected the experiences of the larger sample of breast cancer patients. Data saturation was considered achieved when no new themes emerged among the sample.

A direct announcement was made at the beginning and at the end of the interview. After completing the K-10, the selected participants were told that the PI had additional questions. They were explained that the questions sought to highlight the impact breast cancer had on their lives. At the end of the interview, the participants were asked if they had any questions for the researcher. Finally, they were informed about local mental health resources in the debriefing form (Appendix D).

Qualitative Analysis

As per the phenomenological approach, a priori knowledge and hypotheses were written down in field notes (Richards & Morse, 2007). The researcher practiced bracketing which is defined as “a conscious distancing of their own inner lives and sense making from those of the persons studied to gain a more authentic view” (Giacomini, 2010). Additionally, critical reflexivity was performed throughout: the researcher critically analyzed how personal views and actions may be influencing the interviews, participant-researcher relationships, data collection and data analysis (Hay, 2010). Moments of reflexivity were reported in the field notes. Bracketing and critical reflexivity enhanced the credibility of the research findings.

The first read-through of the transcripts was to write memos and preliminary codes as well as to aid in the development of a codebook that contained codes, sub-codes, themes and sub-themes. The interview schedule and field notes were also sources for the codebook.

The second phase of analysis began with the coding of transcripts and observations using the software program Nvivo. Codes were then grouped into themes. Both within-case and cross-case descriptive and thematic analyses were performed. Using the root system, themes were broken down and subthemes elucidated.

Multiple forms of triangulation were performed during the data analysis. Source triangulation involved analyzing and contrasting field notes, memos and multiple interviews to corroborate themes. Method triangulation was evident as this project utilized both quantitative and qualitative methods. Investigator triangulation and peer debriefing were analytical techniques that were also practiced to ensure the credibility of the data analysis and findings. See Appendix E for additional strategies and practices that satisfy the criteria of credibility, transferability, dependability and confirmability.

Ethics

The participants were asked to give written consent (Appendix F). For those who could not write, they consented by providing a thumbprint. The full name, telephone number and email address (if available) of participants was then collected and stored electronically.

There were several anticipated risks for participants in this study. The scale and interview questions may have stirred feelings of discomfort and possible distress upon reflecting on their current situation. If the participant had a negative reaction to a question, the interviewer offered the following options: take a break, stop the interview for the day, call a friend or family member or withdraw completely from the study. If the participant wanted to continue the interview, the interviewer proceeded to the next question. At the end of the interview, each participant was informed that mental health services were available at Korle-Bu Teaching Hospital and Komfo-Anokye Teaching Hospital. Breast cancer patients were provided with the contact information for the counsellors at PLH.

Participants were uncertain of the confidentiality of the study. To prevent any privacy breaches, the data was kept safely in a password protected laptop that only the PI could access. All identifiers were

removed from the questionnaires. Each participant was given a unique code that labeled each questionnaire to prevent the identification of the respondent. The electronic document containing the names associated with each unique code was password protected within SPSS. The print consent forms with participants' names and unique codes were kept in a locked room. Ensuring confidentiality allowed the women to be more candid when answering the study questions. For example, participants with breast cancer who had kept their diagnosis private may have abstained from participating in the study for fear of discrimination, if their health status were to be made public.

Chapter 3: Results & Evaluation

Descriptive statistics

All descriptive statistics are found in Table 1. While the women came from almost every region in the country, most breast cancer patients and healthy controls were from the Ashanti and Greater Accra regions. This was expected as the PLHs were located in these regions. Twenty breast cancer patients and 14 healthy controls resided in the Greater Accra region while 21 breast cancer patients and 20 healthy controls resided in the Ashanti region. The healthy controls generally had a higher level of education than the breast cancer patients. Most breast cancer (63%) and healthy controls (55%) were married. One healthy participant did not report her marital status and therefore, was omitted from the analysis.

Eleven women (17%) reported being in the early stages of the cancer and 19 women (30%) acknowledged being in the advanced stages of cancer. However, thirty-four participants (53%) were not aware of the cancer stage. Consequently, the cancer stage variable was left out of the analysis. Seventy percent of patients were receiving or had previously received chemotherapy. Thirty-one women (48%) underwent a breast operation. Fifteen women (23%) received radiotherapy. Nine women (14%) received oral tablets and hormone therapy.

Only significant predictors of an outcome were listed below. Complete results can be found in the corresponding tables.

Quality of life & Psychological Distress

Physical health (Table 2): The regression showed that on average breast cancer patients rated their physical health 1.95 [95%CI= -2.93, -.96] points lower than the healthy women. All variables included in the model except cancer diagnosis yielded, $F(6,119)=.82$, $p=.56$, $R^2=.039$, and with cancer diagnosis included, $F(7,118)=2.98$, $p=.006$, $R^2=.15$.

Psychological well-being (Table 3): Individuals diagnosed with cancer had a 1.57 [95%CI= -2.67,-.47] lower mean score on the psychological well-being domain. A regression analysis excluding

the cancer diagnosis variable yielded $F(6,119)= 4.42, p=.00, R^2= .18$. When all the variables were included in the model, the results are $F(7,118)= 5.15, p=.00, R^2= 0.23$.

Social relationships (Table 4): Cancer diagnosis was not significantly related to the social relationships score (Mean difference (MD) = .064, [95%CI=-1.08, 1.2]. Age, education and marital status did not significantly predict the score on the social relationships domain, $F(7,117)= 1.19, p=.32, R^2= 0.066$.

Environment (Table 5): Breast cancer patients had a 1.21 [95%CI= -2.16,-.27] lower mean score on the environment domain of the WHOQoL-BREF scale than the healthy controls. When all variables are entered, the regression yielded $F(7,119)= 4.38, p=.000, R^2= 0.21$. Excluding the cancer diagnosis variable, the model was $F(6, 120)= 3.86, p=.001, R^2= 0.16$.

Psychological distress (Table 6): Breast cancer patients reported more psychological distress with a 2.95 [95%CI= .29, 5.6] higher score than controls. When all the variables are entered, the model is equal to $F(7,119)= 2.9, p=.008, R^2= 0.15$ and excluding cancer diagnosis, the regression analysis yielded, $F(6,120)= 2.47, p=.027, R^2= 0.11$.

Overall quality of life and satisfaction with health

Quality of life (Table 7): The logistic regression with high quality of life as the outcome showed cancer diagnosis was not a significant predictor (OR= .57; 95% CI= [.25, 1.3]). The Hosmer-Lemeshow test showed that the model was an adequate fit for the data, $\chi^2(8)= 11.14, p=.19$.

Satisfaction with health (Table 8): Women diagnosed with cancer were significantly less likely to be satisfied with their health (OR= .23; 95% CI= [.1, .52]). The model was a good fit to the data (Hosmer-Lemeshow test, $\chi^2(8)= 8.48, p=.39$).

Overall Satisfaction with Health and Quality of Life (Table 9): The logistic regression demonstrated that breast cancer patients were less likely to report that they were satisfied with their

health and quality of life (OR=.32; 95%CI= [.14, .7]). The goodness-of-fit test yielded $\chi^2(8)= 11.77$, $p=.16$.

Independent Samples t-test

This section deals with the statistically significant results of the independent Samples t-tests. Cancer diagnosis was the independent variable. K-10 and WHOQoL-Bref question items as well as the WHOQoL-BREF domains and the K-10 psychological distress scores were the primary outcomes. Essentially, Ghanaian women living with breast cancer were fairly worse off than healthy women.

Kessler Psychological distress scale

See Table 10 for complete results. Women with breast cancer reported feeling nervous more often than their healthy counterparts, a difference of -.56 [95%CI= -.97, -.16]. Additionally, cancer cases reported that they felt so restless that they could not sit still more often (MD=-.6, 95%CI=-1.1, -.12). Breast cancer patients also expressed that they felt depressed more often than the healthy women (MD=-.6, 95%CI=-1.02, 1.19). Moreover, there was a significant difference between women with breast cancer and healthy individuals on the question item that measured how often they felt everything was an effort, (MD=-.54, 95%CI=-.97, -.11).

Breast cancer patients reported on average being completely unable to work for nine days, in the past 30 days. In contrast, for healthy women, the average number of days they were completely unable to work in the past 30 days was Two and a half days, (MD=-6.4, 95%CI=-9.59, -3.1).

Breast cancer patients also recounted seeing a doctor or other health professional on average 3 times in the past 30 days whereas healthy women reported seeing a doctor or health professional only once in the same time period, (MD=-1.7, 95%CI=-3.12, -.28)..

Breast cancer patients ($M=3.02$, $SD= 1.09$) tended to attribute the cause of their symptoms of psychological distress to physical health problems more often than healthy women (MD=-.69, 95%CI=-

1.1, -.29). Overall, the breast cancer patients had a significantly higher score on the psychological distress scale than the healthy individuals (MD=-3.6, 95%CI=-6.3, -.94).

WHOQoL-BREF

All means and standard deviations are displayed in Table 11. Healthy individuals were more satisfied with their health than breast cancer patients, (MD= .59, 95%CI=.26, .93). Healthy controls also stated that they felt their lives were more meaningful than breast cancer patients reported of their own lives, (MD= .52, 95%CI= .11, .94). Additionally, healthy controls felt significantly safer in their daily lives than breast cancer patients, a mean difference of .73 [95%CI=.32, 1.2]. Healthy women were more satisfied with their ability to perform their daily living activities than breast cancer patients, (MD= .55, 95%CI= .18, .91). These women were also more satisfied with their capacity for work than breast cancer patients, (MD= .87, 95%CI= .47, 1.27). Healthy women disclosed that they had more access to the information they need in their day-to-day lives than the breast cancer patients (MD= .46, 95%CI=.026, .89). Furthermore, Healthy women had more opportunities for leisure activities than breast cancer patients (MD= .61, 95%CI=.17, 1.05).

In contrast, breast cancer patients reported needing more medical treatment to function in their daily lives than healthy controls, (MD= -.57, 95%CI=-.95, -.19). In addition, they were less satisfied with themselves than the healthy controls, a mean difference of .62, [95%CI= .21, 1.04]. Women with breast cancer also reported that their physical environment was less healthy than their counterparts, (MD= .47, 95%CI=.08, .86). Women with cancer stated having significantly less energy than healthy individuals, (MD= .93, 95%CI=.55, 1.31). Moreover, they reported having more difficulty getting around than healthy women (MD= .52, 95%CI= .18, .86). Both groups felt as though they did not have enough money to meet their needs but the breast cancer group reported having this feeling more often than healthy women, (MD= .63, 95%CI= .23, 1.02). Lastly, breast cancer patients reported having more difficulty accepting their bodily appearance than healthy controls, a mean difference of .89, [95%CI=

.44, 1.33]. Breast cancer patients felt as though physical pain prevented them from doing what they needed to do more than healthy controls, (MD= -1.23, 95%CI= -1.61, -.85). Lastly, breast cancer patients felt negative feelings such as blue mood, despair, anxiety and depression more often than healthy women, (MD= -.71, 95%CI= -1.06, -.36).

There were significant differences in domain scores between the two groups (Table 12). The healthy women scored on average higher than breast cancer patients on the domain measuring physical health, a mean difference of 2.1 [95%CI= 1.15, 3.04]. Healthy individuals also reported having a healthier and safer environment than breast cancer patients (MD= 1.36, 95%CI= .39, 2.34]. Healthy women also scored their satisfaction with their health significantly higher than women with breast cancer, a mean difference of 14.84, [95%CI= 6.36, 23.32]

Breast cancer patients scored significantly lower on the psychological well-being domain than the controls (MD= 1.88, 95%CI= .73, 3.02). Finally, women with breast cancer patients scored significantly lower on their satisfaction with their overall health and quality of life than healthy individuals (MD= 1.75, 95%CI= .49, 3.01).

Quality of life & Psychological Distress (Breast Cancer patients)

Physical health (Table 13): The multiple regression analysis found that none of the independent variables (education, marital status, cancer treatment and age) significantly predicted score on the physical health domain.

Psychological well-being (Table 14): Education was a significant predictor of psychological well-being, partial $F(3,51)= 5.72$, $p=.002$. Higher psychological well-being scores were found among women with higher levels of education. Participants with a high school education had a 3.39 [95%CI=.59, 6.19] higher score than women with no education while the tertiary educated people and those who received private training had 4.05 [95%CI=1.65, 6.44] higher score on this domain. Cancer treatment was also a significant predictor, partial $F(4,51)=3.51$, $p=.01$. Participants who had received or

were receiving radiotherapy had a 2.3 [95%CI= .42, 4.16] higher score on the psychological well-being domain.

Social Relationships (Table 15): Age was a significant predictor for social relationships, with an increase in the estimated social relationships score of 0.08 [95% CI = 0.00, 0.16] for a one-year increase in age.

Environment (Table 16): Although education appeared to be a significant predictor, the partial F was not significant, $F(3,51) = 2.07$, $p = .12$.

Psychological distress (Table 17): Receiving radiotherapy was a significant predictor of psychological distress as women who received this treatment scored 4.89 [95%CI=.53, 9.25] higher than other women.

Quality of life (Table 18): Women who received chemotherapy were less likely [OR= .09; 95% CI= .014, .64] to rate their overall quality of life as high. However, women who had breast surgery were 6.4 times [95% CI= 1.2, 35.6] more likely to do the same. Age was significant as OR was 1.08, [95%CI= 1.00, 1.17]. Although education was significant (Wald $\chi^2(3) = 8.37$, $p = .04$), the results of this variable were imprecise as evident by the very wide confidence intervals. The overall trend was that higher levels of education were related to reporting quality of life as high. The Hosmer-Lemeshow test showed that this model provided only a weak fit to the data, $\chi^2(8) = 15.02$, $p = .06$.

Satisfaction with health (Table 19): Women who received radiotherapy were 7.22 times [95% CI= 1.33, 39.31] more likely to rate their satisfaction with their health as high but the CI was very wide. Women who had breast surgery were 4.17 [95% CI= 1.04, 16.71] times more likely to do the same. The results of the Hosmer-Lemeshow test demonstrated an adequate fit of the model to the data, $\chi^2(8) = 8.73$, $p = .37$.

Overall satisfaction with health and quality of life (Table 20): Women who had breast surgery were 11.26 [95% CI= 1.92, 65.97] times more likely to rate their overall quality of life and satisfaction

with health as high; again, the CI was very wide. Women who received radiotherapy were 11.07 [95% CI= 1.7, 73.3] times more likely to do same. The Hosmer-Lemeshow test indicated that this model gave a good fit to the data, $\chi^2(8) = 11.43$, $p = .18$.

Chapter 4: Qualitative Findings

Utilizing the hermeneutic qualitative approach, the lived experiences of breast cancer patients were assessed (Richards & Morse, 2007). The primary objective aimed at understanding how breast cancer had affected their lives and contributed to psychological distress. The final sample size was 13 patients as data saturation was achieved. The participants had a wide range of educational backgrounds, ranging from no education to college. The youngest interviewee was 38 and the most senior interviewee was 72 years old. The demographics of interviewees are displayed in Table 21. Although most of the participants were married, two single women and a widow were also interviewed.

After thematic analysis of audio-taped semi-structured interviews with an average duration of 20 minutes, the patients appeared to have followed a similar journey. This journey seemed to appear in four stages: breast cancer knowledge & suspicion, navigating health system, impact of breast cancer and regaining confidence.

Breast Cancer Knowledge and Suspicion

Breast cancer knowledge ranged from quite knowledgeable to no knowledge at all among the interviewees. Three of the interviewed women had knowledge about breast cancer because they had a sister, mother and/or other family members who also had the disease. Three others knew about breast cancer due to awareness campaign efforts. Among these three women, one received a workshop on the topic by a non-governmental organization and the two others heard about it on the radio. One woman had never heard of breast cancer until she was clinically diagnosed. Another had heard of the term breast cancer but had no additional knowledge about it, initially.

The first suspicion of health issue for the patients tended to arise after feeling a lump and/or pain in the breast. Two women initially dismissed the lump as mere boils but were compelled to seek medical attention when their condition aggravated. None of the women mentioned having a history of routine

screenings such as clinical breast screening and mammography. None of the participants revealed that their suspicions of breast cancer arose in this manner.

Navigating the Ghanaian Health System

After becoming suspicious of ill-health, the next step is for the women to navigate through the Ghanaian health system for diagnosis and potential treatment. However, many do not know where to go and finding information can be difficult. This is a sentiment that was expressed by Lynn and shared with many of the participants in this study.

For Patricia, her medical attention adventure was fairly simple. She heard about a screening the PLH was holding in her hometown on television. She attended the screening and subsequently, scheduled a hospital appointment. However, it was a common occurrence for women to go through multiple nodes of care before starting proper cancer care. Bridget was transferred to PLH from a doctor in the Eastern Region. Mary was transferred between three hospitals before finally coming to PLH. Mary recounted her terrible experience of mistreatment at another hospital before coming to PLH. She felt dehumanized and felt treated like a test subject. She said:

“They were using me for learning. They would play with me”

Additionally, the doctors botched her biopsy which led to a very foul smelling and leaking wound. Notwithstanding, the situation gravely affected the woman physically and psychologically as she reported weeping often due to her treatment.

Furthermore, it appeared that the women were stumbling upon useful information in non-systematic ways. Referrals to the hospital and breast cancer information were often provided by friends and family.

Fear (n=4) and sadness (n=3) were the most common first reactions to breast cancer diagnosis. These feelings were mainly experienced as weeping and extreme worry. For Talia, it was a traumatic experience that she did not want to remember.

The majority of women chose to not disclose their health status to anyone outside of their immediate family. Mary & Lynn were the only interviewees to reveal that they disclosed their status to non-family members. In Mary's case, it was beneficial as church members were actually the ones who brought her from Korle-Bu in Accra to PLH.

The main reason for non-disclosure was due to fears of stigmatization and judgement. Ann, a nurse at Korle-Bu Teaching hospital, chose not to disclose her condition to her colleagues and to seek treatment at another hospital. She felt as though her whole existence would be related to the cancer and that her colleagues who see her as a patient and not as a respected senior nurse.

However, for Gifty, she just did not feel the need to disclose her condition to others because she had no visible signs of breast cancer. Jane chose not to tell her sons because she does not want to cause them to worry. She opted to only tell her husband and her daughter who is a nurse.

Impact of Breast Cancer and Breast Cancer treatment

The breast cancer patients had diverse experiences living with breast cancer. The impact on everyday activities, physical health, female identity, roles and responsibilities differed among the women. However, all the women expressed having financial difficulties. Moreover, seeking alternative treatment, receiving misinformation and issues accessing medication were among the many life experiences the women faced as they went through their breast cancer journey.

Everyday life and physical health

“My body is like stones in it, small small stones. My head is like gravels”- Jane

The inability to eat, mood swings, lack of sexual desire, loss of substantial amount of weight, pain, urinary incontinence, weakness and hair loss were common effects of breast cancer and disease-related treatment.

Some women reported not being able to do anything and being home. For some, it was due to physical issues and for others, it was due to fear of being stigmatized and judged. Four women completely stopped working due to the direct and indirect effects of breast cancer and its treatment such as fatigue, pain and loss of strength. For Mary, her social interactions were greatly affected by the cancer, namely by impeding her capacity to go church.

In Lynn's case, changes to her physical appearance made her avoid community events for fear of judgement. Talia stopped going to church because she felt as though people were staring at her.

Similarly, Gifty, who underwent a mastectomy, stated:

“Without the silicone to support me, if I leave it with half, I feel like people will see it and say something”.

Female Identity, Role & Responsibilities

For two of the women, their identity as women was greatly tied to fulfilling their wifely duties. Jane's inability to work made her feel as though it put a strain between her husband and herself. It pained her not to be able to help her husband make ends meet. Talia also felt that her marriage had suffered. Her husband did not support the idea of her having a mastectomy. She expressed that he fulfilled his financial responsibility to her but was withdrawn emotionally.

The breast has long been an essential part of the female identity. Any physical change to the breast can evidently have a psychological effect. This was the case for Patricia who had a mastectomy. She expressed that she felt that something was missing when she got undressed.

Although breast cancer has had an effect on a number of patients, many of the interviewees felt a slight impact. A number of women affirmed that the disease did not affect at all or only minimally their interactions with others (n=1), their ability to complete their daily living activities (n=6), their family life (n=2), role as a mother (n=2) and female identity (n=2).

Most disruptions to aforementioned factors were at the onset of the disease. Due to treatment, the condition of these women improved and they could reprise their usual duties. Gifty still felt the repercussions of the disease but minimally. She is unable to do tedious work but can perform the majority of her daily living activities. Lynn could do most things but sometimes having the breast cancer on her mind affected her ability to do her daily living activities. She mainly worried that the recovery from an upcoming mastectomy would hinder her ability to take care of her husband who had stroke.

Financial hardships

Financial difficulty was an issue for all the women. Many are now physically incapable of working. In conjunction with the high costs of drugs, breast cancer is negatively impacting the monetary affairs of patients. A common consequence of financial hardships is women defaulting on treatment. For the five months prior to our interview, Mansah did not come in for treatment. For Patricia, financial obligations to her father and her children were an impediment to doing radiotherapy. Jane would purchase only part of her medication at a time as she could not afford it all at once.

Misinformation

One other issue that must be addressed is making sure that patients are informed about all aspects of treatment side effects and costs. During the interview, Patricia revealed that she did not start radiotherapy because of the cost. She relied on a quote provided by a friend who also underwent cancer treatment. Finally, this was an incorrect figure and the cost of treatment was actually cheaper than she realized.

Alternative treatment

Out of the 13 women interviewed, only Lynn reported that she used herbal treatment. She recalled being afraid of continuing medical treatment because the doctor announced to her that she needed to undergo a mastectomy. She was desperate for an alternative treatment. She stopped treatment for three months and only returned to the hospital when she noticed no improvement.

Access to medication

Access to medication was an issue for the majority of interviewed women. Cancer treatment centers are mainly located in Kumasi and Accra. Anyone living outside these two major cities had to cover the additional cost of transportation. As listed in Table 21, the women came from all parts of Ghana. Mansah and Patricia had to travel from Upper West and Northern region, respectively, every three weeks for treatment. This was not only costly because of travel expenses but they also incurred loss of wages as they had to take time off of work.

The interviewees also highlighted a hospital accreditation issue that also affected access to medication. Medications purchased at the Accra PLH were not covered by the Ghanaian National Health Insurance Scheme (NHIS) whereas the medications at the Kumasi PLH were insured. Consequently, medication that cost 1000 GHC without NHIS in Accra can actually be 150GHC in Kumasi. Many of the Accra based patients would travel to Kumasi for drugs. Gifty relocated to Kumasi from Accra as treatment in Kumasi was cheaper. Ann lamented the expensive cost of transport between Accra and Kumasi.

Regaining Confidence

Women who had been on treatment for a considerable amount of time and/or nearing cancer survivorship expressed an overall sentiment of confidence that they will beat the cancer. They regained confidence due to their received support and coping mechanisms.

“When I came, I was diagnosed with breast cancer. As I said initially, it wasn't easy but with the treatment and now that I am feeling better, I think I can see some changes. So I'm glad I am better as compared to when I started treatment”- Patricia

“It's by the grace of God that we have this woman who has come to save us. If not by the grace of the Lord and having this woman [doctor], things

would have been far worse. It's through her and the team their encouraging words, love and support for us that we are safe today"- Nancy

Support

The women shared similar support systems and coping mechanisms. Support systems were classified as financial, physical and emotional. Most married women were receiving at least one form of support from their husbands. Family was also an important source of support and help as was the case for Talia, Mansah and Gifty. For Talia, her husband was only financially supportive and did not provide any physical or emotional support. Meanwhile, Mansah received help from her siblings and Gifty had support from son and sister.

Interestingly, Mary received most of her physical and financial support from church members. She received assistance being transported to and from the hospital. Additionally, church members would contribute monetarily to the purchase of medication. Notwithstanding that this dependence on church members' generosity made Mary feel as though she was becoming a burden.

Coping mechanisms

Religion is the principal coping mechanism. Going to church and church-related activities, prayer and belief in God are giving these women hope that they will overcome breast cancer. They "remove their mind" from the cancer and focus on thanking God, praying and reading the bible.

"I trust in God. That's why I am strong"- Lois

"I will always concentrate with God and the doctors. God will help them to cure my sickness that's how I made my mind."- Jane

Other important coping mechanisms were physical and breathing exercises as well as having faith in the doctor and their advice.

Counselling by doctors and breast cancer patients also played an important role in decreasing the fears and anxiety of these women. Seeing that breast cancer is a curable disease was quite helpful to

some. For Gifty, speaking with women who had done breast surgery helped her have peace of mind with her decision to undergo the mastectomy.

Overall, despite the complexities of the disease and side effects of treatment, patients express being very hopeful and a strong desire to comply with medical recommendations.

“I want to do whatever they recommend because it's really good for me.

How she [the doctor] is treating me I know if I continue, I will be safe.”

Another remarkable element was women choosing to continue treatment and promising to follow all recommendations, even mastectomy despite opposition, especially from husbands.

“So my husband, just recently I just called him and said, ‘James by all means when the treatment is over by all means they will cut one of my breast’ and he said, ‘I won’t agree’ so me I will do it is my own body so I won’t allow you to say that to me. I will agree for my breast to be removed since is my own body” -Jane

Chapter 5: Discussion

The current study compared the quality of life and psychological distress of breast cancer patients with those of healthy Ghanaian women. Its second objective was to understand how the lived experiences of women with breast cancer contributed to their psychological distress. In this discussion, quantitative results and qualitative findings are interlinked to offer a more complete understanding of the life experiences of breast cancer patients. The results draw from findings from each of the methods.

Physical Health & Satisfaction with health

Breast cancer patients scored significantly lower on the physical health domain. The women reported that the cancer and its effects did not allow them to go about their daily living activities. Furthermore, the women were dissatisfied with their capacity for work as many had to stop working, due to pain and having to go back and forth to the hospitals for treatment. They were also more dependent on more medicinal substances and reported having less energy than healthy women. Moreover, cancer diagnosis was a significant predictor for lower score on self-reported satisfaction with health.

Psychological Well-being

The psychological domain score was lower for breast cancer patients. Breast cancer patients did not perceive their lives were as meaningful as the healthy women did. Moreover, the cancer's effect on physical appearance had a major impact on the women psychologically as they had more difficulty accepting their bodily appearance. Weight loss and breast operations such as mastectomies are among the dramatic changes to appearance that patients struggled to cope with. Lastly, breast cancer cases had more bouts of blue mood, despair, anxiety and depression than healthy women.

Environment

Among the many reported factors that contributed to breast cancer patients scoring lower on the environment domain were safety and finances. The women linked not feeling safe to their uncertainty

about the future. They feared for what lay ahead for their children and significant other should they succumb to their illness.

Scarce financial resources were a major driver for the lower score on the environment domain. The costs of medical treatment and transportation were heavy burdens for these women. The difficulty in accessing treatment in Ghana was previously found (Scherber et al., 2014). Scherber and colleagues reported that, “since both public hospitals are located in the southern, more urban regions of the country, many individuals must travel long distances at significant financial cost to seek diagnosis and treatment” (Scherber et al., 2014). Consequently, women residing outside of these regions with insufficient financial means, notably women in rural areas, are underdiagnosed and undertreated.

Finally, women with breast cancer also had fewer opportunities to partake in leisure activities. The primary reported leisure activity was attending church and church-related festivities. Religion is a very important coping mechanism for the patients. The women reported that their relationship with God and interaction with other church members had provided them with a sense of hope during this difficult time. However, their inability to take part in such a major coping mechanism was a threat to their quality of life.

Psychological distress

The women with breast cancer also had significantly higher psychological distress. They were generally more nervous, stressed, depressed and felt like everything was arduous more often than the healthy participants. The link between psychological well-being and physical health was evident as the women attributed their symptoms of psychological distress to physical health problems more than healthy women did.

Summary

In all, cancer diagnosis had a significant effect on physical health, satisfaction with health, psychological well-being, environment and psychological distress. Women with breast cancer had lower

scores than healthy controls on their overall satisfaction with health and quality of life. Cancer diagnosis did not have a significant effect on social relationships and self-reported quality of life. Despite the statistically significant difference between breast cancer patients and healthy women, the actual score differences were small. Psychological distress was only 3 points different on a scale of 10 to 50. On the quality of life domains, the difference ranged between 1.21 and 1.95 on a 20-point scale.

Temporality of psychological distress among breast cancer patients

The qualitative interviews identified four major steps in the breast cancer journey: breast cancer knowledge & suspicion [of disease], navigating the Ghanaian health system, impact of breast cancer & treatment and regaining confidence.

Cancer treatment appeared to have an effect on the quality of life and psychological distress of the patients. Although the results indicated that those who received radiotherapy scored higher for psychological distress among cancer patients, these same women also scored higher on the psychological well-being domain. Moreover, patients who had radiotherapy and/or a breast operation were also more satisfied with their quality of life and health. In contrast, women who received chemotherapy scored lower on self-reported quality of life scale. An explanation for this result may be where the women lie in their breast cancer journey. Women receiving chemotherapy are usually at the beginning stages of their breast cancer treatment whereas breast surgery and radiotherapy are among the later steps. Hence, women who have had a breast operation and radiotherapy may be in the step of regaining their confidence. Therefore, temporality could be a confounding variable. Those going through chemotherapy have usually just began their cancer journey and may feel more psychological distress as they are trying to cope with this health-related hardship. Those going through radiotherapy and breast surgery have usually learned to deal with the disease through some coping mechanisms. These women may also be closer to the end of their fight with breast cancer and feeling hopeful of their future and survival.

Both breast cancer awareness and patient education are extremely important. Myths surrounding the disease can prevent women from seeking treatment and many did not know where to go to get help when suspicion arose. Indeed, many patients had very minimal knowledge about breast cancer prior to being diagnosed. Increasing breast cancer awareness may contribute positively to alleviating psychological distress and reduce delays to hospital presentations. The initiative can also dispose the notion that breast cancer is a death sentence. Moreover, 34 out of 64 women did not know the stage of their cancer. Patient education in the form of providing the patients with more information of their particular condition may ease the feelings of uncertainty (see further explanation below in recommendations).

Coping Strategies

Religion, counselling and exercise were the primary coping mechanisms for women with breast cancer. Religion was the most common coping mechanism for the women. Studies have already identified religion as an important coping mechanism for breast cancer patients in LMICs (Distelhorst et al, 2015; Gurm, Stephen, MacKenzie, Doll, Barroetavena & Cadell, 2008; Aziato & Clegg-Lampsey, 2015).

Limitations & Strengths

Limitations

Language was a definite barrier to the completion of this study. To address this issue, the scales were translated and two translators assisted with the administration of the scales and interviews. Despite using the back translation technique to reduce the meaning of certain questions being lost during the translation process, the issue may have persisted and affected responses to question items.

The fact that healthy women were recruited from breast cancer screening events may have introduced a bias into the study. Women who have high levels of psychological distress may choose to isolate themselves and not venture to social activities such as screening events. Conversely, women with

high levels of psychological distress may feel compelled to go these events as they may be anxious about their health.

Lastly, the results of the regressions within the breast cancer population must be interpreted cautiously as the sample is small.

Strengths

First, the recruitment objective of engaging 64 breast cancer patient and 64 healthy women for the completion of the study was achieved. This allowed the detection of a medium size effect between women living with breast cancer and healthy women on the quantitative scales. Second, given their diverse backgrounds, the selected interviewed women were close to being representative of the breast cancer sample.

To end, a major strength of this study is the utilization of qualitative and quantitative methods. The interviews were used to further understand the responses to the question items on the K-10 and WHOQol-BREF. Moreover, interview questions enabled the investigator to assess information that was outside of the scope of the quantitative scales providing further insight into the patients' breast cancer journey. Accordingly, the qualitative interviews further confirmed the quantitative results. No contradictions were highlighted..

Future work

Factors to consider

The influence of cancer treatment, age, marriage and education was analyzed within the breast cancer population. Due to the small sample size and resultant wide confidence intervals, it is difficult to interpret the impact of these independent variables accurately. However, certain factors were highlighted and future work may want to consider assessing the influence of these variables on psychological distress and quality of life.

Education was a significant predictor for many of the dependent variables. The general trend showed that those with higher levels of education scored higher for psychological well-being and high quality of life. Education may be a marker for level of income. It is hypothesized that individuals in poverty or with financial trouble are more susceptible to developing a mental health problem “due to factors such as increased levels of stress, malnutrition, exclusion, obstetric risks and exposure to violence” (Patel, 2001). A college educated individual is more likely to have employment and a higher level of income, and thus fewer financial troubles.

A variable that the PI did not explore was employment. Boyce and colleagues (2009) found "that maintaining employment after the onset of mental illness is more important in predicting positive changes in mental health among mentally ill population in Ghana." Undoubtedly, employment provides an income that may be used to purchase mental health treatments (Boyce et al, 2009). This statement is also true for the purchase of breast cancer treatment.

Lastly, age and length of time on treatment could be factors mediating of the level of psychological distress. Age was a significant predictor with older women scoring higher on the social relationship domain and for self-reported quality of life. Alternatively, quality of life and the amount of psychological distress varied per cancer treatment. Those in the later steps of cancer treatment had higher scores on domains for quality of life.

Recommendations

Although the study presented with limitations which limits the significance of the results, there were indications of breast cancer affecting negatively quality of life and increasing psychological distress among the women living with the disease. Breast cancer patient’s psychological distress could be reduced and quality of life improved by implementing patient-centered care approaches. Among the objectives would be to increase access to medication, patient education and counselling services.

Access to breast cancer treatment was a major burden for breast cancer patients as many had to travel far distances for treatment and could not cover the cost of treatment. This was a major source of psychological distress. Advocacy for more national health insurance coverage may help with the affordability of the drugs. Elsewhere, medication for depression and other psychological disorders must also be available. Additionally, a drug delivery service would reduce transportation costs and time off work. Therefore, such solutions can contribute to decreasing psychological distress.

Adopting patient-centered breast cancer care “requires that patients are well informed about their disorder and the resources are available to them” (Distelhorst et al, 2015). Accordingly, patient education should focus on allowing patients to recognize and treat breast cancer related physical and psychological side-effects. They should also be informed of their clinical stage and grade and any information relevant to their particular condition such as likelihood of survival (Distelhorst et al, 2015).

Counselling services with social workers and mental health profession should be available and accessible for these women. However, there is a dearth of health professionals, especially mental health professions, in LMICs such as Ghana (Bruckner, Scheffler, Shen, Yoon, Chisholm, Morris ... & Saxena, 2011). A potential solution would be to train individuals, especially breast cancer survivors, to recognize mental health issues and counselling techniques to act as peer navigators and counsellors. Peer navigators can assist breast cancer patients to deal with the Ghanaian health care systems.

Conclusion

Overall, women with breast cancer did have more psychological distress and scored lower for physical health, psychological well-being and environmental markers of quality of life. The women affirmed that breast cancer had affected their everyday life, physical health, female identity, roles and responsibilities to varying degrees. Patient centered care approaches as well as access to breast cancer and mental health treatment could alleviate the psychological distress and improve the quality of life of breast cancer patients.

Table 1. Descriptive Statistics for Breast cancer patients & Healthy Women

	Descriptive Statistics			
	Breast Cancer		Healthy Controls	
	N	%	N	%
Region				
Greater Accra	20	31	14	22
Ashanti	21	33	20	31
Brong Ahafo	4	6	1	2
Eastern	8	13	13	20
Western	3	5	12	19
Central	3	5	0	0
Volta	3	5	4	6
Upper Western	1	2	0	0
Northern	1	2	0	0
Education				
None at all	10	16	4	6
Elementary School	25	39	22	34
High school	10	16	17	27
College/University/ Private training	19	30	20	31
Marital Status				
Single	5	8	10	6
Married	40	63	35	55
Separated	2	3	2	3
Divorced	6	9	5	8
Widow	11	17	11	17
Cancer Stage				
Early	11	17		
Late	19	30		
Not aware	34	53		
Cancer Treatment				
No Treatment	7	11		
Chemotherapy	45	70		
Breast operation	31	48		
Radiotherapy	15	23		
Oral Tablets/Hormone Therapy	9	14.1		

*Approximated to the nearest integer

Table 2. Results of the multiple regression with physical health as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent variable: Physical Health *		
Independent Variables	B-value	95% CI
Education		
Elementary	.836	-.83, 2.5
High School	1.11	-.74, 2.9
Tertiary and private training	1.04	-.67, 2.76
(No education/less than elementary)	N/A	
Marital Status		
Married	.35	-.84, 1.54
Widowed	.43	-1.21, 2.07
(Single never married, divorced, separated)	N/A	
Cancer diagnosis	-1.95	-2.93, -.96
(Healthy)	N/A	
Age	-.02	-.067, .029

Note: Reference categories for variables are in parentheses.

Without cancer diagnosis variable, $R^2 = .039$

With cancer diagnosis $R^2 = .15$

Using WHO Quality of Life- BREF*

Table 3. Results of the multiple regression with Psychological Well-being as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent variable: Psychological Well-being*		
Independent Variables	B-value	95% CI
Education		
Elementary	.23	-1.63, 2.09
High School	1.9	-.22, 3.94
Tertiary and private training	3.19	1.27, 5.1
(No education/less than elementary)	N/A	
Marital Status		
Married	.11	-1.23, 1.45
Widowed	-.64	-2.49, 1.2
(Single never married, divorced, separated)	N/A	
Cancer diagnosis	-1.57	-2.67, -.47
(Healthy)	N/A	
Age	-.002	-.056,.052

Note: Reference categories for variables are in parentheses.

Without cancer diagnosis variable $R^2 = .18$.

Including cancer diagnosis $R^2 = 0.23$.

*Using WHO Quality of Life- BREF

Table 4. Results of the multiple regression with social relationships as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent Variable: Social Relationships*		
Independent Variables	B-value	95% CI
Education		
Elementary	-1.16	-3.15, .834
High School	.29	-1.9, 2.49
Tertiary and private training	.48	-1.57, 2.52
(No education at all, less than elementary)	N/A	
Marital Status		
Married	-.87	-2.25, .52
Widowed	.39	-2.33, 1.55
(Single never married, divorced, separated)	N/A	
Cancer diagnosis (Healthy)	.064	-1.08, 1.2
Age	.005	-.051, .061

Note: Reference categories for variables are in parentheses.

Without cancer diagnosis variable $R^2 = .07$.

Including cancer diagnosis $R^2 = 0.07$.

*Using WHO Quality of Life- BREF

Table 5. Results of the multiple regression with environment as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent Variable: Environment*		
Independent Variables	B-value	95% CI
Education		
Elementary	-.57	-2.18, 1.03
High School	1.02	-.77, 2.8
Tertiary and private training	1.88	.23, 3.52
(No education at all, less than elementary)	N/A	
Marital Status		
Married	.24	-.91, 1.38
Widow	-.71	-2.29, .87
(Single never married, divorced, separated)	N/A	
Cancer diagnosis (Healthy)	-1.21	-2.16, -.27
	N/A	
Age	.002	-.045, .048

Note: Reference categories for variables are in parentheses.

With cancer diagnosis $R^2 = 0.21$

Without ca diagnosis $R^2 = 0.16$

*Using WHO Quality of Life- BREF

Table 6. Results of the multiple regression with psychological distress as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent variable: Psychological Distress*		
Independent Variables	B-value	95% CI
Education		
Elementary	.3	-4.21, 4.81
High School	-3.09	-8.12, 1.94
Tertiary and private training	-4.97	-9.6, -.33
(No education at all, less than elementary)	N/A	
Marital Status		
Married	.54	-2.67, 3.75
Widow	-.83	-5.27, 3.6
(Single never married, divorced, separated)	N/A	
Cancer diagnosis	2.95	.29, 5.6
(Healthy)	N/A	
Age	.02	-.11, .15

Note: Reference categories for variables are in parentheses.

With cancer diagnosis $R^2 = 0.15$

Excluding cancer diagnosis $R^2 = 0.11$.

*Using Kessler Psychological Distress scale

Table 7. Results of the logistic regression with overall quality of life as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent Variable: Overall Quality of Life*			
Variables	B-value	Exp (B)	95% CI
Education (None at all)			
Elementary	.25	1.28	.37, 4.41
High school	.46	1.58	.39, 6.46
Tertiary education and private training	2.25	9.45	2.07, 43.19
(No education at all, less than elementary)	N/A		
Marital Status			
Married	.41	1.51	.57, 3.98
Widowed	-.51	.6	.16, 2.32
(Single never married, divorced, separated)	N/A		
Cancer Diagnosis	-.56	.57	.25, 1.3
(Healthy)	N/A		
Age	.01	1.01	.98, 1.06

Note: Reference categories for variables are in parentheses.

Hosmer-Lemeshow (Goodness-of-fit test)

Without cancer diagnosis $\chi^2(8) = 4.54$, $p = .81$

With cancer diagnosis $\chi^2(8) = 11.14$, $p = .19$

*Using WHO Quality of Life Scale

Table 8. Results of the logistic regression with satisfaction with health as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent Variable: Satisfaction with health*			
Variables	B-value	Exp (B)	95% CI
Education (None at all)			
Elementary	-.05	.95	.26, 3.47
High school	.84	2.31	.52, 10.22
Tertiary education and private training	1.54	4.65	1.15, 18.78
(No education at all, less than elementary)	N/A		
Marital Status			
Married	.34	1.4	.53, 3.71
Widowed	.076	1.08	.28, 4.2
(Single never married, separated, divorced)			
Cancer Diagnosis (Healthy)	-.1.49	.23	.10, .52
Age	.005	1.01	.97, 1.05

Note: Reference categories for variables are in parentheses.

Hosmer-Lemeshow

Without cancer diagnosis $\chi^2(8) = 1.34$, $p = .1$

With cancer diagnosis $\chi^2(8) = 8.48$, $p = .39$

*Using WHO Quality of Life Scale

Table 9. Results of the logistic regression with overall quality of life & satisfaction with health as dependent variable and cancer diagnosis & three additional factors as independent variables

Dependent Variable: Overall Quality of Life & Satisfaction with Health*			
Variables	B-value	Exp (B)	95% CI
Education			
Elementary	-.05	.95	.26, 3.64
High school	.43	1.54	.34, 6.37
Tertiary education and private training	1.71	5.55	1.35, 21.66
(No education at all, less than elementary)	N/A		
Marital Status			
Married	.44	1.55	.37, 4.59
Widowed	.06	1.07	.18, 4.39
(Single never married, separated, divorce)	N/A		
Cancer Diagnosis	-1.15	.32	.15, .72
Healthy	N/A		
Age	-.01	.99	.95, 1.03

Note: Reference categories for variables are in parentheses.

Hosmer-Lemeshow

Without cancer diagnosis $\chi^2(8) = 7.26$, $p = .51$

With cancer diagnosis $\chi^2(8) = 11.77$, $p = .16$

*Using WHO Quality of Life Scale

Table 10. Results of the independent samples t-test for responses to individual items on Kessler Psychological Distress scale related to cancer diagnosis

Questionnaire items	Healthy		Breast Cancer		Mean Difference	95% CI
	M	SD	M	SD		
In the past 30 days, how often did you feel,						
a. Tired out for no good reason	2.59	1.00	2.73	1.17	-.14	-.52, .24
b. Nervous	2.31	1.13	2.88	1.18	-.56	-.97, -.16
c. So Nervous nothing could calm you down	1.97	1.26	2.38	1.19	-.41	-.84, .022
d. Hopeless	1.84	1.10	1.95	1.21	-.11	-.52, .3
e. Restless or fidgety	2.70	1.35	2.71	1.16	-.011	-.45, .43
f. So restless you could not sit still	2.08	1.28	2.68	1.47	-.6	-1.08, -.115
g. Depressed	2.16	1.11	2.77	1.24	-.61	-1.02, 1.19
h. So depressed that nothing could cheer you up	1.83	1.09	2.14	1.13	-.32	-.71, .71
i. Everything was an effort	2.41	1.15	2.95	1.30	-.54	-.97, -.11
j. Worthless	2.21	1.19	2.60	1.34	-.4	-.84, .05
2. Did these feelings happen more often, about the same or less often than usual?	4.44	1.11	4.38	1.65	.061	-.466, .59
3. How many days out of 30 were you totally unable to work or carry out normal activities?	2.59	5.02	8.95	11.48	-6.36	-9.59, -3.13
4. How many days out of 30 were able to do only half or less of what you would normally have been able to do, because of these feelings?	3.34	4.823	4.95	7.33	-1.61	-.387, .65
5. During the past 30 days, how many times did you see a doctor or other health professional?	1.17	3.93	2.87	3.95	-1.70	-3.12, -.28
6. Physical health problems the main cause if these feelings	2.32	1.11	3.02	1.09	-.69	-1.1, -.29
K-10						
Psychological distress	22.0	7.99	25.59	7.18	-3.59	-6.25, -.94

Table 11. Results of the independent samples t-test for response on WHO Quality of Life- BREF related to cancer diagnosis

Questionnaire items	Healthy		Breast Cancer		Mean Difference	95% CI
	M	SD	M	SD		
1. Quality of life	3.77	.955	3.48	1.16	.28	-.089, .65
2. Satisfaction with health	3.84	.80	3.25	1.11	.59	.26, .93
3. Impediment Physical pain	2.27	1.14	3.50	1.04	-1.23	-1.61, -.85
4. Medical treatment to function in your daily life	2.52	1.11	3.10	1.06	-.57	-.95, -.19
5. Enjoy life	3.21	1.11	2.80	1.3	.41	-.015, .83
6. Feel your life is meaningful	3.57	1.19	3.05	1.14	.52	.11, .94
7. Able to concentrate	3.30	1.18	3.02	1.09	.28	-.12, .68
8. Safe in daily life	3.59	1.14	2.86	1.23	.73	.320, 1.15
9. Health of physical environment	3.64	1.05	3.17	1.16	.47	.082, .86
10. Enough energy for everyday life	3.48	1.1	2.56	1.09	.93	.55, 1.31
11. Ability to accept bodily appearance	3.71	1.16	2.83	1.36	.89	.44, 1.33
12. Enough money to meet needs	2.69	1.13	2.06	1.11	.63	.23, 1.02
13. Availability of information	3.29	1.21	2.83	1.25	.46	.026, .89
14. Opportunity for leisure activities	3.31	1.22	2.70	1.27	.61	.17, 1.05
15. Ability to get around	4.05	.86	3.53	1.01	.52	.18, .86
16. Satisfaction with sleep	3.58	1.04	3.27	1.25	.31	-.089, .71
17. Ability to perform daily living activities	3.92	.989	3.38	1.11	.55	.18, .91
18. Capacity for work	3.67	.97	2.80	1.26	.87	.47, 1.27
19. Satisfied with yourself	3.90	1.06	3.28	1.29	.62	.21, 1.04
20. Satisfied with personal relationships	4.19	.889	4.00	.9	.19	-.13, .50
21. Sex life	3.43	1.15	3.28	1.43	.15	-.43, .73
22. Support from friends	3.35	1.22	3.56	1.27	-.21	-.66, .23
23. Conditions of living place	3.83	1.03	3.80	1.09	.031	-.34, .40
24. Access to health services	3.84	.90	4.05	.84	-.21	-.51, .101
25. Satisfied with transport	3.41	1.12	3.38	1.18	.031	-.37, .43
26. Negative feelings such as blue mood, despair, anxiety and depression	2.57	.84	3.29	1.13	-.71	-1.06, -.36

Table 12. Results of the independent samples t-test for domain score on WHO Quality of Life- BREF related to cancer diagnosis

Questionnaire Domain	Healthy		Breast Cancer		Mean Difference	95% CI
	M	SD	M	SD		
WHOQoL-BREF						
Physical health	14.76	2.48	12.66	2.88	2.09	1.15, 3.04
Psychological	14.06	3.04	12.19	3.46	1.88	.73, 3.02
Social relationships	14.8	3.15	14.7	3.17	.098	-1.02, 1.21
Environment	13.79	2.76	12.42	2.8	1.36	.39, 2.34
Overall Quality of Life	69.14	23.88	62.11	28.86	7.03	-2.24, 16.3
Satisfaction with health	71.09	20.03	56.25	27.82	14.84	6.36, 23.32
Overall Quality of Life & satisfaction with health	15.22	3.12	13.47	4.05	1.75	.49, 3.01

Table 13. Results of the multiple regression with physical health as dependent variable and four independent variables within breast cancer population

Dependent Variable: Physical Health*		
Independent Variables	B-value	95% CI
Education		
Elementary	.83	-1.5, 3.14
High School	1.83	-.99, 4.65
Tertiary and private training (No education at all, less than elementary)	.7	-1.72, 3.12
Marital Status		
Married	.62	-1.34, 2.58
Widow (Single never married, divorced, separated)	.096	-2.81, 3.0
Treatment		
Breast Surgery	.59	-1.03, 2.21
Radiotherapy	.69	-1.2, 2.57
Oral Tablets	-1.31	-3.6, .95
Chemotherapy	.25	-1.56, 2.07
Age	-.04	-.08, .07

Note: Reference categories for variables are in parentheses.

Population: Breast cancer patients

$R^2 = .12$

*Using WHO Quality of Life- BREF

Table 14. Results of the multiple regression with psychological well-being as dependent variable and four independent variables within breast cancer population

Dependent Variable: Psychological Well-being*		
Independent Variables	B-value	95% CI
Education		
Elementary	.97	-1.34, 3.29
High School	3.39	.59, 6.19
Tertiary and private training	4.05	1.65, 6.45
(No education at all, less than elementary)	N/A	
Marital Status		
Married	.44	-1.51, 2.39
Widow	-1.36	-4.24, 1.53
(Single never married, separated, divorced)	N/A	
Treatment		
Breast Surgery	1.54	-.07, 3.15
Radiotherapy	2.29	.42, 4.16
Oral Tablets	-1.72	-3.96, .52
Chemotherapy	-1.46	-3.25, .34
Age	.044	-.03, .12

Note: Reference categories for variables are in parentheses

Population: Breast cancer patients

$R^2 = .40$

*Using WHO Quality of Life- BREF

Table 15. Results of the multiple regression with social relationships as dependent variable and four independent variables within breast cancer population

Dependent Variable: Social Relationships		
Independent Variables	B-value	95% CI
Education		
Elementary	.45	-1.96, 2.86
High School	2.02	-.89, 4.94
Tertiary and private training	.11	-2.39, 2.61
(No education at all, less than elementary)	N/A	
Marital Status		
Married	-2.17	-4.2, -.14
Widow	-3.26	-6.26, -.26
(Single never married, separated, divorced)	N/A	
Treatment		
Breast Surgery	.18	-1.49, 1.86
Radiotherapy	1.42	-.52, 3.37
Oral Tablets	-.47	-2.81, 1.86
Chemotherapy	-.86	-2.73, 1.01
Age	.08	.00, .16

Note: Reference categories for variables are in parentheses.

Population: Breast cancer patients

$R^2 = .21$

*Using WHO Quality of Life- BREF

Table 16. Results of the multiple regression with environment as dependent variable and four independent variables within breast cancer population

Dependent Variable: Environment*		
Independent Variables	B-value	95% CI
Education		
Elementary	.73	-1.39, 2.85
High School	2.0	-.57, 4.56
Tertiary and private training	2.33	.13, 4.52
Marital Status		
Married (Single)	.15	-1.63, 1.94
Widow (Non-widowed)	-1.64	-4.28, 1.0
Treatment		
Breast Surgery	1.39	-.09, 2.86
Radiotherapy	.7	-1.02, 2.41
Oral Tablets	.51	-1.55, 2.56
Chemo	-1.01	-2.66, .63
Age	.002	-.07, .07

Note: Reference categories for variables are in parentheses.

Population: Breast cancer patients

$R^2 = .26$

*Using WHO Quality of Life- BREF

Table 17. Results of the multiple regression with psychological distress as dependent variable and four independent variables within breast cancer population

Dependent Variable: Psychological distress*		
Independent Variables	B-value	95% CI
Education		
Elementary	-.57	-5.98, 4.83
High School	-3.65	-10.18, 2.88
Tertiary and private training	-4.24	-9.84, 1.37
Marital Status		
Married (Single)	-2.93	-7.47, 1.62
Widow (Non-widowed)	-.74	-7.46, 5.99
Treatment		
Breast Surgery	-2.48	-6.23, 1.28
Radiotherapy	4.89	.53, 9.25
Oral Tablets	-3.38	-8.62, 1.85
Chemo	-3.04	-7.24, 1.16
Age	-.03	-.2, .15

Note: Reference categories for variables are in parentheses.

Population: Breast cancer patients

$R^2 = .23$

*Using Kessler Psychological Distress Scale

Table 18. Results of the logistic regression with overall quality of life as dependent variable and four independent variables within breast cancer population

Dependent Variable: Overall Quality of Life			
Independent Variables	B-value	Exp (B)	95% CI
Education (No education)			
Elementary	2.43	11.34	1.07, 119.84
High School	3.51	33.32	1.57, 706.6
Tertiary and private training	4.11	61.58	3.65, 1204.41
Marital Status (Married)			
Single	-.63	.53	.11, 2.72
Widowed	-2.05	.13	.02, 1.11
Treatment			
Breast Surgery	1.86	6.4	1.15, 35.56
Radiotherapy	1.75	5.76	.78, 42.68
Oral Tablets	.32	1.38	.2, 11.4
Chemo	-2.38	.09	.01, .64
Age	.08	1.08	1.00, 1.17

Note: Reference categories for variables are in parentheses.

Population: Breast cancer patients

Hosmer-Lemeshow

$\chi^2(8) = 15.02, p = .06$

*Using WHO Quality of Life Scale

Table 19. Results of the logistic regression with satisfaction with health as dependent variable and four independent variables within breast cancer population

Dependent Variable: Satisfaction with Health*			
Independent Variables	B-value	Exp (B)	95% CI
Education (No education)			
Elementary	.07	1.08	.14, 8.26
High School	1.23	3.42	.29, 39.78
Tertiary and private training	1.5	4.53	.57, 36.27
Marital Status (Married)			
Single	-.74	.48	.11, 2.15
Widowed	-1.4	.26	.03, 2.08
Treatment			
Breast Surgery	1.43	4.17	1.04, 16.71
Radiotherapy	1.98	7.22	1.33, 39.31
Oral Tablets	-.03	.97	.16, 5.76
Chemo	-.25	.78	.15, 3.9
Age	.03	1.03	.96, 1.09

Note: Reference categories for variables are in parentheses.

Population: Breast cancer patients

Hosmer-Lemeshow

$\chi^2(8) = 8.73$, $p = .37$

*Using WHO Quality of Life Scale

Table 20. Results of the logistic regression with overall quality of life & satisfaction with health as dependent variable and four independent variables within breast cancer population

Overall Quality of Life & Satisfaction with Health			
Independent Variables	B-value	Exp (B)	95% CI
Education			
Elementary	1.04	2.2	.25, 31.97
High School	3.2	23.5	1.03, 534.9
Tertiary and private training	2.6	12.88	1.05, 158.6
(No education at all, less than elementary)	N/A		
Marital Status (Married)			
Single	-.29	1.33	.17, 3.4
Widowed	-.77	.64	.05, 4.27
Treatment			
Breast Surgery	2.42	11.26	1.92, 65.97
Radiotherapy	2.4	11.07	1.67, 73.31
Oral Tablets	.43	1.5	.24, 9.64
Chemo	-1.3	.27	.04, 1.85
Age	.04	1.05	.98, 1.12

Note: Reference categories for variables are in parentheses.

Population: Breast cancer patients

Hosmer-Lemeshow

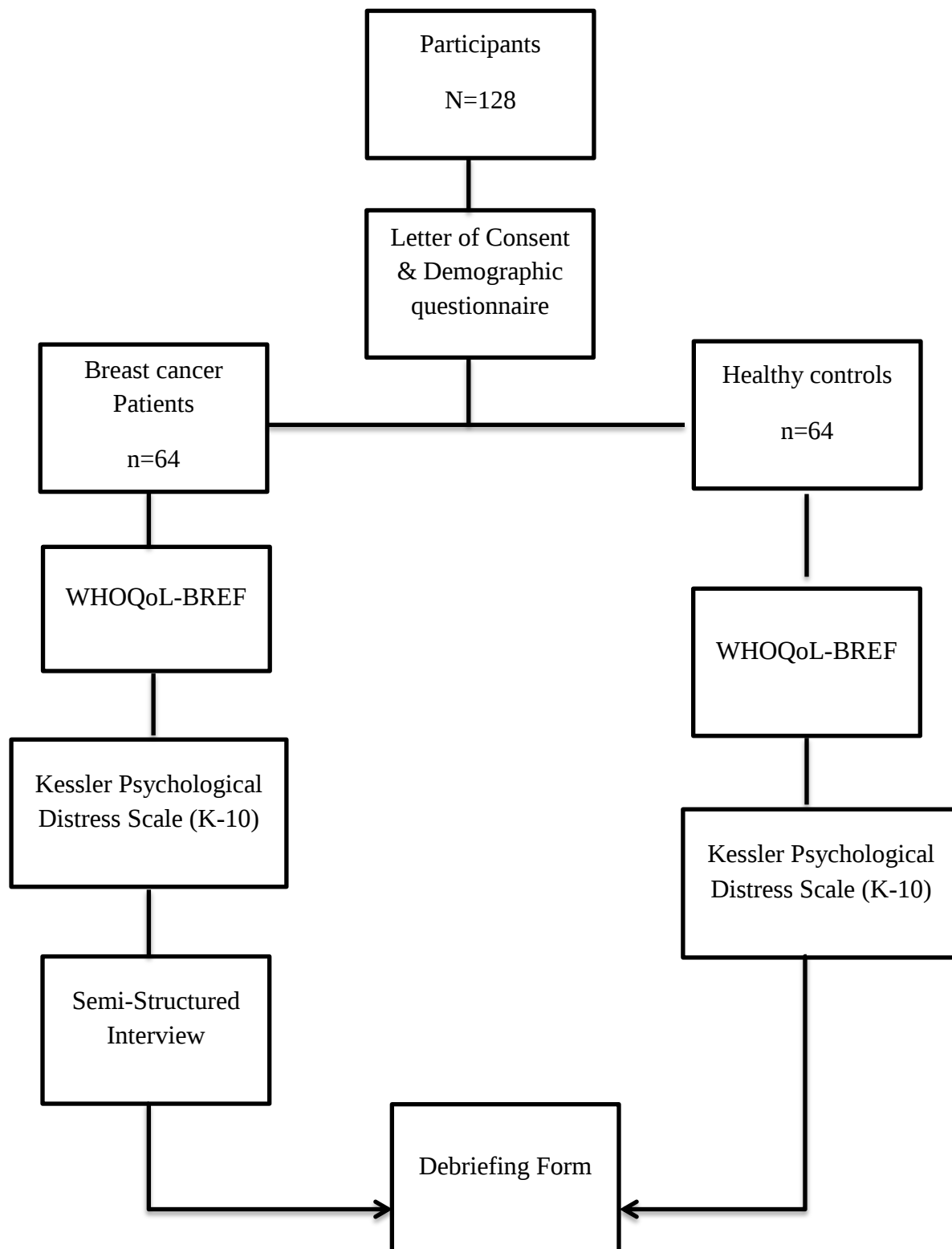
$\chi^2(8) = 11.43, p = .18$

* Using WHO Quality of Life Scale

Table 21. Demographic Table of Interviewed Participants

Participant	Pseudonym	Age	Education	Marital Status	Residence
A001	Bridget	59	no education	Married	Ashanti
A002	Nancy	50	Elementary school	Divorced	Eastern
A003	Jane	57	College/tertiary/private training	Married	Central
A004	Mavis	46	High School	Married	Ashanti
A005	Talia	38	High school	Married	Brong Ahafo
A006	Lynn	58	College/Tertiary/Private	Married	Eastern
A007	Lois	52	College/tertiary/private	Married	Ashanti
A008	Gifty	69	College/tertiary/private	Widowed	Greater Accra
A009	Patricia	40	College/tertiary/private	Married	Upper West
A013	Mansah	41	College/tertiary/private	Divorced	Ashanti
A034	Ann	56	College/tertiary/ private	Married	Greater Accra
A044	Bernice	72	Elementary	Married	Greater Accra
A045	Mary	66	Private training	Married	Greater Accra

Figure 1: Study Procedure



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Appendix A: World Health Organization Quality of Life BREF & Demographic Questionnaire

Demographic Questionnaire

WHOQOL-BREF

About You

Before you begin we would like to ask you to answer a few general questions about yourself by circling the correct answer or by filling in the space provided.

- | | Male | Female |
|---|---|---|
| 1. What is your gender | | |
| 2. What is your date of birth? | <div> <div> <div></div> <div>Day</div> </div> <div>/</div> <div> <div></div> <div>Month</div> </div> <div>/</div> <div> <div></div> <div>Year</div> </div> </div> | |
| 3. What is the highest education you received? | <div>None at all</div> <div>Elementary School</div> <div>High School</div> <div>College</div> | |
| 4. What is your marital status? | <div>Single</div> <div>Married</div> <div>Living as Married</div> | <div>Separated</div> <div>Divorced</div> <div>Widowed</div> |
| 5. Are you currently ill? | Yes | No |
| 6. If something is wrong with your health, what do you think it is? | illness/problem | |

1. Place of residence (region & district): _____
2. What type of breast cancer treatment are you receiving _____

WHOQOL-BREF

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1 (G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5 (F4.1)	How much do you enjoy life?	1	2	3	4	5
6 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

Do you have any comments about the assessment?

.....
.....

Appendix B: Kessler Psychological Distress scale (K-10)

Binding margin – do not write

K10+

Provider: _____

Provider ID: _____

Date completed: ____ / ____ / ____

Please use gummed label if available

Patient or Client Identifier:

Surname:

Other names:

Date of Birth:

Sex:

____ / ____ / ____

Male ☐

Female ☐

Address:

MENTAL HEALTH

The following questions ask about how you have been feeling during the past 30 days. For each question, please circle the number that best describes how often you had this feeling.

Q1. During that month, how often did you feel ...	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. ... tired out for no good reason?	1	2	3	4	5
b. ...nervous?	1	2	3	4	5
c. ...so nervous that nothing could calm you down?	1	2	3	4	5
d. ...hopeless?	1	2	3	4	5
e. ...restless or fidgety?	1	2	3	4	5
f. ...so restless that you could not sit still?	1	2	3	4	5
g. ...depressed?	1	2	3	4	5
h. ...so depressed that nothing could cheer you up?	1	2	3	4	5
i. ...that everything was an effort?	1	2	3	4	5
j. ...worthless?	1	2	3	4	5

K10+ SELF-REPORT MEASURE (1 of 2)

Please turn over the page to continue

- Q2. The last ten questions asked about feelings that might have occurred during the past 30 days. Taking them altogether, did these feelings occur More often in the past 30 days than is usual for you, about the same as usual, or less often than usual? (If you never have any of these feelings, circle response option "4.")

More often than usual			About the same as usual	Less often than usual		
A lot	Some	A little		A little	Some	A lot
1	2	3	4	5	6	7

The next few questions are about how these feelings may have affected you in the past 30 days. You need not answer these questions if you answered "None of the time" to all of the ten questions about your feelings.

- Q3. During the past 30 days, how many days out of 30 were you totally unable to work or carry out your normal activities because of these feelings?

_____ (Number of days)

- Q4. Not counting the days you reported in response to Q3, how many days in the past 30 were you able to do only half or less of what you would normally have been able to do, because of these feelings?

_____ (Number of days)

- Q5. During the past 30 days, how many times did you see a doctor or other health professional about these feelings?

_____ (Number of times)

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Q6. During the past 30 days, how often have physical health problems been the main cause of these feelings?	1	2	3	4	5

Thank you for completing this questionnaire.

Appendix C: Interview Schedule

1. Prior to your diagnosis, when did you know about breast cancer? (This is an introductory question to set the interview process in motion and to get a starting point. Avoid dwelling on it so much)
 - a. How did you learn about it?
2. Take me back to the day you were diagnosed. When you first received the news that you had breast cancer/ when you received your diagnosis, what was your reaction/response? What were first reactions? How did you feel? (Probe for the women's first reaction when they received the news, how did they express their feelings, what was going on in their minds, thoughts, etc).
3. Since you received your diagnosis, how has your condition affected the way you do your day to day activities and work? (Probe for women's lived experiences with the breast cancer, explore their story, allow them to tell their story of this experience)
 - a. How have you managed the impacts?
 - b. Probe for physical, social and mental impacts- how does it affect one or the other?
4. Within your community/family, what roles and responsibilities do you have? Given these responsibilities, how has living with breast cancer affected these roles and responsibilities?
 - a. How has your role in your family/community changed?
5. How has breast cancer affect you as a woman in your community?
 - a. Probe about their perception of their female identity and their role in the community
 - b. Probe for the effects that having breast cancer has caused the women, probe for any personal effects arising out of the women's fears and any other external effects as perceived by other people in the community.
6. We've been discussing the impact of breast cancer on various aspects of your life, now I'd like to discuss how you have been coping with the effects. Could you please tell me what (coping mechanisms) has helped you? How have these been helpful? (Examples include services, family, friends, etc... Probe for coping strategies that the women have employed to continue with breast cancer, let them tell their story of how they have coped)
 - a. Are there any other factors that have helped you deal with breast cancer and remain productive in your community?

Any other comments please?

Thank you very much

Appendix D: Debriefing Form

This study looked at whether Ghanaian women living with breast cancer were more likely to have signs and symptoms of depression than healthy Ghanaian women. Examples of depression symptoms include long periods of sadness and/or fatigue.

The purpose of the one-on-one interviews with the researcher was to get a better understanding of routine and obstacles the participant faces every day. Additionally, this information will allow researchers to see how every day experiences and obstacles affect mental health and quality of life.

The results of this study may lead to more research into the mental health and quality of life of Ghanaian women. The research may not benefit you directly. However, it might help develop strategies that you can use to deal with difficulties that come up in your everyday life.

If you have any concerns about your mental health, do not hesitate to contact the psychiatry services at Korle-Bu Teaching Hospital and Komfo-Anokye Teaching Hospital.

If you are interested in learning about the results of this study or have concerns about your rights as a participant in this experiment, please contact Rhonda Boateng at 054-283-7636 or at boatengr@mcmaster.ca.

Thank you again for your participation.

Rhonda Boateng, BSc
Master of Science in Global Health Candidate,
McMaster University, Canada
Phone: (054) 283-7636



Appendix E: Criteria for evaluating qualitative research

Criteria	Definition	Strategies/practices to satisfy criteria	Current Thesis Project
Credibility	Authentic representations of experience	Purposeful sampling Disciplined subjectivity/bracketing Prolonged engagement Persistent observation Triangulation Peer debriefing Negative case analysis Referential adequacy Member checking	• Bracketing • Method, Investigator and Source triangulation • Peer debriefing • Member checking
Transferability	Fit within contexts outside the study situation	Purposeful sampling Thick description	• Random sampling
Dependability	Minimization of idiosyncrasies in interpretation Variability tracked to identifiable sources	Low-inference descriptors Mechanically recorded data Multiple researchers Participant researchers Peer examination Triangulation, inquiry audit	• Low-inference descriptors • Peer examination • Mechanically recorded data • Multiple researchers • Triangulation
Confirmability	Extent to which biases motivations, interests or perspectives of the inquirer influence interpretations	Audit trail products Thick description Autobiography Journal/notebook	• Journal/ notebook • Audit trail products

(Baxter & Eyles, 1997)

Appendix F: Consent Form



LETTER OF INFORMATION / CONSENT

**Local Principal**

Dr. Harry Shannon
Department of Clinical Epidemiology and
McMaster University
Hamilton, Ontario, Canada
(905) 966 0849
E-mail: shannonh@mcmaster.ca

Investigator:

Biostatistics

Student Investigator:

Rhonda Boateng
Department of Global Health
McMaster University
Hamilton, Ontario, Canada
(054) 283-7636
E-mail: boatengr@mcmaster.ca

Purpose of the Study: We are trying to understand the mental health and quality of life of Ghanaian women. You are invited to take part in this study. We are seeking to learn more about the factors and everyday experiences that affect the lives of Ghanaian women. We will also explore whether and why Ghanaian women are experiencing feelings of sadness, fatigue or depression. Participants will be asked about how they feel their physical health, sleep, daily activities and other factors affect their mental health. This research is for a Master's thesis project.

Procedures involved in the Research: We will start by collecting some background information such as your name and phone number. You will be asked to fill out a quality of life questionnaire and mental health questionnaire. You have the option of completing the questionnaires at the Peace & Love Hospital or in your home under the supervision of the researcher. The session will last approximately one hour. You might be asked to take part of a one-on-one interview with the researcher. In the interview, you will be asked questions that explore how your life experiences affect the way you feel and your quality of life. For example, does your health affect your daily routine and how does that make you feel?

Potential Harms, Risks or Discomforts: The risks involved in participating in this study are minimal. You may feel uncomfortable with questions within the questionnaires and the interview that require that you think about your current situation. You may worry about how others will react to the answers you provide during the study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You can also withdraw from the study at any time. I describe below the steps I am taking to protect your privacy.

Potential Benefits: We hope to learn more about the events that affect the quality of life and mental health of Ghanaian women. The findings from this study may lead to more research into the experiences of Ghanaian women. The research may not benefit you directly. However, it might help develop strategies that you can use to deal with difficulties that come up in your everyday life.

Payment or Reimbursement All participants will receive a small gift of 10 GHC as token of our appreciation.

Confidentiality You are participating in this study confidentially. Every effort will be made to protect (guarantee) your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. No one but the members of the research team will know whether you were in the study unless you choose to tell them. The information/data you provide in the questionnaire will be kept in a locked cabinet where only I will have access to it.

Personal information and interview transcripts will be kept on a computer that will be protected by a password. Once the study has been completed, the data will be stored for three years. After three years, the data will be destroyed.

Participation and Withdrawal: Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can stop completing the questionnaire and interview for whatever reason, even after signing the consent form. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. You may request to withdraw any data you have provided up until September 15th 2016. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results: We expect to have this study completed by approximately December 2016. Brochures with the summary of the results will be at the Peace & Love Hospital at the end of January 2017. Participants may also request to receive the study findings by email.

Questions about the Study:

If you have questions or need more information about the study itself, please contact me at:

boatengr@mcmaster.ca
Ghanaian telephone number(will be available)

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

- I have read the information presented in the information letter about a study being conducted by Dr. Harry Shannon and Rhonda Boateng from McMaster University.
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I understand that if I agree to participate in this study, I may withdraw from the study at any time. Information I have provided may be withdrawn up until **September 15th 2016**.
- I will receive a signed copy of this form.
- I agree to participate in the study.

1. I agree that the interview can be audio recorded.

Yes / No.

2. ...Yes, I would like to receive a summary of the study's results.

Please send them to me at this email address _____

... No, I do not want to receive a summary of the study's results.

3. I agree to be contacted about a follow-up interview, and understand that I can always decline the request.

... Yes. Please contact me at: _____

... No.

Name of Participant (Printed)

Signature

Date

Consent form explained in person by:

Name and Role (Printed)

Signature

Date

Appendix G: Hamilton Integrated Research Ethics Board Letter of Approval



Hamilton Integrated Research Ethics Board

2 June 2016

Project Number:1610

Project Title:The Mental Health, Quality of Life & Life Experiences of Ghanaian Women Living with Breast Cancer

Student Principal Investigator:Ms. Rhonda Boateng

Local Principal Investigator:Dr Harry Shannon

We have completed our review of your study and are please to issue our final approval. Please note that as a condition of our approval we require the following:

- Please submit to us a copy of the final ethics approval from Ghana
- If you are required to make any revisions to satisfy local ethics requirements, we require a copy of the revised documents for our files. However, please also note that you do *not* require our approval for those revisions—we simply need a copy of the revised documents.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Advertisement V#2	26/May/2016	2
Debriefing Form V#2	27/May/2016	2
Letter of Consent V#2_clean	24/May/2016	2
Phone Script V#2	26/May/2016	2
Protocol V#2	27/May/2016	2
Questionnaire V#2	24/May/2016	2

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented. This applies to any changes that are made *after* you receive local ethics approval in Ghana, and not to any revisions they request in order to grant their final approval.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a Study Completion Form.

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an Annual Review Form with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices, Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations, for studies conducted at St. Joseph's Hospital, HiREB complies with the health ethics guide of the Catholic Alliance of Canada

Appendix H: Peace & Love Hospital letter of approval

PEACE AND LOVE HOSPITAL

Tel: +233-244-145-064
Email: peaceandlove2002@gmail.com
URL: <http://breastcareinternational.org/>



Breast Care International Ave
Plt 1, Blk C, Oduom-Kumasi
PO Box X374
FNT, Kumasi, Ghana

Our Ref: RB002/PLH

Your Ref:

Date: July 4, 2016

Rhonda Boateng
Department of Global Health
McMaster University, Canada
Hamilton, Ontario, Canada
boatengr@mcmaster.ca

Dear Rhonda,

Letter of Approval

Study Title: Mental Health, Quality of Life & Life Experiences of Ghanaian Women Living with Breast Cancer
Proposed Study Site: Peace and Love Hospital, Oduom-Kumasi
Sponsoring Institution: McMaster University, Ontario, Canada

Your submission to the Peace and Love Hospital (PLH) and Breast Care International (BCI) Ethical and Protocol Review Committee (EPRC) on the above named study based on the following documentation:

- Research protocol
- Advertisement
- Questionnaire
- Phone Script
- Debriefing Form
- Letter of Consent
- Researcher application
- Hamilton Integrated Research Ethics Board approval letter

The committee considered the ethical value of your submission and approved the protocol, therefore; you can start your study as planned. This approval is for a specific period of time between July 11, 2016 and July 10, 2017. However, the committee has the right to suspend or revoke this ethical approval at anytime if it is found that your study contravenes the approved protocol.

Please note that data gathered for this study should be used for the approved purposes only and permission should be sought from the committee if there is any need to make amendment to the protocol.

A final report on your study should be sent to the committee at the close of your study and any publication that may arise from it.

We wish you all the best in your study.

Sincerely Yours,

Beatrice Wiafe Addai, M.D.,PhD
For Chairperson

** Community Participation **

Appendix I: Hamilton Integrated Research Ethics Board Student Research Committee acknowledgement of receipt of local ethical approval letter



HiREB Student Research Committee

Acknowledgement

Date:	29 July 2016
REB Number:	1610
Title of Study:	The Mental Health, Quality of Life and Life Experiences of Ghanaian Women Living with Breast Cancer
Student PI:	Rhonda Boateng
LPI:	Harry Shannon

Dear Rhonda:

We wish to acknowledge receipt of the ethical approval letter, dated 04 July 2016, from the Peace and Love Hospital (PLH) and Breast Care International (BCI) Ethical and Protocol Review Committee (EPRC).

This letter satisfies our request for ethical review at the local site.

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

The HiREB SRC complies with the guidelines set by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and with ICH Good Clinical Practice.