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Breast Cancer Treatment Decision making: an ethnographic exploration of how the cultural context of Ghana influences treatment decision making for women with breast cancer

By

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PhD Thesis

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Abstract

Faculty of Environmental and Life Sciences

School of Health Science

Thesis for the degree of Doctor of Philosophy

Ethnographic exploration of how the cultural context of Ghana influences breast cancer treatment decision making

Linda Serwaa Agyemang

Background: Breast cancer in Ghana is characterised by a high mortality rate with 5-year survival approximated at 25%. This has mostly been attributed to advanced disease presentation. While advanced disease may be a salient factor contributing to the poor breast cancer survival in the country, it is increasingly being recognised that even when women present with early disease, some do not take up and or complete a recommended treatment. Many of these women return later with an advanced disease, which results in poor outcomes. The reasons for this have however, not been adequately explored and understood. The few studies conducted in this area identified pertinent cultural factors such as the disapproval of family members of women who take up surgical treatment (mastectomy), which means women often refuse surgery while other women choose traditional medicine (herbal and/or spiritual healing). Although cultural beliefs, values and practices seem fundamental in breast cancer treatment decision making, these studies were mostly quantitative, which are limited in allowing in-depth understanding. Moreover, studies were conducted on women who started treatment but had not completed the remaining courses of treatment. There was limited focus on women who are newly diagnosed and are considering whether or not to start treatment, which limits understanding concerning this patient group. It is essential to understand these issues in this patient group to guide interventions aimed at supporting treatment decision making in women who are newly diagnosed with breast cancer. This study aimed at exploring and understanding how the cultural context in Ghana influences treatment decision making for women with breast cancer attending a breast clinic in southern Ghana. Ethnographic approach was adopted. 89 hours of participant observation was conducted over a period of 16 weeks (July 2017 to November 2017), at a breast clinic, in a teaching hospital, in southern Ghana. 31 participants (16 women diagnosed with curative breast cancer and yet to start treatment; five nominated relatives; five nurses and five doctors) were included in the study.

29 participants took part in in-depth interviews following participant observation. Fieldnotes and interview transcripts were analysed thematically and iteratively in keeping with ethnographic data analysis approach.

The study found that quality information necessary for breast cancer treatment decision making is hidden from women. Factors that contribute to the hiddenness include unequal power relationships between patients and healthcare professionals (HCPs). Patients ascribed their passive and deferential behaviours to their cultural constructed role as laypersons who needed to submit to the experts. Doctors also deliberately miscommunicated treatment information with the intention of preventing patients from refusing treatment. This unequal power relationship, reinforced by a lack of patients' involvement in treatment decision making and lack of privacy during consultation to facilitate quality patient engagement, contributed to the hidden information around the disease and treatment. Furthermore, a lack of local terms in the local Twi language to explain the concepts in cancer and treatment, a lack of information materials appropriate for the women who attend the clinic, in addition to a prevalence of stigmas and taboos around cancer all act to effectively deny access to or hide quality information from women.

Patients fill in the gap left by the lack of information with lay explanations around the disease and treatment. Decision making amongst participants was influenced by factors such as a belief in a spiritual cause of breast cancer; beliefs that cancer is incurable, and that mastectomy actually contributes to death. There were concerns that treatment would disrupt women's day-to-day gender roles, such as housekeeping; breastfeeding; trading; taking care of children, and these influenced their treatment decision making. Awareness of survivors and the belief that treatment will lead to a cure or prevent disease progression influenced women to consider biomedicine. Other factors include faith in God; and the easy access of traditional medicine as opposed the high financial cost (regardless of the National Health Insurance Scheme package) and hidden cost of biomedical treatment. While some of the factors (awareness of survivors; a belief that treatment will lead to a cure or prevent disease progression and faith in God for bringing healing with biomedicine) pulled women towards biomedicine, majority of the factors pushed women away from it.

This study has shown that breast cancer treatment decision making is underpinned by a complex interplay of structures, practices, beliefs and values which strongly influence women against biomedicine. These findings highlight the need for caregivers to be aware of the socio-cultural factors that limit access to quality information. Policymakers should also be aware that the cost of cancer treatment continues to be a barrier despite NHIS package. Policies that aim at addressing this financial barrier and increasing staffing levels with adequate logistics and staff cultural awareness training are recommended.

The findings of this study make a significant contribution to the literature on how the cultural context in Ghana influences treatment decision making for women with breast cancer. This calls for a culturally appropriate treatment decision support intervention.

Faculty of Environmental and Life Science

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Thesis for the degree of Doctor of Philosophy

An ethnographic exploration of how the cultural context of Ghana influences treatment decision making for women with breast cancer attending a breast clinic in Southern Ghana

by

Linda Serwaa Agyemang

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Research Thesis: Declaration of Authorship

Print name: Linda Serwaa Agyemang

Title of thesis: An ethnographic exploration of how the cultural context of Ghana influences treatment decision making for women with breast cancer

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Linda Serwaa Agyemang Date: 04/04/2020

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God bless you all.

Definitions and Abbreviations

1. Culture

Wolman (1989) states that culture is a way a certain society lives; the totality of manners, customs, beliefs, values and practices of a given society inclusive of its socio-economic system, political structure, religion, education, art and entertainment. This study draws on this definition to define cultural context as the ideals, assumptions, beliefs, practices and values of Ghanaian society, not excluding its socio-economic and politics (Wolman, 1989).

2. Medical pluralism

Medical pluralism is the existence of different healing approaches and the social and cultural organization of their practices in a given community (Dashti, 2007).

3. Values

The beliefs people have about what is right and wrong and what is most important in life that controls peoples' behaviour or worth of something for someone (Cambridge Dictionary, 2020).

4. Belief

The feeling of being certain that something exists or is true (Cambridge Dictionary, 2020)

5. Instrumental support

Instrumental support is the provision of tangible aid and services that directly assist a person in need (Glanz et al., 2010).

6. Stigma

The degree to which a body is blemished/deformed or the character of a person is discredited (Goffman, 1968).

7. Traditional medicine

Traditional medicine refers to the knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, used in the maintenance, and the prevention, diagnosis, improvement or treatment of physical and mental illness (WHO, 2017).

8. Power

Power, according to Wildavsky (1964), is defined as the ability to obtain the obedience of others to a particular command.

9. Structure

Refers to the resources, including the human and non-human resources that are recursively implicated in the reproduction of societies (Giddens, 1984).

Acronyms and Abbreviations

CASP	Critical Appraisal Skills Programme
CIA	Central Intelligence Authority
GDP	Gross Domestic Product
HBM	Health Belief Model
NCDs	Non-Communicable Diseases
PICO	Population Intervention/exposure Comparison Outcome
SET	Socio-Ecological Theory
SSA	Sub-Saharan Africa
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
WHO	World Health Organisation

Chapter 1 Background

This chapter outlines the rationale for the chosen research topic and provides contextual and background information relating to breast cancer and treatment decision-making of the research context, Ghana.

1.1 The research aim

Breast cancer is the most frequently diagnosed cancer among women worldwide. In 2018, the global estimates of breast cancer were 2.1 million new cases (Bray et al., 2018). Of these, it was estimated that approximately 50% occurred in developing countries including Ghana (Bray et al., 2018). Breast cancer is a cause of public health concern, especially in developing countries, because the disease is also associated with a higher mortality rate. According to WHO (2016), 58% of the 0.5 million deaths recorded for breast cancer in 2008 occurred in developing countries.

In many developing countries, there is an absence of population-based screening programmes, women with breast cancer are diagnosed late (stages 3 and 4) and therefore have a poorer chance of survival (Youlden et al., 2012; Cancer Research UK, 2014). In contrast, the majority of women in developed countries have access to population-based screening and hence diagnosed with early disease (stages 1 and 2), which translates into a higher survival rate (Youlden et al., 2012).

Ghana, like many developing countries, has an increasing burden of breast cancer. Published data on the disease from a hospital series indicated that from 1972 through to 1975, breast cancer accounted for 7.5% of all cancers seen at the hospital (Cancer Registry, 1977). However, recent publications showed that in 2009, breast cancer accounted for 26% of the total new cancer cases presented at the same hospital (Ghana Ministry of Health, 2010), and is the second most common cancer seen there (Ghana Ministry of Health, 2010). The rise in documented breast cancer cases in the country is attributed to increased prevalence of breast cancer risk factors including lifestyle changes (e.g., excessive alcohol consumption, physical inactivity or obesity), early menarche, delay in childbearing, having fewer children, and the ageing population (Wiredu et al., 2014).

Breast cancer in Ghana is characterised by a higher mortality rate. The WHO estimates the incidence-mortality rate of breast cancer in Ghana as 0.68 compared to 0.2 in the USA (Ferlay et al., 2014). Ghana's Ministry of Health (2010) asserts that five-year survival for breast cancer is 25%, which is low when compared to 85% in the USA. The disparity is in large part due to late presentation (Wiredu et al., 2014; Clegg-Lamptey et al., 2009). About 50%-70% of women present with stage 3 and 4 disease in Ghana (Ministry of Health, 2010) compared to less than 37% in the USA (National Cancer Institute, 2014).

However, from personal experience as a nurse on a surgical ward, even when women present early, many do not take up or complete a recommended treatment. Studies conducted among women diagnosed with breast cancer in Ghana also found suboptimal treatment use. Clegg-Lamptey et al. (2009) showed that out of 101 women with breast cancer attending a breast clinic in Ghana, 35 (35%) did not take up or continue with the treatment offered following diagnosis. Similarly, Sherber et al. (2014) found in their two-year retrospective medical review that of a total of 394 Ghanaian women whose medical records were available, over 70% had not continued with treatment at the breast clinic for more than six months. When women elect to refuse treatment or choose to receive suboptimal treatment, they are likely to return later with more advanced and/ or metastatic disease that will both have a poorer prognosis and be costly to manage (Irvin et al., 2011; Clegg-Lamptey et al., 2009). Suboptimal treatment may, therefore, also account for the poor breast cancer survival in Ghana. The reasons for this have not been adequately explored.

In the literature (details provided in the literature review of Chapter Two), few studies have identified the factors influencing breast cancer treatment decision-making in Ghana. Socio-cultural factors such as family members' disapproval of conventional treatment and use of traditional treatment (herbal and spiritual healing) were found to influence the uptake of recommended treatment (Clegg-Lamptey, 2009; O'Brist et al., 2014). Nonetheless, there is a limited understanding of these factors as the studies were mostly quantitative. Moreover, these studies were conducted on women who had started and then abandoned the remaining courses of treatment. There are limited studies focussed explicitly on women who are considering whether or not to start treatment, which limit understanding concerning this patient group.

Another issue is that there is veneration for the opinion of authority figures such as doctors, and patients often concede medical decisions to doctors who are perceived to make decisions in patients' best interests (Norman, 2015). The prevalence of this cultural perception of doctors might suggest that women in Ghana would be more likely to follow a recommended breast cancer treatment by medical doctors. However, some women do not follow clinicians' recommendations, which indicates the existence of other influencing factors. It could also be argued that since most doctors in Ghana have attitudes that could be described as paternalistic (Norman, 2015), women may be less likely to be actively involved in discussions around treatment. Lack of active involvement in treatment discussions could impact on the extent to which women's values and concerns are raised and/or addressed (Stacey et al., 2011), and consequently whether they persevere with a recommended treatment. This is equally confirmed by survivors of breast cancer in Ghana, who indicated their lack of involvement in breast cancer treatment decision-making (Clegg-Lamptey et al., 2009).

Overall, the factors outlined above indicate that breast cancer treatment decision making in Ghana may often not lie solely with the woman, but rather may be complex, involving family members and doctors. Yet, there is little exploration of how the cultural context in Ghana influences treatment decision making for women with breast cancer.

As cultural beliefs and values appear fundamental, this study will adopt an ethnographic approach to explore and understand the phenomenon. Ethnographies are suitable for understanding the behaviour of individuals from their perspective with respect to their culture (Creswell, 2013). A greater understanding of this phenomenon may inform the development of interventions that can help improve and support women in making decisions, improve treatment uptake, and ultimately improve their health outcomes.

In this study, the focus is on women with a breast cancer diagnosis (stage 1 to stage 3), who are considering whether or not to start a recommended treatment with curative intent, their self-nominated family member, and doctors and nurses at a breast clinic in southern Ghana.

1.2 Breast cancer treatment

Breast cancer is a disease in which malignant (cancerous) cells form in the tissues of the breast (National Cancer Institute, 2018). With breast cancer, the stage at which the disease is diagnosed is critical because optimal treatment and aim of treatment (curative or palliative) are mostly dependent on the stage at diagnosis. The table below describes the stages of breast cancer:

Table 1.1: stages of breast cancer (NCI, 2018)

Stage	**Characteristics**
Stage 0	Carcinoma in situ
Stage 1	The tumour is 2cm or smaller and has not spread outside the breast
Stage 2A	No tumour found in the breast, but cancer found in the axillary lymph nodes (i.e. lymph nodes under the arm); the tumour is 2cm or smaller and has spread to the axillary lymph nodes; or the tumour is larger than 2cm but not larger than 5cm, and has not spread to the axillary lymph nodes

Stage 2B	The tumour is larger than 2cm but not larger than 5cm and has spread to the axillary lymph nodes; the tumour is larger than 5cm but has not spread to the axillary lymph nodes
Stage 3A	No tumour found in the breast, but cancer is found in the axillary lymph nodes that are attached to each other or to other structures; the tumour larger than 5cm and has spread to axillary lymph nodes that may be attached to each other or to other structures
Stage 3B	The cancer maybe any size and has spread to tissues near the breast (e.g., skin, chest wall, including the ribs and muscles in chest) and it may have spread to lymph nodes within the breast or under the arm
Operable Stage 3C	The cancer has spread to lymph nodes beneath the collarbone and near the neck, and it may have spread to lymph nodes within the breast or under the arm and to tissues near the breast§§§
Inoperable Stage 3c	The cancer is found in 10 or more of the lymph nodes under the arm, in the lymph nodes beneath the collar bone and near the neck on the same side of the body as the breast with cancer or in lymph nodes within the breast itself and in lymph nodes under the arm; The cancer has spread to lymph nodes above the collar bone and near the neck on the same side of the body as the breast with cancer
Stage 4	The cancer has spread to other organs of the body most often the lungs, liver, bones or brain

According to International treatment guidelines for Stages 1, 2, 3A, 3B and operable 3C breast cancer, the recommendations are that treatment should comprise surgery either mastectomy or breast conservation and adjuvant treatment (drug therapy). Adjuvant therapy is offered after surgery to raise the chance of cure by eliminating the micro metastases that cause relapse (NICE, 2019). Radiotherapy is advocated after breast conservation to reduce local recurrence rates. It is also used after mastectomy if there is a high possibility of recurrence. Drug therapy can be offered before surgery (neoadjuvant therapy) to achieve local tumour downsizing and allow for a possible breast conservation surgery (NICE, 2019). These treatment recommendations are particularly important as background information to this study because improving survival for breast cancer is mostly attributed to two main factors: stage at diagnosis and access to optimal treatment (WHO, 2014).

Randomised controlled trials and longitudinal studies have consistently documented that patients with early and operable breast cancer who received optimal treatment had better prognosis in terms of local recurrence, distant metastasis, contralateral breast cancers or death from the disease (Hershman et al., 2011; Hershman et al., 2009). In spite of the evidenced-based prognostic outcomes of optimal treatment for early and operable breast cancer, some women in Ghana with breast cancer may not receive optimal treatment. My observation as a nurse on a surgical ward is that when some women present with the disease where they stand a chance of cure, some do not take up or complete a recommended treatment. Unpublished evidence (Table 1.2 below) from a teaching hospital affirms this observation.

Table 1.2: Patients with breast cancer who received optimal treatment and those who did not receive optimal treatment in a teaching hospital in southern Ghana between 2012-2016 (Courtesy, Kumasi Breast Cancer Records)

Treated	**2012**	**2013**	**2014**	**2015**	**2016**
Yes	41 (61.2%)	61 (77.2%)	70 (64.2%)	58(42.0%)	83 (56.1%)
No	25	8	13	23	11
Not Specified	1	10	26	57	54
Total Number of Cases	**67**	**79**	**109**	**138**	**148**

From the table above, of a total of 541 patients diagnosed with breast cancer in a single Teaching Hospital between 2012-2016, approx. 43% were either found not to have had treatment or it could not be determined whether they had received treatment. This situation is alarming, but studies conducted in Ghana have mostly focused on factors leading to a delayed presentation (Clegg-Lamptey et al., 2007; Wiredu et al., 2014; Agbeko, 2017). While it is important to explore reasons underpinning delayed presentation in Ghana to improve breast cancer control, it is equally important to understand the factors influencing sub-optimal treatment, because even when some women present comparatively early, they may not receive optimal treatment. Consequently, these women are likely to return with a more advanced disease which has a poorer prognosis and is more expensive to treat. It is thus critical to explore and understand the factors that may influence the uptake of optimal treatment for breast cancer to improve breast cancer control in the country.

1.3 Contextual Factors that may impact on optimal treatment uptake in Ghana

1.3.1 Ghana

Ghana is situated in the sub-Saharan Africa region (see Figure 1.1 below). The topographical area is around 238,533 km² (Central Intelligence Agency, 2020). There are about 29 million people in the country. The population growth is estimated at 2.15 % per annum (CIA, 2020). Approximately 58% of the population are between the ages of 15-64 years (CIA, 2020) with a majority of the population (51%) being female (CIA, 2020).

Figure 1.1: Location of Ghana in the African region (Sourced from Google images, free to use)

Ghana is classed as a middle lower-income country (CIA, 2020) and has a Gross Domestic Product (GDP) per capita of $4700 (CIA, 2020). The country's economy is wide-ranging, but the agricultural sector is more dominant (WHO, 2012), contributing about 44.7% of GDP. The services and industrial sectors are also approximated to contribute the remaining 55% (CIA, 2015). Recent estimates of poverty levels indicated that the majority of the people live on around two dollars a day (Ghana Web, 2019; CIA, 2015). Although this rate is above the poverty line, nonetheless, socio-economic challenges remain (see figures 1.2 to 1.9 below).

Figure 1.2 Population living in an urban centre in Ghana compared to sub-Saharan Africa[1]

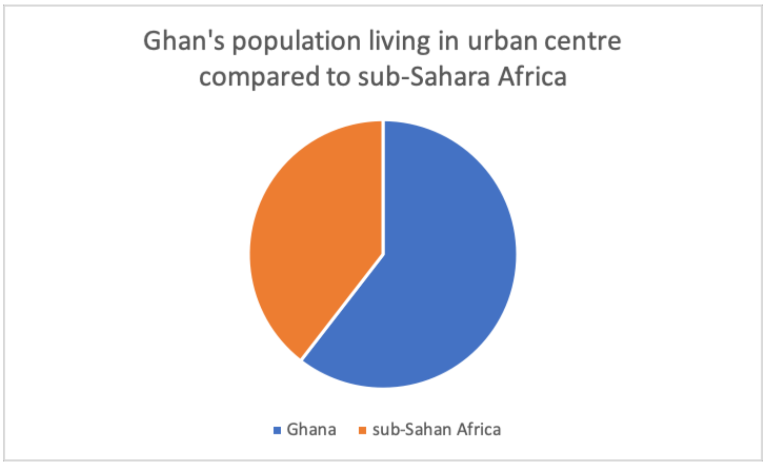
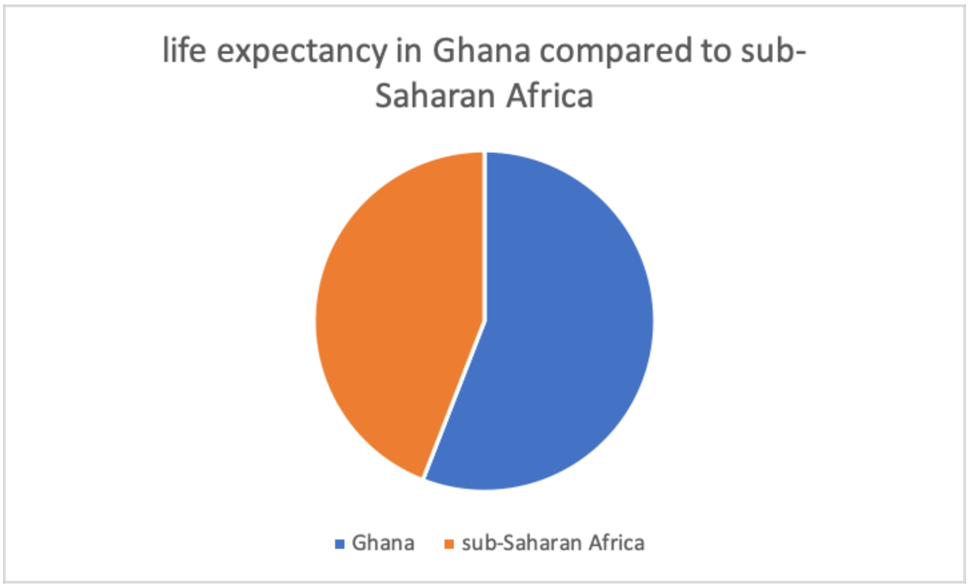


Figure 1.3 Life expectancy in Ghana compared to sub-Saharan Africa[2]



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[1] The total Population sizes are Ghana= 29340248; sub-Saharan Africa= 1,078,000,000 but 57.3% of Ghanaians live in urban centres compared to 37.43% of the sub-Saharan population.

[2] Life expectancy in Ghana: 68.2; sub-Saharan Africa is 53.8
(WHO, 2018; Marquez and Farrington, 2013)

Figure 1.4 Number of children born per woman in Ghana compared to sub-Saharan Africa

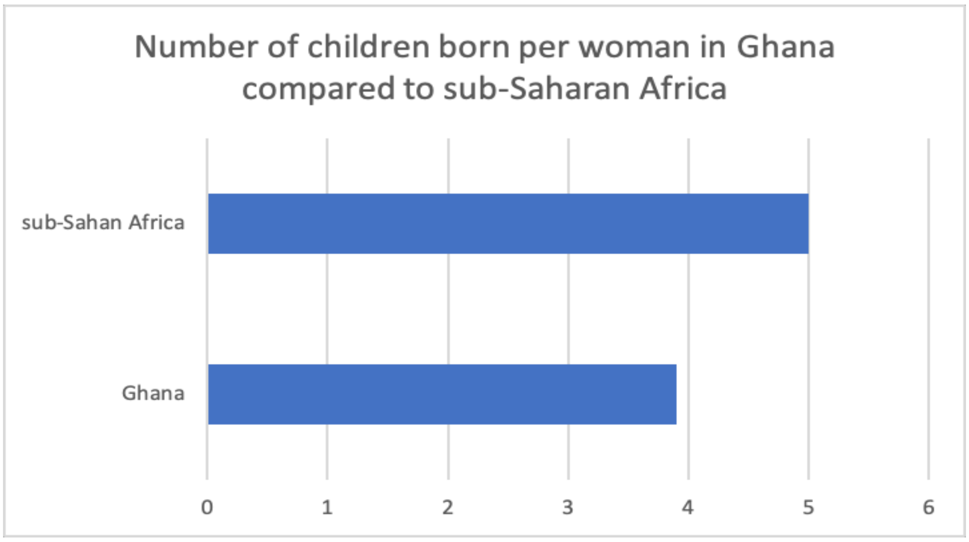


Figure 1.5 Maternal mortality in Ghana compared to sub-Saharan Africa

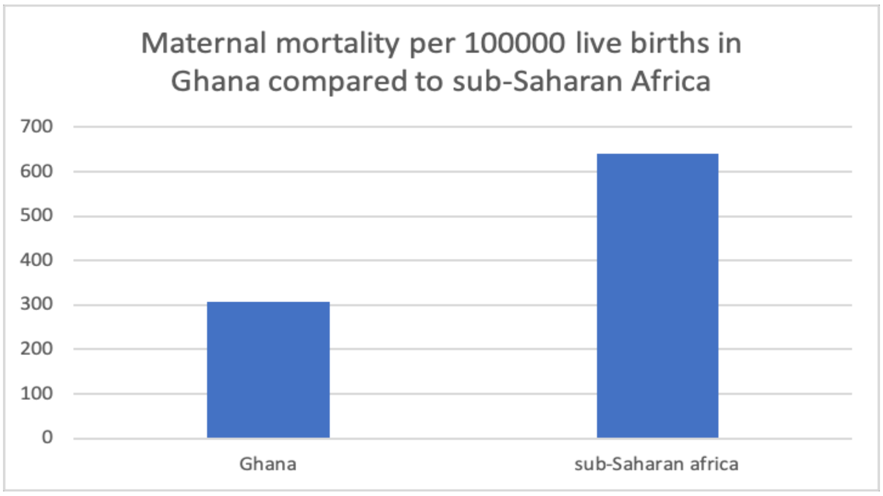


Figure 1.6 Under-five mortality in Ghana compared to sub-Saharan Africa

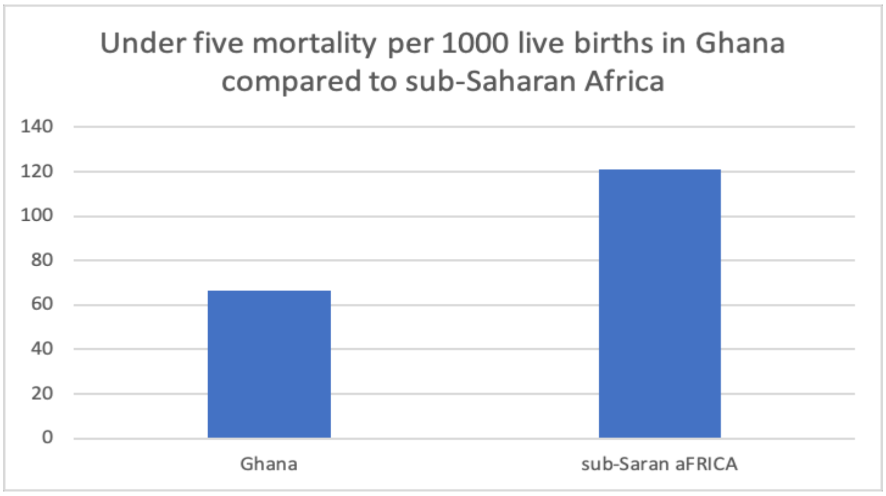


Figure 1.7 Population with access to sanitation in Ghana compared to sub-Saran Africa

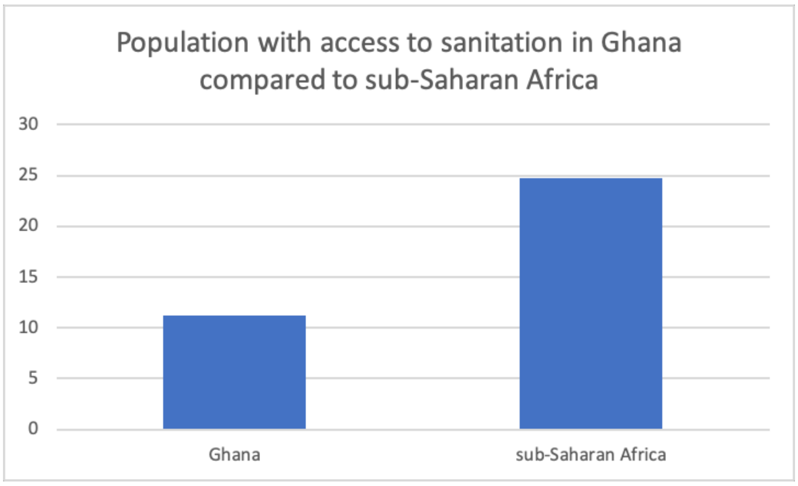
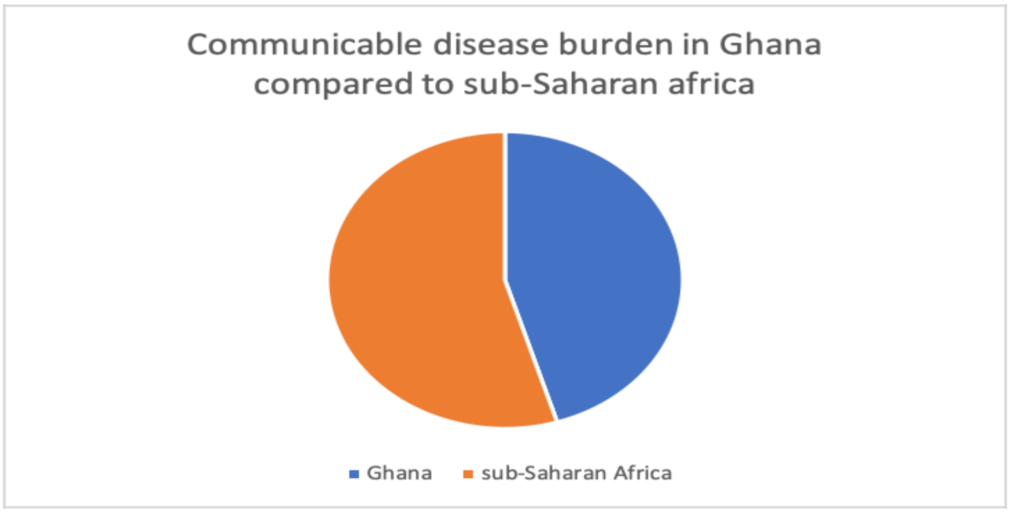


Figure 1.8 Communicable disease burden in Ghana compared to sub-Saharan Africa[3]



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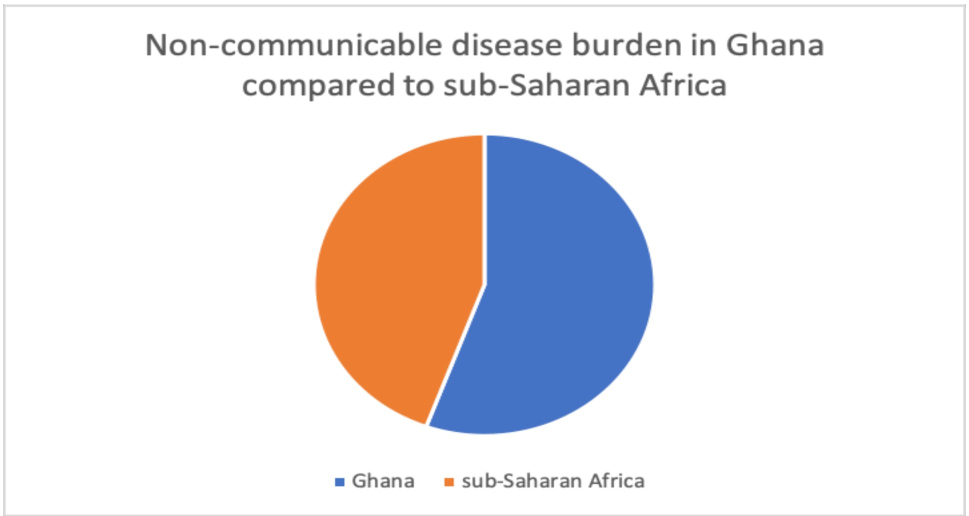
[3] Communicable disease burden (Age Standardised Mortality Rate) (%) in 2010 is 43% compared to 52% in sub-Saharan Africa
(WHO, 2018; Marquez and Farrington, 2013)

Figure 1.9 Non-communicable disease burden in Ghana compared to sub-Saharan Africa[4]



Reflecting on figures 1.8 and 1.9 above, the non-communicable diseases (NCDs) burden in Ghana compared to the Sub-Saharan Africa (SSA) countries' average suggest that Ghana is in an epidemiologic transition. The main causes of mortality have moved away from infectious diseases to a combination of infectious and chronic diseases over the past decades (Agyei-Mensah et al., 2010). The implicated NCDs are diabetes, hypertension, stroke and cancer and these are among the major causes of death and disability in the country (Agyei-Mensah et al., 2010). The increasing incidence of chronic diseases has been attributed to urbanisation and lifestyle changes, which were hitherto associated with economic development (e.g., low physical activity, low vegetable diet, and excessive alcohol consumption) (Agyei-Mensah et al., 2010). While the rising chronic disease burden has been acknowledged, the country still lacks a functional chronic disease policy, not least a blueprint to curb this epidemic. Bosu (2012) attributes this to inadequate research, fragile surveillance systems, and limited political interest and donor investment.

1.3.2 Healthcare system in Ghana

The healthcare system in Ghana is pluralistic. Medical pluralism refers to the existence of different approaches to healing and the social and cultural organisation of their practices in a given community (Dashti, 2007). In Ghana, the plural health system is on two dimensions: public versus private; and biomedicine versus traditional or folk systems (Abor, 2009).

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[4] Non-communicable disease burden (Age Standardised Mortality Rate) (%) in 2010 is 50% in Ghana compared to 40% in sub-Saharan Africa
(WHO, 2018; Marquez and Farrington, 2013)

1.3.2.1 Biomedical health system

Ghana is a former British colony. The health service in the country is inherited from the British colonial rule after independence in 1957. This encompassed a group of government and mission hospitals and health centres situated in the southern coastal regions. These hospitals and health centres were established to serve the colonial officials (de-Graft Aikins and Koram, 2016). Unfortunately, even after independence, health infrastructural development imitated that of the colonial era where the Northern sector and rural areas saw less development (Saleh, 2013).

This is also the case in terms of physician training and distribution across the country. Physicians in the county are trained mainly by two leading public universities: University of Ghana and Kwame Nkrumah University of Science and Technology. They produce about 200 graduate physicians each year with a third new University at Tamale in the North, also adding a couple of dozens to the number (Saleh, 2013). Saleh (2013) argues that the number of medical schools is insufficient for the growing population (0.08 physician to 1000 population)[5] and it is skewed in favour of urban areas by appealing to students from urban areas who then stay in the cities and big towns. Secondly, the existing universities that train medical students do not have many speciality sections, which means there are limited specialist physicians in the country as most would require such training abroad. When they do, some of them do not return (Drislane et al., 2014).

With regards to the nursing workforce, in 2010, their numbers to population ratio were 0.39 per 1000 population (Saleh, 2013). Although the numbers are low, the range is within the benchmark (0.2 to 1.9 per 1000 population) acceptable by the WHO (Saleh, 2013) and it represents the most substantial cadre of the clinical healthcare workforce in the country. Trends in nursing education highlight that the Ghana Ministry of Health has always tried to accelerate the training of nurses post-independence. The reason being that after independence in 1957, the socio-political change and healthcare needs of the country (communicable, maternal and nutritional) were such that there was a need to train more nurses to meet the needs of the country (Saleh, 2013). The content of nursing education continued to be what was provided by British nurse expatriates and was organised around the subjects of Anatomy and Physiology, Hygiene, Surgical and Medical Nursing, Nutrition and Dietetics and First Aid Techniques (Zutah, 2017). Today, although there is at least one nursing training college in each of the ten regions in the country (Ministry of Health,

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[5] [5] United Kingdom: 2.8 physicians per 1000 population (BMJ, 2017)
7.9 nurses per 1000 population in 2015 (Organization for Economic Cooperation and Development, 2017)

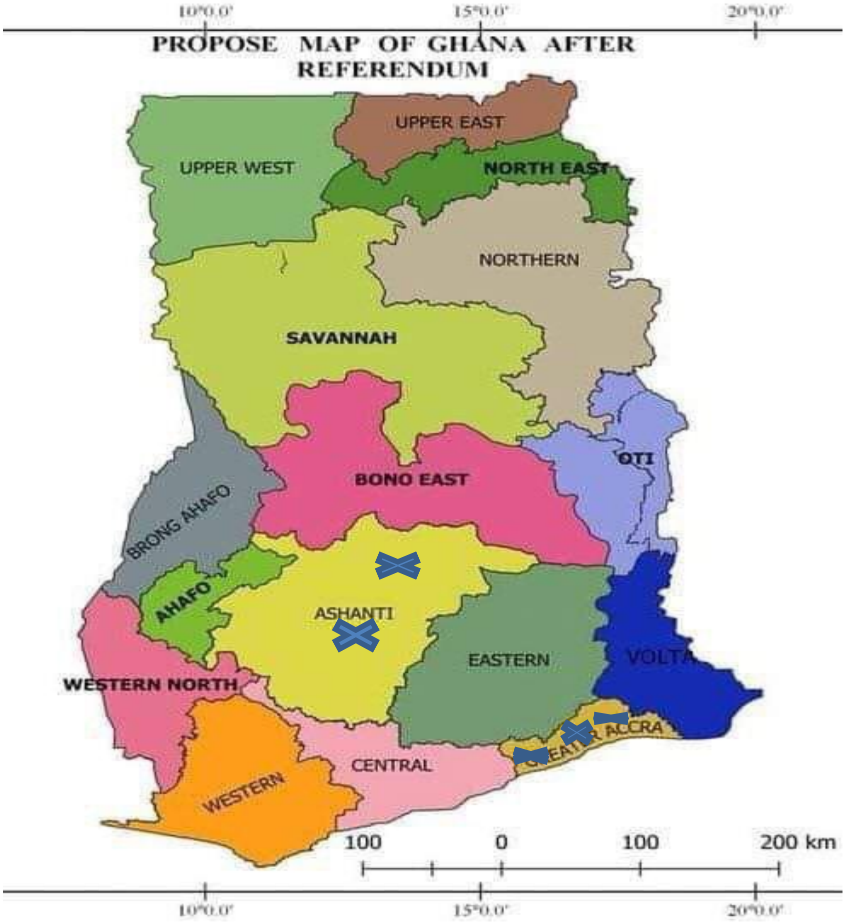
2011), and despite the epidemiologic transition with a consequent increase in chronic disease burden, not much has been done in terms of training nurses to address this transition. Nurses are still trained in the capacity of general nurses with few post basic speciality programmes in ophthalmic nursing, public health nursing, critical care and perioperative nursing programmes. The lack of specialist training for nurses not least in oncology means nurses with generalist training take on this role and may thus lack the skills adequate to support patients diagnosed with cancer through their treatment journey effectively.

1.3.2.2 Organisational structure of the biomedical healthcare system in Ghana

The biomedical healthcare system is organised into regional hospitals; district hospitals; health centres and Community-based Health Planning and Services (CHIPS). The CHIPS compounds, which are overseen by community health nurses, are least resourced. Some of the common illnesses they treat include uncomplicated malaria, diarrheal disease, maternal and childcare related to pregnancy and vaccination (Agbeko, 2017). Agbeko (2017) further added that the district hospitals, on the other hand, have in addition to nursing and biomedical staff, physician assistants, general doctors, and sometimes specialist doctors like surgeons and gynaecologists. However, although the regional hospitals also have a specialist doctor, there are insufficient pathologists and radiologists that are needed to assess tissue biopsies (Agbeko, 2017).

Across the whole country, there are four tertiary/teaching hospitals which function in a semi-autonomous way (Ghana Ministry of Health, 2011). Only two, receive referrals for the treatment of breast cancer from all over the country, and these are located in the southern part of the country. In addition to these two public hospitals, there is a third private hospital also situated in the south of the country. These three facilities have well-established chemotherapy and radiation centres with multidisciplinary teams to offer comprehensive breast cancer management (Agbeko, 2017). These hospitals include Komfo Anokye Teaching Hospital; Korle-Bu Teaching Hospital and Sweden Ghana Medical Centre. Aside from these three facilities, two other private hospitals also offer some management of breast cancer, including screening and pathologic diagnosis; chemotherapy; hormone therapy and surgery. In sum, all these five hospitals are located in two regions of the country (Figure 1.2). This means for patients with breast cancer living in other parts of the country; they would need to travel long distances to these hospitals to receive treatment. Since transportation is mostly in the form of public transport, this could be a potential barrier due to the associated transportation costs. Also, the poor road network, especially in rural communities, means transportation may not even be accessible for some patients and may thus impact on the uptake of conventional breast cancer treatment.

Figure 1.10: Map of Ghana showing regions with oncological services (Source: Google)



Key ✕ Oncological treatment centres in each region

1.3.2.3 Healthcare financing and role of the National Health Insurance Scheme

After independence, the healthcare system in Ghana was tax–funded system, which means the general public received free healthcare services (Blanchet et al., 2012). Economic challenges resulted in the non-sustainability of this free health service (Blanchet et al., 2012). Low user fees were subsequently introduced to recoup some costs locally, dissuade unnecessary use and generate provider performer incentives. This not-withstanding, government expenditure on health continually declined leading to shortages of medicine and supplies and consequently deteriorating in quality of care (Blanchet et al., 2012). A ‘cash and carry’ system (patients pay fees before receiving healthcare) was then introduced as a means of expanding revenues generated for health facilities. However, it was found to have created a significant barrier in access to care particularly for the poor (Blanchet et al., 2012).

The NHIS was introduced by the government of Ghana under Act 650 in the year 2003 to increase access and consumption of drugs and health services in general, particularly among the underprivileged. To benefit from the scheme, one has to register to enrol and registration is optional. This suggests that individuals or members of households are not automatically enrolled. All people resident in Ghana can enrol with the exception of the armed forces, the police force or anyone registered under a private insurance scheme (Blanchet et al., 2012). Registration entails completing paperwork at an NHIS office in a district with a national identity card (e.g., voter identity card, passport, driver's licence). The individual is also required to pay a registration fee of 8 cedis (£1.50) to cover costs associated with photo and administration expenses. Following registration, a member pays an annual premium of 20 cedis (£4) on average, which covers in addition to themselves all their dependants below 18 years (Blanchet et al., 2012). The source of funding for the NHIS is primarily from four sources: 2.5% value-added tax on goods and services (70%); social security taxes from formal sector workers (23%); individual premiums (5%); and investment returns (2%) (Blanchet et al., 2012).

Majority of the diseases (95%) that affect Ghanaians are covered by the NHIS (Blanchet et al., 2012). The NHIS package includes outpatient services, diagnostic tests, most surgical procedures, in-patient services, specialist care, dental health, maternal health, emergency care and drugs on NHIA medicines. However, costly procedures such as cancer treatment, organ transplant, cosmetic surgery and dialysis are excluded. Nevertheless, in an attempt to improve women's health, the government of Ghana incorporated breast and cervical cancer treatments on the NHIS package in 2013 (NHIA, 2016; O'Brist et al., 2014). Despite the benefits, not everybody is covered by the scheme with active membership being around 34% (of the total population) in 2010 (Blanchet et al., 2012). Some researchers have documented financial difficulties with the payment of premiums by individuals, a perception that NHIS holders receive poor quality care and poor knowledge about the benefits of NHIS as possible causes of the low enrolment (Alhassan et al., 2016).

The inclusion of breast cancer treatment on the NHIS package means cost may not be a potential barrier for women with breast cancer. However, individuals who do not have this cover would have to pay themselves (Saleh, 2013), and this could be a potential barrier to the uptake of conventional treatment.

1.3.2.4 Policies for breast cancer control

Ghana, comparable to most countries in sub-Saharan Africa, lacks a national operational policy, national guidelines for the management or national statistics for breast cancer (Center et al., 2011). Even when policy documents exist, this does not necessarily result in substantive actions by key stakeholders, including government agencies (Ghana Ministry of Health, 2010). For example, the Ministry of Health has documented the following key points as a national strategy for breast cancer control in Ghana since 2010 (see appendix 1):

- Develop a cancer registry and research and strengthen routine data collection to provide evidence for decision making;
- Promote breast self-examination through public education and awareness campaign;
- Train healthcare professionals to offer clinical breast examination every three years to women below 35 years and yearly to women above 35 years; use mammography as a diagnostic tool;
- Develop treatment protocols and guidelines for managing breast cancer;
- Make primary standard treatment available to all women including surgery, radiotherapy, chemotherapy, hormone therapy and biologic therapy;
- A patient shall be given all the information about a procedure to make an informed choice
- Promote social, behavioural, environmental, psychological, and health services research to determine effective methods and timely access to screening, diagnosis, treatment, palliative care, rehabilitation and supportive care.

Nevertheless, there remains an absence of national population cancer registries (Laryea et al., 2014). As such, an accurate estimation of the national cancer burden is difficult to determine. Consequently, valid information about the distribution of cancers upon which to match resources for equity and accessibility is lacking. While new breast cancer cases are estimated annually at 2,260 with an age-standardised incidence around 37 per 100,000 women (Ghana Ministry of Health, 2010), yet this estimated number of breast cancer cases may not truly reflect the disease burden in the country. The reason for this is that data is mostly reliant on hospital records; hence, other breast cancer cases that do not present at hospitals go unrecorded. Another issue is that there is a lack of any national screening programme for breast cancer; therefore, in the majority of cases, the disease is diagnosed in the advanced stages (3 and 4). When the disease is diagnosed in the advanced stage, a woman’s treatment options and the chance of cure are limited.

Perhaps, more importantly, is the lack of specialist breast cancer healthcare personnel as healthcare workers involved are those with a generalist training background who may lack the skills needed for adequate management and/ or to support patients through their treatment effectively. Also, the limited number of oncological services in the whole of the country means HCPs working in breast clinics may have a heavy workload, which may limit their ability to explore the concerns and values of patients sufficiently.

1.3.3 Traditional health system

Before the establishment of biomedical health facilities in the colonial era, Ghanaians practised traditional medicine which has continued to grow in strength and symbolism even after independence (De-Graft Aikins and Koram, 2016; Abdullahi et al., 2011). Abdullahi et al. (2011) and Abor (2009) found that people continue to access traditional medicine or biomedicine sequentially or in combination. Individuals may choose traditional medicine (spiritual healing or herbal healing) due to a perception of cultural compatibility. For example, herbal remedies are perceived as indigenous (owned by the people and handed down by the forefathers) with minimal side effects compared to biomedicine, which is seen as foreign as they were introduced by colonial rulers and also professed to have undesirable side effects (Abdullahi et al., 2011).

In Ghana, as in many parts of Africa, traditional healers are readily available and located in places where the community has easy access to them (Abdullahi et al., 2011). This contrasts with biomedicine, which has many access barriers (Abdullahi et al., 2011), and individuals may, therefore, more readily consider traditional healing modalities (herbal and spiritual) that are readily available in their communities.

1.3.3.1 Traditional medicine types and compatibility with religious practices

A study conducted in Ghana indicated the existence of two main categories of traditional medicine: those who practice without invoking supernatural cause such as herbalists, traditional birth attendants and bonesetters; and those who rely on the supernatural (Faith-based healing) (de-Graft Aikins, 2004). The traditional herbalists who do not implore the supernatural could vend their commodities in public transport; market centres; and herbal stores or operate organised clinics (de-Graft Aikins, 2004). de-Graft Aikins (2004) further added that faith-based healing practitioners have been known in the past as ‘fetish priests’ or ‘juju men’. These practitioners utilised a combination of herbal treatment, divination, possession and the calling of deities in their healing practice (de-Graft Aikins, 2004). This practice can be traced from the animism belief system where there is a general belief that spirits exist (Harvey, 2005). Spirits can exist in objects, whether natural or man-made. Harvey (2005) also stressed that in animism societies there is a belief that not all persons are mere mortals and that some are spirits; therefore, it is prudent for humans to act decently towards persons and even objects. Failure to do this can attract misfortunes, including ill-health. For this reason, faith-based healing features strongly in traditional Ghanaian communities. Faith-based healing has historically been offered by traditional shrine priests and Islamic diviners during the pre-colonial and colonial times (de-Graft Aikins and

Koram, 2016). However, currently, the situation has changed into a system operated by Charismatic Pentecostal churches which usually offer prayer and fasting. These are performed in prayer centres across various parts of the country (de-Graft Aikins, 2004). The author asserts that because faith-based healers profess the ability to offer divine help in solving everyday life challenges, e.g., work, health, etc., they continue to prosper in the country (de-Graft Aikins, 2004). Majority of the people in Ghana practice Christianity (71.2%), most of whom are predominantly in the southern areas. About 17.6% practice Islam, mostly the northern ethnic groups while the rest practice other traditional religions (CIA, 2020; de-Graft Aikins, 2004).

Aside from the indigenous traditional medicine, Ghanaians practice other imported alternative healing approaches including Chinese medicine, Ayurvedic, Chiropractic and acupuncture (de-Graft Aikins and Koram, 2016; Kretchy et al., 2014). de-Graft Aikins and Koram (2016) emphasise that the indigenous healthcare sector is widely acknowledged by the government of Ghana, which has merged some aspects of it with the biomedical health system. For instance, the authors reported that in 1975, the Centre for Scientific Research into Plant Medicine was established to oversee the production of safe and efficient herbal medicine. Also, in 1991, the Traditional and Alternative Healing Directorate was commissioned to manage the Traditional medicine sector. In 2004, a four-year Bachelor of Science Programme in Herbal Medicine was commenced at the Kwame Nkrumah University of Science and Technology (KNUST) in Kumasi to train students in Physician Assistants' (Herbal) role. The Ministry of Health subsequently organised a pilot programme in 2012, where thirteen government hospitals (Table 1.4 below) have supplementary herbal clinics to offer choice to people when accessing healthcare (Saleh, 2013).

Table 1.3: Pilot Hospital with access to herbal medicine in Ghana (Courtesy, Ministry of Health, 2012)

Region	Name of Hospital
Greater Accra	LEKMA Hospital, Teshie; Police Hospital, Cantonments
Eastern	Eastern Regional Hospital, Koforidua
Volta	Ho Municipal Hospital, Ho
Ashanti	Obuasi Municipal Hospital, Obuasi; Suntreso Government Hospital, Suntreso; Kumasi South Hospital, Kumasi; Tafo Government Hospital, Tafo
Western	Tarkwa Municipal Hospital, Tarkwa

Central	Cape Coast Metro Hospital, Cape Coast
Northern	Tamale Central Hospital, Tamale; Salaga Government Hospital, Salaga
Brong Ahafo	B/A Regional Hospital, Sunyani

De-Graft Aikins and Koram highlight that although the traditional health sector is firmly ingrained in the Ghanaian health system and despite the recognition that the traditional medicine sector is a significant provider of health services across the country, the reality is that regulations and policies developed over decades towards this sector have not been effectively applied. Consequently, traditional medicine including faith-based healing has been associated in 'healer shopping' (shopping around for the cheapest and/or best healer) and late presentation of health conditions leading to preventable disease morbidities and mortalities (Degraft Aikins and Koram, 2016).

1.3.4 Beliefs around cancer

Because traditional Ghanaian communities have no clear conceptual distinction between the physical world and the supernatural world (Busia, 2005; Hellman, 2007), health, illness and healing form part of this integrated worldview. Consequently, illnesses, including breast cancer, are often interpreted as a punishment by an angry spirit or by witchcraft. In a qualitative study by Asobayire and Barley (2014) in the Northern part of Ghana, respondents attributed breast cancer to spiritual causes. Others were also of the view that breast cancer is caused by a curse (Asobayire and Barley, 2014). People have these beliefs, particularly around diseases perceived to be chronic and severe. For example, Attobrah (2012) found that younger people affected by diseases like cancer and renal failure deemed it 'unnatural' for a young person to be afflicted by such chronic severe diseases. The respondents believed in spiritual causality and added that it is only when the spiritual cause of the disease is eliminated that the patient can be cured. Such beliefs have been found to influence patients' choices regarding their course of treatment and lead them to combine biomedicine with spiritual and herbal healing (Attobrah, 2012).

In Ghana and certain other parts of Africa, it is not uncommon for some people to believe that diagnosis of breast cancer will always result in death (the higher mortality rate associated with breast cancer in this part of the world could contribute to this belief) (Clegg-Lamptey et al., 2009; Pruitt et al., 2014). These beliefs around breast cancer have been found to impact active participation in health-promoting activities in Ghana (Clegg-Lamptey et al., 2009). A cross-sectional study by Spurlock and Cullins (2006) examined the relationship between fatalism and participation in a breast cancer control program among 71 African-Americans. Although the convenience sampling method used in the study limits the generalizability of findings, the study nevertheless highlighted a key point; that people who tended to be fatalistic were not actively involved in health-promoting practices such as breast cancer screening. Aziato and Clegg-Lamptey (2015) undertook a qualitative study on factors influencing treatment decisions among breast cancer survivors in Ghana. Analysis from the qualitative interviews revealed that decisions about which treatment to undergo for the breast cancer were based on the influence of other people, including surgeons, families, friends, prayer camps and herbalists. The authors further added that the cultural aspect, including fear of mastectomy and partner abandonment in the Ghanaian context, also contributed to the women seeking treatment from traditional and faith healers.

1.3.5 Women’s roles and expectations

In Ghana, women’s roles and expectations of their body image can impact their health-seeking behaviours. For example, in Ghana, women have traditionally been socialised as the primary caregivers in the home. This was found in an earlier research by Amu (2006) who stated that parents were hesitant to send their female children to school because their services were required in the home and on the farm. Also, the belief that women will inevitably be supported by their husbands (Amu, 2006) impacted on women’s level of education. As a result, even when female children were sent to school, many of them did not continue after receiving the basic education certificate (Amu, 2006).

The rates of females in higher education compared to males have always been lower and although there is a gradual improvement (as a result of institutional and social reforms that guarantee rights and favour women’s emancipation and contribution to national development, e.g., Millennium Development Goal Three), in 2010, only around 9% of females 25 years and over were students within tertiary institutions (The World Bank, 2019). The low levels of females in secondary and higher education have impacted on the female literacy rate. For example, a crude estimate of the country’s literacy rate for individuals 15 years and over was around 58% in 2010, but the female literacy rate was lower at 49.8% compared to a male literacy rate at 66.4% (Ghana Statistical Service, 2010). As English is the official Language in Ghana (a legacy from British colonial rule), it remains the medium of communication in formal education and official public communication. Consequently, women with poor literacy may have difficulty accessing information, particularly health information written in the English Language. This can impact on women’s ability to maintain good health (WHO, 2020).

Also, the low levels of education and literacy rates among women have created barriers in acquiring vocational skills for self-employment; access information on support services for making their businesses successful and earn an income (Amu, 2006). In effect, about 70.8% of women in Ghana are less empowered and their economic activities are often based on self-employment in low capital input and labour-intensive activities (Saeed et al., 2015; Amu, 2006). Examples include subsistence farming and trading businesses (Saeed et al., 2015; Amu, 2006). For this reason, a woman may experience some financial difficulty in accessing healthcare. Indeed, studies have reported an association between poor education and low socioeconomic status with advanced breast cancer presentation (Ohene-Yeboah and Adjei, 2012; Elgaili et al., 2010).

Another aspect of women's roles that may impact on healthcare utilisation is the perceived 'norms' for a woman and the societal expectations of her. The benchmarks for ill-health are set high for women in Ghana and many African countries. Women are expected to tolerate high workloads regarding house chores, childbearing and working on the farm (Tetteh, 2017). In Ghana, there is a popular Akan saying that "akoko batan na enim de ne mma bedi" (it is the mother hen that knows what her chicks will eat). This cultural role defines the expected behaviour of women (Hausmann-Muela et al., 2012). So, although husbands are the providers of the material well-being for their wives and children, mothers do accept the responsibility of ensuring that their children are well cared for (Clark, 1999). In effect, a woman would combine housework and economic activities as paid work proved her readiness to safeguard that her children are cared for. Clarke (1999) further added that among the Akans in Ghana, this economic and caring role is implored strongly for mothers that by implication, fathers may not show the same concern. A woman would thus go to any extent to ensure commitment to this cultural role as she may feel a sense of prestige or shame depending on whether she has abided by this expectation or failed to fulfil it (Hausmann-Muela et al., 2012). Fear of being labelled as a bad mother and/or wife could lead a woman to put the needs of the family first to the detriment of her own needs. This has implications for whether a woman would spend money on travel to clinics or medication rather than food and clothes for the children.

Thirdly, the cultural value placed on the female breast may also impact their health-seeking behaviours. For example, the role of the female breast in suckling infants give it functionality that is specifically female (Spadola, 1998). Moreover, its very nature of being observable and palpable is a woman's most public and yet private part (Spadola, 1998). Therefore, breast cancer is not only seen as a disease that affects an individual woman but also as a condition that threatens femininity and womanhood (Spadola, 1998).

Across many cultures, where Ghana is not an exception, women are socialised to perceive their personality to be reflected in their external appearance and that their breasts are not exclusively their own but exist for the evaluation and gratification of others (Jones, 2004). Women in Ghana hold similar views about their breasts as a defining element of their femininity, sexuality, motherhood and nurturance, and this makes the idea of losing a breast to cancer devastating for them. Furthermore, because the breasts are associated with these defining characteristics of womanhood, losing a breast has been found to accentuate a culture of stigma in Ghana and many other African societies (Meachamp, 2016; Tettey, 2017; De Ver Dye et al., 2011).

Some feminist theorists in Ghana note that despite the cultural and traditional expectations from women in the country, breast cancer education and awareness campaigns provided by mass media (television and radio) and non-governmental groups, have failed to address these socio-cultural factors (Tettey, 2017). Tettey (2017) argues that the majority of education and awareness campaigns are focused on the medical aspect of the disease. Also, the constant focus on traditional notions of the breast means some women with breast cancer would be more likely to desist from presenting to the hospital out of fear of undergoing mastectomy and consequent stigmatisation.

1.3.6 The role of the family

In Ghana, there is lack of state welfare support for individuals; hence, the family (including spouses, children, parents, siblings, uncles, aunts and grandparents) plays a significant role by providing its members with a sense of community, identity, security, stability and instrumental support (Richmond and Gestrin, 2010). A person's incomes or accomplishments are shared with other members of the family. Likewise, the family shares in any loss of honour, making the society a collective one. As individuals attain recognition and social status through the family system, members endeavour to live in harmony and tend to accept decisions made by the family as a whole, including medical decisions.

Decisions on health and treatment can be made by families with or on behalf of the patient (Norman, 2015). An individual's ability to participate in treatment decision-making usually depends on crucial factors such as their gender roles and social relations, age, authority and social position. For example, husbands have more authority in households than their wives and also tend to control economic resources. Consequently, husbands make most decisions about how funds should be used in the home. Adu Gyamfi (2014) also found that Ghanaian men typically make decisions regarding the type of healthcare to be accessed by individuals in the household, the type of educational institution in which to enrol a child and the daily expenses needed for the home.

Secondly, Ghana is culturally a ‘hierarchical society’ (Adu-Gyamfi, 2014); hence, respect flows from ‘bottom to top’. Consequently, it is anticipated that children have profound respect and veneration for parents and elders always (Hofstede, 2001; Schwartz, 2006; Van der Geest, 1998). The common and shared belief is that respect for elders begets rewards for a meaningful life (Salm and Falola, 2002). Therefore, younger people concede to adults and thus cannot context or oppose the decisions made by their parents that affect them. For these reasons, a woman may accept treatment decisions made by her parents or elders in the family.

Research Question

Overall, many factors may influence women’s decision whether or not to persevere with a recommended breast cancer treatment. The above contextual background information highlights that beliefs, values, healthcare practices and cultural norms may influence the uptake of breast cancer treatment, but not much is known about the relative importance of each of these issues when it comes to women’s decision making. In addition, women’s educational and socio-economic situations may impact their uptake of breast cancer treatment, but there is limited understanding regarding these issues. This study thus aims to explore how the cultural context of Ghana may influence treatment decision making for women with breast cancer.

Main research question:

- In what ways does the cultural context in Ghana influence treatment decision making for women with breast cancer?

Sub-questions:

1. What beliefs, values and practices influence breast cancer treatment decision making for women attending a breast clinic?
2. What structural factors influence breast cancer treatment decision-making?

1.4 Personal rationale for the chosen research study

My motivation for conducting this research is from my experience as a nurse who worked in a surgical ward and also as a volunteer at a breast clinic in Ghana. I volunteered to work in a breast clinic subsequent to a breast cancer workshop I attended in one of the Teaching Hospitals in the country.

At both the surgical ward and particularly the breast clinic where I did the voluntary service, most of the women attending the clinic had at one time received a cancer diagnosis but declined to have surgery only for some to return with more advanced disease at a later date. Having observed these issues, I became keen to gain an in-depth understanding of the decision-making process for women with breast cancer in the Ghanaian context. I applied and received funding from the Schlumberger Foundation to undertake a PhD to explore this issue.

1.5 Summary of chapter

Breast cancer has become an emergent public health issue in Ghana. Documented cases in the country indicate that the disease is increasing rapidly. The increased prevalence of breast cancer risk factors in the country further suggest that the incidence of breast cancer in Ghana will continue to rise (Wiredu et al., 2014).

Ghana has a significant burden of breast cancer mortality, which may be associated with women's underuse of optimal treatment. Although several factors may be associated, the background information discussed above indicated that cultural beliefs, values, practices and women's socio-economic situations might have considerable influence on breast cancer treatment decision-making. Nevertheless, evidence is needed to understand better how these issues influence treatment decision-making to guide future decision support interventions.

Also, considering the objective in the national strategy for breast cancer control in Ghana (Ghana Ministry of Health, 2010), which is to provide women with all the information needed to make an informed treatment choice, it is critical to understand the values that may influence women in their breast cancer treatment decision-making. A greater understanding of this phenomenon may help improve the support provided to women in making treatment decisions.

Outline of the thesis

The thesis is divided into eight chapters. The first chapter has explored background literature relating to breast cancer in Ghana and the socio-cultural factors that may impact breast cancer treatment decision making.

Chapter Two reports a systematic review conducted on the factors influencing breast cancer treatment decision making among women in Africa. The review will explore the socio-cultural factors influencing breast cancer treatment uptake and highlight the gaps in the literature to make a case for a new research study.

Chapter Three outlines the methodology of the research study. It discusses the theoretical and methodological issues with regards to research methods and defends an ethnographic approach for this research. The chapter also outlines the research methods employed in this study, including participant observation; in-depth interviews, and thematic data analysis. Furthermore, ethical issues of the research work and fieldwork account are included in the chapter.

Chapter Four describes the first part of the findings of the research. It describes the breast clinic context, the people involved, and the activities carried out. It further describes relationships among the people in the clinic and how this relationship, the clinic context, and the activities shape participants' behaviour and practices in the clinic.

Chapter five is the second part of the findings of the research. It presents the first theme around breast cancer treatment decision making. The theme highlights how the structures at the clinic, practices and beliefs of participants hide quality information and understanding around breast cancer.

Chapter six, the third part of the findings of the research, details how the hidden nature of information and understanding is substituted with lay explanations around breast cancer and consequently influence breast cancer treatment decision making.

Chapter seven discusses the findings around structures; practices; beliefs; and values that influence treatment decision making with the existing literature.

Chapter eight is the final part of the thesis with concluding remarks. It concludes with an overview of the study and argues how hidden information leaves women with gaps in knowledge. Information from other sources including, shared beliefs and individual's experiences, fill the gap, which then influences their decision on breast cancer treatment. It highlights the study's contribution to knowledge and also presents the strengths and limitations of the study as well as recommendations for future research.

Chapter 2 Systematic Narrative Review

2.1 Introduction

This chapter outlines the systematic narrative review conducted as part of this study. It provides a detailed review of the existing literature on the factors influencing decisions on breast cancer treatment uptake among women diagnosed with the disease in Africa. It critically analyses the current body of research, based on their methodological qualities and core findings. Furthermore, this review uncovers the weaknesses and knowledge gaps in the literature, which will be the focus of this study.

2.2 Systematic narrative review

A systematic narrative approach was adopted to summarise and synthesise papers in the review. Primary research papers concerning factors that influence decisions by women in Africa diagnosed with breast cancer on whether to start or continue treatment were considered. A systematic narrative review searches, appraises and collates all the relevant empirical evidence to provide a comprehensive narrative summary of the existing literature on a particular topic or question (Chronin et al., 2008). It often follows a guideline, e.g., Centre for Reviews and Dissemination (2009) to ensure that the methods are transparent and reproducible, which is characteristic of systematic reviews. While such an approach enhances its comprehensiveness, nonetheless, because the review question is usually very focussed, there are concerns that it may be limited in providing a general overview of research conducted within an area of interest (Chronin et al., 2008). To mitigate this challenge, some authors advocate for the inclusion of a broader range of study designs including quantitative, qualitative and mixed methods (Grant and Booth, 2009). Although the addition of such multiple study methods means the primary studies are likely to be heterogeneous, a narrative representation of the evidence makes this applicable. Other approaches to reviews, including scoping review, were considered. Although a scoping review could have been appropriate because it is comprehensive, able to assess the state of knowledge on a topic as well as identify research gaps, it was not adopted because it does not include a quality assessment process (Grant and Booth, 2009). A systematic narrative review, on the other hand, considers the methodological concerns in research studies, which can be used to improve future research on the topic area (Poklepovic and Tanveer, 2019). Furthermore, it can reveal the gaps in the literature on a research topic, which were all considered important in this review.

To facilitate the process, the review was carried out in accordance with the Centre for Reviews and Dissemination (2009) guidelines.

2.2.1 Search strategy

This review sought to identify, critically evaluate and summarise primary studies that explored factors influencing breast cancer treatment uptake to address the review's question:

1. What factors influence the uptake of breast cancer treatment (decision to start or continue treatment) among women diagnosed with the disease (all stages) in Africa?

A systematic three-step strategy (Table 2.1) was applied to selected databases to identify relevant studies and also minimise publication bias. The Population, Intervention or exposure, Comparison and Outcome (PICO) mnemonic was used as the organising framework to reflect the main concepts in the review. Although this review sought to include both qualitative and quantitative studies, the Sample, Phenomenon of Interest, Design, Evaluation and Research Type (SPIDER) tool, relevant for selecting qualitative studies, was not applied to the qualitative studies. Instead, the nature of the research question was such that the PICO tool was considered more appropriate. Furthermore, the PICO mnemonic has been found to have higher specificity and sensitivity for all study types and produce more notable findings compared to the other highly specific tools (Methley et al., 2014). Five nursing, medical, psychology and social science-related databases including CINAHL, MEDLINE, PsycINFO, SCOPUS and Web of Science were searched to allow for the identification and consideration of all relevant papers to be included in the review. These databases (see Table 2.2 below) were selected because they covered a wide range of health and medical disciplines. Firstly, a scoping search was conducted using the Delphis database (with the help of a librarian) to identify keywords for the main search. A comprehensive search strategy (Table 2.1) was developed from the keywords of relevant studies identified from the scoping search. This was used across the selected databases on 30th August 2016 and updated on 30th March 2019. Although grey literature was used in chapter one to provide background information, it was not used for this review as if it is not peer-reviewed, it may not yield the most robust evidence. The references sections of retrieved papers were searched to identify studies not found within the search, which led to the identification of one other paper. This process also identified the additional keyword, 'delay', and when subsequently added to the search terms, two more articles were identified. The database searches continued as certain words were rephrased until it was clear that the same papers were emerging. The search strategy for one of the databases is provided in appendix 2.

Table 2.1: The search terms used in the PICO search

PICO tool	**Search terms**
Population	"Breast cancer" OR "breast neoplasm" OR "breast malignancy" OR "breast tumour" OR "breast tumor"
Intervention/exposure	"Socio-cultural" OR "economic" OR "beliefs" OR "barriers" OR "facilitators" OR "knowledge" OR "provider" OR "interaction" OR "patient-provider" OR "information" OR "values" OR "cultur*" OR "context*" OR "social" OR "ethnicity" OR "stigma"
Comparison	Not required
Outcome	"Treatment" OR "uptake" OR "decisions" OR" decision-making" OR "delay" OR "adhere*" OR "nonadherence" OR "comply*" OR "noncompliance" OR "abscond*" OR "incompletion" OR "acceptance" OR "chemotherapy" or "mastectomy" or "neoadjuvant therapy" or "adjuvant therapy" or "breast surgery" or "radiotherapy" or "hormonal therapy" or "systemic therapy" OR "use"

Table 2.2: Summary of characteristics of selected databases (Sources: Web of Science, 2014; University of Adelaide, 2014)

Database	**CINAHL**	**MEDLINE**	**SCOPUS**	**PsycINFO**	**Web of Science**
Field	Covers citations in the fields of • nursing • allied health • biomedicine adds descriptors specific to nursing and allied health over 2 million citations from 1982 to date	Covers citations including: • biomedicine • nursing • life sciences • allied health Over 19 million citations from 1966 to present	Covers citations in • health science • life science • social science • physical science searches on subject headings assigned by Medline	Covers the psychological literature, behavioural science Psychological aspects of nursing, medicine, psychiatry Over 2.8 million citations from 1872 to date	Perform an all database search on the content of multiple searchable products in a wide range of discipline in science and technology Able to analyse top authors in the related field of interest Able to trace the history of particular areas of study

					Performs cited reference searching

Table 2.3: Inclusion criteria and exclusion criteria

Articles were included if they:

- Were qualitative, quantitative or mixed methods studies
- Were primary research
- Involved women 18 years and above with a diagnosis of breast cancer (regardless of stage)
- Involved women who were on breast cancer treatment
- Inquired about factors influencing breast cancer treatment decisions or uptake (whether or not to start, whether or not to continue)
- Reported on the treatment decision made
- Were conducted in Africa
- Were reported in English

Studies were excluded if they:

- Included other types of cancers but did not give a separate report on breast cancer
- Did not have clear reports on factors influencing treatment decisions or uptake
- Involved women who were only on follow-up treatment (i.e., have completed primary treatment for breast cancer)

The above inclusion and exclusion criteria were applied to maintain the focus of the review. The inclusion of qualitative and quantitative papers was to ensure that all relevant study findings are included. Moreover, as qualitative studies helped reveal the ideas and concepts associated with the area of inquiry, the quantitative studies offered information on the frequency of the concepts identified. Studies were limited to the English language due to insufficient time for translation. Studies were widened to all African settings (see CINAHL search strategy in appendix 2) due to possible similarities with the healthcare system of Ghana. There were no limitations on time and stage of breast cancer at diagnosis as a large number of studies were not expected to be found. Moreover, excluding time limitations helped evaluate how the passage of time may have contributed to changes.

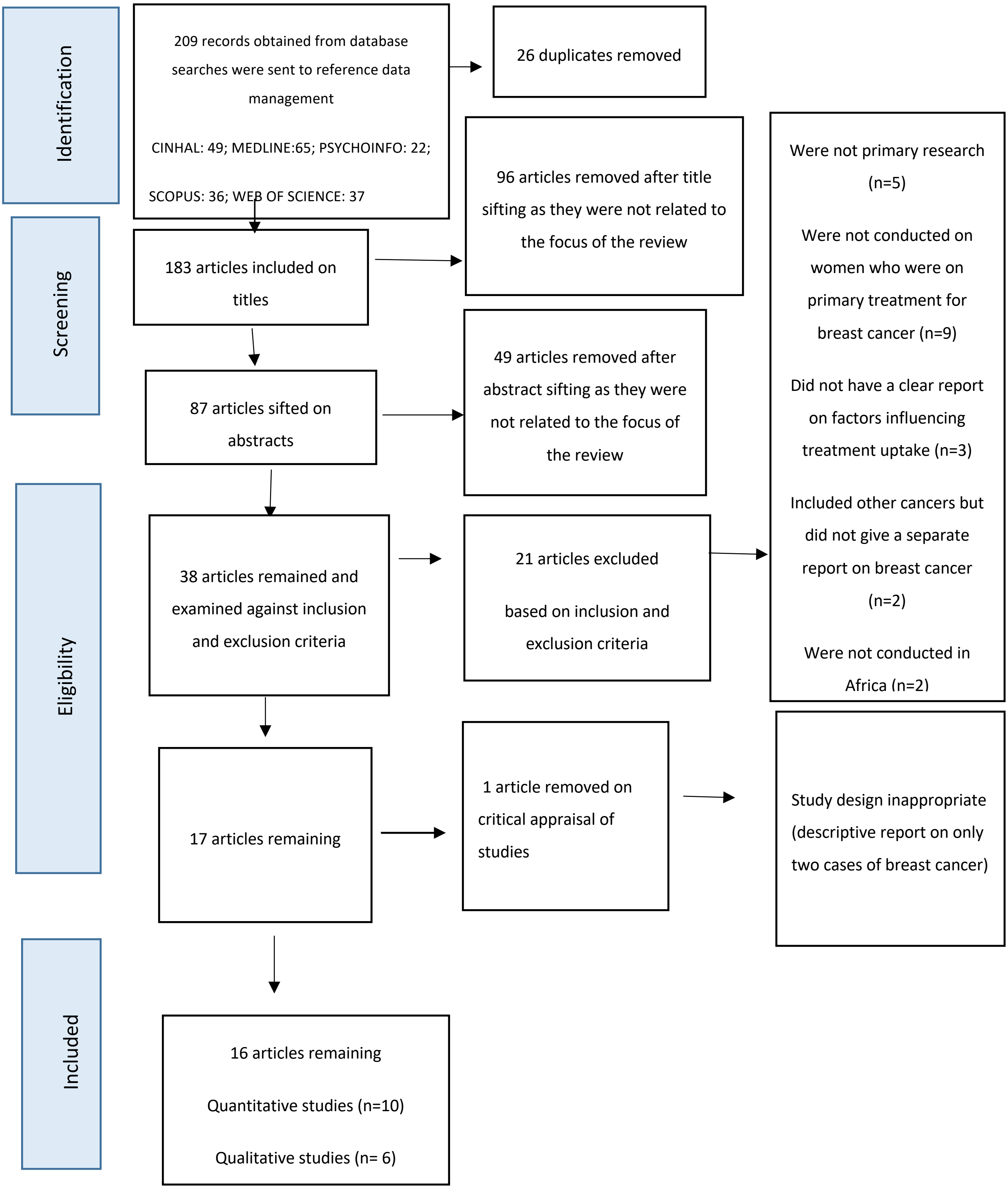
2.2.2 Study selection

The titles and abstracts of the search results were assessed, and studies that clearly did not meet the inclusion criteria were excluded. The remaining studies had the full texts examined against the inclusion and exclusion criteria. To ensure standardised appraisal of selected studies, Critical Appraisal Skills Programme (2013) tools (appendix 3) were used to critique both the qualitative and quantitative studies (appendix 4). These appraisal guides (appendix 3) were chosen because they are very detailed and explanatory.

2.2.3 Study results

The diagram below (figure 2.1) represents the flow diagram for the study selection process. Seventeen papers were identified as meeting inclusion and exclusion criteria for the study. One paper (Ekotarl et al., 2007) was excluded after critical appraisal of selected studies. Ekotarl et al. (2007) were excluded because the study reported on only two women diagnosed with breast cancer. The study design was hence considered inappropriate. Sixteen papers were finally included in the review.

Figure 2.1: Flow diagram for the study selection process



2.2.4 Data extraction

To ensure the extraction of similar data across the included studies, data extraction forms (see appendix 14 for quantitative and qualitative data extraction forms) were developed for the review. The quantitative data extraction form was adapted from the Centre for Reviews and Dissemination (2009) guideline for data extraction process. Similarly, the qualitative data was adapted from the JBI SUMARI (2014) data extraction tool for qualitative studies. The forms were adapted in order to tailor it to the review's objectives. From each quantitative study, the data extracted included; author, year, country, setting, study period, number of participants, age of participants, stage of breast cancer, type of breast cancer treatment, the definition for treatment (non)completion, period of treatment (non)completion, reasons for treatment (non)completion, patients' outcome, the method used to measure outcome and analysis. For those quantitative studies that had comparison groups, the number of participants in each comparison group and those included in the analysis was also extracted. For the qualitative studies, the data extracted included; author, year, setting, country, culture, the period of data collection, number of participants, age of participants, the phenomenon of interest, method of data collection, findings and analysis. The data extraction process was undertaken by one reviewer (LSA), but the whole process was overseen by supervisors to enhance accuracy and limit errors in reporting.

2.2.5 Findings

2.2.5.1 Characteristics and quality of included studies

2.2.5.1.1 Quantitative studies

Ten quantitative papers published from 2008 to 2017 were included in the review (see appendix 5 for characteristics of included studies). Six of the studies were conducted in Nigeria; three were from Ghana, and one was from South Africa. Among these, five were retrospective chart reviews (Cubasch et al., 2017; Dedey et al., 2016; Adesawale et al., 2008; Ntekim et al., 2009; Oguntola et al., 2011), three were case series (Anyanwu et al., 2011; Clegg-Lamptey et al., 2009; Ukwenya et al., 2008), one retrospective study (O'Brist et al., 2014) and one was a prospective study, which followed participants for one year (Egwuongwu et al., 2012). Studies assessed factors leading to surgical treatment choice (Cubasch et al., 2017) and treatment delay or non-completion following diagnosis (Dedey et al., 2016; Adesawale et al., 2008; Ntekim et al., 2009; Ukwenya et al., 2008; Oguntola et al., 2011; Anyanwu et al., 2011; O'Brist et al., 2014; Clegg-Lamptey et al., 2009; Egwuongwu et al., 2012). Delay was defined by Ukwenya et al. (2008), according to the protocol at the clinic setting as having a definitive treatment after one month of a breast cancer diagnosis. This definition of delay, nonetheless, contrasts with the typical description in the literature which is the start of treatment after three months of the first presentation of symptoms to an HCP (Richardson et al., 2010; Hershman et al., 2010). This reflects the evidence that delay of treatment for more than three months is associated with lower survival rates (Hershman et al., 2010). Six studies explored reasons for treatment non-completion and nonadherence. Definitions used by studies for treatment non-completion and nonadherence were either based on the protocol at the clinic setting or from the literature. Non-completion was defined by the studies as not completing the recommended courses of treatment. Breast cancer treatments reported in the studies included chemotherapy, breast surgery, radiotherapy and hormonal therapy. One study, on the other hand, explored the factors influencing the time to start of treatment. Studies recruited participants from clinics or reviewed medical notes at the clinics according to predetermined criteria such as not completing the recommended courses of chemotherapy (Adesawale et al., 2008). The total number of participants recruited ranged between 35 (Clegg-Lamptey et al., 2009) and 445 (Cubasch et al., 2017). Participants involved in the studies were aged between 18 and 99 years. None of the studies discussed any theoretical perspective as underpinning the enquiry.

2.2.5.1.2 Selection bias

All the studies utilised non-random sample. Studies were assessed for the potential of selection bias in this review based on the following: whether it was a population-based sample selection; sample size and baseline information; and the methods chosen to assess exposure and outcome of interest. None of the studies conducted a population-based study which means all the studies have a potential for selection bias. One study, Egwuongwu et al. (2012) (n=44), was rated good for selection bias because participants were enrolled into the study before they experienced the outcome of interest, i.e., treatment non-completion or refusal. Eight studies were rated moderate for potential selection bias (Cubasch et al., 2017; Dedey et al., 2016; Ntekim et al., 2009; Ukwenya et al., 2008; O'Brist et al., 2014; Oguntola et al., 2011; Adesawale et al., 2008; Anyanwu et al., 2011) for the following reasons. Cubasch et al. (2017) (n=445), Dedey et al. (2016) (n=205) and Ntekim et al. (2009) (n=221) were relatively high powered and reviewed cases from a high volume centre with varying demographics. O'Brist et al. (2014), Oguntola et al. (2011) and Ukwenya et al. (2008) had medium sample sizes of between 117 and 111 and adequate demographic data. Anyanwu et al. (2011) and Adesawale et al. (2008) had high sample sizes (n= 173 to n=152, respectively) but with inadequate demographic reports. Clegg-Lamptey et al. (2009) were rated 'poor' for selection bias as the study was relatively low powered (n=35). Studies with high potential for selection bias may be limited in generalising their findings to the general population (JBI, 2011).

2.2.5.1.3 Measurement bias

It is unclear from the presented findings on how the research instruments were developed to collect data in all the studies other than O'Brist et al. (2014). The validity and reliability of these research instruments cannot be verified. Most of the studies collected retrospective data on reasons for treatment delay or non-completion except Egwuongwu et al. (2012) who followed participants for a year to assess reasons for treatment non-completion. As a result, there is a potential for recall bias in all the studies other than Egwuongwu et al. (2012). Also, three studies (Cubasch et al., 2017; Adesawale et al., 2008; Anyanwu et al., 2011) relied only on information from the participants' medical record. This could subject the studies to biases resulting from missing information from participants' medical notes and errors in documentation. For the remaining studies, five employed interviewer-administered questionnaires in addition to data from medical records. Two of them did not state how the questionnaires were administered (Dedey et al., 2016; Ntekim et al., 2009). Although interviewer-administered questionnaire allows for questions and responses to be clarified when needed, nonetheless, because the questionnaires were administered by clinicians involved in the care of the women, it raises concern about the possible impact of the interviewer's (clinician) presence on the potential responses from participants. This may introduce bias in the study. Two studies were rated moderate for measurement bias (O'Brist et al., 2014; Egwuongwu et al., 2012). O'Brist et al. (2014) were rated moderate because the study utilised standardised validated questionnaires but more of the respondents in the 'did not complete treatment group' were patients' relatives compared to the 'completed treatment group'. It is possible that this could lead to less reliable information from this group (did not complete treatment). Egwoungwu et al. (2012) were also rated moderate for measurement bias because although data were collected prospectively, it was unclear how the questionnaires were validated. The remaining eight studies were rated fair for measurement bias.

2.2.5.1.4 Confounding potential

Five studies included comparison groups (Cubasch et al., 2017; Dedey et al., 2016; O'Brist et al., 2014; Oguntola et al., 2011; Ukwenya et al., 2008). Cubasch et al. (2017) compared participants who chose total mastectomy with participants who chose breast conservation with radiation. Ukwenya et al. (2008) and Dedey et al. (2016) compared participants who started treatment in less than one month to those who delayed treatment, i.e., after one month. Similarly, Oguntola et al. (2011) and

O’Brist et al. (2014) compared participants who completed treatment to those who did not complete the recommended treatment. The studies matched the comparison groups to specific demographic, socio-economic and health system-related variables. However, Cubasch et al. (2017) did not have data on the socio-economic status of participants. Among the studies that did not have patient-matched controls, results could be impacted by confounding factors. Consequently, any identified relationship between the assessed variables and treatment decisions is weak. To limit this effect, statistically rigorous multivariate regression is required for effective covariate control (Sharma et al., 2012). However, only three studies used statistically rigorous multivariate regression to control for potential confounders (e.g., age, stage of disease and provider’s factors) and were therefore rated as good quality for confounding (Cubasch et al., 2017; Dedey et al., 2016; O’Brist et al., 2014). Oguntola et al. (2011) and Ukwenya et al., 2008 were also rated good quality for confounding as they matched patients with comparison groups. The five remaining studies were evaluated as moderate quality for confounding.

On the whole, although there were methodological weaknesses with many of the studies, they provide emerging evidence about the importance of the variables identified in influencing breast cancer treatment uptake.

2.2.5.2 Qualitative studies

Six studies published between 1997 and 2018 were included in the review. Three of the studies were conducted in Nigeria (n=3), one from Egypt (n=1), one from Ghana (n=1) and the other from South Africa (n=1). Four of the studies explored factors leading to treatment delay and or absconding after diagnosis (Sanuade et al., 2018; Wright et al., 1997; Pruitt et al., 2014; McEwan et al., 2014). Delay was defined by Mc Ewan et al. (2014) as presenting for treatment after three months of diagnosis and or recognition of symptoms. This contrasts with that of Ukwenya et al. (2008) who defined delay as presenting after one month following diagnosis. Absconding was described by Wright et al. (1997), according to the clinics’ protocol, as a failure to return to complete treatment. Pruitt et al. (2014) and Sanuade et al. (2018) did not provide any clear definition for ‘delay’. The factors explored by the four studies included patient, social, cultural, economic, provider and structural barriers. Of the two remaining studies, one explored women’s experiences and desired nursing assistance on breast cancer chemotherapy (Anarado et al., 2015). The other examined the role of information, communication and support on breast cancer management (Adejoh and Olurunlana, 2016). Three out of the six studies mentioned that the studies were aligned with a specific theoretical perspective. Anarado et al. (2015) were underpinned by grounded theory; Mc Ewan et al. (2014)

were underpinned by the Socio-Ecological and the Health Belief Models and Sanuade et al., (2018) employed the Social Representation Theory.

The studies employed purposive sampling to recruit participants. This allowed the selection of participants who were more likely to provide data of sufficient relevance and depth (Gerrish and Lathlean, 2015). The total number of participants recruited for the studies varied from 15 (Mc Ewan et al., 2014) to 36 (Pruitt et al., 2014). A total of 135 participants were involved in qualitative interviews and their ages ranged between 21 to 80 years. Wright et al. (1997) failed to provide the ages of participants. Two out of the six studies collected data from multiple sources (Pruitt et al., 2014; Wright et al., 1997). Pruitt et al. (2014) interviewed women with breast cancer who delayed treatment following diagnosis and healthcare providers. Wright et al. (1997) interviewed women with breast cancer who did not return to complete treatment, healthcare providers, laypersons and traditional healers (Wright et al., 1997). This allowed exploration of alternative perspectives on the phenomenon of interest. Excerpt for Wright et al. (1997) and Mc Ewan et al. (2014) who conducted interviews in participants' venue of choice, the remaining four studies conducted interviews (Adejoh and Olurunlana, 2016; Pruitt et al., 2014) and focus group discussions (Anarado et al., 2015; Sanuade et al., 2018) at the clinics. Participants who are interviewed at the healthcare settings may be constrained from expressing any undesirable experiences with service provision. Two studies described how the semi-structured interview guides were developed: Pruitt et al. (2014) employed the McGill Illness Narrative to explore from women how they first found their breast cancer, their healthcare-seeking behaviours, delays they had experienced in care and beliefs about disease causation and stigma to understand the cultural and social barriers that delay breast cancer treatment uptake. McEwan et al. (2014) on the other hand employed the Kleinman's Theory of Explanatory Model, and the Health Belief Model to explore patients' experiences, the process of their journey, how they perceived their delays, their care and support, as well as the factors influencing their readiness to act and respond to cues around breast cancer. Among the six studies, only Anarado et al. (2015) pre-tested the interview guide. There are fears that a lack of pre-testing of interview guide raises issues about the appropriateness and usefulness of the guide to produce the required data (INVOLVE, 2015). With the exception of Anarado et al. (2015) and Sanuade et al. (2018), the remaining four studies did not provide a sufficient and exhaustive account of their analysis process. The concern about this is the justification of how themes emerged from the original data. This not-withstanding, all the included studies other than Wright et al. (1997) utilised other quality checks including multiple analysts to improve the studies' rigour.

Finally, aside from Mc Ewan et al. (2014) and Sanuade et al. (2018), the majority of the studies did not provide detailed information on contextual issues. Failure to outline background information regarding the social and cultural aspects of the settings in the interpretation of the findings has implication for the transferability of findings to other similar contexts. Despite the methodological weaknesses, the qualitative studies provided evidence and insight into some of the factors influencing treatment decisions.

2.2.6 Synthesis of findings

A narrative synthesis was applied to integrate the findings from both the qualitative and quantitative studies. This entailed identifying recurrent concepts and patterns across the studies and then organising them into themes (Mays, 2005). From the review, the majority of the studies focused on factors influencing treatment non-completion of women who had already started treatment. Only two studies explored factors influencing the initiating of treatment. Three main themes were identified across all included studies. These themes are presented under patient factors; healthcare provider and system factors and treatment factors.

2.2.6.1 Patient factors

2.2.6.1.1 Educational status

Nine studies gave demographic reports on the educational status of participants (Sanuade et al., 2018; Dedey et al., 2016; Anarado et al., 2015; Adejoh and Olurunlana, 2016; Pruitt et al., 2014; Clegg-Lamptey et al., 2009; Ntekim et al., 2009; Egwoungwu et al., 2012; Ukwenya et al., 2008). The percentage of participants with at least high school education ranged between 40% (n= 8) (Sanuade et al., 2018) and 100% (n=20) (Adejoh and Olurunlana, 2016). Two studies reported on the relationship between women's level of education and treatment uptake following diagnosis (Dedey et al., 2016; Ukwenya et al., 2008). Ukwenya et al. (2008) found a statistically significant difference in the level of education between women who delayed treatment for one month following diagnosis and those who did not ($p<0.05$). Similarly, Dedey et al. (2016) found a statistically significant association between level of education and median waiting time to start of treatment ($p< 0.01$). In both studies, women who had lower levels of education were more likely to delay starting treatment. This suggests that educational levels may be an important factor for women to engage in breast cancer care services.

2.2.6.1.2 Place of residence

This review found inconsistent reports on the association between place of residence and treatment uptake. O'Brist et al. (2014) and Ukwenya et al. (2008) compared place of residence and treatment non-completion/delay. O'Brist et al. (2014) found no statistically significant difference (p=0.21) between the place of residence and treatment non-completion in Ghana. Ukwenya et al. (2008), on the other hand, found a statistically significant difference between the place of residence and treatment delay in Nigeria. Participants who resided outside the state where the hospital is located were more likely to delay treatment uptake (p<0.05).

2.2.6.1.3 Age

Similarly, the association between age and uptake of treatment was not consistent among the five studies that examined this factor (Dedey et al., 2016; Cubasch et al., 2017; O'Brist et al., 2014; Oguntola et al., 2011; Ukwenya et al., 2008)). Dedey et al. (2016) and Ukwenya et al. (2008) found a statistically significant difference between participants' age and treatment delay. According to Ukwenya et al. (2008), participants who delayed treatment for a month or more were more likely to have a younger median age (43 years) compared to those who did not delay (50 years) (p< 0.05). In Cubasch et al. (2017), older age (50-59 years and over 70 years) was significantly associated with mastectomy compared to conservation (p< 0.01). However, in Oguntola et al. (2011), although the authors reported that the rate of non-completion to prescribed tamoxifen increased with decreasing age, this was not statistically significant (p=0.15). Similarly, O'Brist et al. (2014) found no statistically significant difference in age between those who completed treatment and those who did not (p=0.82).

Overall, the evidence in support of demographic variables and treatment uptake were inconsistent in the literature with the exception of formal education. The inconsistencies observed may be secondary to the methodological weakness amongst the studies (Ukwenya et al., 2008; Oguntola et al., 2011). They may also reflect geographical variations because although all the studies were conducted in Africa, societies, cultures and governments in the individual countries (Ghana, Nigeria, South Africa) are different.

2.2.6.1.4 Knowledge

This review found that inadequate knowledge of breast cancer treatment influenced treatment uptake. Across three studies, between 9% (n=4) to 18% (n=18) of participants did not complete the remaining courses of treatment when they felt better (Adewale et al., 2008; Egwuongwu et al., 2012; Clegg-Lamptey et al., 2009). Also, some women were waiting until they experienced what they thought were the symptoms of cancer before commencing treatment (n=3/35) (Clegg-Lamptey, 2009). From these responses, it is possible that the women had poor knowledge of the fact that achieving clinical response (feeling better) did not necessarily mean that the cancer is cured. Also, they may not have known that commencing treatment for breast cancer in the symptomatic stage correlates with poorer outcomes compared with the asymptomatic stage (Cancer Research UK, 2014). Thus, inadequate knowledge of breast cancer and treatment may have influenced treatment non-completion. In contrast, findings from three qualitative reports showed that women who followed treatment recommendations possessed knowledge of the disease and treatment (Adejoh and Olurunlana, 2016; Anarado et al., 2015; McEwan et al., 2014). Some of the responses of women such as 'danger of the condition if untreated' (McEwan et al., 2014); and treatment benefits on health outcomes (Adejoh and Olurunlana, 2016; Anarado et al., 2015), suggested that women had knowledge of the disease and treatment. Women acquired knowledge on the disease and treatment from care providers, peers (breast cancer survivors) and the media (Adejoh and Olurunlana, 2016; Anarado et al., 2015; McEwan et al., 2014).

It is unclear why some women had poor knowledge of the disease and treatment even after presenting to health facilities. The three quantitative studies that reported on this finding lacked standardised instruments (Adewale et al., 2008; Egwuongwu et al., 2012; Clegg-Lamptey et al., 2009). It is, therefore, possible that the studies failed to identify other pertinent factors that may have contributed to poor knowledge of the disease and treatment.

2.2.6.1.5 Socio-cultural factors

Cultural beliefs about supernatural causes of breast cancer

The review found that women's beliefs about the causes of breast cancer influenced their decisions on whom to consult for treatment. Women who believed in supernatural causes of breast cancer (Sanuade et al., 2018; Pruitt et al., 2014; Wright et al., 1997) abandoned recommended medical treatment following diagnosis to seek alternative healing such as spiritual healing. Traditional and faith healers were often considered to be appropriate sources of healthcare for health problems perceived to be caused by supernatural forces (Wright et al., 1997). Women often returned later for medical treatment when the remedies prescribed by the alternative healers had not been effective (Sanuade et al., 2018; Pruitt et al., 2014).

Beliefs about consequences of medical treatment

Findings from the review showed that women's beliefs about the consequences of breast cancer treatment influenced treatment non-completion. Some women believed that hospital treatments do not work (Oguntola et al., 2011; Wright et al., 1997) and that medical treatment aggravates breast cancer (Wright et al., 1997). Other women feared the consequences of mastectomy (Sanuade et al., 2018; Pruitt et al., 2014; Egwuongwu et al., 2012; Clegg-Lamptey et al., 2009; Ukwenya et al., 2008). Women feared for the fate of their relationship with spouses after mastectomy and believed mastectomy leads to disfigurement (Sanuade et al., 2018; Ukwenya et al., 2008). Mastectomy was also feared because it was believed to lead to death (Sanuade et al., 2018; Ukwenya et al., 2008). Across three quantitative studies, between 9% (n=4) (Egwuongwu et al., 2012) and 57% (n=20) of women refused surgery due to fear of mastectomy.

On the other hand, Adejoh and Olurunlana (2016) and Anarado (2015) found in their qualitative reports that although some women were fearful of cancer diagnosis, information from caregivers on the hope of recovery with treatment could allay their fears. Women were more receptive of treatment recommendation when they received information that supported the potential for recovery with treatment. The differences in beliefs about the consequences of medical treatment for breast cancer may be due to differences in care models underpinning the clinical care of women with breast cancer as well as differences in women's socio-cultural context. Nonetheless, none of the qualitative studies sufficiently interpreted findings based on such contexts, which limits how the results are transferable to other settings with similar backgrounds.

Family influence

Findings from the review showed that women's families influenced treatment decisions. According to Wright et al. (1997), women with breast cancer are not the only decision-makers regarding treatment uptake and that decision-making is a collaborative process. This decision-making process led some women to refuse recommended treatment. (Wright et al., 1997; Pruitt et al., 2014). Two quantitative reports found that 8.5% (n=3) and 18% (n=18) of the women were influenced by their families to refuse treatment (Clegg-Lamptey et al., 2009; Ukwenya et al., 2008).

In contrast, two other qualitative reports showed that women were provided with informational and instrumental support from families, which motivated them to take up and continue with treatment (Anarado et al., 2015; McEwan et al., 2014). It is unclear why some women were prevented by their families to refuse treatment, whereas others were supported by families to take up treatment. The qualitative studies lacked insight from family members. Input from family members may have provided insight into why breast cancer treatment is accepted or rejected.

Traditional medicine

From the review, the use of traditional treatment influenced treatment non-completion following diagnosis. Across three quantitative reports, 38% (n=38) to 80% (n=28) did not complete treatment because the women decided to use traditional healing instead of biomedicine (O'Brist et al., 2014; Clegg-Lamptey et al., 2009; Ukwenya et al., 2008). Examples of traditional medicines used included herbal, Chinese medicine, acupuncture, food supplements, herbal treatment and prayer camps (O'Brist et al., 2014; Clegg-Lamptey et al., 2009; Ukwenya et al., 2008). In Ghana, Sanuade et al. (2018) reported that traditional healing was used by women because they believed in it and also because of the aggressive campaigns of traditional healers. These advertisements promote public trust and engagement with it (Sanuade et al., 2018). Wright et al. (1997) also found in their qualitative study that traditional healing was used because some women believed that only an indigenous healer would be successful. Furthermore, traditional healing was used because cancer is perceived to be associated with stigma and people remained secretive about it. Accepting hospital treatment meant going public about one's diagnosis (Wright et al., 1997).

2.2.6.2 Treatment factors

2.2.6.2.1 Unpleasant treatment side-effects

Treatment side effects were found to be a factor influencing treatment non-completion of women in two studies. Between the two studies, a total of 10 women (15.8%) did not complete treatment due to treatment side effects (Oguntola et al., 2011: Clegg-Lamptey et al., 2009). Reported side effects included hot flushes, nausea and vomiting (Oguntola et al., 2011). Anarado et al. (2015), on the other hand, found in their qualitative report that women did not stop treatment despite the unpleasant treatment side effects. The women continued with treatment because of the anticipated benefits of the treatment (Anarado et al., 2015).

Women's experiences of treatment side effects may impact their continuation with treatment, but the inconsistencies in studies' reports may be subject to the lack of exploration of the support available to women in the clinics. The quantitative studies could not provide in-depth exploration. In the qualitative study, Anarado et al. (2015) did not consider women's socio-cultural context and the care models underpinning clinical care of women with breast cancer in the interpretation of findings, which limits the extent to which this finding can be transferrable to other similar contexts.

2.2.6.3 Healthcare provider and system factors

2.2.6.3.1 Financial barriers

This review found financial constraints as a factor influencing treatment delay and non-completion. Twelve out of the sixteen studies found financial difficulties as a factor influencing treatment delay and non-completion (Sanuade et al., 2018; Dedey et al., 2016; Egwuongwu et al., 2012; Clegg-Lamptey et al., 2009; Pruitt et al., 2014; Wright et al., 1997; Oguntola et al., 2011; Ukwenya et al., 2008; Anyanwu et al., 2011; Ntekim et al., 2009; Anarado et al., 2015; Mc Ewan et al., 2014), seven of which were quantitative reports. From the seven quantitative reports (Dedey et al., 2016; Egwuongwu et al., 2012; Clegg-Lamptey et al., 2009; Oguntola et al., 2011; Ukwenya et al., 2008; Anyanwu et al., 2011; Ntekim et al., 2009), financial constraints influenced treatment non-completion of women from between 2.7% (n=6) (Ntekim et al., 2009) to 36% (n=62) (Anyanwu et al., 2011). Similarly, in Dedey et al. (2016) about 70% (n=143) of participants were more likely to delay the start of breast cancer treatment because they were either unemployed or had lower levels of income ($p< 0.001$).

The high numbers of studies reporting on financial constraints suggest that this may be an essential factor influencing treatment uptake, considering the high rate of poverty in sub-Sahara Africa (World Bank Facts, 2013). However, O'Brist et al. (2014) did not find financial constraint as a factor influencing treatment uptake. Instead, the authors found knowledge on health insurance provision for breast cancer treatment as significantly associated with treatment non-completion ($p<0.01$). Nevertheless, this finding may have emerged in O'Brist et al. (2014) because the study was conducted in Ghana, which has health insurance provision for breast cancer treatment. Furthermore, the study was conducted at a time when the insurance provision for breast cancer treatment had just been introduced in the country.

2.2.6.3.2 Non-availability of drugs and resources

This review found inconsistent evidence in support of the non-availability of drugs and treatment non-completion. Sanuade et al. (2018) found in their qualitative study that non-availability of medicine, shortage of healthcare workers and breakdown of machines contributed to treatment delay. Oguntola et al. (2011) also found non-availability of drugs as a factor contributing to treatment non-completion in 7% (n=2) of the women in his study. Similarly, Anyanwu et al. (2011) found non-availability of drugs as a factor influencing treatment non-completion in 15% (n=27) of respondents. However, although O'Brist et al. (2014) found that women who did not complete treatment were more likely to attribute it to non-availability of chemotherapy drugs compared to women who completed treatment (p<0.05), yet, after adjusting for all variables in the regression model, non-availability of drugs was not found to be significantly associated with treatment non-completion (O'Brist et al., 2014). The differences in findings between the studies may be due to the differences in studies' methods.

2.2.6.3.3 Experiences with providers' interactions on breast cancer treatment

From the review, some aspects of healthcare interactions influenced women's decisions on breast cancer treatment. Sanuade et al., 2018, Wright et al. (1997) and Mc Ewan et al. (2014) found the unpleasant experience with care including poor communication and attitude of HCPs as a theme leading to treatment non-completion and delay following diagnosis. According to Wright et al. (1997) and Pruitt et al. (2014), women had difficulty in comprehending information from healthcare professionals about breast cancer due to differences between patients' and doctors' perceptions about the causes of breast cancer. Women believed in spiritual causes, whereas doctors believed in biomedical causes. Anarado et al. (2015) also found that women felt they were not adequately prepared for chemotherapy as they did not receive adequate information on the side-effects of chemotherapy and how to manage them. This threatened adherence to prescribed courses of treatment. The women emphasised the need for nursing care and support that will inspire hope to continue with treatment. In contrast, in Adejoh and Olurunlana (2016), some women expressed their views that they were actively involved in discussions with their doctors and were hence provided with support and adequate information about breast cancer treatment, which facilitated treatment uptake. A similar finding was reported by Dedey et al. (2016) who mentioned that women who received information from HCPs were significantly more likely to start treatment within a shorter time following diagnosis compared to those who received inadequate information from HCPs (p<0.05).

2.3 Summary of findings, gaps in the literature and the need for research

In conclusion, it emerged from the review that patient factors (level of education; beliefs in spiritual causes of cancer, beliefs in the consequences of breast cancer treatment, use of traditional medicine, family influence, lack of knowledge about cancer), treatment factors (unpleasant treatment side effects) and provider and health system factors (financial barriers; availability of drugs and equipment, experiences with providers' interactions) contributed to decisions on treatment delay and non-completion. Most of the factors are socio-cultural and structural. Nevertheless, studies in the review mostly gathered data on women who had started some form of treatment and had then abandoned the remaining courses. There is limited knowledge about the factors influencing treatment decision-making in women who are considering whether or not to start treatment. Although two studies explored factors influencing commencement of definitive treatment, both studies were conducted in one of the two leading public hospitals offering comprehensive breast cancer treatment in Ghana. This hospital is accessed mostly by patients living in the coastal and eastern parts of the country. The views of women from the northern and middle parts of the country who present at the other teaching hospital are hence unknown. Also, it emerged that when women received adequate information on breast cancer treatment and were involved in discussions around treatment options, it facilitated the uptake of treatment. This is also inadequately explored, particularly in the southern context of Ghana. As women in Ghana may be less likely to be involved actively in medical discussions as a result of the cultural issues discussed above (i.e., because there is a cultural assumption that the educated professional knows best), having insight into this issue will be valuable. Lastly, although qualitative methods may enhance a deeper understanding of what influences breast cancer treatment decision-making, particularly in women who are considering whether or not to start treatment, studies conducted in Ghana are limited in qualitative methods. The gaps identified in the review include the following:

1. Lack of exploration of the beliefs, values and practices influencing treatment decision making for women (attending a breast clinic in southern Ghana) who are considering whether or not to start treatment;
2. Lack of research on the structural factors (e.g., clinic resources) which influence women (who are considering whether or not to start treatment) during treatment decision-making.

A new study is needed to fill the gaps identified in the literature.

2.4 Significance of research

International guidelines on breast cancer control indicate that the stage of disease in addition to prompt optimal treatment are predictors of survival outcomes (WHO, 2017). Optimal treatment for breast cancer is multimodal, consisting of surgery, radiation, chemotherapy and often hormone therapy and biological therapies (Mahon, 2011). There is evidence to support this multimodal breast cancer treatment in improving survival in early (stage 1 and 2) and locally advanced (stage 3) disease (SIGN, 2013; NICE, 2009). Despite this evidence, some women in Ghana diagnosed with breast cancer elect for suboptimal treatment. The literature has shown that several factors including beliefs about breast cancer causes, beliefs about the consequences of breast cancer treatment, family influence, use of traditional healing, financial constraints, poor knowledge about breast cancer treatment, treatment side effects and experiences with HCPs' interactions contributed to treatment non-completion of women diagnosed with breast cancer in Africa (O'Brist et al., 2014; Pruitt et al., 2014; Oguntoa et al., 2011; Adewale et al., 2008; Ukwenya et al., 2008; Clegg-Lamptey et al., 2009; Wright et al., 1997). While the majority of these factors seem to have a strong socio-cultural underpinning, studies mostly focused on factors contributing to treatment non-completion. There are limited studies that have adequately explored how these factors influence treatment decision making for women who have been diagnosed with breast cancer and are considering whether or not to start treatment, particularly amongst women attending a breast clinic in southern Ghana.

Also, the recognition that time to initiating treatment is a critical step in improving cancer outcomes (Scotts et al., 2013; Weller et al., 2012) suggests an urgent need to understand these issues. Nonetheless, it seems that little attention has been paid to the factors that underpin the decision to start or not start breast cancer treatment following diagnosis (Dedey et al., 2016; Sanuade et al., 2018). A new study is needed to fill the gap in the literature and enhance an understanding of the factors influencing optimal breast cancer treatment uptake following diagnosis.

The review has underscored that beliefs, values, practises and structures may be important in breast cancer treatment uptake. Therefore, one approach to exploring these concepts adequately is by adopting ethnography. The reason being that ethnography allows an understanding of behaviour surrounding health and illnesses within a given context (Savage, 2000). Ethnography is a valuable method of viewing patients' beliefs about an illness (cultural knowledge) and their purposive action in a given cultural context. Ethnography has thus been applied in healthcare studies in numerous ways. For instance, in a maternity clinic in the USA, Souza and Scrimshaw (1982) identified that pregnant women arrived at the clinic too early, which caused them to make repetitive trips to the hospital. Using ethnography, the authors found that the instructions given by HCPs to the pregnant women were often misinterpreted by the pregnant women because the HCPS mistakenly assumed the pregnant women had the same conceptualisation of the birthing process and its stages. The ethnographic methods allowed the authors to successfully design a culturally appropriate information booklet for the accurate identification of active labour. This intervention had the effect of reducing repeated clinic visits. In a more recent study, in Pakistan, Naeem et al. (2009) found that despite the evidence-based success of Cognitive Behavioural Therapy (CBT) for treating people with schizophrenia, including those in developing countries, CBT was rarely available in these countries. Using an ethnographic approach, the authors found that patients with mental illness and their carers attributed the illness to a model that had biological, psychosocial and spiritual causes. For this reason, patients and their carers would usually consult healers from more than one system. The findings from the study were used to deliver a culturally appropriate CBT for psychosis in a preliminary study and were found to be effective (Habib et al., 2014). In Ghana, ethnographic research has given valuable insights into maternal and child health-related issues. Bazzano et al. (2008) used the ethnographic approach to explore the reasons influencing neonatal mortality in a rural community in Ghana. The authors found that labelling of illness as not for hospital, previous negative experiences with health services, financial problems and complex decision-making processes influenced timely response to health-seeking. This study's findings raised awareness for communication training for health service personnel in the local community.

In sum, using ethnographic approach is a valuable means of understanding the ways women's beliefs, values and practices and structures influence decision making for breast cancer treatment. Understanding this may enable healthcare professionals, such as nurses, to provide culturally congruent care that will best support women in making decisions. It is expected that this will improve uptake and continuation of treatment, and lead to improved outcomes.

2.5 Chapter summary

This chapter has reviewed relevant literature on factors influencing decisions on breast cancer treatment uptake among women diagnosed with the disease in Africa. It identified that socio-cultural factors (financial difficulties, spiritual beliefs in causes of cancer, beliefs in consequences of breast cancer treatment, traditional medicine, family influence), knowledge, treatment factors (unpleasant treatment side effects) and provider factors (availability of drugs and equipment, experiences with providers' interactions) contributed to decisions on treatment delay and non-completion. It also identified the following evidence gaps: lack of exploration of the beliefs, values and practices influencing treatment decision making for women (in Ghana) who are considering whether or not to start recommended treatment; lack of research on the factors (values) that are important to women during treatment decision-making. It is therefore critical to explore and understand these issues in order to promote best care and support to women with breast cancer during treatment decision making. It is also considered essential to explore these issues to guide interventions to support women with quality information, to facilitate informed treatment decision-making (refer to the national strategy for breast cancer control in Ghana in appendix 1).
The next chapter (Chapter 3) will discuss the methodology and methods employed in the conduct of this study.

Chapter 3 Research Methodology and Methods

3.1 Introduction

The cultural context of Ghana was explored to identify what factors influenced treatment decision making for women with breast cancer. The main focus was on women diagnosed with breast cancer at a breast clinic in southern Ghana who were considering whether or not to persevere with a treatment recommended by HCPs. I investigated the information these women (including their relatives) received, the sense they made of this information and how they behaved as they were interacting with HCPs. I then explored contextual issues (beliefs, values, practices and structures) impacting this interaction, their sense of understanding and consequently how all these influenced their decision making. This chapter hence presents the research questions, study aim and objectives and discusses in particular, the methodological perspective and the rationale behind the adopted methods to achieve the research aim and objectives.

3.2 Research aim

The cultural context in Ghana may influence treatment decision making for women who have breast cancer; however, there is a gap in knowledge concerning this issue. This study thus aims to explore and enhance a deeper understanding of how the cultural context in Ghana influences treatment decision-making for women who have breast cancer (and attending a breast clinic in the Ashanti Region of Ghana).

3.3 Research question

Main research question:

- In what ways does the cultural context of Ghana influence treatment decision making for women with breast cancer?

3.3.1 Study objectives:

1. To explore the beliefs, values and practices influencing breast cancer treatment decision making for women attending a breast clinic in southern Ghana?
2. To explore the structural factors influencing breast cancer treatment decision-making.

A qualitative ethnographic design was adopted. The decision to use a qualitative approach will first be outlined, and then the rationale for ethnography.

3.4 Methodological considerations

A qualitative research design was deemed appropriate to provide a deep understanding of how the cultural context of Ghana influences treatment decision making. This was considered after exploring the defining characteristics of the two main approaches- quantitative and qualitative designs.

The terms quantitative and qualitative research designs are used to describe different philosophical views. These philosophical views relate to the issues of the nature of knowledge and the ways in which social reality should be understood (Gerrish and Lathlean, 2015). Quantitative research is an approach to the conduct of social research which applies the natural science, positivist, approach to social phenomena (Bryman, 1984). The underpinning characteristics are that it exhibits operational definitions, aims for objectivity, to be value-free (or neutral), valid, reliable and capable of generalising to other settings (Bryman, 1984). Quantitative methodology is directed towards theory testing and a perspective of a single reality, which can be separated into variables capable of independent study (Lathlean, 1995). Within this convention, surveys are construed as instruments that are preferred as they can be readily adapted to such parameters (Bryman, 1984). The argument for this methodological approach is that if a survey respondent and its replication are faced with an identical set of stimuli, then their responses will be commensurable (Hammersley and Atkinson, 1992). Where such standardised procedures are not employed, then it is impossible to interpret responses due to the difficulty in establishing what they are responding to. Blumer (1956) nonetheless argues that data produced from survey research is nothing other than superficial evidence of the social world because the data lacks a great deal of depth as it is focused on the arbitrarily causal relationship between variables with little or no meaning to the individuals whose social world they are meant to represent.

This study aimed to have a deeper understanding of how women with breast cancer view the world in order to make sense of why they may not seek biomedical treatment. Hence, qualitative research which is based on seeing the social world from the point of view of the actor (Bryman, 1984) is appropriate. To see through the eyes of participants, qualitative methodology advocates for close involvement with the participants. The philosophical underpinning of qualitative research is based on naturalism, where social phenomena are studied in their natural state, unobstructed by the investigator (Hammersley and Atkinson, 1992). The reason being that human actions or behaviours are based upon or imbued with social meanings which are under constant review. For this reason, using standardised methods will not ensure the commensurability of the data generated (Hammersley and Atkinson, 1992). Qualitative research designs thus allow the use of methods that aid interpretation of human behaviours and actions in natural settings (Lathlean and Gerrish, 2015). Participant observations and in-depth interviews are ways of getting close to participants and understanding the meanings of their behaviour. These two methods were adopted to get close to participants and understand their point of view during breast cancer treatment decision making.

Precisely, to understand beliefs, values and practices of women with breast cancer as well as what is important to them, participant observation enhanced the investigation of the way women navigate the breast clinic and interact with care providers around breast cancer and treatment recommendation. Furthermore, observable behaviours reflect underlying beliefs and values (Spradley, 1980), which participant observation in addition to in-depth interviews complement each other and allows for a deeper understanding.

Lathlean (1995) asserts that the differences in the philosophical position do not imply one approach is superior to the other, rather, researchers ought to consider the aims of the research and the questions to be addressed before deciding on the research design. Moreover, the literature review in chapter two has highlighted the limited application of qualitative methods to breast cancer treatment decision-making among Ghanaian women, even though such methods can make a meaningful contribution to enhancing understanding of this phenomenon. Of the different possible qualitative approaches, including grounded theory; phenomenology; narrative research and ethnography, ethnography has been adopted for the study.

3.4.1 Ethnography

The literature review and the research question for this study underscore the need for an ethnographic study because it would allow the examining of the culture of women attending a breast clinic in southern Ghana. This includes exploring the ways their beliefs; values and practices influence treatment decision making, an aspect that is core to ethnographic studies (Gerrish and Lathlean, 2015). My interest in examining cultural beliefs, values and practices during breast cancer treatment decision making is that some Ghanaians have beliefs about cancer being caused by witchcraft or by a curse. Secondly, Ghanaians have strong religious beliefs (whether Christian, Islam or traditional) where there is a belief that spiritual healing is linked to physical healing and that God is the provider of spiritual healing. Such beliefs may influence women on the care they should use when afflicted with an illness. Adopting ethnography was hence deemed appropriate to uncover the beliefs, values and practices of women as they make decisions about breast cancer.

Uncovering these would require the ethnographers' engagement in the society; gathering descriptive data through fieldwork; being preoccupied with the culture of the members of a group; interpreting descriptions based on the perspective of the meanings members of the group attach to their social world as well as presenting the collected data in a manner that is significant to fellow academics and readers (Bryman, 2001).

To become immersed in society, and to get closer to participants (i.e., women attending a breast clinic in southern Ghana; relatives and HCPs) and examine their cultural beliefs, values and practices, methods that allow for this including participant observation and in-depth interviews were adopted. Indeed, participant observation is a defining characteristic of ethnography. It allows the observer to directly participate in the setting and also the activities, and collects data in a systematic manner, but without the meaning being imposed on them (Brewer, 2000). In doing so, the participant observer can see the world from the perspective of the participants (Bryman, 2001).

This also brings to the fore the need to consider the nature of participation (Gold, 1958). Gold (1958) emphasises four possible roles when conducting field research. These include: complete participant; participant observer; observer participant; and complete observer. In the complete participant role, the genuine identity and aim of the complete participant are not known to those she or he observes in the field. The researcher is viewed as a member of the group being observed, although this is deceit known to her or him alone. With regards to the participant as observer role, both the researcher and the participants acknowledge what they have as field relationship. This means that although there is a mutual understanding that the researcher is there to observe, both parties develop some friendship in the field with the passage of time. Consequently, the researcher spends some time participating than observing. In observer as participant role, the researcher conducts more formal observations compared to participation. In the complete observer role, the researcher is totally distant from social interaction with participants because she or he observes participants in ways that they do not know that he is observing them (Gold, 1958).

In this study, the complete participant and complete observer roles were not adopted because of ethical issues (observation under pretence) and also because of the risk of ethnocentrism (judging the culture of the participants) (Gold, 1958). Based on these convictions, the intention was to be fluid between 'participant as observer' and 'observer as participant' roles. This fluidity would enhance the building of a relationship with participants and allow for access to places in the setting that would enhance a rich and detailed exploration of the research phenomenon. Furthermore, it would ensure the regain of control in the event of over-identification with participants while in the field. Nevertheless, there are methodological issues associated with these roles. For example, with the participant observer role, there is a risk of the researcher going native, and with the observer participant role, there can be issues of trust (Gold, 1958; Gerrish and Lathlean, 2015). Indeed, it is argued that adopting a dual role for example (being a nurse and a researcher), poses a risk for the researcher to become submerged in the culture of the group (in this case the breast clinic) and fail to keep sufficient distance between herself, the culture and the participants. The researcher may thus lose her research perspective, which can threaten the credibility of the data (Gerrish and Lathlean, 2015). Perhaps more significantly, the presence of the researcher (or observer) in the field may influence the behaviours which are the focus of the study (Gerrish and Lathlean, 2015). This is referred to as ‘observer effect’. Schnelle et al. (2005), however contend that prolonged exposure to observation reduces the probability of behaviour that may result from ‘observer effect’. Many authors therefore assert that observations should be conducted for an extended period of time to minimise observer effects (Gerrish and Lathlean, 2015; Brewer, 2000). Nevertheless, time constraints may not allow for observation to be carried out for such a prolonged period. Brewer (2000) also asserted that on some occasions, it is not clear-cut as to the maximum period of observation.

To address these methodological issues, there was a need to strike a balance and be reflexive during the research process. The issue of reflexivity is discussed later in 3.6.1

In spite of the methodological issues, ethnography as a methodology is very useful in exploring and understanding cultures and sub-cultures of a group. It is particularly useful in nursing because cultures and sub-cultures exist within the healthcare system (Gerrish and Lathlean, 2015). While there may be ethical issues with for example observing research participants in healthcare contexts, yet the unique benefit of ethnographic research in enhancing the understanding of patients and clinician’s worlds from their own point of view makes this approach worthwhile (O’Reilly, 2005). Ethnography has thus been employed in a large number of studies to explore cultures in nursing and to discover the ‘insider view’ of patients and colleagues in healthcare settings (De Chesnay, 2014).

3.4.1.1 Ethnography and epistemology

Ethnography can be conceptualised using different epistemological positions including, positivism; constructivism, and critical ethnography (Howell, 2013). This ethnography is underpinned by constructivism. Before explaining the rationale for adopting constructivist ethnography, a brief overview of positivist and critical ethnography and why they were not adopted is provided.

Positivist ethnographers advocate objectivity and distance from the object of inquiry (Bryman, 2001). For positivists, the individual mind starts out as an empty sheet and knowledge is acquired from sensory experience and interaction with it (O'Reilly, 2005). For this reason, the researcher retains power and authority over the inquiry and the community being studied (Howell, 2013). However, it is argued that individuals make meaning of what they see and hear and that experience has to be conceptually ordered (Geertz (1973). For this reason, it will be naive for a researcher to start out as an empty sheet and hence positivist ethnography was rejected.

Critical ethnographers on the other hand seek to consider how participants and communities are characterised, and explore the restraints and oppressive aspects of injustice, inequality and control (Madison, 2012). Critical ethnographers are thus opposed to positivism (by removing authority from the researcher) and as such rely heavily on reflexivity on the part of the researcher (Madison, 2012). In critical ethnography, there is an emphasis on social transformation through raising awareness of domination and power structures in society in order to bring about change. However, these underlying assumptions mean that researchers enter the field with negative assumptions about structures which may ultimately bias the process of inquiry (Stacey, 1988).

Constructivist ethnographers reiterate that reality is generated through human interactions, perceptions and experiences of the social world (Sinead, 2017). To understand the social world, there is a need to get close to the individuals or groups and understand their behaviour in the context of their society or culture (O'Reilly, 2005). This means that there are multiple realities and this position is thus associated with the search for the 'native's point of view' and pursues to extrapolate hermeneutically the kinds of people being studied, the nature of their social life and how their life is conveyed in words and institutions (Bryman, 2001). This position signifies the fundamental principle that informed this research. This study reflects an understanding that socially constructed phenomena around illness, disease and healing influence what people do in terms of decision making, hence, constructivism grounded in ethnography is considered appropriate to get closer to participants and understand their world during breast cancer treatment decision making.

This epistemological position has several implications. For example, it postulates that 'humans' should be the main data collection tool in order to interact with participants and divulge their multiple constructed perspectives (Lincoln and Guba, 1985). It also emphasises that since realities cannot be understood in separation from their contexts, the study participants should be a natural setting, which is the context related to the study. Furthermore, it adds that each research participant has their own viewpoint or reality, consequently, the inquiry should be geared towards revealing the contextualised meanings of these numerous points of view with the ultimate aim of producing a reconstruction from the multiple truths that exist (Guba and Lincoln, 1985). For these reasons, the researcher was the key research instrument who conducted participant observation and also interacted with all participants during interviews. Also, the participant observation was conducted at the breast clinic which is the setting where women formally receive a diagnosis of breast cancer and treatment recommendation. Thirdly, thematic analysis was employed for the data collected and this allowed the identification of the numerous accounts of women, relatives and HCPs that existed when the data was being collected (detailed explanation of chosen methods provided in later part of the chapter). During this process, there was a consideration about applying a theoretical perspective to treatment decision making to aid the data collection and analysis. This was subsequently discounted in order not to constrain and force emerging concepts from the data into pre-determined constructs (Collins and Stockton, 2018).

3.4.2 Data collection

In-depth interviews and participant observation were utilised to generate data in the field. This section outlines the procedures involved including how the site was accessed; what ethical issues were considered; how the participants were recruited and how the participant observation and interviews were carried out. It further highlights how thematic analysis was applied to the data generated by the study. Finally, the chapter presents a reflexive discussion of the role of the researcher on the research process.

3.4.2.1 Site selection and negotiating access

The breast clinic in the Ashanti Region is one of the two public teaching hospitals providing comprehensive breast cancer management (e.g., imaging; pathologic diagnosis; surgery; chemotherapy; hormone therapy; radiotherapy and palliative care). However, given the distance of location of this hospital to that of the other teaching hospital (250 kilometres apart), it was considered impractical to conduct the study in both settings, especially considering the time limitation of a PhD study. The breast clinic in the Ashanti Region serves as the regional centre for cancer treatment, and breast cancer is the most common cancer presented at the hospital (O’Brien et al., 2013) and this makes the setting ideal to conduct the study. Also, as a referral point for the northern, middle, western and central parts of the country, the clinic is accessible by a heterogeneous group of people. This was considered valuable in exploring the different contextual factors influencing treatment decision for women with breast cancer. Although there is another hospital in the same region that offers some breast cancer care (pathology, surgery and chemotherapy), this hospital was discounted because it did not offer comprehensive care including radiotherapy, which could be influential in the decision-making process. Another important consideration was geographical proximity because of logistical reasons. I did not work at this breast clinic, but I lived in the same city where the hospital was situated and thus had easy accessibility to and from the hospital.

Before I had access to the setting to begin field work, I had met the oncology nurse in-charge at a breast cancer conference in Europe. I established a good rapport with her prior to beginning field research. She assisted me in negotiating access to the breast clinic. She introduced me to the breast clinic unit head who in turn introduced me to the rest of the staff at the breast clinic including the breast clinic nurse in-charge, doctors, staff nurses and the non-clinical staff on the unit. This introduction facilitated subsequent meetings with the doctors and nurses about the purpose and nature of the study. Meeting with the staff on the unit allowed me to gain support from them for the study. I also placed a poster with information about the nature of the study in the nurses' room, treatment room and the clinic corridor. As I already had ethical approval from Kwame Nkrumah University of Science and Technology (KNUST), the unit head and the nurse in-charge agreed I could begin field work.

3.4.2.2 Ethical consideration

Ethical approval was first obtained from the University of Southampton (appendix 6). An introductory letter from the University and research protocol were then sent to the Southern Hospital Committee for Human Research and Ethics Board. Following a review by the hospital's research board, an acknowledgement letter was issued. This letter and the study protocol were then sent to KNUST. This university oversees all researches conducted in this hospital. After about two weeks, an ethical approval letter (see appendix 7) was issued by the University.

Ethnography, like other qualitative research, raises ethical issues that need to be addressed. This study involved moving into the lives of healthcare professionals at the breast clinic as they interacted with women; engaging in conversations with them; observing them; thinking about what is being said; inscribing and probing all events. These activities required reflection on ethical principles to avoid any exploitation, coercion, deception or stress/harm caused to the participants (Gerrish and Lathlean, 2015; Kirk, 2007).

Recent ethical principles indicate that people who are able to consider what participation in a study will involve should be given information in order to decide whether or not to take part (Gerrish and Lathlean, 2015). Easily understandable information sheets (appendix 8) outlining the aim and purpose of the study and the research process were explained to participants in the local language (Twi) and written consent given by participants before participation in the study. Potential participants were given at least 24 hours to decide whether or not to take part in the study. Participants were informed of their right to decline participation and were informed how to refuse participation or decide not to respond to particular questions (Roberson, 2007). Furthermore, participants were informed they have the right to withdraw at anytime from the study without needing to give an explanation and would not experience any adverse consequences. Additionally, to reduce coercion of patients' participants, the nurses were allowed to inform potential patients about the research study. Patients who were keen about the study were asked to contact me after they had gone through their routine care for the day. Participants who came back to see me were given further information and participant information sheets. The agreement was that on their next clinic appointment, if they were still interested, they would then sign a consent form (appendix 9).

Confidentiality and anonymity were assured throughout the data collection and analysis processes by following data protection procedures stipulated by the University of Southampton. For example, to maintain anonymity, codes, letters and pseudonyms were used to identify participants and link them to tapes and transcripts (Huberman and Miles, 2002). Electronic data was password-protected and encrypted on a University of Southampton computer, while hard copies were locked in a filing cabinet that could only be accessed by me (Huberman and Miles, 2002). Reassurance of confidentiality was provided before and after every interview session (Legard, et al., 2004). However, total confidentiality could not be guaranteed as it is the duty of a researcher to disclose information that suggests participant may be 'at risk' (Gerrish and Lathlean, 2015). Information on restrictions to confidentiality and how disclosures of information indicating the way possible risks/harm will be resolved were discussed with participants.

The ethical principle of non-maleficence requires careful consideration in healthcare research. Although this study is not an intervention study, there was the potential to upset participants or cause distress due to discussions around sensitive issues on breast cancer. I remained sensitive to this and I discussed the possibility of such harms and discomfort openly with participants. I pre-arranged with a senior nurse at the oncology clinic who provided supportive care to patients that a referral will be made to her should a participant be distressed during an interview.

As some interviews would take place in participants' homes or venue of choice, there were risks involved with lone working. An arrangement was made to inform a colleague of my location through a phone call before arriving at a participant's home and when leaving the premise. I also arranged with my colleague to contact me in case I do not call to provide an update of my location.

3.4.2.3 Defining the field

From the outset, this study set out to explore how the cultural context influences treatment decision making for women with breast cancer. The study however is focused on women whose treatment had curative intent and who (after a formal pathologic diagnosis) were considering whether or not to choose the recommended treatment by HCPs at the breast clinic. The aim was to explore these influential factors from the perspective of women, so there was no intention to have an in-depth exploration from HCPs as to, for example, why HCPs recommend a particular type of chemotherapy; fractions of radiotherapy; radical or modified mastectomy. It was considered that these factors were beyond the scope of this study. The study was however interested in exploring HCPs experience of women's breast cancer treatment decision making and how HCPs supported women in their decision making.

Another defining characteristic of this study was that the literature review had underscored limited research conducted on the factors influencing treatment decision making for women who have been diagnosed and are considering whether or not to start treatment. Therefore, the study was not interested in exploring in-depth about the factors influencing the time to presentation to the breast clinic. This study was focused on the time points from formal diagnosis (where core biopsy reports were available to patients) to the tumour board meeting. The rationale for these time points are that formal diagnosis occurred when the results of core biopsy were available and according to HCPs, the tumour board meeting was where women are informed about their recommended treatment. These time points provided a defined field for observing all the behaviours and practices involving women, relatives and HCPs at the breast clinic. It was intended that in-depth interviews would follow from having observed these time points. All these issues involved in the research process were explained to participants.

There were, however, some occasions that there were some doubts about conducting focused observations in some areas of the clinic. I had discussions with my supervisors about whether to include focused observation of a participant (patient and relative) as they sit at the waiting area. It was considered impractical to follow a participant around in the clinic corridors. The consensus was that a general observation of the waiting areas was instead conducted. Another doubtful issue was whether to interview a patient participant who had been diagnosed but had not been staged. Staging precedes diagnosis. This means some participants were observed during diagnosis but throughout the period of observation, they did not return to the clinic with results of requested metastatic investigations (indicator for breast cancer stage and whether treatment will be curative or palliative). Since this research was focused on patients whose treatment had curative intent, it was agreed with supervisors to only focus on patients whose disease had been staged and are being recommended treatment with curative intent.

3.4.2.4 Sampling

Recruitment of participants in this study reflected the aim of the study. With regards to patient participants, the intention was to include women with breast cancer whose treatment had curative intent. Consequently, women with metastatic and inoperable breast cancers were excluded (National Cancer Institute, 2018). Secondly, from my own personal knowledge of the research setting, relatives mostly accompany patients to clinics and as mentioned above, may also be involved in treatment decision making. It was thus decided to include relatives of women if only women gave consent to nominate a relative. The third consideration was that breast cancer diagnosis and treatment recommendation are provided by HCPs at the breast clinic. Hence, doctors and nurses involved in this process were also considered for inclusion. The population for this study included: women diagnosed with breast cancer (up to stage 3 breast disease); their self-nominated family member; nurses; and doctors at a breast clinic in Ashanti Region. The breast clinic was going to be the source of participant recruitment.

The breast clinic opens from Monday to Friday, between 8am-4pm, it was realised that approximately four patients are diagnosed with breast cancer every week. This number included those who are only clinically diagnosed but not histologically diagnosed as well as those with metastatic disease. Secondly, there was no database at the breast clinic which meant it was difficult to know the average number of patients with operable breast cancers. Thirdly, according to HCPs, from their experience, less than half of patients diagnosed (either clinically or histologically) progress through staging and treatment. For these reasons, it was decided that with regards to patient participants, since knowledge on whether the person is for curative or palliative intent would not be known from the outset, it was decided to recruit as many of them as were available and willing to consent to participate especially during the period of observation. Those who were later found to be inoperable were thanked and excluded from the study. This process continued within 14 weeks of participant observation until data saturation was reached i.e. no new issues were emerging. Within the 14-week period, a total of approximately 26 patients were observed. However, using the inclusion and exclusion criteria (Table 3.1 below), 17 patients were invited but one declined to be included in the study. 16 patients were finally recruited into the study.

Table 3.1: Inclusion criteria for participants

Inclusion criteria	Rationale
i. Women 18 years and above with a histologically proven diagnosis of breast cancer (stage 1 to 3) attending the clinic ii. Women who are offered treatment with curative intent and are considering whether or not to start treatment (period will be from time of diagnosis up to the scheduled time for the first treatment to commence)	To generate insight into the phenomenon under investigation; stage 4 breast cancer excluded because local therapy has no effect on mortality (Jatoi and Benson, 2013) To focus the research on this group of women This period will also enhance the gathering of current information which is not subject to recall bias
Eligible professional nurses working in a teaching hospital in the Ashanti Region Professional nurses working at the breast cancer clinic for a minimum of one year	To focus the study in a setting with similar cultural characteristics These participants have acquired relevant experience in treatment decision making from interacting and engaging with women diagnosed with breast cancer
Eligible doctors working at a southern Ghana breast clinic Doctors involved in breast cancer diagnosis and treatment recommendations for at least one year	To focus the study on participants in a setting with similar cultural characteristics. These participants have relevant experience and will be able to provide insight into the phenomenon under investigation.
Speak local language (Twi) or English	To enhance communication in a language that participants can understand and speak well: English is the official language in Ghana
Nominated family member who is willing to participate in the study	To provide additional perspective on the phenomenon under study

Table 3.2: Exclusion criteria for participants

Exclusion criteria	Rationale
Women and nominated family members who do not have mental capacity (i.e. are not able to understand what participation in the research will involve)	Lack of mental capacity falls outside the scope of this study

The sampling approach was purposive. Purposive sampling is a type of non-probability sampling whereby the researcher makes decisions about the type of individuals to include in the study (Gerrish and Lathlean, 2015). In this study, the criteria were to include women diagnosed with curative disease (i.e., up to stage 3 operable breast cancer) since local therapy has no effect on mortality in metastatic disease stage (Jatoi and Benson, 2013). Additionally, for women's relatives, because they often accompanied women to the clinic and could be involved in the decision-making process, they were also included. Nevertheless, their inclusion was only dependent on their nomination by the women. For HCP participant, the criteria were to include those who have worked at the breast clinic for one year or more. The rationale was to enhance the selection of participants with relevant experience who are more likely to provide data of sufficient relevance and depth (Gerrish and Lathlean, 2015). In addition to purposive sampling, it is also intended that a maximum diversity sample (i.e., ethnicity, religion, socio-economic status), who meet specified criteria and are available, accessible and willing to give consent to participate in the study, will be selected in order to ensure reflection of all perspectives.

For reasons mentioned above, the 16 patients were invited to nominate a family member to participate in the research. Family members who accompany women were asked for consent prior to being observed. Although all the 16 women verbally agreed to nominate a family member, in the end, only five family members contacted me and were recruited into the study.

With regard to the healthcare professionals, there were four staff nurses and two principal nursing officers at the breast clinic. Using inclusion and exclusion criteria, all the staff nurses and one of the principal nursing officers were eligible and they were all invited to participate. The other principal nursing officer had been transferred to the unit just at the time I began data collection, so she was considered ineligible as she had less than a year's experience at the clinic. All the invited nurses consented to participate with the exception of the principal nursing officer (charge nurse) who consented to participate but when it was time for interview, she declined saying she had too many commitments and did not have time. With regards the doctors, on each day of the clinic, there were one consultant, a resident, and house officers or two consultants and house officers. Using the inclusion and exclusion criteria, at least one doctor for each clinic day was invited to participate. I did not invite any doctor who worked on Thursdays because the nurses advised that there were a few challenges with the doctors who consulted on that day. In the end, five doctors were recruited into the study.

A total of 31 participants consisting of 16 women patient participants, five nominated family members, five nurses and five doctors were included in the study. Aside from these participants who gave written consent, verbal consent was obtained from any other person who happened to be present during observation.

3.4.2.5 Observation

Breast cancer diagnosis and treatment recommendations occurred at the breast clinic. Before I proceeded to the field, and to promote descriptive observation, I had planned a guide, which followed the nine steps provided by Spradley (1980) for participant observation. These included: space (the physical place e.g. consulting room); actor (the participants involved e.g. woman, doctor, family member); activity (a set of related acts people do e.g. talking about treatment, writing about medical history); object (the physical things present e.g. doctor's stethoscope, information sheet); act (single actions people do e.g. communication); event (a set of related activities that are carried out e.g. tumour board meeting); time (the sequencing that takes place over time); goal (the things people are trying to accomplish e.g. treatment recommendation); and non-verbal behaviour (e.g. nodding, silence, expressed emotions). Observation was expected to be conducted on the physical setting; on the interactions between doctors, women and nominated family members during diagnosis and treatment recommendations; and between the women, nominated family members and nurses at the breast clinic as the nurses provided information related to the recommended treatment. The observation was particularly expected to focus on the information women received; the dynamics between healthcare professionals and women (i.e., sitting arrangements, who leads the discussion, verbal and non-verbal communication) as well as the women's family members. Observing these dynamics would allow interpretations to be made about the cultural rules for breast cancer diagnosis and treatment decision-making. This is based on the assumption that observable verbal and nonverbal actions and practices can reflect underlying cultural beliefs and values and provide important clues on the culture of the group under study (as the ethnographer can subsequently explore the meanings of the observed behaviours from participants) (Spradley, 1980).

However, during fieldwork, I quickly realised that following the nine-step observation guide (Spradley, 1980) was impractical. A general observation of the clinic (using a modified version of the guide, appendix 10) in the initial stages was deemed practical. This included observing the clinic structure and lay out; general routine of the clinic; activities carried out in the clinic; the people in the clinic and how patients navigate the clinic. The general observation was conducted over a four-day period lasting 6 hours every day. During this period, I observed that patients came earlier than clinic start time and queued for a consultation card. I observed the payment method for receiving a consultation card and where patients sit and wait for a card. I also observed how nurses set up the clinic; offered clinical breast examination (CBE) and history taking; wound dressing; how nurses prepared and assisted doctors with performing core biopsy; how they assisted doctors with consultations and offered information to patients; how doctors performed consultations for new patients and returning patients; how doctors offered diagnosis of breast cancer and management plan. I also observed the general atmosphere of the clinic including relationships and how the tumour board meeting was organised. During this period, I sought to get to know the clinic's routine as much as I could. Consequently, I kept a broad focus until it eventually narrowed towards observing interactions between doctors and patients (including their relatives if present) or nurses and patients during discussions around breast cancer diagnosis and management plan. For this reason, I ensured that I was always present (to observe) at any place in the clinic where interactions on breast cancer diagnosis and management plans occurred. It is for this reason that I was also present at the tumour board meeting. During observations, I realised that meaningful interactions between HCPs and patients (i.e., doctors and patients followed by nurses and patients) around breast cancer diagnosis and management did not last more than an hour. For this reason, focused observations mostly lasted between (1-4 hours) a day depending on the number of patient participants who received diagnosis and or management plans on that day.

3.4.2.6 Field notes recording

Some earlier ethnographic authors have long noted that field notes are the traditional means for recording observational data in ethnography (Hammersley and Atkinson, 1992; Lofland and Lofland, 1984). Field notes represent the data that researchers collect through their own presence and interaction with persons, places and activities in the field (Le Compte and Schensul, 2013). In keeping up with the ethnographic tradition, which is committed to discovery, I kept field notes (appendix 10) to make these recordings. The idea is to capture concrete descriptions of social processes and their contexts (Hammersley and Atkinson, 1992). Keeping field notes is thus critical because it serves as a useful reference point. Because of the central activity of keeping field notes, I reflected on these key issues: what was I going to write; how do I write it down; and when do I write this (Hammersley and Atkinson, 1992).

Having these questions on mind, I approached field work using the following approaches:

I approached the research setting with the goal of writing down what I see and hear by documenting all the various characteristics and properties. In this way, I can capture the social processes and their contexts (LeCompte and Schensul, 2013). Gertz (1973) has long emphasised that researchers ought to retain thorough field notes if they are to get close to the social group they study and understand their way of life. Nonetheless, I was also aware that descriptions are somewhat selective because researchers tend to select what to describe based on their fore shadowed questions (Hammersley and Atkinson, 1992; Schensul and LeCompte, 2013). There is also the challenge of what do I write. LeCompte and Schensul (2013) assert that in order to know what is important to write, the researcher ought to focus on the study problem and to constantly ask during participant observation whether and how an emergent topic is related to the study problem. Hammersley and Atkinson (1992) further add that it is equally important to note the level of detail required for that emergent topic. In keeping up with Hammersley and Atkinson (1992) and LeCompte and Schensul (2013) principle of recording field notes, and in order not to have too narrow a focus, particularly during initial stages of participant observation, I decided to balance this by adopting a wide focus in my description. Within the early part of participant observation, the scope I adopted in recording field notes were mostly general, but, as the research progressed, and I began to identify emergent issues, field notes became more defined. I would also say that as I became focused, I would also constantly go back and forth and review the notes I had made because the longer I spent in participant observation, the more I got to understand the social interactions I was observing. In doing so, my field notes became more and more concrete and detailed especially with regards to emergent issues (Hammersley and Atkinson, 1992).

I wrote field notes while in the setting. I was aware that if I did not write field notes during observations or as soon as possible after the observed action, the quality of the description in the notes may diminish (O'Reilly, 2012; Hammersley and Atkinson, 1992). The plan I took was to write notes during actual participant observation. However, this was not always possible because I felt that it interfered with developing a rapport with participants. At other times, the situational context made it impractical. For example, during an unexpected conversation with some participants. I therefore had to balance this. I had a pocket size notebook into which I made jottings during participant observation. Jottings are words, phrases and whole sentences that act as reminders of entire conversations or behaviours that transpire in the lives of participants (Schensul and LeCompte, 2013).

A page of jottings on ‘a patient (first attendance) seeing a nurse for screening’ included the use of the following words: ‘que and pay for consultation card; wait on a que until called by the nurse; other patients waiting close by; nurse checks details of patient and payment; documentation; patient asked to explain history of symptom experience; patient is called into treatment room for breast examination’. Right afterwards, as soon as time would permit, I would retreat to a quiet place in the setting, mostly in the nurses’ room (when it was empty) and sometimes under a shady tree, to write down the details of what transpired during participant observation as shown in Figure 3.1 below:

Figure 3.1: Field notes

Date: Wednesday, August 2nd 2017

Time: 9:30am

Location: Breast clinic, nurses’ station

Events and topics

New patients presenting to the breast clinic and undergoing screening by nurses

Three of the new patients were seated close to each other on a bench at the nurses’ station. The nurse picked the first folder from among the pile of folders. She called out the full name on the folder and one of the patients (first on the queue) responded ‘yes’ and the nurse asked her to come and sit on a chair close by. The nurse then asked for some personal details including place of residence and contact details. She also cross-checked receipt to confirm payment of consultation fee. The nurse then wrote the receipt number, phone number and place of residence in the new patient record book. The nurse then began to take history by asking what brought them to the clinic. During history taking, patients narrate their stories. The most common complaints were feeling of lump in the breast and breast pain. They were asked which particular breast had the lump or pain and how long that had been. One patient reported that she started feeling the pain after lifting a heavy object. After history taking, the nurse then asked the patient to go to the treatment room where a different nurse would perform breast examination. All this while, the patients seated on the bench close by occasionally raised their head towards the nurse and the patient engaged in interaction.

Afterwards, I added comments on the observation made, hunches and emergent issues and record them alongside in the field notes. Because participant observation occurred between 8:00am-4:00pm, I also devoted the entire evening mostly after 7:00pm, when I went back home, to work up on the field notes, expand upon it and develop it by typing it on a computer.

Overall, my field notes included my initial impressions of the setting, patients, staff, general routine and my role as a researcher. It also included reflections, preliminary analyses, initial interpretations and new questions to be answered or tested in subsequent observations or interviews. As data collection progressed, observation became more focussed on behaviours of my participants when women were offered diagnosis and treatment recommendation. I paid attention to verbal and non-verbal behaviours; concerns that are raised and or discussed during these interactions. I observed closely for differences between different age groups (e.g., pre-menopausal versus menopausal), women with differing number of children, socio-economic, educational, different ethnic or religious backgrounds, women whose relatives were present and those whose relatives were not; I also looked at doctors, if there were differences in their experiences as female or male doctors; number of patients attending the clinic. The thoughts that are written down helped in developing analytic leads and provided more insights, direction and guidance for the research. These were explored through interviews, as they were able to reveal underlying beliefs and or values influencing the decision-making process. Hence, I also kept a summary of salient points covered in interviews in my field notes.

To conclude, my field notes acted as a vital evidence of what I was observing and experiencing at the breast clinic. My reflective diary on the other hand allowed me to reflect and critically discuss this experience.

3.4.2.7 Interviews

In-depth interviews were employed to supplement observations conducted at the clinic. The rationale was to facilitate an exploration of the meaning of the behaviours and practices observed during interactions (between the participants i.e., healthcare professionals, women and family member) around diagnosis and treatment recommendations (Gerrish and Lathlean, 2015). Moreover, ‘cultural knowledge’ (i.e., beliefs, ideas and values) can be discovered through speech (Spradley, 1980). Thus, in-depth interviews can elicit women’s beliefs or perceptions about breast cancer and treatment, who is important, and what is important during treatment decision making.

In-depth interviewing hence fit well with an ethnography because they can facilitate engagement with participants and access life on the 'inside'.

Although interviews are valuable in exploring meanings of behaviours, it is however critiqued that interviews are not allowed to arise naturally, but they are deliberate constructions to fulfil the researcher's goal (Murphy and Dingwall, 2003; Murphy, et. al., 1998). Also, some authors argue that interviews are utilised as a means for participants to enact behaviours acceptable in society (Hammersley and Atkinson, 2007; Murphy, et. al., 1998).

In spite of these critiques, the interview as a data collection method is acknowledged to produce insights into participants' perspective about the world and meaning of their experiences (Fontana and Frey, 2005). This is based on the assumption that participants' verbal descriptions are a reliable indicator of these accounts and that the questions asked during interviews are a reliable indicator of the subject of the research (Brewer, 2000). To aid this process, an interview guide (appendix 11) was developed for use with participants in this study. While the prompts in the interview guide were from the literature review, they were not intended to be overly prescriptive, but as a general guide to direct the conversation and allow for a deep exploration of the phenomenon under investigation.

Certain strategies were planned for the interview process. The first strategy was for patient participants to be interviewed after they had attended the tumour board meeting (the minimum time period for patients to attend the meeting was often three weeks after receiving a diagnosis). Patients are officially informed of the recommended treatment after attending the tumour board meeting. The second strategy was for interviews to be scheduled with a nominated relative only after the patient herself had been interviewed. This would facilitate the exploration of relevant issues that emerged from interviewing the patient participant. For HCP participants, the plan was to begin interviews (half-way through field work) after conducting repeated participant observations. The rationale was to ensure adequate familiarisation of the clinic context and to compare what they say to what they actually do in the setting (Gerrish and Lathlean, 2015; Brewer, 2000). Prior to fieldwork, it was not clear cut as to when this period was going to be, but after conducting four weeks of observation, it became obvious that staff had become used to my presence. Interviews with staff were scheduled from the fourth week onwards.

Interviews with participants were similar in-terms of the approach although the questions differed between each participant sub-group (patient participant; nominated relative participant and HCP participant). Also, the questions were asked in a way that mimicked that of natural conversation.

With regard to patient participants, interviews started with broad questions about their daily lives and routine to get a sense of what life was like for the woman. This knowledge into participants' lives would also enhance deeper exploration of how breast cancer treatment might impact on their lives and vice versa, and consequently how this may influence the decision-making process. For example, during one interview with a patient participant, Maame Saa, I explored from her what she did when her children were ill. This was a way of getting an idea about an aspect of a participant's daily life in-terms of her health seeking behaviour. Having gathered this data, I would note it and at the later part of the interview, I would then explore her daily life and her thoughts around how breast cancer had been impacted upon it.

After gaining insight into a participants' daily life, I focussed the interview on a behaviour observed at the clinic, the ones that particularly reflect the studies' objectives. This included the actual information received from HCPs, verbal and other non-verbal behaviours. For example, during observation of patient-doctor interaction on treatment recommendation, I observed that Maame Mamuna raised concern of not being able to finance the treatment (i.e., Mastectomy) after having spent so much money on previous investigations and operations (excision biopsy and scar revision).

I explored this during the interview because I felt this was very relevant to the study in that there may be more meaning to concerns raised during patient-clinician interactions. This insight allowed me to proceed with deeper exploration from patient participants about concerns as well as those not raised during patient-clinician interaction.

After gaining insight into the meaning of participants' behaviour, I used the interview guide to explore women's beliefs about breast cancer and treatment and what is influencing their decision making. With regards to nominated relatives, I jotted down issues raised by patient participants during interviews and explored them with the nominated relatives to gain a deeper understanding.

For HCP participants, I explored from them the meaning of behaviours observed as they interacted with women around diagnosis and treatment recommendation (to gain insight into underlying beliefs). I then explored their general experience with regards to the factors influencing women's treatment decision making and how they support women in the decision-making process. Data gathered from all these sources provided insight into treatment decision making process for women with breast cancer at Southern Hospital.

Interviews were conducted mostly in the Twi Language but a few of the participants chose to speak in English. The interview guide was written in English, but it was translated into the local language, Twi, during interviews. To ensure the content validity of the interview guide, I conducted an interview on one nurse and a woman with breast cancer, in order to test the guide, check the feasibility, acceptability and comprehension of the questions/probes. Interviews were arranged at venues and times that suited participants and was also quiet, private and relaxed to avoid undue distractions (Legard, et al., 2004). Participants were allowed to choose a place and time for the interview session. Before I went into the field, I imagined many of the patients and nominated relative participants would opt to be interviewed outside the hospital. However, this was not the case as most preferred to be interviewed at the hospital. A few of them chose to be interviewed in their homes and workplaces. For provider participants, interview sessions were conducted in the clinic setting. During interview sessions, actions that put participants at ease to narrate their views and feel included in the research process were considered. For instance, the beginning of the interview was focused on establishing rapport before presenting fundamental areas of the interview guide (Smith and Osborn, 2002).

The keenness of participants to partake in the interview were observed closely for any verbal and non-verbal actions that suggested otherwise (Thomas and O'Kane, 1998). To reduce the possible impact of power imbalances between the researcher and participants during the data collection process, I did not impose my views on them but remained sensitive to participants' agenda. I also ensured ethical values (discussed above) were adhered to mitigate any exploitation, coercion and causing harm to participants when conducting interviews (Kirk, 2007).

In order not to lose data, I audio recorded participants' words during interviews and then made thorough fieldnotes on conversations, context, personal reflections and self-evaluations. I ensured ample recording procedures, including checking audio recorders for efficiency prior to interviewing (Creswell, 2009). As interviews were conducted mostly in Twi, I ensured that audio recordings were transcribed verbatim in 'Twi' before translation into English Language. But translation from a source language to a target language raises many questions and challenges. For example, translated data may not be as accurate as the source data because of the possible impact of errors during translation (Temple and Young, 2004). Furthermore, lack of availability of equivalent words in the two languages was another potential challenge that was anticipated prior to translation. Nonetheless, to ensure that my translation of interviews is congruent, a validation check from a local expert was sought (appendix 12). In this case, the English transcription was compared sentence-by-sentence with the original Twi transcription by an academic in Ghana (letter provided in appendix).

Additionally, when an exact word could not be found, the local word was kept and a literal explanation was provided.

During transcribing, certain conversions in Jeffersonian transcription (Atkinson and Heritage, 1984) were used to provide more context where necessary. This was necessary to maintain a verbatim account of all verbal and even non-verbal utterances. Using the conversions in Jeffersonian transcription allowed the needed information to be retained in a way that reflects the original nature and meaning of the data (Braun and Clarke, 2006) to aid analysis. For this reason, some of the conversions used included the use of brackets [] to show where a talk overlapped and the use of loud pitch and low pitch symbols (i.e., ↑or ↓).

3.5 Data analysis

Thematic analysis was employed to data collected from this study. Thematic analysis is adopted because of its flexibility and compatibility with many theoretical and epistemological approaches, as well as provide rich and detailed data (Holloway and Todres, 2003). While this flexibility seemed to be an advantage, there were some perceived challenges with this. For instance, specific guidelines on what aspects of the data to focus on is limited which is quite perplexing for an early career researcher (Tuckett, 2005; Attride-Stirling, 2001). It has also been criticised that thematic analysis is limited with regards to its interpretative power beyond descriptions (Tuckett, 2005). Nonetheless, a rigorous thematic approach can produce an insightful analysis that answers research questions (Braun and Clarke, 2006). Furthermore, thematic analysis is considered appropriate to conduct within this constructivist ethnography as it would allow the exploration of the cultural and structural conditions that enable the multiple individual accounts given around breast cancer and its treatment.

Thematic analysis involves data segregation, grouping, regrouping and linkage to consolidate meaning and explanation (Grbich, 2012). As a novice researcher, I needed some form of structure to assist in data analysis, hence, I read from a variety of ethnographic data analysis sources including O'Reilly (2005), Spradley (1980), Roper and Shappira (2000), Creswell (2013), Lofland and Lofland (2006) and Girbich (2012). Although these authors were helpful in gaining some insight into data analysis, nonetheless, I found some quite challenging to apply as an early career researcher. I hence considered Creswell’s (2013) general approach to ethnographic data analysis as the overall method to assist in analysis for this study. The rationale for choosing this approach is that it is explanatory and appears compatible with computer software.

Table 3.3: Ethnographic data analysis (Creswell, 2013)

- Create and organise files for data
- Read through text, make margin notes, form initial codes
- Describe the social setting, actors, events; draw picture of setting
- Analyse data for themes and patterned regularities
- Interpret and make sense of the findings-how the culture works
- Present narrative presentation augmented by tables, figures and sketches

Qualitative data analysis involves the preparation and organisation of data (i.e., transcripts) for analysis and reducing the data into themes through coding and condensing the codes, and ultimately representing the data in figures, tables or a discussion (Creswell, 2013). Creswell (2013) notes that data analysis is not a separate phase on its own, but it is interconnected with data collection and report writing, and as a result they often proceed concurrently in a research project. Dey (1993) also stressed that because qualitative researchers usually “learn by doing” data analysis, most qualitative researchers therefore espouse analytic procedures that often evolve while they are in the field. I would thus admit that likewise in this study, the analytic procedures also evolved during the research process.

Ethnographic authors emphasise that data analysis in ethnography is iterative, which involves collecting data, exposing the data to a critically reflective process of data analysis to make sense of emerging issues in the data and to guide the next stage of data collection (Gerrish and Lathlean, 2015). To begin data analysis, I prepared the collected data through the following steps:

I transcribed the field notes and audio recorded interviews (in Twi and translated them into English) so that I could work with texts. The transcripts were undertaken by using ‘word processor’. All names, places and distinctive identifiers were removed. Each participant was allocated a unique pseudonym that was used with all the data (O’Reilly, 2005).

The transcripts were kept on a computer file. Storing data on a computer file allowed for computer assisted data analysis (Nvivo) (O’Reilly, 2005; Creswell, 2013). A computer software program offered a means of storing the data and retrieving the codes assigned by the researcher (Creswell, 2013). This permitted a material (an idea, a statement, a phrase or a word) to be identified easily for storage in one place (Creswell, 2013). In this way, all the instances where such ideas, phrase or word occurred in the database could easily be identified (Creswell, 2013). In spite of the several advantages with computer-assisted analysis such as ease of retrieval of ideas associated with codes or theme, storing similar codes and their contexts in one location, visualising the relationship among codes, and allowing the researcher to look closely about the meaning of sentences and ideas (Creswell, 2013), it is not without challenges. For example, computer software could cause a distance between the researcher and the data (Creswell, 2013). Furthermore, it often warranted the researcher to study how to run the program, which could be daunting (Creswell, 2013). Nevertheless, a computer software package was employed to assist in data analysis because of its unique advantage of assisting in storing and analysing large volumes of text, which is characteristic of qualitative data. Among the different software programmes, NVivo was used because I had received some training on its application from the University of Southampton Doctoral College. Other advantages included the ability to manipulate the data and conduct searches (to locate all the text that fit a code label), make comparisons among code labels as well as its ability to provide a graphical display of codes and categories emerging from the data (Creswell, 2013).

3.5.1 Reading through text, making margin notes and forming initial codes

To familiarise and immerse myself in the data, I read the transcripts (field notes and interviews) line by line in order to scrutinise the words, make sense of the data before assigning initial codes (Creswell, 2013). Codes are descriptive labels assigned to sections or group of words, sentences or paragraphs (Miles and Huberman, 1994). Coding augments data condensation and reduction and also allows the researcher to scrutinise the codes separately and later join them into wider and abstract categories (Creswell, 2013).

With the research question at the back of my mind (beliefs, values, practices and structures influencing treatment decision making for women with breast cancer), I tried to code by answering the questions (see below) asked by Lofland and Lofland (2006) while reading the transcript:

- What is this?
- What does it represent?
- What is this an example of?
- What is going on?
- What are people doing (what values underpin what people are doing)?
- What is the person saying (what belief or value underpin what the person is saying)?
- What do these actions and events take for granted?
- What special circumstances or contextual issues might have impacted on the statements and or actions (Lofland and Lofland, 2006)?

As I read the transcript, and asked myself the questions above, I first coloured the sections that revealed answers to ‘the practice of breast cancer diagnosis and treatment recommendation’ using a word processor. I looked through the data to identify all the ‘steps towards diagnosis and treatment recommendation’. Whenever I identified a word, phrase, sentence or paragraph that showed a ‘step towards breast cancer diagnosis and treatment recommendation’, I would reflect on the larger thoughts presented in the data and form codes (Creswell, 2013), by assigning phrase tags, mostly with what participants were doing or being engaged in (see appendix 13 for initial codes). For example, an extract of my field notes transcript was analysed as:

I noticed the seats (long wooden benches) at the outside corridor appeared fully occupied with people. As more patients arrived at the clinic, they sat at the inside corridor. The inside corridor where I sat also opens into another corridor and separated by a half-opened door. This was where the man in scrubs was sitting- just behind the half-opened door. I did not know what purpose it served (I thought initially that it served as a reception but later found out that was where the revenue clerk sits). As I sat there, I observed some of the women who were coming to clinic (some perhaps for the first time) ask the man in scrubs what they needed to do. They were asked to put their small cards or ID cards in a certain box in front of the records office at the outside corridor so that their folders can be retrieved or in the case of a new patient, a card can be made for her. They were then asked to wait on the queue.

The above data was assigned with the codes below. These codes, showed what the women were engaged in.

Table 3.4: Coding

Steps to breast cancer diagnosis		
	Receiving consultation card	Placing insurance card in arrival box
		Joining ‘new patient’ queue on the bench to see unit clerk for consultation card

I read through the data set to identify all the steps towards receiving breast cancer diagnosis and a treatment recommendation. I later combined all the codes on ‘steps to breast cancer diagnosis and treatment recommendation’ under a new label ‘the way women navigate the clinic to receive a diagnosis and treatment recommendation’

In addition to coding, I also inputted short descriptive notes (i.e., memos, which are ideas or key concepts that occurred to me) in the margins as I read the transcripts (Creswell, 2013). Consequently, before I progressed to more coding and data collection, I had a separate worksheet where I compiled the memos from my initial analysis. For example, with the analysed extract above, the following points occurred to me and I wrote them down to consider as I progressed with data collection and analysis.

- what is the average waiting time to queue for a card
- are there any objects (artefacts) at the waiting area
- is there any event going on while waiting
- what beliefs and or values impact waiting times
- how does waiting at the corridor impact treatment decision making process
- what factors impact waiting times at the corridor

The insights I gained from following my hunches and questions then led me to more data collection and analysis.

3.5.2 Description

As data collection and analysis progressed, and with my research question in mind, I looked through the data and developed codes (descriptive codes) to describe those behaviours or actions that occurred regularly in the setting (Roper and Shappira, 2000). For example, I developed descriptive codes for ‘interaction between patients and HCPs as patients receive formal diagnosis and treatment recommendation’ as shown in the text box below. I achieved this by examining behaviours (both verbal and non-verbal) exhibited by participants during the interaction.

Interaction between patients and HCPs as patients receive formal diagnosis and treatment recommendation’

20th September 2017

11:30am to 11:36am

Consulting Room Two

Maame Mamuna wears a loose dark skirt and blouse attire and has a head gear hanging down her shoulders. She sits on a plastic chair adjacent Doctor A and places her bag on her lap. Doctor A in blue shirt tucked in trousers sits on a padded swivel chair. He lowers his head and glances through Maame Mamuna’s folder on top of his desk for a couple of minutes. Dr A raises his head and shoulders and turns to face Maame Mamuna and says, ‘is the report in?”. Maame Mamuna moves head up and down (nods) and looks into her bag. She places her right hand inside her bag and brings out a report and extends her right hand and gives it to the doctor who also takes the report in his right hand.

Dr A looks at the report and his eyes moves from left to right. He turns his gaze back to the table and looks at a particular page in the folder for about a minute. Consulting room door opens and Nurse A in blue uniform walks a few steps back to her seat, on the leather chair, and her gaze looks distant.

Dr A sits up straight in his swivel chair and gazes at Maame Mamuna directly and says, “the biopsy report from the excision biopsy, the first operation confirmed breast cancer. But before that the previous investigations did not state the breast mass was cancerous. So, at the tumour board meeting we decided to excise the scar and send a sample from the scar tissue for histology. The results here show that there are cancer cells still there (2) so now we will remove the whole breast”.

Maame Mamuna looks at Dr A as he talks to her and she places her right hand over her left shoulder.

Dr A leans against his chair and gazes at Maame Mamuna and says, “so I will write some investigations for you to do and bring”.

Maame Mamuna shifts a bit in her chair and replies, “where am I going to get the money to do these investigations you are asking me and the treatment?” ((her tone sounding irritated)). Nurse A turns her gaze towards Maame Mamuna ((obviously looking shocked)).

Dr A gazes at Maame Mamuna and says, “nobody nor any doctor is going to collect money from you”↑ ((looking angry, obviously not happy with Maame’s line of questioning)). Maame Mamuna replies “but what you are telling me requires money, it is not free”↓ ((in a low tone)). She looks down and puts her hand in her bag and brings out something like papers from her bag. Maame Mamuna, “All these are receipts for the previous investigation and surgical procedure, so money is involved. I do not have any money at the moment” ((in a sad tone and her gaze was more towards me than towards the doctor)).

Dr A looks up and sighs, “SHE JUST DOES NOT WANT TO DO MASTECTOMY” ((in a loud voice in English Language)). Maame looks down at her bag and puts the receipts inside the bag.

Analysis

Descriptive codes for woman’s behaviour	**Doctor’s behaviour**	**Nurse’s behaviour**
Sitting on plastic chair	sitting on swivel chair	sitting on leather chair
Nodding is a cultural gesture for ‘yes’ and ‘OK’	reading folder	looking surprised
Giving report to doctor	facing woman	
Listening	requesting histology report	
Questioning doctor about cost	reading histology report	
Showing emotion of irritation	giving summary of medical information	
Bringing out receipts as proof of payment	giving current diagnosis of cancer in breast scar tissue	
Having breast care requires money	deciding treatment, ‘we will remove	
Raising concern of not having money	the whole breast’	
	requesting further investigation	
	Showing emotion of anger	
	Shouting ‘woman does not want mastectomy’	
	Speaking English Language	

Further exploration

A. What brings Maame to the clinic →explored with Maame during interview

B. Maame has breast cancer staging two i.e., T2N1M0 (factual information from folder), so why is mastectomy the only surgical treatment option→explored with doctor during interview

C. Conflicting core biopsy result and excision biopsy result: to what extent is core biopsy result reliable; what factors impact core biopsy result; what are the implications → explored with HCPS during interviews

D. Why is Maame sounding irritated and questions doctor where to find money for further investigation and 'removing whole breast' → will explore from interview

E. What are all the ways doctors communicate diagnosis and management plan→ more focused observations

F. What are all the ways other women respond when doctors communicate management plan→explored through focused observations

G. Why is doctor sounding angry following Maame's response→ implicit?

H. Why does doctor think Maame does not want mastectomy→ interview with doctor

From the above descriptive coding, I would then explore further using 'further exploration hints'. As I do that, I applied descriptive codes to those similar behaviours. If there is a change in a behaviour, the descriptive code is also changed to reflect the change. This was repeated until nothing new seemed to be emerging. As I proceeded back and forth and closely examined the data to give the descriptive codes, I also assessed the transcripts (field notes and interview data) for meanings attributed to those practices and behaviours and about any differences observed. This allowed me to code for varying perceptions of participants related to behaviours observed (Creswell, 2013; Roper and Shappira, 2000).

As I progressed with analysing for descriptive codes, it helped me to group similar descriptive codes. This allowed me to uncover common patterns and to also note the differences between the different participant groups (patient participant, HCP participant; nominated relative participant) (Creswell, 2013). Since the descriptive codes are short phrases, which make them lack context, I utilised Nvivo to retain the paragraphs that those descriptive codes denoted. In this way, it was easy to keep and refer to the context of the descriptive codes (Creswell, 2013).

3.5.3 Analysing data for themes and patterned regularities

In the next stage of the analysis, I needed to make sense of what is happening in the data. In this process, I read through the data and assigned a label to codes with similar meaning. These labels denoted information that I anticipated to find in the field, surprising information that I did not foresee or information that is theoretically interesting or strange to researchers (Creswell, 2013). The rationale for attaching labels to codes with similar meanings is to allow groupings and subgroupings (Creswell, 2013).

As I progressed, these groupings were conceptualised into wider and more abstract categories (Creswell, 2013) as more and more groupings were added. Comparable sets of categories were subsequently grouped, and connections and relationships were then established between them. Broad patterns of behaviour and perceptions began to emerge, and major themes were then established to reveal important idea about the data in relation to the research question (Creswell, 2013).

For example, when I examined the codes on patient participants' behaviours, I grouped similar codes and assigned a label of 'passivity and deference to HCPs'. I looked through the entire data (both field notes and interviews) and placed all codes that supported that label 'passivity and deference to HCPs' under it (shown in Table 3.5 below) while taking note of non-conformity. I then expanded 'passivity and deference to HCPs' by adding other grouped labels including 'language' 'structural layout and kinds of chairs'; dealing with resource challenges; 'involvement of patients and or relatives in treatment discussion'; 'miscommunication around breast cancer treatment' into a larger 'dealing with patient-provider relationship'. This process was enhanced as patterned regularities began to emerge from the data. As I spent more time studying the data, 'patient-provider relationship' changed into 'hidden information about breast cancer and treatment' to explain the different behaviours, practices, contextual issues and underlying assumptions (beliefs and values) that supported or hindered interactions around breast cancer diagnosis and treatment decision making at the clinic. I have explained this in detail in the next chapter.

Table 3.5: Generating theme from codes

Descriptive codes for women's behaviour during interaction with HCPs on breast cancer diagnosis and treatment recommendation	**A label for similar codes**	**Category**	**Theme**
Field notes	1. Passivity and deference to HCPs	1. Dealing with patient-provider relationship	Hidden information around breast cancer and treatment
i. Nodding			
ii. listening			
iii. Asking questions only when asked to			
iv. Sitting on a chair after being told			
v. Not asking question nor clarification throughout			
vi. Patient nodding to treatment decision made			
vii. Laughing			
viii. Showing happiness with doctor's decision for conservation with no explanation on risk/benefit			
Interviews			
Descriptive codes for meanings ascribed to behaviour			
ix. Not wanting to challenge staff			
x. Doctors are the experts			
xi. Staffs are busy			
xii. Lack of privacy			
xiii. Sadness			
xiv. Not accepting diagnosis (denial)			
xv. Not knowing what is going on			

Throughout data analysis, I took notice of codes that were exceptional. Atkinson and Coffey (1996) have emphasised the importance of identifying and highlighting deviant cases. They assert that the presence of deviant cases often enhances the analysis as they underscore the complexity of the phenomena and the researcher's reluctance to skimp difficult evidence. In my own research, negative cases found included:

Maame Mamuna's assertion: "I am concerned about another person finding out about the condition because they may talk about it behind my back". Although Maame Maamuna expressed concern about someone finding out of her condition, she however contradicted herself later and said, "if someone gets to know, I am not the only one with the condition, even someone has AIDS the person is happy, as for this one I did not go to infect myself…as for this illness, I do not know where it is from, so someone getting to know does not really bother me".

Madam Comfort, "I remember the doctor said they could either remove the lump or remove the breast but … with my age, I did not want to be going through all that, I did not want all the other strong treatment like radiotherapy and chemotherapy…". This contradicts the rest of my findings which suggested that there was minimal discussion between HCPs and patients about treatment options (if any) and the consequences of each option.

3.5.4 Interpretation and making sense of the culture-sharing group

To interpret ethnographic data, I advanced beyond what is happening in the data to what is to be made of them (Creswell, 2013). I drew inferences from the data and turned to the literature to interpret the data in a form of discussion. Interpretations were centred on cultural themes found to influence treatment decision making for women with breast cancer (Creswell, 2013).

I finally employed a thematic narrative style to write this ethnography supported by descriptions, verbatim quotations and self-reflections.

3.6 Rigour and trustworthiness of the research

In ethnographic study, my direct involvement in participant observation and in-depth interviewing increases the likelihood for my presumptions and personal influences on the interpretation of data (Rolfe, 2006). Some critics therefore contend that such influences create doubts about the data and the interpretations made of them, which would have been different if standardised quantitative methods were applied (Bryman, 1984). This stresses the need to provide a rationale underpinning any decision made in the research process for readers to determine for themselves the robustness of the study (Rolfe, 2006). This is necessary for the findings to be viewed as suitable to inform policy and practice (Hammersley, 1995). In this study, the plan was to follow the four trustworthiness criteria proposed by Lincoln and Guba (1985).

The first was credibility, which refers to the truth of the data, its interpretation and representation by the researcher (Ritchie and Lewis, 2003). The strategies adopted to enhance credibility included conducting the study at the breast clinic (Lincoln and Guba,1985) using participant observation and in-depth interviews. This ensured familiarisation with participants during breast cancer diagnosis and treatment recommendations. There was also prolonged engagement in the field to ensure that data saturation was reached. This also ensured that the data collected was adequate to support the analysis presented. Another strategy employed was using more than one group of participants (i.e., patients, families, HCPs) to facilitate a broader understanding of the phenomenon under investigation. Also, feedback from supervisors was constantly pursued to enhance different views and ideas for additional exploration, and appropriate interpretation of data (Shenton, 2004).

Lincoln and Guba (1985) also stressed the need for confirmability (i.e., degree of neutrality) of the study and dependability (i.e., how the study is consistent and could be repeated). Two main strategies including audit trail and reflexivity were employed to meet these criteria. To achieve these, a detailed description of the research process and the decisions made from the start of the study to the end were provided. This has been done transparently throughout the conduct of the study to allow readers to assess the extent to which the stated processes were followed and also to appraise the quality of the study. Issues of reflexivity has also been discussed extensively in the next section 3.6.1.

The final criterion employed to enhance trustworthiness was transferability, and this refers to how the findings can be applied to other settings (Lincoln and Guba, 2000). In this study, sufficient information has been provided on the participants and the research context to enable readers and other researchers to assess the findings' capability of being transferable.

3.6.1 Reflexivity in this ethnographic study

Reflexivity involves a critical examination and consciousness of the researcher recognizing the way in which the products of research are affected by the personnel and processes involved in conducting research (Pillow, 2003). It is argued that in order to incorporate such insights, ethnographic researchers need to recognize, reflect and utilise subjective experience as an intrinsic part of the research (Davies, 2008).

During the conduct of this study, I kept a reflective diary where I reflected on the data collection phases, my role in the process and any underlying meanings made. For example, during participant observation, it was impossible to capture everything that happened, which means there is a selective recording. Therefore, it was important that I became aware of the kinds of preconceptions and unconscious biases that I bring to the field including my background, educational level and even religion because such awareness helps moderate the extent to which impressions written down suffer from being filtered through the mind of the ethnographer (Schensul and LeCompte, 2013). I kept a field diary to record my experiences, feelings, my role and presumptions and made a critical discussion of these on the research experience. For example, I conducted this ethnography as a Ghanaian in Ghana and this implied, I had some familiarity in the culture and also had some knowledge about certain concepts (Peirano, 1998). I am proficient in the most popular Ghanaian Language (Twi) and also proficient in Ghana's second Language i.e., English Language. Furthermore, I am also a professional nurse, having practised as an adult nurse for more than five years. I have thus acquired knowledge, experience and skills in these years of practice. I am hence an insider, a Ghanaian healthcare professional and a member of one of the sub-groups of participants of this research (i.e., Healthcare professionals). To the healthcare professionals, I am one of them which perhaps to some ethnographic positivist, might be a weakness (Howell, 2013; Rabe, 2003; Bozzoli, 1991). My personal association with the lives of participants might be interpreted as a possible hindrance to my perception of the cultural nuances that are important in ethnographic research (Rabe, 2003). However, I perceive this subjective involvement with participants as a strength because it allowed me to share some common understandings with participants (Bozzoli, 1991). For example, my proficiency in the Twi Language means I can communicate with participants easily. Also, my knowledge of some cultural norm like addressing an elderly woman as 'mother' is commonplace which an 'outsider' may not have known. Despite my insider status, I am also an outsider, having received further education (Master's degree and currently PhD training) in the United Kingdom for the last six years. I therefore bring some particular characteristics to this research. In particular, during my education and training in the United Kingdom, I became increasingly aware of a kind of culture where people who are making decisions about their health and care are supported to be involved in the decision-making process to the extent that they wish to be (NHS, 2019). In this case, during treatment decision making, people are supported to understand the care, treatment and support options available as well as the risks, benefits and consequences of the options available. It also means supporting people to make decisions about a preferred choice based on evidence-based good quality information and the individual's personal preferences.

This experience of the UK healthcare culture sensitised me during data collection and analysis by reflecting on the data at hand (Strauss and Corbin, 1998). It helped me look at things during participant observation and analysis with 'new eyes' which may have been a challenge without the experience. I approached field work to find out what 'goes on in this breast clinic setting'.

My identity as a nurse influenced my relationships in the field. Being a nurse, I was treated in many ways as an insider (participant) by the HCPs. This obviously had some influence on my field roles in many respects. My introduction to potential participants as a nurse doing the research straight away made me become a participant. This was evident in for example, the language that HCPs used to explain things to me. For instance, during interaction with nurses, they would use ‘CA’ which referred to cancer. The use of such language suggested that the nurses’ assumed I shared this ‘specialist’ language. Some authors argue that ‘a type of language’ can be an indicator of group boundaries (Meehan 1981; Allen, 2004). Meehan (1981) has long argued that one of the ways in which health professionals maintain a boundary with lay people is the use of medical jargon. It was thus frequent for nurses to use such jargon as ‘mets’; ‘true cut’ ‘biopsy’ when communicating with me. There were however some occasions that nurses’ assumption that I understood this language was wrong. For example, I did not understand ‘true cut’ and I asked for the meaning and it was then explained to me as core biopsy.

Being a nurse also meant I had access to places that would otherwise have been challenging for a non-HCP. For example, I had access to consulting rooms and treatment rooms where procedures that involved exposure of body parts occurred. I had access to such intimate places because my nursing profession legitimized this role, and also as a nurse it was assumed that my professional code of conduct required me to maintain confidentiality with regards to patients’ information and care (Ghana Nurses and Midwifery Council, 1997).

As a nurse, I participated in some activities such as passing investigation request forms, patients’ folders and procedural equipment to a nurse or a doctor who required them. For example, during the performance of core biopsy, I was asked to pass the core biopsy needle and I recorded this in my field note about ‘performing core biopsy’ procedure. There were however some occasions that I was treated as a non-participant (I did not work at the breast clinic nor any other breast clinic for that matter). This was considered as a strength because it allowed me to withdraw, stand back and take stock. It also allowed me perceive things with some sense of naivety and gave me the opportunity to ask all manner of questions however naive they seemed.

There were other times that my research role conflicted with my nursing values because I found it difficult to just observe without doing anything. I had to intervene when I felt it would be in the patient’s interest. Intervening meant disrupting the very practice I was there to observe. I recorded this in my reflective diary on how such interventions could impact the research process. There were other issues that I found challenging between my research and nursing roles. For example, the nurses’ introduction of me to patients as a nurse doing research impacted their perception of me. The patients were generally receptive of me and some perceived me as one of the breast clinic staff.

For instance, one patient with breast cancer told me that when she gets better, she will thank God for all of us for taking care of her while she was sick. Another patient also said to me that God is the overall healer of every sickness and that we (i.e., healthcare professionals including myself) receive the remuneration. Since I was aware that such a perception of me might impact upon the information that these patients may want to divulge, I had to constantly reiterate that although I am a nurse, I do not work at the breast clinic and that I was there to conduct research. Furthermore, I constantly reassured them of confidentiality.

At other times, some participants would ask me questions pertaining to their care. For example, after completing a session of observation of a patient-doctor interaction around her breast cancer diagnosis, I went out of the consulting room. The corridor was busy with patients and relatives. I took shade under one of the trees in front of the clinic to write some notes. I saw this same patient passing by and she looked distracted. I approached her and engaged her in a casual conversation. She told me she was having so much pain in her breast that she was unable to sleep at night. I asked her if she had shared this concern with staff at the breast clinic. She told me she did not know if she could ask questions. I asked her what she meant by that and she said she did not know what to do and that she did not know what would be done for her, whether the HCPs would give her injection (chemotherapy). She said she had heard that the injection can make one lose ones' hair. As I listened to her, I experienced conflicting issues. My research obligations demanded that I observe patients' behaviours and how they discuss their concerns with HCPs. On the other hand, my nursing ethics would not let me only listen to a patient who said she was in pain and unable to sleep. I therefore reassured her that she could go and speak to the doctor or any of the nurses about it. She felt a bit hesitant, so I led her to one of the staff nurses for her to speak with her.

I had a feeling that such actions might impact upon my relationship with participants and on the research process. On the one hand, it could heighten a power imbalance between myself and the patients if they perceive that they can channel their concerns to HCPs through me. On the other hand, when participants directed their questions at me, for example, during an interview, a nominated relative asked me what breast cancer exactly was, I did not answer the question and asked him to speak to the staff about it because assessing participants own ideas about breast cancer was part of the research. Participants may feel disappointed that they could not get the explanation from me that they expected and wanted, because they assumed I had expertise knowledge. On the whole, I would say my professional role as a nurse enabled me to participate in the setting to some extent. This enhanced my success in my observational role as it facilitated my acceptance as a member of the group. Also, my acceptance means a potential reduction in observational effect from participants (i.e., the influence of the presence of the observer on the behaviours which are the focus of the study).

My role in this research did not only have an impact on the research, but the research also had an effect on me. Prior to my beginning the fieldwork, I imagined being involved with patients who had received cancer diagnosis was going to be a difficult situation for me because of the emotions involved in receiving a cancer diagnosis. I had a plan in place that in the event of any stressful situation, I would debrief with one of the senior nurses at the breast clinic. What happened to me was more than I had envisaged. The whole experience aroused much emotion in me. In my reflective note, I wrote about how upset I felt after interviewing a woman. When I came back home, I tried unsuccessfully to control myself and tears rushed down my cheeks. The woman’s words kept flooding my memory. She told me how she has always been crying ever since she received her cancer diagnosis. She, a single parent, had to work to feed her children, yet she had been told to attend the hospital for treatment. Paying treatment that is barely financially affordable meant her and her children would not eat. Another woman also told me how she had been sleeping on a bench at the hospital because she did not have money to pay for transportation to and from the clinic. As she narrated this, tears stood in her eyes. I held her hand and we sat in silence for some time. All that I could think of was that when it comes to diseases like cancer, we in the developing world, particularly those on low incomes are faced with a double war. A war against the cancer itself and another against the socio-cultural context within which the individual is living.

Despite being confronted with such emotionally challenging situations, I found the whole experience rewarding and one that I will never forget. It has also been a learning experience for me. I was aware that my experiences, feelings, judgement and assumptions could impact on the research process. Hence, as I mentioned above, I balanced this by keeping a reflective diary to make a record of my experiences and feelings during the research process. I recorded the experiences and feelings to ensure that the impact of these are minimised during data collection, analysis and interpretation.

Another approach I employed was to be in constant communication with my supervisors as I received comments from them. Throughout the process, including the preliminary data analysis, my supervisors discussed the data with the analysis and interpretations I made of it. My supervisors’ verification was particularly important because of their strangeness to the culture I was studying as this allowed them to highlight and question issues I had not fully considered and that needed further analysis.

3.7 Chapter summary

This chapter has presented the research design and the philosophical considerations that were made for this study. Qualitative ethnographic research design has been discussed and the reasons for utilising this approach has been explained. It has further justified constructivism as the preferred epistemological approach in situating this ethnography. This chapter has also outlined the procedures including participant observation and in-depth interviews that were carried out throughout the fieldwork. Additionally, it has detailed how the data was managed and analysed to explain how the cultural context influences treatment decision making for women with breast cancer. Finally, the chapter ended with a discussion of my role and how this was managed to enhance the transparency of the findings and its interpretation. The next chapter introduces the findings generated by this study.

Chapter 4 Findings: Introduction to the breast clinic context

Between July 2017 and November 2017, a total of approximately 89 hours of participant observation was conducted at the breast clinic over 49 days. This included both general and focused observations. During the period of general observation, I familiarised myself with the breast clinic and its routine. This familiarisation period occurred 6 hours a day for the first four days and throughout this period, I observed almost every activity in the clinic and also interacted with staff at the clinic to get a general sense of what goes on at the clinic. Following familiarisation of the clinic routine, focused observation of participants' interactions during breast cancer diagnosis and treatment recommendation ensued. Depending on the number of patients who received breast cancer diagnosis on a particular day, participant observation lasted between 1-4 hours a day. After spending about 40 days on participant observation of interactions on breast cancer diagnosis and treatment recommendation, nothing new seemed to be emerging at which point it was clear that data saturation was reached. Within this period, a total of 31 participants (16 patient participants; 5 nominated relatives and 10 HCPs) were included in the study. Twenty-nine out of the 31 participants were available and interviewed. Interviews lasted between 45-60 minutes. Women and their nominated relatives were interviewed after they had attended tumour board meeting. Some HCPs were interviewed in the middle of participant observation and others towards the end of it. Two HCPs were unable to proceed with interviews following participant observation. One gave a reason of having time constraints while another was away on a project while the interviews were being conducted. Analysis of the data was therefore conducted on both the observational data (recorded in the field notes) and the interview data. This has ensured the development of a rich description of the breast clinic context, the participants and activities. This chapter is predominantly focused on describing the breast clinic setting including its structural layout and artefacts (the next two chapters present the overriding themes generated from the analysis). It then presents a description of the background of the participants in this study. The latter part of the chapter is a description of the clinic's routine, activities and events.

4.1 Description of the breast clinic context

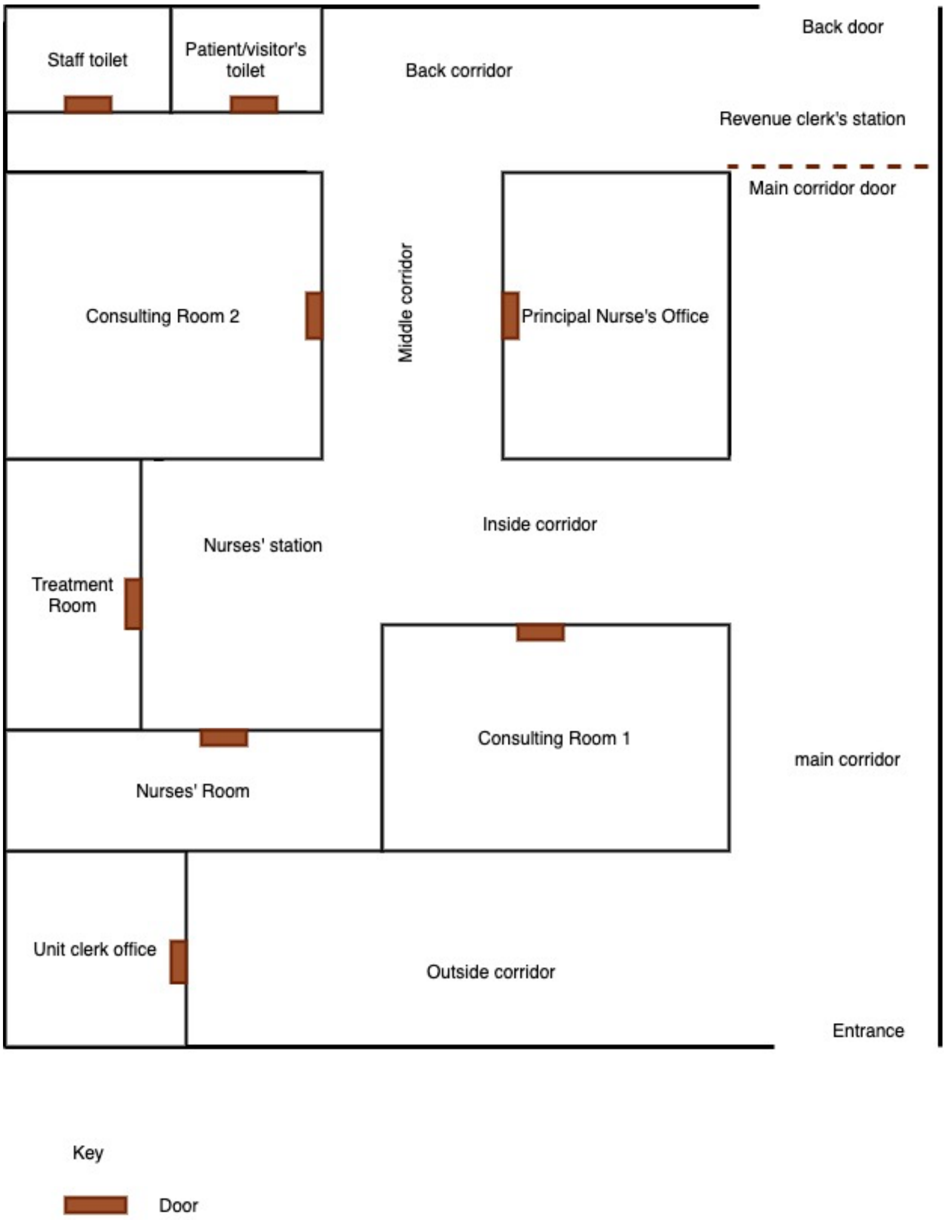
The breast clinic, where the study was conducted, is located within a 1200-bed capacity teaching hospital in a metropolitan city in southern Ghana. The hospital is a big referral centre for the Ashanti, Bono, Western, Eastern, Central and Northern parts of the country. The hospital offers a range of hospital services including but not limited to radiology; internal medicine; dentistry;

haematology; ophthalmology; obstetrics and gynaecology; pathology; oncology, emergency medicine and surgery

4.1.1 The breast clinic layout and artefacts

The breast clinic (Figure 4.1) itself is situated about 100 metres at the right side of the main hospital gate. The building is on one level and its entrance opens into two corridors; one to the left (outside corridor) and the other right in front (main corridor). The outside corridor ends at the unit clerk office. There is a box placed on a wooden tray by the window of the unit clerk's office. Going through the main corridor, the clinic consulting rooms run down another corridor (inside corridor) on the left of the main corridor and behind the unit clerk's office. There are two consulting rooms separated by an open space that serves as the nurses' station. Adjacent to the nurses' station are the nurses' room and treatment room. There is a corridor running from the right of the nurses' station i.e. middle corridor. The middle corridor separates Consulting Room Two from the Principal Nurse's Office. The middle corridor also opens into a back corridor. It is at this back corridor that two toilets are located: one is the staffs' toilet which is locked, and the other is a patients' toilet which is unlocked. At the far end of the back corridor are two separate doors: one that exists outside the clinic (back door); and the other opens into the main corridor (main corridor door). The space between these two doors serves as the revenue clerk's station. The back door is always fully opened during clinic hours, but the main corridor door is always half-opened during clinic hours. This half-opened door in the main corridor serves as a barrier between patients and the revenue clerk.

Figure 4.1: The breast clinic layout



The types of seating available in this setting is striking. There are long wooden benches placed beside the corridor walls, but at the nurses' station, there are three leather chairs and a swivel chair. Likewise, at the revenue clerk's station, there is a leather chair and a swivel chair. There is no television at the clinic. This is the norm in most Ghanaian clinics. The swivel chairs are used by the charge nurse or the most senior person on duty. The leather chairs are used by staff nurses. The chairs that appeared least comfortable are the benches and these served as seats for patients and relatives.

Figure 4.2: Breast clinic

Figure 4.3: Breast clinic outside corridor

Figure 4.4: Breast clinic inside corridor showing nurses' station

4.1.2 Breast clinic corridor posters

There are posters displayed on the walls of the clinic. There is a cervical cancer early detection poster, breast cancer posters, tuberculosis as a curable disease poster, EBOLA and cholera control posters. The majority of the posters concern breast cancer. This includes a breast self-examination (BSE) poster which displays the position for BSE and the steps to take to perform BSE. This is displayed pictorially with words written in English. Other breast cancer control posters displayed are 'signs and symptoms of breast cancer' including lump, peau d'orange, bloody nipple discharge; 'breast cancer diagnosis and treatment modalities'. All cancer posters on the corridor walls are about detecting signs and symptoms of breast cancer with the exception of two. Among the two, one is on 'cancer risk reduction' and the other is 'breast cancer diagnosis and treatment modality'. Some of the breast cancer posters are attractive; a few are dull, and a couple are torn but had been taped. A few posters have a black woman's picture, but the majority are mostly drawing images of women with white skin. All the posters are written in English, a language learnt during formal education, which make them inaccessible to patients with less formal education.

4.1.3 Consulting Rooms

There are two consulting rooms. In one of the consulting rooms, what is striking is the size of the nicely polished wooden desk relative to size of the room. The desk, placed on the right side of the room, occupies about half the size of the room and this makes it quiet constraining to walk in the consulting room. Behind this desk is a black leather swivel chair. This chair serves as the doctor's chair. The desk has no computer, which is the norm in most Ghanaian clinics. This means all documentations have to be hand-written. On top of the consulting room desk are neatly arranged investigation forms, prescription forms, in-hospital referral forms, surgery case notebooks, a stapler and sanitiser. On the opposite side of the desk is a black leather wooden chair about half-foot less the size of the swivel chair. This chair is used by the nurse assisting the doctor with consultations but in situations where there is a junior doctor conducting a consultation in addition to a consultant/specialist, then the junior doctor uses that chair. Upon entering the consulting room, two small plastic chairs are placed next to the right side of the door and one is placed on the left side of the door in the corner. These chairs serve as seats for patients and their relatives.

The top half of the walls in the room are painted white and the bottom half are painted cream, hence when the lights are switched on, one is greeted with a sense of brightness upon entering the room. Two breast cancer signs and symptoms posters are pasted on the top part of the left and right walls. This means one has to raise one's head to look up in order to read the content of the posters when seated. The posters have a drawing of a breast with dotted marks showing a lump. The content is also written in English and they highlight signs of advanced cancer including peau d'orange, bloody nipple discharge and breast ulcer; diagnosis procedures and a little bit of information on treatment. This consulting room is not spacious therefore when sitting or standing, the content of the posters can be read easily. Other objects on the walls include an up to date calendar, a clock, a telephone, a xelodar pharmacology poster and 'breast cancer markers to look out for' poster. Interestingly, the xelodar and breast cancer markers posters are placed on the wall facing the doctor but behind the patient, perhaps indicating these posters are meant to be read by the doctors rather than patients.

In this same consulting room, there is an extension room separated by a curtain. The extension room has a trolley covered by a sheet and then a mackintosh at the foot end. This trolley is where patients sit or lie for breast examination. At the base of the bed is a stool, presumably, a stepping aid onto the trolley. In a far corner in the same extension room is a sink, a tap and soap. At the bottom of the sink are two bowls: one has an inscription 'clean towel' written on the cover of the bowl; the other has no inscription on it, possibly to dispose of the reusable dirty towels. There are small towels in the 'clean towel' bowl. There are a couple of towels in the other bowl. The extension room has another breast cancer 'signs and symptoms' poster similar to the one in the consulting room and this is pasted on one side of the wall, at the head end of the trolley. Thus, when lying on the trolley and facing upwards, it is almost impossible to read the content in the poster.

This consulting room does not feel highly aerated as there are only two windows: one in the main consulting room and the other in the extension room, nonetheless, a functioning air conditioner is switched on to cool the temperature in the room. What perhaps is also striking is the loud noise from people talking that can be heard in the room. The noise emanates from the nurses' station just behind the wall of the consulting room and on top of this wall is the window.

The other consulting room has similar artefacts and spatial arrangements to the one described above except that the room is big, enough to accommodate up to three doctors who are able to simultaneously see different patients. Also, this room has no extension nor screen, hence the trolley on which patients lie is exposed, and when a patient lies for physical examination, she is visible to the other people in the room.

Figure 4.5: Consulting Room 1

Figure 4.6: Consulting Room 2

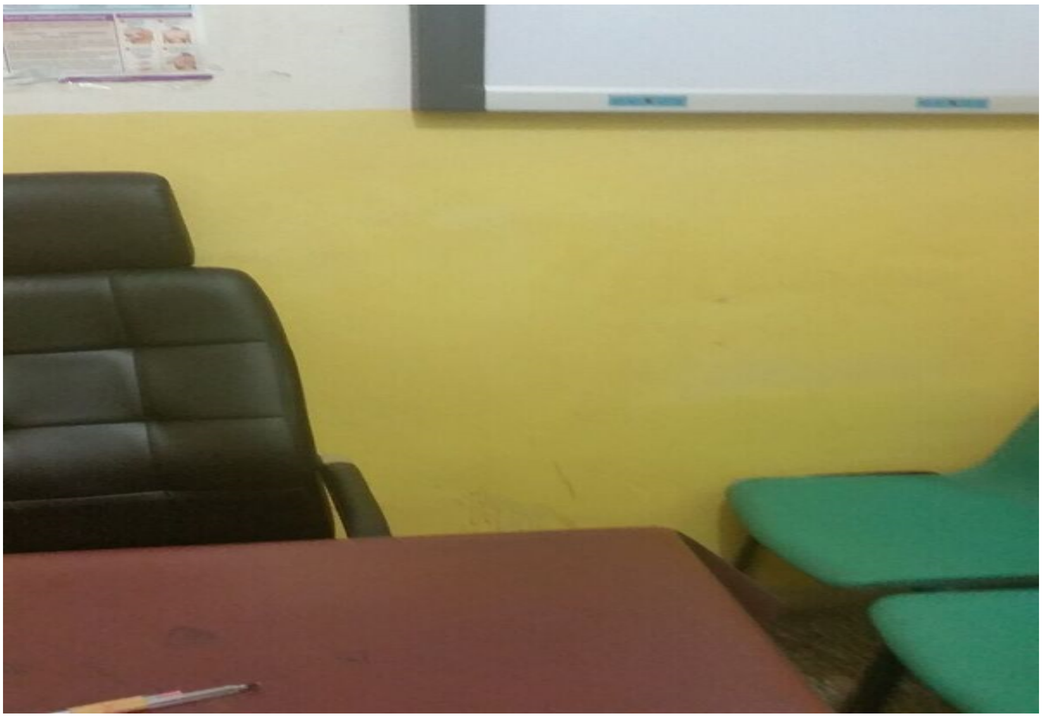


Table 4.1 Summary of the kinds of chairs observed at the breast clinic and their uses

Type of chair	**Purpose**
Swivel chair	Used by consultants/residents and charge nurses
Leather chair	Used by junior doctors or nurses
Plastic chairs	Used by patients and relatives in consulting room
Wooden benches	Used by patients and relatives at the waiting area

Overall, the structural and spatial layout of the clinic is interesting. The layout of the clinic is such that patients will need to pass through the physical spaces overseen by the administrative and nursing staff before finally seeing the doctor. Thus, the people whom the patients first meet and interact with in the clinic are generally the administrative and nursing staff. The patients only meet their doctor when they enter the consulting rooms. Secondly, patients' spaces are clearly demarcated with wooden benches and plastic chairs. The most comfortable chairs, the swivel chairs, are used by the care providers with the highest positions in their respective roles, i.e., the consultants/residents and charge nurses. My impression of these structural and spatial arrangements is that they strengthen the hierarchical relationship in the clinic. For instance, when women are allocated plastic chairs while the consultants have a leather swivel chair, it may appear to purposefully highlight their lack of equality, but it may also be an unconscious assumption of the lack of equality between patients and consultants which means patients have plastic chairs. The implication of these is that they may act as a barrier to active collaboration between patients and clinicians during interactions around the disease and treatments. Lastly, the content of the clinic posters is written in English, which is different from the main medium of communication (Twi Language) at the clinic. Since English is learnt during formal education, it means people with little or no formal education may not be able to access the information in the posters, which may impact on effective decision making.

4.2 The people

The breast clinic is open between Monday and Friday, between 8:00 to 16:00. It serves as a referral and a walk-in centre for breast cases. There are four groups of people in the clinic: patients and relatives; clinical staff; the administrative staff and ancillary staff. The first group of people I describe are patients and their relatives. The patients and relatives are mostly women and most of them are middle aged, but some are young, and a few are elderly. The elderly and most of the middle-aged women wear ‘slit and kaba’ (typical clothing style for most Ghanaian women and these are wax print sewn in long skirt and blouse) in different colours of blue, brown and green while others, mostly the younger ones, are in dresses or skirt and blouse and a few are in trousers and blouse.

The next group is the administrative staff and they are in charge of archiving folders, issuing new folders and ensuring payment of consultation fees. The third is the ancillary staff, the clinic janitor, and he ensures the cleanliness of the clinic. He is usually the first person to arrive at the clinic in order to ensure it is clean. He is mostly seen assisting patients to navigate the clinic although it is not clear if this is part of his ‘job role’ as cleaning staff.

The last group of people are the clinical staff and they include the nursing staff and medical staff. The nursing staff, headed by the Principal Nursing Officer (matron), oversee the effective running of the clinic. There were six professional nurses (all females) on the unit, however, one of them was transferred to the unit during the course of participant observation. With the exception of those on leave, all the nursing staff report every weekday from 8:00am to 16:00pm. When the nursing staff report in the morning, the matron or most senior nurse allocates tasks to her colleagues. The tasks include: wound dressing; assisting doctors with consultations; providing health talks; setting up and assisting doctors to perform core biopsy; screening and performing clinical breast examination (CBE) for new patients; escorting patients to theatre; and documentation and writing reports. In addition to these tasks, on Tuesday afternoons, one of the nurses is also delegated to attend the tumour board meeting with patients and doctors at the oncology clinic. The most senior member of the nursing staff usually sits at the nurse's station and writes documentation of patients who attend the clinic as well as of procedures performed on the day. At the end of the week and or month, she writes a report of the total number of patients seen at the clinic and the diagnosis received by each patient.

With regards to the medical team, there were 'five surgical teams' and each team saw patients on a separate day of the week. Each team had one to two consultants (all males); residents (majority of whom were males; two were females) and house officers (males and females). All doctors at the breast clinic (consultants, residents and house officers) saw patients. Usually the house-officers saw 'new patients'. This involved medical history taking and clinical breast examination. Afterwards, the house officers consulted the consultant or most senior doctor on duty and decided the way forward; whether to request a biopsy or breast imaging investigations. The resident doctors saw both 'new' and 'follow-up' patients and performed clinical breast examination (CBE). The consultants usually saw 'follow-up patients' but they also saw new patients. In addition to CBE, the consultants were the ones who performed 'core biopsy'. Since it was resident doctors and consultants who saw 'follow-up patients'; they were the ones who offered breast cancer diagnosis and provided patients with a management plan, including requesting metastatic investigations and inviting patients to tumour board meeting.

Since this study involves patients, relatives and clinical staff, a detailed background is presented about the study samples of participants from within each of these groups.

4.2.1 Patient participants and nominated relatives

In this study, all participants' characteristics (summary provided in Table 4.3 below) were considered during the analysis because they would potentially influence treatment decision making, and so help provide an understanding of the process. Nonetheless, all participants were anonymised. Sixteen patient participants were included and all were given pseudonyms e.g. (Maame Mamuna), while a nominated relative was identified as a husband, son or daughter. The rationale for presenting relatives as such was to maintain a balance between identifying the relationship between the person (i.e., relative) and the patient participant as well as maintaining their anonymity. For patient participants, ages ranged from 28 to 81 years, with a median age of 51 years and a mean age of 52 years. Seven, out of the 16 (44%) patient participants, were premenopausal. All the premenopausal patient participants had between one to three children while seven of the post-menopausal patient participants had between three and six children. Two of the post-menopausal patient participants had no children.

With regards to their social background, four of the patient participants were divorced, five were widowed, six were married and one was single. All the patient participants with the exception of one (Sister Foriwaa) lived with some family members. These family members were either husbands, children, grandchildren, siblings, parents or other extended family. Aside from the family members they lived with, all patient participants were also able to contact other family members including those in the diaspora through mobile phones. Sister Foriwaa is a divorcee and although she has three children, they are all independent and engaged in various economic activities elsewhere in the country. Sister Foriwaa thus lives alone in a private rented flat but has a co-tenant that keeps her company. Her children also pay regular visits (at least every other month) to her.

Regarding place of residence, seven of the patients lived in the Ashanti region, the same region as the location of the breast clinic. The rest of them lived in other regions including Brong (4 hours travel time to the city where the clinic is located); Central (3.5 hours travel time); Western (5 hours travel time); Eastern (3 hours travel time) and Northern (7-8 hours travel time). Travel to the clinic is mostly by public bus. Two of the patient participants (Maame Mary and Madam Comfort), who lived in the Eastern and Northern parts of the country, moved to join family members in the city where the breast clinic is located.

The highest level of education amongst this sample was a bachelor’s degree (Natasha). Two of the patients were retired nurses and had post-secondary (certificate) qualifications in nursing (Maame Abigail and Madam Comfort). One patient had secondary education (Sister Adwoa) and the remaining 12 patients (75%) had either some basic education or no education at all.

With regards to economics, two of the patients were unemployed and relied mainly on family (husband or children) remittances for their daily living (Sister Sarah and Maame Saa respectively). Nine patient participants, though employed, did not have a regular income from either their trading or farming activities. This was due to the nature of the work they performed. The farmers made an annual income from the sale of their farm produce and varied on a year to year basis of between

600 cedis (£100) to 2000 cedis (£350). The other employed patients who earned irregular incomes could not name an exact amount of money they were earning because, it was often spent on daily living expenses and it was difficult to calculate a total sum. Maame Mamuna however mentioned that she is able to save 1 cedi (20 pence) a day from her trading. Five patients had a regular monthly income, one of whom was earning as high as 5000 cedis (£800) monthly from her importation business (Auntie Twumwaa).

All patients indicated they practised a religious faith, either as a Christian or a Muslim. Overall, with regards to patients' socio-cultural background, there were similarities in many aspects, including economic and inter family dependence and varied ethnic diversity, which is characteristic of the Ghanaian population. The only unique characteristics were identified among three participants. Firstly, Auntie Twumwaa was the only participant who mentioned she was economically independent, secondly, Sister Foriwaa who said she lived alone, and thirdly, Madam Comfort, stated that her son, whom she had moved down from the North to stay with, was a medical officer at the Southern Hospital. None of the other patient participant mentioned a family relationship with an HCP at this very hospital.

4.2.1.1 Characteristics of nominated relatives

Relatives and patient participants were similar in some aspects. Nominated relatives and patients belonged to the same ethnic background and religious faith. Four nominated relatives lived in the same region as the patients. One nominated relative, Maame Mary's daughter, lived in the region where the breast clinic is located, consequently, her mother moved from her original place of residence to live with her. With regards to educational backgrounds, the nominated relatives were similar to the patients who nominated them, except Maame Saa's son who had secondary education while his mother had no basic education. All five nominated relatives were employed but only two earned regular income.

4.2.2 Characteristics of HCP participants in this study

For HCP participants, the letters of the alphabets, A-E were used to preserve anonymity. The five nurses were identified as Nurse A to Nurse E, and the five doctors were identified as Doctor A to Doctor E. Aside from preserving anonymity, the use of these pseudonyms facilitated the linkage between the findings of the data and all participants included in the study.

All HCPs were proficient in the 'Twi Language' regardless of whether she or he was from a different ethnic background. With regards to their professional experience, none of the HCPs was a specialist in breast care. The two consultants (Drs B and C) were general surgeons and hence involved with the management of other surgical conditions other than breast cancer. They have nonetheless been involved with the management of breast cancer cases for more than ten years. The three residents (Drs A, D and E) were qualified doctors undergoing further training to be surgeons. The residents were also involved in seeing and managing patients with other surgical conditions aside from breast cancer. The resident doctors have been involved in managing breast cancer cases between three and seven years.

With regard to the nurses, four (Nurses A, B, C, D) had a diploma in general nursing. One nurse (Nurse E) had a Bachelor of Science degree in nursing as well as a diploma in both nursing and midwifery. Nurses B and D started their professional nursing practice at the breast clinic following their nursing registration, the other nurses had practised in other departments of the hospital. Nurse A had worked in the community, HIV clinic and on in-patient medical admission ward. Nurse C and Nurse E had both worked in medical and surgical in-patient admission wards prior to working at the breast clinic. Nurse E had additionally worked in antenatal and postnatal clinics in the same hospital. All the nurses' participants have been practising at the breast clinic for between one to 12 years.

Overall, certain issues were noted. HCPs had generalist background and or were specialist in general surgery (i.e., doctors). None of them had a specialist training in breast care. There were other HCPs involved in the care of women including oncologists, pathologists, radiologists and the nurses who worked in oncology, but they were not directly involved in providing formal diagnosis to women with breast cancer. However, because they were members of the tumour board, they were also observed if they happened to be present at the tumour board meeting. Despite the lack of a breast specialist at the clinic, HCPs had a higher educational status compared to most of the patients' participants. The higher educational status of HCPs and their ability to draw on the institutional knowledge of medicine means they had the potential to exert an influence on patients (Drinka et al., 1986). The other issue was that most of the women had an irregular income and were economically less independent. Because participants relied on their social network for financial support, such people likewise could exert an influence on patients. In this study, power is defined as the financial resources and expert knowledge available to individuals that allow them to exert an influence on others or shut down discussions between patients and clinicians whether consciously or unconsciously (Wildavsky, 1964).

Table 4.2: Summary of participants' characteristics

Patient Participant characteristics

Patient Participant	Age	Marital status	Number of children	Ethnicity	Region of residence	Religion	Educational level	Occupation	Monthly Income	Nominated relative	Breast cancer stage	Recommended treatment	Decision to take or not to take treatment
Maame Mamuna	41	Divorcee	3	Frafra (Northern tribe)	Ashanti, sub urban	Muslim	None	Trading/Cleaning	Irregular from trading Regular salary of 120 cedis (£20) a month from cleaning	None	Stage 2	Mastectomy	Declined treatment
Maame Saa	72	Widow	6	Asante	Ashanti, rural	Christian	None	Unemployed	None	Son	Stage 3	Neoadjuvant chemo followed by mastectomy; before adjuvant treatment	Decided initially not to proceed with treatment but accepted treatment at time of interview
Maame Abigail	68	Widow	3	Bono	Brong Ahafo-sub urban	Christian	College	Retired Nurse/Midwife	800 cedis (£140)	None	Stage 2	Neoadjuvant chemo; mastectomy;	Accepted treatment

												adjuvant treatment	
Madam Comfort	72	Widow	3	Dagarte (Northern Tribe)	Northern region-rural	Muslim	College	Retired Nurse	850 cedis (£150)	None	Stage 2	Mastectomy or Breast conservation with adjuvant treatment	Accepted treatment
Sister Adwoa	32	Married	3	Asante	Ashanti-urban	Christian	Secondary	Teaching	500 cedis (£90)	None	Stage 3	Neoadjuvant chemo; mastectomy; adjuvant treatment	Decided initially not to proceed with treatment but accepted treatment at time of interview
Sister Akos	38	Single	3	Asante	Ashanti sub urban	Christian	Elementary	Trading	Irregular	None	Stage 2	Neoadjuvant chemo; mastectomy; adjuvant treatment	Declined treatment
Sister Sarah	35	Married	3	Fanti	Central-sub urban	Christian	Primary	Unemployed	None	None	Stage 3	Neoadjuvant chemo; mastectomy; adjuvant therapy	Decided initially not to proceed with treatment but accepted treatment at time of interview

Sister Foriwaa	48	Divorcee	3	Asante	Ashanti-sub urban	Christian	Elementary	Trading	Irregular	None	Stage 3	Neoadjuvant chemotherapy; mastectomy; adjuvant treatment	Accepted treatment
Natasha	28	Married	1	Akuapim	Brong Ahafo-urban	Christian	Tertiary	Marketing in a private firm	1000 cedis (£180)	Husband	Stage 3	Neoadjuvant chemotherapy; mastectomy; adjuvant treatment	Accepted treatment
Auntie Ceci	57	Widow	5	Kwahu	Eastern-sub urban	Christian	Primary	Farming	Irregular	None	Stage 2	Mastectomy; adjuvant treatment	Accepted treatment
Sister Lydia	45	Married	3	Asante	Ashanti-urban	Christian	Elementary	Trading	Irregular	Brother	Stage 3	Neoadjuvant chemo; mastectomy; adjuvant treatment	Accepted treatment
Maame Tawia	52	Divorcee	0	Wassa	Western Region-sub urban	Christian	Elementary	Farming/Cleaning	Irregular from farming; regular salary of 200 cedis	None	Stage 3	Neoadjuvant chemo; mastectomy; adjuvant treatment	Accepted treatment

									from cleaning (£40)				
Auntie Twumwaa	56	Married	0	Asante	Ashanti-urban	Christian	Elementary	Trading (Imports goods from outside the country)	~5000 cedis (£800) a month	None	Stage 2	Breast Conservation; adjuvant treatment	Accepted treatment
Auntie Serwaa	50	Widow	5	Bono	Brong Ahafo-sub urban	Christian	Elementary	Trading	Irregular	None	Stage 3	Neoadjuvant chemo; mastectomy; adjuvant therapy	Accepted treatment
Maame Mary	68	Married	4	Akyem	Eastern-rural	Christian	Elementary	Farming	Irregular	Daughter	Stage 3	Neoadjuvant chemo; mastectomy; adjuvant therapy	Accepted treatment
Maame Akyiaa	81	Widow	5	Sefwi	Western-rural	Christian	None	Farming	Irregular	Daughter	Stage 2	Mastectomy; adjuvant therapy	Decided initially not to proceed with treatment but accepted treatment at time of interview

Nominated relative characteristics

Nominated relative participant	**Age**	**Place of residence**	**Ethnicity**	**Religion**	**Educational status**	**Occupation**	**Monthly Income**
Maame Saa's son	29	Ashanti- Rural	Asante	Christian	Secondary	Welder	~500 cedis (£90)
Natasha's husband	32	Brong Ahafo-urban	Akyem	Christian	Tertiary	Health administrator	1200 cedis (£200)
Sister Lydia's brother	52	Ashanti-urban	Asante	Christian	Elementary	Trading	Irregular
Maame Mary's daughter	30	Ashanti -urban	Akyem	Christian	Elementary	Hairdressing	Irregular
Maame Akyiaa's daughter	50	Western-rural	Sefwi	Christian	Primary	Farming	Irregular

Healthcare professional participant characteristics

HCP participant	Number of years caring for women with breast cancer	Professional background
Doctor B (male)	Over ten years	Consultant general surgeon
Doctor C (male)	Over ten years	Consultant general surgeon
Doctor D (female)	Over five years but less than ten years	Resident
Doctor E (male)	Less than five years	Resident
Nurse A	Less than five years	Adult nurse (general nurse)
Nurse B	Over five years but less than ten years	Adult nurse (general nurse)
Nurse C	Less than five years	Adult nurse (general nurse)
Nurse D	Over five years	Adult nurse (general nurse)
HCPs observed but not interviewed	**Number of years working with women with breast cancer**	**Professional background**
Nurse E	Over ten years	Nurse/Midwife
Doctor A (male)	Less than five years	Resident

4.3 Overview of activities and events in the clinic

The breast clinic, as a walk-in centre, does not have an appointment system in place, hence, the breast clinic can be busy with over thirty patients reporting each clinic day. The busyness of the clinic was particularly extreme in the month of October, one possible reason being the increased breast cancer awareness created within that period. October is breast cancer awareness month and during this period, public breast cancer awareness campaigns are conducted by non-governmental organisations (e.g., Breast Care International). These campaigns are mostly in the form of public marches in towns and villages, offering health talks and breast examination to churches and other social groups. These events are subsequently captured by the media houses (Radio and Television) and broadcasted.

The table below provides a summary of the numbers of patients who were seen at the breast clinic from 24th July to 3rd November. The weekly compilation (performed by the charge nurse) was taken from the breast clinic records and the summation was done by me.

Table 4.3: Summary of the total number of patients reporting at the breast clinic from 24th July to 3rd November 2017 (Courtesy, Breast Clinic Records)

Date	Total number of patients seen	Number of New cases	Number of lumps	Number of cancer diagnosis (Clinical and histological diagnosis)
24th-31st July	191	63	17	6
1st -4th August	115	38	13	5
7th-11th August	128	57	13	4
14th-18th August	125	51	10	4
21st-25th August	159	61	13	4
28th-31st August	117	47	14	4
4th-8th September	161	72	32	10
11th-15th September	163	63	22	8

18th-22nd September	134	48	13	3
25th-29th September	140	52	17	4
2nd-7th October	158	69	28	12
9th-13th October	166	73	14	5
16th-20th October	205	117	19	13
23rd-27th October	207	113	28	11
30th-31st October	124	57	11	6
1st-3rd November	82	42	10	5
Total	2,374	1023	356	104

From the table above, within the fifteen-week period, a total of 1023 new patients were seen, of which 104 patients were diagnosed either clinically or histologically with breast cancer. This represents 1 out of every 10 new patients who present to the clinic.

4.3.1 A typical day in the clinic

The breast clinic has no appointment system in place; hence, a typical day starts as early as 8:00am for patients, some reporting as early as 6:00am. As at 8:00am, there are about 20 people (both new and follow-up patients) already waiting at the corridor of the breast clinic for a consultation card. They sit in a queue on the long benches placed at the corridor for a 'consultation card/folder' for the visit, without which the patient will not be seen by the nurse or the doctor. Receiving a consultation card/folder is not free. It needs to be paid for irrespective of whether the patient holds a valid National Health Insurance Scheme (NHIS) card. For a woman who has a valid National Health Insurance Scheme (NHIS) card, she pays 21 cedis (£4) as top up for the first visit. On each subsequent visit, she pays 11 cedis (£2). If she is not insured, she pays 63cedis (£11) on the first visit and 33 cedis (~£6) on each subsequent visit. Folders are retrieved on first come first served basis. Before a card/folder is issued, the unit clerk gives the folder to the revenue clerk who then writes the consultation fee on an invoice for the patient to pay. Patients make payment at a bank outlet in the physio building about 40 yards from the breast clinic. After payment, the patient shows the receipt to the revenue clerk to confirm payment and the revenue clerk writes this in a record book. The revenue clerk then brings the folder to the nurses' station and the patient continues to wait until she is called by the nurse. What I observed is that there is no television in the clinic to engage the women as they wait, hence, the women waiting are either conversing with one another, leaning against the walls with distant looks on their faces, sitting with heads bowed in their laps or are engaged with their phone. Also, although, I could read the content of some of the breast cancer posters displayed on the walls as I sat on one of the benches (because they had bold inscriptions), I did not observe any patient or relative engaging with the clinic posters. The main focus for all patients and relatives was waiting for a card.

What I also observed is that when people interact, they address one another using their social positions. For example, elderly women are referred to as 'mother' and younger people as 'my children'. People of the same age group refer to one another as 'sister' and 'brother' before adding their names. This behaviour is the norm in Ghanaian public settings and households. Whenever patients are being called by HCPs, they are mostly addressed by the HCPs as 'mother' or 'sister' before adding their names. The only exception are teenagers who are addressed by their names only. Patients, particularly the middle aged and the elderly, address doctors as 'doctors' and nurses as 'my lady' or 'madam nurse'. The younger patients also address nurses as 'mother' or 'madam nurse' and doctors as 'doctors'. Any behaviour, outside of this norm, is heavily frowned upon. Thus, members of this setting value relationship and social position.

The third observation was that although patients arrive early, doctors generally do not arrive early. They usually arrive around 10:00am, which is about two hours behind the scheduled time. The nurses will screen new patients while the follow-up patients continue to wait. For this reason, the clinic can be packed, busy, full and noisy with people talking and staff calling out names accompanied by shuffling of feet. With such an atmosphere, nurses screening patients are often heard shouting or repeating names of patients. Repetition of names is usually accompanied by open reproach by the nurses. The nurses would question a woman (whose name has been repeated) why the woman did not respond immediately at the mention of her name but would have to wait until her name is repeated. The women would generally be apologetic and reply that they did not hear the first time their names were called.

Screening of new patients was performed by two nurses: The senior nurse sits on the swivel chair at the nurses' station by the table (mostly others in earshot) and takes patients' history, records this in their folders, and makes some documentations in the attendance book; the second nurse will then be in the treatment room and perform CBE on a new patient. After screening, if the nurse finds a lump or the new patient comes with a breast imaging report/referral letter, the patient is made to queue and see a doctor that same day. Since the doctors do not start consultations until around

10:00am, and the clinic is busy with both ‘new’ and ‘follow-up patients waiting to be seen, and also because there are only two consultation rooms available, the doctors practice simultaneous consultations. This is where two or more patients are seen in the same consulting room by two or more doctors at the same time as recorded in my field notes:

At around 11:20, I noticed Dr B (consultant) and three doctors approaching the nurses’ station. When the doctors got to the nurses’ station, they stood still, and Dr B greeted Nurse E, “Auntie E, good morning, ei, there are many patients today”. Nurse E raised her head and looked at the doctors, (three patients were seated on a bench at the nurses’ station and raised their head to gaze at the doctors as Dr B talked), “doctor, good morning, as for today, you have kept long in arriving”. Dr B replied (smiling), “mmm, when we went for surgery rounds, there was a particular case that delayed us, that is why. Where is Nurse C, let’s start consultation, today we will have to be fast, there is tumour board meeting and patients are many”. Dr B turned to the three doctors standing beside him and said, “Akosua (pseudonym for house officer), come with me to Room Two and see patients there with me, Dr A (resident) will go to Room One with Daniel (pseudonym for another house officer)”. Dr B and Dr Akosua both walked into Consulting Room Two while Dr A and Dr Daniel walked into Consulting Room One. Nurse C came out of the nurses’ room and divided the pile of folders on the nurses’ table into two: she picked the top half of the folders and walked into Consulting Room Two. Field notes 2017.

The practice of simultaneous consultations means limited privacy for individual patients which could impact on quality patient-provider interactions.

At the breast clinic, it was not uncommon for a patient to present with advanced disease. When this happens, there is open irritation by staff towards such patients. Staff can be heard (by other people close by including other patients) using words such as ‘ei we are dead oo’, ‘they will keep it at home till it rots’; ‘a big case is in’; ‘the smell is not easy’ to label such patients. This observation was recorded in my field notes during an interaction between Nurse E and Nurse D:

Nurse E (called out loudly), “Nurse D, the doctors are in, Nurse C has gone to Room Two, so you will go to Room One”. I noticed Nurse D come out of the back corridor in a haste and put her phone into her pocket. She picked the remaining pile of folders and raised her head towards Nurse E and grins, “mmm, today, there is a big case coming, she is even in a wheel chair and the smell alone, ‘you can’t get a nose outside’, ei God, we are dead oo, they will keep it at home until it rots”. Nurse E asks, “where is she?” (obviously not happy with the news). Nurse D replies, “she is outside, under the tree, *her relatives are now getting her card" and turns to walk away to Consulting Room One holding the pile of folders.* Field note 2017.

This exchange between the two nurses was loud enough to be heard by anyone seated at the nurses' station including the three patients waiting at the nurses' station. Under such circumstance, staff usually do not see such patients in the consulting room because of the offensive odour. Screening and consultation are usually conducted on the corridor. My impression of this behaviour exhibited by staff is that they disapprove of patients who present with very advanced stages, as there is open resentment and discrimination towards such patients.

4.3.1.1 Breaking protocol: 'This is my KDK'

The breast clinic operates on a first come first served basis. I noticed however that this is not entirely the case for every person. Some people jumped the queue and staff referred to such people as 'KDK' (Twi Language acronym). This means the person is either a member of staff or is related to a member of staff in the hospital, and as such these people are assisted to go through the process of getting a consultation card, screening and seeing a doctor quite quickly. As these 'KDKs' jumped queues, they are sometimes met with outbursts from the other patients waiting in the queue. This outburst is not directed at the staff openly, but the patients talk among themselves in disgust about other people jumping the queue. The staff on the other hand seem to 'normalise' the situation of letting 'KDKs' jump queues as depicted in the following extract:

Nurse B (standing beside Nurse A), "Auntie A, hmm, when I was coming from the corridor just now, mmm, the patients at the waiting area, some have frowned, muttering to themselves and saying they have been waiting for a long time and some people are by passing the queue. Hmmm, eii, I think it is because of the nurses who did not join the queue, but what do they expect, there is 'protocol' everywhere in Ghana even at the banks, we always see our colleagues first, so that we will also be treated the same when we go to their unit" (Field note 2017).

This behaviour is not restricted to the breast clinic, but it is a 'norm' in most Ghanaian healthcare settings. Staff value relationships with co-workers and their relatives. As a 'norm', it has become an acceptable workplace practice and for patients who are waiting on the queue, they may be disgruntled but they may not directly lodge a complaint about it to staff. The practice of 'KDK' which happens at least once every other clinic day means longer waiting times for the 'ordinary' patient who may have even arrived early.

4.3.2 Core biopsy

Following clinical breast examination and or breast imaging, core biopsy is requested by doctors for suspicious lumps. The doctor will usually inform the patient that they will need to perform core biopsy in order to know exactly what the lump is. One of the doctors, Dr B, goes further and informs the patient particularly those he suspects clinically as cancerous that the lump looks like cancer but he needs to perform core biopsy to know exactly if it is cancer or not. According to Dr B, he uses this approach so that if the pathology result is positive for cancer, breaking the news of cancer diagnosis will be easier for him. The other doctors are however, sceptical and do not mention their suspicions of cancer because they stated they did not want to alarm patients.

Core biopsy is performed in the treatment room. The nurse first goes inside the treatment room and sets up a trolley. She covers the top shelf with a sterile green towel. Items on the sterile field include scalpel blade, scissors, syringe and needle, sponge holder, gauze, gallipot, two containers for receiving the specimen, disinfectant and local anesthetic. For the two containers; one is analysed locally (i.e. in Ghana) and the other is for an ongoing research to be analysed in the USA. On the other side of the trolley which I perceive is a non-sterile field were cutting scissors, plaster and clean towels in a bowl.

The cost of the procedure is 323 cedis (£60) and patients need to make upfront payment before the procedure is carried out. This meant that if patients needed to do core biopsy and did not have money, the patient would need to return the following week or whenever her money was ready to have it done. This was the case for everybody whether the person was insured or non-insured.

Patients who during the procedure are able to provide a specimen for the US research are informed about the research and given a refund of 100 cedis or ~£20 (the reason for this is that the research team pays for the core biopsy needle for those who provide a tissue sample for them). The whole core biopsy procedure takes about fifteen minutes.

During the performance of core biopsy, the patient will remove her top clothes and will lie on the trolley with the affected breast closer to the consultant. The nurse assisting the procedure will then place a clean towel underneath the patient. The consultant will wear a pair of disposable gloves and will feel for the mass. He will then remove the disposable gloves and will wear a protective gown. Afterwards, he will disinfect his hands and will wear sterile gloves. When this is done, the consultant will disinfect the site of the breast where the sample will be excised. The patient will be injected with the local anaesthetic. The doctor will ask the patient if she feels any pain before proceeding. The doctor will pick a gauze and a blade and will make a cut at where the mass is. The nurse will also wear sterile gloves and will then pick a gauze and clean the blood. The nurse will give the core biopsy needle to the doctor. The doctor will insert the core biopsy needle through the mass and the needle will make a pop sound before he will pull it out. Afterwards, the consultant will open the needle and will use the scalpel to get the specimen into the container. Consultants say they usually repeat the process about six times so that they put three breast tissue specimen into each labelled container. Consultants repeat the procedure to ensure adequate sample is sent for histological investigation. When the procedure is completed, the consultant will put the core biopsy needle and the blade into the sharp bin. The nurse will take over by applying a firm dressing and a plaster and will then clean the patient from any blood. The patient will be asked to get up and come back on the third day to have the dressing changed. The patient is also informed that it will take up to three weeks for the results to be ready after which she will be contacted by a phone to come for the report. Patient is informed that she will need to ensure she picks up her phone call.

4.3.3 Seeing a doctor with core biopsy results

There are several stages to this event. The first stage is ‘collecting the report and waiting to be seen’. During this stage, the patient collects the report from a nurse at the nurses’ station and makes two copies of the report. She gives one copy to the nurse for record keeping but as a rule the nurse does not mention anything about the content of the report to the woman. The woman keeps the original report and the second copy. She then goes through the routine process of queueing and paying for the consultation fee. When payment is completed, her medical folder is then sent to the nurse. The woman further waits on the bench until the nurse confirms payment of fees after which she puts the patient’s folder on a pile to see the doctor. The woman is then asked to go back to the waiting area until her turn to see the doctor. When it is her turn to be seen, the nurse assisting the doctor with the consultation inside the consulting room, picks the patient’s folder from among the pile of folders on the consulting table, and places it in front of the doctor. The doctor opens the folder and reads through to check how the previous consultation went. The nurse then stands by the door and calls the full name of the patient. The woman will normally respond “yes” or “yes madam” from the waiting area and then walks into the consulting room.

The second stage is ‘receiving a diagnosis’. A woman only gets to see her doctor when she enters the consulting room. In the consulting room, she is the first to greet the staff, ‘good morning or good afternoon’, after which she takes a seat on the plastic chair by herself or she waits until the nurse points to the plastic chair for her to sit. The doctor leads the discussion by asking the patient if the report is available and the patient would respond ‘yes’ and then bring it out. The doctor takes the report, reads it and says to the woman,

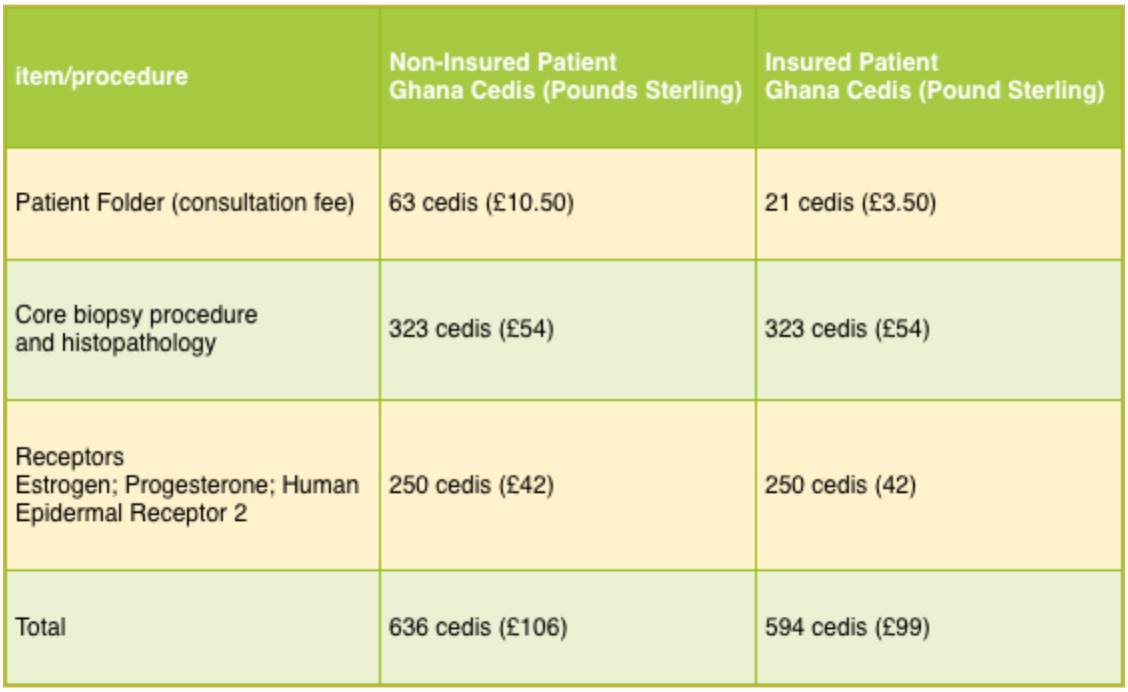
“mother, the tissue that was taken from your breast and sent to the lab, the result says it is cancer or kokoram” Field note 2017.

Usually, the doctor will look directly at the patient while offering the diagnosis and the patient will also look on silently. Other patients express signs of shock at the diagnosis by exclaiming ‘eish’.

After diagnosis, the third stage is ‘proposing a management plan’. Immediately following a diagnosis, the doctor further adds that even though it is cancer, they can do something about it but before they know what to do, whether to give injection or operation, they would need the woman to do further tests, metastatic investigation (full blood count, liver function test, kidney function test, abdominal ultrasound and chest computed tomography (CT)). This will show whether the cancer is localised in the breast or has spread to any other place. Some doctors may also caution that with cancer, ‘it does not stay at one place, but can spread to other parts of the body which will be devastating’. The doctor will then inform the patient that when the metastatic results become available, she will be invited to the tumour board meeting where all the doctors will meet and discuss her treatment with her. All this while, the patient will usually look on quietly as the doctor leads the discussion.

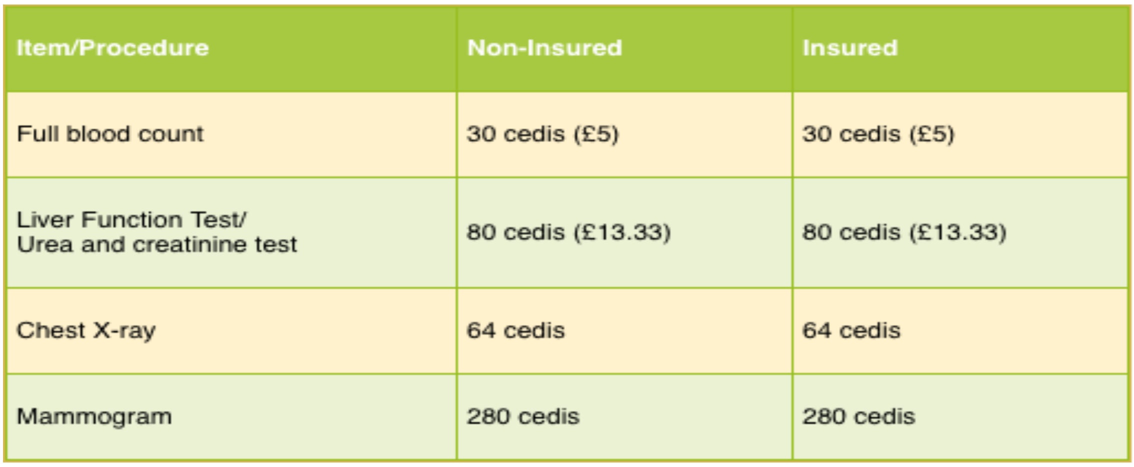
The final stage is the ‘concluding phase’ where the patient is invited to ask any question she wants. Whenever patients are invited to ask questions, they rarely ask questions about the cancer or treatment, rather, they mostly ask about cost of investigations or places to conduct the tests. The doctors usually do not divulge information on cost of investigations or treatment but would refer patients to speak to the nurses about costs and where to conduct the tests. The general observation was that there is ‘lack of talk about costs of investigations and treatment’ despite the high costs of investigations and treatment associated with breast care (see tables 4.4 to 4.6 below for estimated cost of breast care). The doctors distance themselves from discussions about money. Similarly, the nurses only divulge information on places to conduct the investigations but not on the expected costs and will request patients to check the prices at the respective investigation departments. The only exception is with core biopsy where nurses inform patients about the cost of the biopsy. With the cost of biopsy, the nurses actually receive the money from the patient at the clinic. My impression of this behaviour is that the ‘lack of talk about money’ means if some patients have concerns (e.g., financial challenges) about the costs of investigations and treatments, they may not be able to share these concerns with staff.

[6]Table 4.4 Cost of diagnosis for breast cancer (Courtesy, Breast Clinic and Oncology Records, 2017)



item/procedure	Non-Insured Patient Ghana Cedis (Pounds Sterling)	Insured Patient Ghana Cedis (Pound Sterling)
Patient Folder (consultation fee)	63 cedis (£10.50)	21 cedis (£3.50)
Core biopsy procedure and histopathology	323 cedis (£54)	323 cedis (£54)
Receptors Estrogen; Progesterone; Human Epidermal Receptor 2	250 cedis (£42)	250 cedis (42)
Total	636 cedis (£106)	594 cedis (£99)

Table 4.5 Cost of staging



Item/Procedure	Non-Insured	Insured
Full blood count	30 cedis (£5)	30 cedis (£5)
Liver Function Test/ Urea and creatinine test	80 cedis (£13.33)	80 cedis (£13.33)
Chest X-ray	64 cedis	64 cedis
Mammogram	280 cedis	280 cedis

Text

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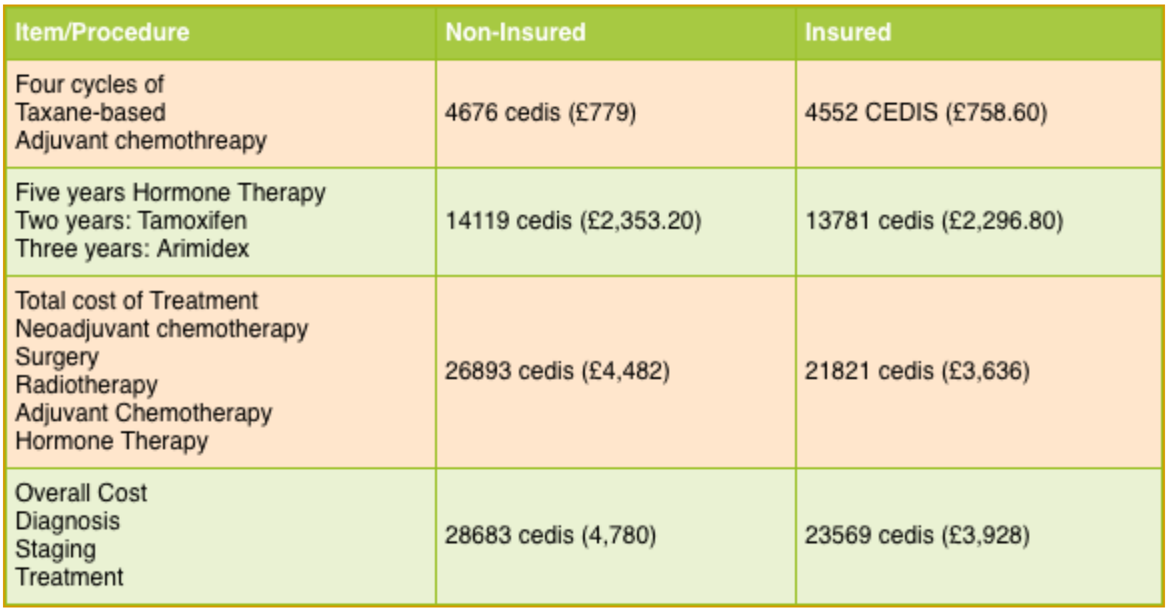
[6] Daily minimum wage is approximately $2.00 dollars (Ghana Web, 2019)

Table 4.6 Overall cost of breast cancer care



Item/Procedure	Non-Insured	Insured
Four cycles of Taxane-based Adjuvant chemothreapy	4676 cedis (£779)	4552 CEDIS (£758.60)
Five years Hormone Therapy Two years: Tamoxifen Three years: Arimidex	14119 cedis (£2,353.20)	13781 cedis (£2,296.80)
Total cost of Treatment Neoadjuvant chemotherapy Surgery Radiotherapy Adjuvant Chemotherapy Hormone Therapy	26893 cedis (£4,482)	21821 cedis (£3,636)
Overall Cost Diagnosis Staging Treatment	28683 cedis (4,780)	23569 cedis (£3,928)

Aside from the 'lack of talk about money', certain behaviours and practices were also evident during patient-HCP interactions around diagnosis and management plan. Doctors inform patients about the diagnosis using the word cancer or 'kokoram' but do not inquire from patients their understanding of the diagnosis. The junior doctors often interrupt the senior doctors to discuss the cases they (junior doctors) were seeing and would request the senior doctors to confirm a breast lump. Thus, patients who are receiving a diagnosis may spend a considerable length of time in the consulting room, but this time is devoid of any quality engagement between them and the staff. This lack of engagement was observed and recorded in the field notes when Maame Tawia looked on silently and helplessly during interaction with Dr A about her diagnosis. During the interaction, there were two other simultaneous consultations in the same room. Dr A was interrupted four times by junior doctors, two of whom were seeing patients in the second consulting room.

Dr A picks the tests report one after the other and begins to glance through. He gets to the third report and says, [gazing at Maame Tawia] "Oh it has not gone into the abdomen". Consulting room door opens and another junior doctor walks in holding a folder and says, "Dr A, there is something I want to ask about the woman I am seeing". Dr A turns to look at the junior doctor and says, "What is it?" the junior doctor and Dr A are engaged in discussion for some time. The conversation is loud and can be heard by people in the room. Maame Tawia looks on quietly. Just when the junior doctor is leaving, another junior doctor comes to stand close by Dr A holding a folder and engages him in discussion over a patient he is also seeing. This engagement lasts longer than the first one for about *three minutes. Maame Tawia looks at the two doctors as they talk and then looks away with a distant look in her face* (Field note 2017).

This interaction could clearly be seen as disengaging because of the repeated interruption of the doctor. Secondly, the doctor did not continue the information from where he stopped during the interruption.

Another behaviour frequently observed was interactions in the clinic corridors between patients and nurses post diagnosis. This is where patients received information on places to conduct requested metastatic investigations. All such interactions could be clearly heard by any other person close by, which exposed patients' vulnerability.

One other behaviour was also observed, although, less frequently. During patient-clinician interactions around diagnosis and management plans, some doctors would caution patients to avoid visiting traditional healers because that would worsen their situation and would not lead to a cure. Doctors do not ask patients about their thoughts around traditional healing but would straightaway caution patients to desist from that practice. The following extract from my field notes describes Dr D who, after informing Sister Sara of her breast cancer diagnosis, cautions her against visiting traditional healers.

"…We do not want you to be worrying about it as I said we can manage it. What we don't want is for you to go for herbal treatment." Field notes 2017.

During observation of patient-clinician interactions around diagnosis and management planning, one practice was not observed. There was no signposting of patients to any other source of information or support group outside the clinic. Patients were also not provided with any information material that may be appropriate for them. Lastly, patients were not provided with any follow-up contact to discuss their concerns outside the clinic. The absence of this practice means patients who required further information about the disease and treatment may find some difficulty accessing appropriate information. It also means patients may find difficulty sharing their concerns when outside the clinic.

4.3.4 Tumour Board Meeting

During interactions between patients and clinicians around diagnosis, patients are informed by HCPs that when their metastatic results become available, they will need to attend the tumour board meeting where they will meet with HCPs to discuss their treatment. Patients are then informed to report to the breast clinic by the latest at 2:00pm on Tuesday afternoon to attend the meeting.

On Tuesday afternoon, patients who are scheduled to attend the tumour board meeting first report to the breast clinic by 2pm. They inform any of the nurses at the clinic that they will be attending the meeting. The nurse who has been delegated to attend the tumour board meeting walked with all the patients who had arrived (together with their folders) the 400 metres to the oncology clinic where the meeting will be held. The tumour board meeting is held at the oncology conference room, but the patients will be asked to take a seat at the oncology out-patient area. From the oncology out-patient area to the conference room is distance of about 30 yards.

In the conference room, the atmosphere is a serious one, an impression I had from the appearance of the room. It was a well-lit room with chairs arranged in a circle with a big wooden table at the centre. The chairs numbered approximately 40. The room is quite cold from the air conditioning. There is a screen that looks like a television set placed on a wall. There is another screen for highlighting radiological photos. There is a giant marker board adjacent the television screen. Next to the marker board was a poster advertising a 2-day breast cancer symposium that was going to take place the following month. There were nicely coloured curtains that hanged from all the four windows in the room. The chairs are arranged such that it is easy to walk through the room. The chairs are padded and are comfortable to sit on. I asked the oncology nurse manager about the television screen and she explained that it is for teleconferencing with some breast specialist from Michigan. She further added that on some occasions, during tumour board meetings, there was live conference with the specialist from Michigan to discuss treatment options for patients. At a corner in the conference room is a smaller table with certain documents on top. I looked closely at the documents and found that they were investigation request forms including X-ray, endoscopy and ultrasound.

The tumour board meeting is scheduled for 15:00 pm. Nonetheless, members of the tumour board usually start to arrive at 15:15. As they enter the room, they would usually stand and chat with one another before taking their seats. The seats are taken in no particular order. The board members conversed with one another as they wait for others to arrive. Usually, the men are dressed in shirts tucked in their trousers while the ladies wore smart casual dresses (mostly not the traditional cloth). The nurses are always in uniform. Some of the nurses wear blue while others wear white uniform (the colours indicated level of rank; senior nurses wear white; junior nurses wear blue).

The members who regularly attended the meeting were five surgeons, two radiologists, three oncologists, one clinical psychologist and one pathologist. Three nurses (one from the breast clinic; two from oncology) were also usually present. Most of the doctors (surgeons and oncologists) have at least one folder in front of him or her. The meeting usually starts when one of the doctors calls the attention of the rest to start. Members present their medical cases in turn without any particular order. When a case is presented, the presenter would describe the patient's age, parity, breast cancer type, stage and metastatic reports. Members would then deliberate and decide which treatment modalities are appropriate. Members could interrupt by asking for clarifications or for something to be repeated while the case is being presented. Any member could interrupt but I noticed the head of oncology mostly interrupted to get clarification on what is being presented. He and another doctor (radiologist) were the most vocal in recommending the course of treatment they deemed most appropriate. For some cases, lengthy deliberations were conducted as to the appropriate course of action. Cases presented included breast carcinoma, bowel cancer and throat cancer. Breast cancer cases were the most common condition presented.

Patients were rarely present in the room where the meeting was held, but remained seated at the oncology waiting area, which was the norm during tumour board meetings. Only very occasionally were patients with very complex cases invited into the conference room, which this occurred twice throughout the 16-week observation period. When the doctors had decided on a course of treatment for a patient, the doctor who presented the case or sometimes the breast clinic nurse comes out and informs the patient at the corridor of the waiting area about the decision made. They would usually inform the patient (i.e., if the decision is neoadjuvant chemotherapy before surgery) that she has been referred to the oncology for a course of injections to make the lump smaller after which she will come back to the breast clinic and surgery will be performed for her. A patient who required upfront surgery will be informed that the doctors have decided she needed to come to the breast clinic for a date for breast surgery.

In sum, certain key behaviours were consistent during tumour board meetings. Patients and relatives were rarely involved in discussions. Although they received some information on the need for (injections) neoadjuvant chemotherapy, which is 'to shrink the tumour before mastectomy' but overall, there was limited information about the risks and benefits as recorded in the field note and interview extracts below:

Nurse A handed over an internal referral form to Dr A. Dr A then wrote patient details, staging and neoadjuvant chemotherapy followed by 'mastectomy' on the form. Dr A got up and walked out of the room to the oncology out-patient waiting area where the women invited for tumour board meeting were sitting. He stood at the corridor and called out, "Sister Adwoa" [loudly].

Sister Adwoa responded 'yes' and walked over to where the doctor was standing. Both Dr A and Sister Adwoa stood at a corner of the corridor. Dr A gazed at Sister Adwoa and said, "you have been referred to this oncology unit as all the doctors have decided that you will need to be given drugs to shrink the tumour before the operation" (Field note, 2017).

A second observation was that when HCPs were communicating among themselves, they talked about women's stage of disease, whether stage one; two or three and what that meant in terms of their treatment options and prognosis. However, whenever they communicate with patients, there was no mention of the disease stages. HCPs generalised all the curable stages when communicating diagnosis i.e., 'the cancer is localised in your breast'; 'it has not spread outside your breast'. Providing information in this manner does not empower patients to know about the different stages and the implication of each with respect to treatment options and prognosis.

It was also observed that HCPs sometimes intentionally use ambiguous terms when communicating with patients around their treatment. HCPs acknowledged that because of the misconception that mastectomy inevitably means 'death', and that when they inform women about the need to 'cut the breast' (mastectomy), they lose women to follow-up, they therefore intentionally used ambiguous terms like 'operation'. HCPs thus adopted an approach where they sometimes intentionally withhold certain information from the women in order to prevent them from refusing treatment.

*"not telling them straight away is better because they are scared of mastectomy" (*Field note, Tumour Board Meeting, 2017).

"using operation is intentional, we don't want them to run away" (Field note, Tumour Board Meeting, 2017).

Other HCPs were however not in support of this approach and encouraged the members to try and be open and explain everything that will be done for the patient.

"they have a right to know, if they are well prepared ahead of time, they can go through treatment well prepared" (Field note 2017).

On the whole, my general impression of behaviours in this setting is that HCPs led discussions around diagnosis and treatment and they provided patients with limited information about their disease stages.

4.4 Chapter summary

This chapter has described the clinic context and the background of the participants in this study. It has provided an overview of the clinic's structure, its artefacts, activities and events. In so doing, it portrayed that hierarchy existed in the clinic. Other issues described in this chapter were that although communication is in the local language, posters are written in English, which is less accessible to most of the women. Furthermore, there was limited engagement between patients and HCPs because of the busyness of the clinic and also because of simultaneous consultations. Additionally, during tumour board meetings, patients were not involved in treatment discussions or provided with information about the risks and benefits. Furthermore, patients were sometimes misinformed about the recommended treatment. Finally, there was lack of information or discussion about the costs of investigations and treatment. These observed behaviours rendered patients less empowered because they were denied the quality information necessary for effective treatment decision making. The next chapter presents the first overarching theme and explains the meaning of the practices and behaviours observed at the clinic. The theme also describes how the cultural context of Ghana influences treatment decision making for women with breast cancer.

Chapter 5 Hidden information around breast cancer and its treatment

The preceding chapter provided an overview of the breast clinic context including the people and the routine activities and behaviours seen at the clinic. This description allowed identification of some of the behaviours and practices that may influence women's breast cancer treatment decision making. This chapter first describes the overarching theme (second theme presented in the next chapter), which is hidden information. Next, it illustrates how this hiddenness is influenced by the wider structural and cultural factors including language; unequal power relationship; resource constraints; and fear of cancer disclosure and stigma.

5.1 Hidden information about cancer and treatment

Analysis of the data revealed a pattern in which quality information about the disease and treatment is hidden from patients. It is 'hidden' in the sense that accurate information on the basis of which women needed to make treatment decisions was not available to them. This was evident in the limited discussions around diagnosis and treatment during patient-clinician interactions. This was recorded in my fieldnotes and I provide an extract of the interaction between Dr C and Auntie Ceci in the text box below:

Extract from patient-clinician interaction

Dr C opens the four envelopes Auntie Ceci gave him and begins to glance through one after the other. Afterwards, he begins to copy the results of the tests into the folder. This last for about five minutes. He then raises his head to look at her and says "mother, all the test, they all say the cancer is only in your breast, it has not gone anywhere"

In the above extract, information about the stage of the cancer is restricted to 'the cancer is only in your breast, it has not gone anywhere'. This information does not reveal the exact disease stage although stage of the disease has implications for treatment options as described in 1.2.

In sections 4.3.3 and 4.3.4 above, it was observed that during patient-clinician interactions around diagnosis and treatment, much of the information about the disease stage, what the treatment will involve as well as what the expected outcomes will be for women including risks and benefits were hardly revealed. During interviews, when patients and relatives were asked about their thoughts around the diagnosis and treatment, most of them mentioned that they have not received much information about the disease and treatment.

“they have not really informed me of anything when I came to the breast clinic, the doctor made me go and do some tests and then I went to do some other tests too, but they did not really inform me anything…” (Maame Abigail)

“when I came, I have not been told much, so cancer I don’t know anything” (Sister Foriwaa)

“the doctors too they don’t tell you anything because she did labs and the doctor sees it, he just looked at it without saying what is in it” (Maame Mary’s daughter).

“Umm they did not say much, they just said they will give drugs and then they will do operation for her” (Maame Saa’s son).

The limited information and discussion provided by HCPs about the disease and treatment effectively hides this information from women. The way information about the disease and treatment is hidden is reinforced firstly by the language used during patient-clinician interactions.

5.1.1 Language

Diagnosis is provided as ‘cancer’ or ‘kokoram’. The word ‘cancer’ is an English word and although English is spoken in Ghana as a second Language, it is learned during formal education. This means people without formal education may have some difficulty with understanding what the word ‘cancer’ actually means. ‘Kokoram’ is the local Twi word for cancer, however, the reality is that there are over 40 languages spoken in Ghana amongst the different ethnic groups. The unfortunate issue is that these languages are limited in having words that provide an accurate description of cancer. As women who present to the clinic are ethnically diverse, this lack of appropriate language terms constitutes a barrier to their understanding.

A second challenge with language is that the Twi word ‘kokoram’ basically refers to all kinds of cancer (Basel Missionary Society, 1909). This word is used to portray an ulcerous condition (‘ekuru’) which is difficult to treat (‘koankro’) (Basel Missionary Society, 1909). From the local conceptualisation, ‘kokoram’ does not offer a full understanding of what cancer is, i.e., ‘an out of control growth of abnormal cells that can spread’ (American Cancer Society, 2018). Thus, the word ‘kokoram’ does not reveal the actual meaning of the disease.

Aside from the lack of definitive description of cancer provided by ‘kokoram’, there are limited words to explain certain concepts such as ‘the different kinds of breast cancer’; cancer staging;

metastasis; chemotherapy; radiotherapy; hormonal; and biologic therapies. This was evident during interactions with staff where breast cancer and the disease stage were simply explained to women in the study as ‘cancer behaves in mainly two ways: either it stays where it is; or it spreads to other places within the body; ‘the disease is localised in your breast’; ‘it has not spread beyond your breast’; ‘it has not gone into your stomach or lung’. Furthermore, it was also observed that chemotherapy was referred to as ‘cancer injections’ and radiotherapy was referred to as ‘heat’ by staff. The limited concepts to explain cancer and treatment means quality information remains unavailable to patients and constraints informed decision making.

A third issue with language is the content of posters at the clinic. The posters which are to disseminate information about cancer and treatment are written in English. English is learnt during formal education which makes the posters inaccessible to patients and relatives with limited formal education. Furthermore, investigation results are coded in medical terms and so people with little or no health literacy background may find some challenges in understanding the terms.

“Umm they have not said anything whether it is this or that. He said they will give drugs and then they will do operation for her, but the tests we went to do, I read the report and it says there is nothing but the histology report too when I read, I could not really make anything out” (Maame Saa’s son).

For this reason, while patients and relatives may have access to information in the form of posters or investigation reports but overall, their content may not be meaningful or helpful. The overall implication is that the language and terminology in this context hides quality information about breast cancer and treatment from patients and relatives.

5.1.2 Unequal power relationship

This sub-theme is used to describe the expertise knowledge of clinicians and how this influenced the behaviours of participants when they interacted around breast cancer and its treatment. Patients felt that care professionals know best (have expertise knowledge) about the disease compared to themselves. Since HCPs are the experts, they are the ones with power, patients felt they needed to submit to this power. Many of the patients felt that since they are lay people there was no need to ask questions about the disease and treatment even if they did not understand something. They would rather defer to the ‘experts’ (HCPS).

"Umm madam, I know if anything at all it is doctors who are going to do everything, so I did not ask question (Sister Lydia).

The need to acquiesce to authority therefore reinforces silence. Asking HCPs questions or raising concerns may be interpreted as challenging the authority, competence and professionalism of staff, and that they might receive poorer care as a consequence. For this reason, even when some patients do not understand the information they receive, they do not raise any concern about this. Patients felt that since they are the ones who need help, they need to be submissive to receive the required help.

"so I don't do anything that will sound that I am challenging them and be asking too much questions, so I need to come down so they also take care of me" (Maame Abigail)

"Mmm, I just sit waiting because I cannot be saying this or that, I don't think it is good to be complaining and asking questions, I can't be complaining, they are the ones taking care of us so I can't be complaining when I come to clinic, so I was there waiting to see what they will do next" (Maame Tawia).

When patients acknowledge this relationship, it means they are not active in pushing for information about the disease and treatment. This was evident during observation where patients were generally passive during patient-clinician interactions around diagnosis and treatment. As patients remained passive and hardly asked questions, many of their concerns about the disease and treatment remained unanswered and undisclosed.

5.1.2.2 Lack of talk/involvement of women regarding treatment

The unequal power relationship between women and HCPs led to a lack of discussion and involvement of women regarding their treatment. Sections 4.3.4 above described how when patients and relatives are invited to tumour board meetings, they wait outside, while the experts, the HCPs, discussed their treatments in their absence. Patients are thereafter informed of the outcome of the decision made. This is a clear power message where those with power, the HCPs, make treatment decision. As patients are not involved, it means patients are excluded from having their concerns heard or addressed. It also means, information on the basis for which such decisions are made are not available to patients. This results in further disempowerment of patients.

"I was expecting the doctor to talk to me when I do the test but he did not say anything…mmm, no one really tells me anything, even the day I went to the meeting we sat waiting for a long time, it was later the nurse came to tell me I will be coming to oncology for some injection, so I have not been able to talk to anyone, I don't really know what the treatment will involve" (Maame Tawia).

“as for me, I have not really been informed about the actual drugs because the doctor told me I should come to the meeting and there all the doctors will meet and discuss my treatment, so I was thinking they will tell me a lot when I go there but that day, the nurse, one nurse came to tell me that the doctors discussed and have referred me to that place the oncology, so they will give me drugs there so after that I will come back to the breast clinic and the doctors will do the operation for me, yes she said the drugs will help the lump to melt so the doctors can do the operation for me” (Maame Abigail).

Not only are patients not involved, but it was also discovered that HCPs sometimes hide the intended treatment from patients. As highlighted in chapter 4, HCPs used ambiguous terms like ‘operation’ to hide the intended treatment of mastectomy. This was recorded in my field note.

A woman came to the nurses’ station and stood close to Nurse B and greeted good morning with smiles (I perceived they knew each other). The nurse responded good morning. The lady asked whether the doctors were in. The nurse responded yes and told her that the consultant had mentioned to the nurses that he will need the lady to have made a decision concerning the upcoming breast surgery whether she was going to undergo the operation on the proposed date or not. I noticed the lady kept nodding that she was going to go through the operation (‘yes I will do the operation’). The nurse then went ahead to inform her that it is not only the lump that was going to be removed and that it was the entire breast. The lady was silent for a while and she looked surprised. She said the doctor said they will remove it (the lump) and that she did not know it was the entire breast that will be removed. She added no one had told her. I was very shocked at this revelation, I wondered how a woman who needed to make decision for mastectomy had no idea about it and thought it was rather a lumpectomy. Later, the nurse informed me sometimes the doctors do not use the word ‘mastectomy’ when communicating with patients about surgery.

Field note 2017.

This was very surprising although it later turned out to be a common practice. At one tumour board meeting, the HCPs were discussing another woman who was refusing mastectomy because she said she had not been informed it involved the removal of her breast prior to her beginning neoadjuvant chemotherapy. Rather, she was under the impression she would undergo a lumpectomy. The HCPs then openly acknowledged in the meeting that they sometimes intentionally hide the nature of the intended treatment from women to prevent them refusing it.

“using ‘operation’ is intentional, we don’t want them to run away” (Field note, Tumour Board Meeting, 2017).

In the above statement, two points are evident: HCPs acknowledge explicitly that they are in a position of power, referred to here as ‘awareness of power’ and this power is utilised to influence the behaviour of women and prevention ‘treatment refusal’ by ‘hiding information related to the intended treatment'. 'Hiding information related to the intended treatment' is used to denote 'handling of power'. Across the data, there were several instances that HCPs handled power to solve perceived problems.

"he just called one after the other and said something briefly that I will have drugs after they will do operation and remove it for me, so he did not sit down with me… he did not say he will cut the breast, he said he will remove the lump" (Sister Foriwaa).

Another example where HCPs indirectly 'handled power' was the practice of simultaneous consultations. The observation showed the large numbers of patients who attended the clinic, a situation exacerbated by the limited number of staff and consulting rooms available at the breast clinic. Consequently, HCPs resorted to simultaneous consultations to allow all patents to be seen and mitigate the problem of a 'busy clinic. Although the practice of simultaneous consultations may be outside HCPs control (due to limited resources), the reality is that simultaneous consultations reduce quality engagement during patient-HCP interactions as both patients and HCPs are not able to ask certain sensitive questions or discuss sensitive information. This was evident in some of the interviews:

"Mmm, the people in the consulting room were many, they keep coming to interrupt and ask him something and I was thinking me too I want to ask this question, but these people keep coming to the doctor to show him things, so the doctor did not get time, he could not get anytime" (Maame Tawia)

"…because I think it should be confidential, but there were people there, the other patients were there and the doctors looked busy so me when we came in fact the doctor did not speak to us directly that this is the issue and also they did not tell us in the first place if we can ask questions, secondly there was no time everything like a rush and thirdly there were other patient she seemed to be suffering, so the doctors attention was on that patient" (Maame Saa's son)

Patients and relatives felt helpless as 'lay people' about simultaneous consultations and frequent interruptions of HCPs during the medical encounter. But, as lay people, they navigate the clinic passively without raising concern about it with HCPs. Again, this practice reflects patients/relatives' deference to the more powerful position of HCPs.

HCPs admitted that simultaneous consultation is wrong because it deprives patients of their privacy and impact on effective patient-provider interactions, but the lack of resources means HCPs find themselves in a helpless situation.

"you know the problem we face here, there can be two doctors, three doctors or even four in one consulting room, it does not help, so if we had a big place where about six doctors will see patients in different consulting rooms at the same time, then things will go smoothly" (Doctor C).

HCPs handled the busyness of the clinic through the practice of simultaneous consultations to allow the clinic to run fast, but this is clearly disengaging for patients. As patients are less engaged, it impacts on quality patient-provider interactions. The resultant implication is that patients are less empowered with quality information about the disease and treatment, and this leaves such information hidden from patients.

5.1.2.3 Lack of discussion of treatment costs

Section 4.3.3 described the cost intensive nature of breast cancer for both insured and non-insured patients. HCPs and patients acknowledge these costs are one of their biggest challenges. HCPs stressed that the cost of investigations from diagnosis to staging is not covered by the NHIS and this creates a barrier for many of the women. As evident in 4.2.1, majority of the women were not economically independent. HCPs hence find discussions about money difficult because of the disempowerment it involves. HCPs therefore avoid discussions about money issues because they believed that for the majority of the women, diagnosis and staging alone drain all their financial resources. HCPs thus distance themselves from 'talks about money' because they believed money is a potential barrier for the women and they find such discussions uncomfortable and distressing.

According to HCPs, they do not want to talk about money because they find discussions around it distressing. The reason being that many of the women who attend the clinic are less empowered and so discussions around money may be interpreted by women as if they (HCPs) are the ones charging them those monies. The truth of the matter is, the breast clinic is run like a private clinic as all the investigations are performed by private companies (Fieldnote 2017).

HCPs not wanting to discuss treatment costs was recorded in my field notes when Sister Sara was interacting with Dr D.

"…Now what I am going to do is to write some investigation request for you to do. You will need to have chest CT, abdominal ultrasound, liver function test, urea and creatinine and full blood count. Do you have any question?" Sister Sara looks at doctor D as he talks and then replies, "how much do the things you are asking me to do cost?" Dr D (looks at Sister Sara), "I do not know but the nurses may be able to assist you. Field note 2017.

Although doctors refer patients to talk to nurses about money, the nurses do not divulge this information but rather ask patients to check at the various departments where the investigations are performed. Women therefore navigate the clinic not knowing how much it will cost them to have a requested investigation and or treatment.

“the doctor even told me to ask any question I do not understand, so I said that please, when it is time for me to come and do it, how much money will I pay because my main problem is money issue so how much money will they charge me then he said he cannot know the amount… when I asked him he said he does not know the amount I will pay, hmm, so in case I want to go and borrow money and the person asks me how much are they charging and then you are not able to say how much, how will the person get the money for you, so that is my problem” (Auntie Ceci).

HCPs also used their position of power to withhold information about some of the consequence of treatment from women to prevent the women from refusing treatment. For example, HCPs stressed that ‘in this setting’, breast cancer is usually diagnosed among women who are young, some of whom are yet to get married or give birth. They believed childbearing is valued in the setting and worried that since treatment may impact on women’s fertility, some of the women may be unwilling to undergo treatment. Also, there are limited resources to assist with fertility and reproduction after cancer treatment, with even the limited available fertility centres being very expensive, HCPs find difficulty in discussing fertility issues with women.

“childbearing is important in this setting, so it is also a problem we face…some don’t come back when we tell them treatment can delay or prevent childbearing and we don’t have resources to help women to conceive after treatment in this hospital” (Doctor E)

“one of women’s concerns is when they need to go through chemotherapy, how the drugs may affect future delivery, so it is a problem for us” (Doctor C).

In this case, due to the issue of childbearing and fertility being a potential barrier for women in accepting treatment, there is limited open discussion around this. This was evident in a few of the women’s narratives. Sister Lydia said she would like to have another child but she was unsure if this will be possible. Similarly, Natasha (28 years with one child) said she had plans with her husband to have three children but she suspects the treatment may have effect on her fertility though HCPs were not very forthcoming with information about it.

I was thinking about childbearing, that what if, so I am thinking will the chemo affect my ability to have other children, I want to have more children in fact it is a plan me and my husband made towards our life to have three children but it seems the way the doctors they were asking me do I have only one child, so it seems there is a question mark somewhere that they don’t want to bring it out” (Natasha).

The above description clearly depicts how HCPs used their position of power to limit open discussions around treatment and fertility and influence women to accept treatment. The lack of discussion means patients' concerns around fertility may not be addressed. It also means patients may not be equipped with quality information around the issue of treatment and fertility. This means such information is hidden from women.

5.1.2.4 Structural reasons which limit information

Aside from unequal power issues and resultant lack of information, limited resources also influenced quality patient-provider interactions. HCPs mentioned the problem that 'the job is plenty' (demanding) for them because they are not breast specialists but general surgeons which means they have other commitments from other surgery clinics. Consequently, they are busy and hence do not have ample time and resources to dedicate to breast care. For this reason, HCPs mitigate this workload problem by not following-up with women who attend the breast clinic.

"here we are not breast specialists, if we do breast today, tomorrow we are doing hernia, the next day goitre, the next day stomach cancer so it does not make the focus to be solely on the breast" (Doctor C).

"We do not have structured or routine follow –ups because it is not part of how we run the clinic…so sometimes we forget entirely about the patient until she comes back later" (Nurse D).

The lack of follow-up was recorded in my field notes:

Following diagnosis and treatment recommendation, there was no signposting of patients to any other source of information or support group outside the clinic, neither were patients provided with any follow-up contact to discuss their concerns outside the clinic. Field note 2017.

From the analysis, many of the patients, mentioned that following a life-threatening diagnosis, they reacted with sadness, confusion and fear and this means they were not able to be receptive of information or did not want to ask for clarification at the time of diagnosis. Hence, two patients mentioned they would have liked to have a follow-up contact for some information later on, but the lack of follow-up contact at the clinic means they were unable to do so.

"on that day, when the doctor told me about the results that it is cancer, hmm, all that I was thinking about was I am coming to die, therefore, all the things he said afterwards I did not hear anything at all. I heard him talking, but none made any meaning to me because all that kept coming back to my mind was the word cancer…so when I went home, I felt there is no telephone number to call but I wanted more information later on…" (Sister Adwoa).

The lack of follow-up could hinder patients' from discussing their concerns outside the clinic, but HCPs mentioned 'the job is plenty' or was very demanding and time-consuming for them which meant they were unable to follow-up with patients. However, the limited resources might also be an excuse for not following-up when staffs would rather not do so anyway, another expression of a power asymmetry. The reason is that the clinic was evidently busy with many patients attending the clinic, however, on many occasions, I observed HCPs being interrupted by staff from other departments of the hospital. I observed HCPs chatting with the staff from the other departments while patients were waiting to be seen or during patient-clinician consultations. My impression of this behaviour was that cancer diagnosis has been so routinized and normalised that it was practised in a manner devoid of quality engagement between HCPs and patients. A second issue is that since none of the clinicians were specialist in breast care, they may have lacked the skills necessary for quality engagement with women with breast cancer.

Overall, the analysis revealed a pattern where HCPs used their position of power in a way that hid information from patients either intentionally or unintentionally: 'the lack of discussion about the costs of treatment'; 'lack of talk around fertility'; 'intentionally hiding intended treatment by using ambiguous term'; lack of involvement of patients in treatment discussions; and 'lack of engagement with patients during simultaneous consultations'. These practices leave patients with inadequate information about the disease and treatment to make informed decisions. This, in addition to structural factors such as the high workload of HCPs and the lack of follow-up for patients, also limit information made available to patients. Consequently, HCPs continue to retain power (medical knowledge about the disease and treatment) while patients are disempowered by inadequate information relating to their own care.

The power asymmetry is also reflected in the clinic structures. For example, the physical demarcations of the clinic in-terms of physicians' spaces; nurses' spaces and patients/relatives' spaces clearly depict differences in the power relationship. The physical structures at the clinic highlighted the difference in HCPs authority and the patient/relatives as lay people.

5.1.3 Fear of disclosure and stigma

Another way that keeps information about cancer hidden outside clinical setting is fear of disclosure and stigma. From the analysis, cancer is a disease that people do not want to disclose to others in the community. There is a pervasive negative social reaction to cancer diagnosis and consequently, cancer is hardly talked about. This implicitly prohibits discussions about the disease in the community. Even if it is raised in discussions, cancer is referred to with euphemisms such as 'yade bone' (bad disease); 'saa yade bi no' (that disease). The lack of open discussion about cancer in the community hides quality information about the disease. Three main reasons emerged for lack of talk about the disease in the community: social stigma; fear of spiritual attack and preventing bad advice.

5.1.3.1 Social stigma

Most of the patients and relatives did not want to disclose the cancer diagnosis due to social stigma. They stressed that cancer has a poor prognosis driven by the high mortality rate associated with the disease. Two participants (one patient and one relative) feared that disclosing diagnosis means people in their community would talk about them and would not expect them to survive.

"I do not want others to know because if you tell people, it will go public and everyone will say ei this woman is suffering from cancer, she will not live long" (Maame Mary).

Many of the participants mentioned that disclosing cancer diagnosis can lead to public ridicule and exclusion. They feared that the news of their diagnosis will mean people will not want to associate with them. Sister Foriwaa mentioned that disclosing the cancer diagnosis will mean people will treat her as 'filthy' and that she is not worthy to be associated with.

"if someone hears it, they will 'declare' you that you are unworthy, you are not part of them, you so nobody wants to get close to you because you have this cancer the person will not be happy to come close to you and so you will be treated filthy. You are filthy because some people when they see someone has this disease, they don't want to associate themselves with the person" (Sister Foriwaa).

Similarly, Maame Tawia mentioned that she does not want other people in the community aside from her sister and brother to know about her breast cancer diagnosis as people will spread the news that 'one of her breasts has been cut'. The norm is that women have two breasts, but the news of her diagnosis will mean that she has lost one of her breasts which will lead to ridicule.

"if I tell people I have cancer, they will go about telling other people spreading it everywhere that yes this woman is suffering from cancer… the doctors have cut my breast people will spread the news that this woman they have cut her breast and they will be spreading it around" (Maame Tawia).

Due to the fear of stigma, there is unwillingness to talk about the disease to other people in the community. The lack of open discussions about the disease means people are not able to share their experiences, which reinforces the hiddenness of information about the disease and treatment.

5.1.3.2 Fear of spiritual attack

The second reason for fearing disclosure is the belief that when people with evil spirits get knowledge of the diagnosis, they will employ evil means to kill the patients in the spiritual realm. Due to this belief, there is general unwillingness to talk about cancer. Many of the patients mentioned that through spiritual means, people with evil spirits can use the news of the cancer diagnosis to prevent cure. As a result, the patient can have all the treatment but will never get cured, rather, it will lead to impoverishment as the patient spends all her money on treatment. For these reasons, many of the patients did not want to disclose aside from trusted friends and relatives. They used this metaphor, 'I do not want to sell my story'. For many of the patients and relatives, if you 'sell your story', the 'buyer' can choose to do anything she or he wants with it, including 'killing you' or 'preventing cure'.

"the reason why I don't tell someone is because, maame it is not every issue that we tell people, see, I have gone well in age, you see, even some people when you tell them about your issue, the person may have evil spirit…those who have evil spirits, they can do evil incantations in the spirit to block your chance for a successful recovery so what will be done for you, the evil spirit will break it that is why we don't sell our story" (Maame Saa)

Such superstitious belief hides information about the disease by limiting discussions about the disease in the community.

5.1.3.3 Preventing bad advice

The third reason that emerged from fearing disclosure is the belief that the patient may receive bad advice. The reason being that many people generally believed in traditional medicine, hence, disclosing one's diagnosis gives other people the opportunity to suggest women use traditional medicine. Sister Lydia's brother admitted that since many people believe in herbal healing, he has advised his sister against disclosing to anyone to prevent her from being advised to use herbal treatment.

"I think in this country when you are sick people will keep saying go and do herbal treatment and all that, that is why I discourage my sister from talking to other people about it" (Sister Lydia's brother).

The belief in the possibility of bad advice was documented during observation of an interaction between Dr E and Sister Lydia. Following diagnosis, Dr E cautioned Sister Lydia not to disclose the diagnosis to her mother because she would wrongfully advise her to choose herbal healing.

"You are married right (Sister Lydia nods) ok, so when you go home, only discuss your condition with your husband and not your mother because your mother will tell you to go for herbal treatment and that will not help you" (Field notes, 2017).

From the reasons enumerated above on disclosure, many of the participants were sceptical about disclosure. Relatives in particular wanted the diagnosis to be kept within the family in order to protect their loved ones. This was their family secret and should remain as such.

In summary, as people are not wanting to disclose the diagnosis or discuss cancer in the community, there is a possibility that people may not be able to share or receive quality information about the disease and treatment. The lack of open discussions around the disease in the community means information about it would remain hidden.

5.2 Chapter summary

This chapter has demonstrated that quality information about breast cancer and its treatment is hidden, not least, when HCPs recommend biomedical treatment. Lack of local terms to accurately describe breast cancer, unequal power relationship and beliefs around patient and clinicians' roles, as well as resource constraints limited discussions about the disease and its treatment. Outside the clinic context, stigma and taboos around cancer also hid quality information from women. In the next chapter, the second theme, 'filling in the gap' explains how the void created is filled in with lay explanations around the disease and treatment.

Chapter 6 Filling in the void with lay explanations around the disease and treatment

The previous chapter has shown that quality information about breast cancer and treatment is hidden from patients. This means that for patients, the actual nature of the disease and its treatment remains elusive. This chapter describes the gap created throws patients to their own stock of knowledge, past experiences and beliefs, information from their social network as well as the cultural context in which they live. For example, at the individual level, a woman's previous experience with biomedical or traditional medicine during the breast cancer event (recognition of breast cancer symptoms and/or diagnosis of breast cancer) reveal to her the effectiveness of that particular treatment. In this case, if a woman had used traditional or biomedical treatment but her breast symptoms had remained or worsened, then the woman perceives that treatment to be ineffective to treat the disease.

Women also gleaned information about the disease through interactions with their social network (family and friends). These interactions either occurred before their own breast cancer event or after the breast cancer event usually through disclosure. From interacting with their social network, women developed meanings and beliefs about breast cancer and the consequences of treatment.

To fill in the void, women also turned to information from the media (television, radio and internet) and outreach programmes. Information from these media reveal to women ideas and concepts about the disease and treatment held by the general public and wider than what they would receive from clinicians.

Finally, women's religious faith conveys meanings about the disease and treatment. Women consult their spiritual leaders to identify the cause of the breast disease or to find a cure. Through this, women developed meaning about breast cancer and its appropriate treatment.

Overall, women accessed multiple diverse sources and derived ideas and concepts to explain the possible causes of the disease and also anticipate the consequences of having or not having the recommended treatment. These explanations consequently influenced their treatment decision making. The theme 'filling in the void with lay explanations around cancer and treatment' emerged from the data where Dr D admitted that during patient-clinician interactions, patients do not ask questions and HCPs are also not divulging as much information as they should, consequently, there is a lot of gaps about the disease and treatment which women fill in with misinformation.

"So, if women are not able to ask questions and we also don't give much information, it contributes to us losing them because there is a lot of misinformation. What I will say lot of gaps so they begin to fill in the gaps themselves with wrong information, they begin to assume oh ok the doctor said this,

so it is like they have the information A and information D but they don't have B and C so they themselves assume the B and C then if that information happens to be wrong then that is it, we lose them" (Dr D).

Using six sub-themes (table 6.1 below), this chapter elaborates the explanations, ideas and concepts about breast cancer and treatment which influenced the decision-making process.

Table 6.1: Main theme and sub-themes

Main theme	**Sub-theme**
Filling in the void with lay explanations of breast cancer and treatment	Describing of breast cancer
	Causes of breast cancer
	Consequences of biomedical breast cancer treatment
	Traditional medicine
	Anticipating high financial costs of treatment
	Filling in the void with religious beliefs

6.1.1 Describing of breast cancer

The malignant nature of breast cancer means the cancer cells can spread to other organs in the body and potentially cause death by blocking the essential functions performed by some vital organs. However, at the local level, though women knew the disease is life-threatening, they tended to name it by its observable symptoms or by the fact that it is difficult to treat. For example, women mentioned that breast cancer is a 'lump in the breast'; a 'bad/evil boil' (a boil difficult to treat); a 'hard mass' and a 'sore in the breast'. These descriptions are used to portray the outward manifestation of the disease and the fact that it is difficult to treat.

"Breast cancer, what I know is that it is a bad boil" (Maame Mary)

The use of symptoms of the disease in its description is reinforced by the content of health information messages in the media like television and radio as well as those of breast out-reach programmes. They disseminate information about signs and symptoms of breast cancer including ‘lump in the breast’; bloody nipple discharge and ‘peau d’orange’. These signs and symptoms therefore describe the disease.

“I felt something, a hard mass in my right breast, so I said to myself what is happening to my breast, so there is this woman in my house and she said to me she will like to have a look so she saw it and she said ah they have been announcing on the radio that breast cancer, your breast will become hard” (Sister Foriwaa).

These health messages, although correct, give women the impression that breast cancer is a ‘symptomatic disease’. This perhaps reflects a country that does not offer routine mammographic screening to women at risk of the disease and hence will have to rely on signs and symptoms of the disease as triggers for health seeking. Indeed, all the patients in the study experienced one or more breast cancer symptoms prior to attending the breast clinic. One of the implications of perceiving breast cancer through its observable symptoms is the question of whether the cancer is still present in the absence of that observable symptom, and consequently the relevance of some of its treatment. If breast cancer is described as a breast lump, then questions could arise as to the significance of undergoing breast surgery in the absence of a lump.

For example, Sister Akos mentioned that she is struggling to understand why the doctors will remove the breast after completing cancer injections (chemotherapy). She is considering herbal treatment which will melt the lump without the need for mastectomy.

“*the doctor said the treatment, they will give me injection, and after they will remove the breast, and me too what me is beyond my comprehension is that even after I finish taking the injections they will still remove the breast,…as for the herbal doctor, he will give me some herbs that will melt the lump without the need for any operation” (Sister Akos).*

From the quote above, Sister Akos is questioning the need for breast surgery after completing chemotherapy. In this case, the absence of the observable symptom may seem to suggest an absence of the disease which means women could question the need for further treatment.

6.1.2 Causes of breast cancer

Cancer is a disease whose origin is not exactly understood. Many of the women did not know where to place its aetiology. Other women who talked about its cause struggled to link cancer to an exact cause and described its cause within the cultural context of ‘bayie’ (witchcraft); ‘ntoyare’ (bought disease) and ‘ahonhom bone’ (evil spirits). These women believed the cancer had a spiritual causality and blamed other people for the disease. This was particularly the case when women found difficulty in associating themselves with some of medical explanations they have been hearing in the community and in the media e.g., not breastfeeding after childbirth, not having had a child, then what made sense to them was attributing it to spiritual cause.

"I think about it that what exactly brought about this condition, that is what I think about that how did this illness affect me because I have heard that some people are saying it affect those who have never had children but me too I have children so I never thought something like that can affect me because when I give birth, I give them only breast milk so I was surprised that it came to affect me…it was at the prayer ground that while we were praying that the pastor revealed that some people want to give me breast cancer so the pastor gave me water to wash the breast so I went to wash the breast, so as for that pastor he saw it and told me before I came to the clinic" (Sister Lydia).

In this case, women believed some people (including family members; friends or neighbours) who possessed mystical powers had brought the disease upon them. These people were either witches or people with evil spirits who did not like them and hence inflicted the disease directly or bought the disease in the supernatural realm and inflicted it on them.

"my mother, she thinks it is a witch that is causing the cancer…" (Maame Saa's son).

The belief in spiritual causality is reinforced by the teachings of women's spiritual leaders.

"the pastor said he has seen a lump in my breast and that he saw some people putting something like tt ball (tennis ball) into my breast and that he has seen that it is being orchestrated by some evil people (Auntie Ceci).

Three women were informed directly by these spiritual leaders that an evil person is inflicting them with breast cancer. Other women were not informed directly but the advice from their spiritual leaders suggested the cancer could be perpetrated by an evil person.

'my osofo (pastor) said let's do the spiritual part, so that if it is anything causing the disease spiritually, then we can defeat it' (Sister Foriwaa).

Women find explanations as to why witches or evil people inflicted them with cancer, mostly through their social circumstances. For example, one woman attributed disagreement between herself and her sister as a possible underlying cause. Another woman believed her engagement in her trade may have aroused envy from some evil people.

"Some people when they see you up and about, it irritates them so if someone has 'evil eye' and they see you going about your trade, they are not happy with you (Sister Lydia)".

In this case, breast cancer was a symptom of social tensions and envy within the family or community. The perception of breast cancer in this sense has implication on whether biomedical treatment will be effective in treating the disease. If breast cancer is blamed on spiritual causes, then, biomedical treatment may not be effective. Spiritual means is needed to expel it.

Not all the women believed in spiritual cause of the disease. Some women tried to speculate causal factors such as poisonous chemicals sprayed on foods. The consumption of such foods may have contributed to developing the condition.

"the chemicals in our food is too much, previously you go to farm and pluck your vegetables and eat them fresh but now all vegetables like tomatoes, pepper and those things on our market are not wholesome, they have sprayed with chemicals even the meat we eat are not good so all these things will bring many such diseases yes" (Madam Abigail).

Auntie Twumwaa says it could be caused by wearing a second-hand brazier because her sister who died from breast cancer used to wear second-hand brazier. She added that she has also heard on radio that breast cancer could be caused by not having had a child.

"I can't really tell because when my sister (referring to the one who had breast cancer) was alive she used to wear foos brazier (second-hand brazier) *…but I also heard it being said on the radio that if you don't have a child, it could also cause it" (Auntie Twumwaa).*

Other causes that were speculated by women include 'not breastfeeding' and familial tendencies.

I was just thinking where from this, where did I get it from, I have not seen anybody who died out of it in my family, but my father has prostate cancer so maybe the cancer is running through my father's line (Natasha).

Thus, breast cancer was not only associated with spiritual causes but also to other non-spiritual causes including environmental factors; familial predisposition; and personal situations (not having had a child; not having breastfed after childbirth). This indicates that lay explanations can be a complex mix of folklore and scientific explanations. The significance of lay explanations of causalities lies in the appropriate action to take. Whether linked with a spiritual cause or not, the unfortunate reality is that cancer is a disease whose treatment has not been very successful in Ghana evident by its local labels 'koankro'; 'evil' and 'bad'. For this reason, women may hesitate when deciding on the biomedical treatment.

6.1.3 Anticipated consequence of biomedical treatment

The study showed a course of action women could take was having biomedical treatment. However, during the decision-making process, women rely on lay explanations of anticipated consequences of the treatment on themselves and loved ones. Women evaluate these anticipated consequences and depending on the value they place on each; they may decide whether or not to persevere with the recommended treatment.

6.1.3.1 Anticipating a lack of cure or death with biomedical treatment

Women have seen or heard of other people who have died from breast cancer in the community, hence the perception is that cancer is a disease that is intractable because there is no cure for it. Women's thoughts, particularly their initial thoughts, were that they were going to die and that there is no cure.

"what I have heard is that as soon as one is diagnosed with cancer, the person will die because it cannot be cured" (Sister Adwoa).

Closely related to this belief is that 'mastectomy equals death'. Mastectomy, one of the main treatments offered to patients with breast cancer, is believed to equate to death. This perhaps reflects a country where most women with the disease present in advanced stages and when chances of survival are poor regardless of biomedical treatment. Nevertheless, women's lay explanations did not link dying from mastectomy with the stage at which the disease was presented. Dying from mastectomy was perceived to be caused by the use of the surgical knife to cut the breast. Women voiced views such as 'my breast that the doctor is going to cut, I will not survive long'; 'what I have been hearing is that as soon as they cut the breast, then you die'. This belief is mostly gleaned from anecdotal stories within the women's social network about what happened to other people with breast cancer in the community.

"According to some informants, the woman went to the hospital for it to be removed but when they removed the breast, she died between 3-5 months, the woman, she came to the Southern hospital and the doctors said they will cut the breast. As soon as they cut the breast, within 3-6 months the woman died. So, when they told me, I felt that I am also going to die and leave my children" (Maame Mamuna).

The death that results from mastectomy may not only be a physical event but could also be a spiritual event. Women believed that if the cancer has spiritual causality, then the person with evil spirits will use the operation as a means to kill.

"so, if in your family, the disease has been bought for you by an evil person in the family, when the doctors use the knife to cut it, then the evil person in your family will use the operation as a means to kill you" (Auntie Ceci).

This implies that in lay explanations, scientific evidence that stage of disease correlates with survival may not always hold as other influential factors like spiritual causes may be more important and deterministic of survival.

The fear of mastectomy leading to death or the belief in the incurability of cancer could lead women to decline the recommended biomedical treatment. Indeed, five of the women decided not to persevere with biomedical treatment (three of them changed their decision at the time of interview and reasons provided in this and the next section) because they either believed the treatment was fruitless or mastectomy would kill them.

"when I came, the doctor mentioned operation and I became afraid so I went away and did not come back, it is because I am an old woman and people have been saying things at home that it is scary, that if you do the operation, so many issues, you will die so that is why when I came and the doctor mentioned it, I run away" (Maame Saa).

Although the study showed that some women did not want to persevere with the recommended treatment due to belief of incurability of cancer and that mastectomy leads to death, this was not always the case for everyone. Some women were aware of survivors in the community or received contact of survivors (from significant others) following their diagnosis and shared these survivors' experiences. Other patients shared the experiences of peers in the clinic who have completed some phases of treatment. Survivors gave women hope for cure and encouraged them to persevere with the recommended treatment including mastectomy. For example, Sister Adwoa recounted that she initially decided not to continue with treatment because she believed breast cancer means death, but after sharing an experience with a survivor, she changed her attitude about the incurability of the disease.

"when I came to the breast clinic and I was told the diagnosis, I told my employer and she asked me to go and speak with her mum because she has done those treatment before as she also had breast cancer and so she (the proprietor's mum) knows a lot about the cancer…I was encouraged because

she had breast cancer and had her breast cut (mastectomy) for about 20 years now but she is still alive so I changed the way I used to think that when you have cancer you will die" (Sister Adwoa).

Thus, knowledge of survivors influenced some women to choose biomedical treatment because they anticipated possible cure with biomedical treatment.

6.1.3.2 Anticipating biomedical treatment will control disease progression

Although many women perceived cancer was incurable even with biomedical treatment or that having mastectomy would lead to death, there were a few other women who were optimistic that biomedical treatment would prevent disease progression. Often, these were women who have had previous negative experience with traditional medicine. Women's previous experience of using traditional medicine during the recognition of breast cancer symptom and/or diagnosis left them with feelings that their symptoms have remained or worsened. Women described poor outcomes with traditional treatment including persistence of lump, painful breast, bloody and or offensive nipple discharge. Based on the poor outcomes of using traditional medicine, the women were now anticipating that the recommended biomedical treatment would heal them and/or relief their symptoms.

I was using herbal medicine, but I was not seeing any improvement with the herbal preparation, when I smear on the breast, I don't feel pain, but the thing inside did not melt, it was still hard inside, so maybe that is not where my healing lies (Maame Mary).

Maame Saa and Maame Akyiaa feared mastectomy would kill them and declined biomedical treatment but they changed their decision in favour of mastectomy at the time of interview due to disease progression.

"…I did not want to come back because I was afraid the operation will kill me, but when I went to do the herbs…my breast, is paining me now and blood is coming out so now I have agreed to do it …" (Maame Akyiaa).

The quotation from Maame Akyiaa explains that she opted for traditional medicine following diagnosis due to fear that mastectomy would kill her. However, when her symptom worsened, she decided to persevere with biomedical treatment. In such cases, in the absence of information, women learned by experience and this informed them about the disease.

Women's observation of other people's negative experiences of using traditional medicine in the community also informed women about the consequences of disease progression. Some women had observed a relative or a member of the community with breast cancer who suffered with offensive gangrenous wounds and pain after using traditional medicine. Hence, for these women, the distressing symptoms of disease progression could be avoided with biomedical treatment.

"I saw one man in my village who had the disease but did not go to the hospital, he used herbal treatment, but the wound became big, he suffered a lot, the stench from his wound, it was difficult to get close to him…if I don't use hospital treatment, I will suffer same fate, just like the man I saw in my hometown, that one will not help me…my children cannot even get close to me (Auntie Ceci).

The narrative from Auntie Ceci revealed she feared that when the disease progresses, the odour from the breast wound may prevent her children from getting close to her, in order to avoid this, she is deciding to follow-up with biomedical treatment.

Although some women considered the possibility of controlling disease progression with biomedical treatment, however, with regards to how urgently they are to be treated, women felt this was not within their control. There were other tensions that they needed to manage. This included the availability of resources, e.g. money to pay for treatment.

6.1.3.3 Anticipating biomedical treatment will interfere with gender roles

Locally, a woman is often compared to the mother hen where she is known to cater for her young ones. This is implicit in the popular Akan idiomatic expression, 'akoko batan na enim de ne mma bedi' (it is the mother hen that knows what her chicks will eat). Thus, women are expected to ensure commitment to catering for their young ones, such as breastfeeding.

Two women anticipated that mastectomy would impact on their ability to breastfeed. They worried that a woman who has mastectomy will be constrained by the absence of a breast and affect the performance of this nurturing role.

"I asked him if I could breastfeed with the affected breast in future because…I know breastfeeding is important, but he told me that with the surgery, they will take the entire breast" (Sister Adwoa).

An inability to breastfeed can impinge upon accepted social norms. For example, Natasha describes how mastectomy will impact the normal social behaviour around breast feeding, which includes breastfeeding in public and alternating the breast during breast feeding. The inability to perform this role will be interpreted as a ‘deviation from the norm’, and her concern is evident in the following extract in which she plans to disguise the absence of a breast from the public gaze.

“I was thinking am I going to breastfeed with only one breast and someone who does not know I have had mastectomy will say ah, why don’t you give the baby the other breast too, what am I going to do? so I was just thinking of those things… I keep telling myself I will say oh the child has finished taking that breast (Natasha).

Natasha’s description reveals how mastectomy is a threat to the performance of her nurturing role. The taken for granted everyday life of breastfeeding and offering two breasts during breastfeeding will now have to be contemplated. Contemplations on how to restrict societal gaze or answer questions from the members of the community.

The nurturing role of women is not only limited to that of breastfeeding but includes provision for the family’s upkeep. Although traditionally, men are the bread winners in the family, the symbolism of a woman to the mother hen highlights the unique role of women in ensuring their children are well catered for. Catering for children’s needs includes feeding, education and healthcare. However, for some women, they anticipated that mastectomy would lead to an inability to provide for their children’s upkeep.

Maame Mamuna for example describes how mastectomy could lead to loss of strength and confinement to her room and consequently cheat her out of feeding, educating and catering for her children.

“I know the woman (employer) may be able to help me with money to pay the hospital bills for the operation but if I go now what will my children do? She may help me with money for the operation but when that is done and I come back, and become confined to my room, what will my children eat? When I went for the previous operation and was hospitalised for 5 days and came back home, did anybody come to ask whether me and my children have eaten or not eaten? Who will ask? And who will I also ask to bring me food for myself and my children to eat?...This room I live , who will come and pay the rent for the children to sleep in, the school he attends who will pay for his fees? what he will eat who will give to him? (Maame Mamuna).

The third nurturing role that emerged was housekeeping. Women feared ‘cutting of the breast’ will reduce their strength with resultant implication of an inability to perform housekeeping. The socialising of women as housekeepers is the point of reference in these issues. Mastectomy hence is anticipated to lead to the loss of strength to perform this very role and consequently threaten the identity of the women.

"I did not want to let them cut the breast, even my mother said I should stop because I was thinking about the family because as a woman I do all house chores, I take care of the home, take care of my ailing mother so I thought if the doctors cut the breast I will not be able to do all the things I used to do" (Sister Sara).

6.1.3.4 Anticipating biomedical treatment will lead to loss of fertility

One concern for some women in the child-bearing age was that of fertility. Some women talked about their desire to have a certain number of children, but they expressed worry about the possible effect of the disease and or treatment on their fertility. For example, Sister Lydia describes how she wanted to have another child but feared the treatment may reduce her ability to have one.

"I wanted to have another child when my son- died but now because of the treatment, I may not be able to go through childbirth again" (Sister Lydia).

The concern of these women stems from the fact that as women in their prime they have previously had no problem with childbearing prior to receiving the diagnosis. The proposed treatment is making them re-consider this identity.

6.1.3.5 Anticipating changes in body image and identity with biomedical treatment

Some women were concerned about how the treatment will impact their appearance and includes changes in skin colour, loss of hair and a breast. Women feared the change in body image would reveal the cancer diagnosis to the public. Women felt the changes that would occur in their body would mean a deviation from 'normal' to outsiders. Having two breasts is the 'norm' for a woman, therefore, mastectomy would remind them of the change to their body and would bring sadness to them. It would be a constant reminder about their deviation from the normal appearance of a woman. The symbol of femininity is traditionally presented as a woman with two full breasts. This has long been portrayed in puberty initiation rites by ethnic groups in southern Ghana where females displayed their breasts as a sign of transition into an adult female. For some women, mastectomy is an affront on womanhood.

"the thing is I am alive and 'sebe' (a word used as a sort of apology before uttering something unpleasant) nobody will be happy to let doctors remove her breast while she is still living, to be honest, as a woman, I would not want my breast removed because it is part of me as a woman and nobody prefers something evil to happen to her (Auntie Twumwaa).

“I was concerned that I will wake up one day and I would not find one of my breast, as a woman having only one breast bothered me a lot so that was my concern” (Natasha).

The absence of one breast may also set the woman apart from other women because it will identify her as ‘sick’. Auntie Serwaa anticipates mastectomy will identify her as a ‘sick person’. Becoming a sick person is undesirable, it is an unacceptable role because it will disrupt the performance of day-to-day activities (norms).

“hmm madam when the doctor said operation, I think about it because when they remove the breast, I will become ‘yarefo’ (will become a sick person), I cannot go about my duties as before, I cannot do anything hm” (Auntie Serwaa).

Similarly, Sister Lydia describes her daily life as one which involves trading in the market. Based on what she has heard from a friend in the community, she feared the side effects of chemotherapy will darken her light skin and also lose her hair. She describes such changes as looking ‘shabby and unkempt’ and worried that such changes will prevent her from going to work and engaging in social activities.

“when the doctor told me, I was thinking about it a lot and was crying with this treatment can I go to work without looking ‘basaa’ [shabby], what I am thinking about is that I won’t look ‘basaa’ that my fair skin won’t get darker so I cannot go to work… Sister Lydia).

Thus, biomedical treatment could let women perceive themselves differently from the way they used to be. The undesirable changes that cancer treatment (chemotherapy) can have on one’s body may also reveal the diagnosis to other people in the community highlighting the stigma associated with this disease. Although stigma concerns emerged strongly, none of the participants were deciding against treatment due to stigma. This indicates that tensions may arise among women’s values, in which case women prioritise according to the value they place more weight upon. For example, the narrative above indicated that Sister Lydia was concerned biomedical treatment could lead to changes in body image with possible implication of stigma. At the same time, biomedical treatment was anticipated to delay disease progression and prevent the ‘pain, malaise and being in a vegetable state’. She eventually decided to persevere with biomedical treatment in order to relieve her symptoms (restore her health).

6.1.4 Traditional medicine

The popularity of traditional medicine was evident in the study. In many of the women's narratives, it served as another option to biomedical treatment particularly with regards to its undesirable consequences. For example, the fear of death from undergoing mastectomy led some women to choose traditional medicine. Sister Akos believed biomedical treatment would lead to death. She believed this could be averted with traditional medicine, and her mother was also supportive of this option.

"…my mother said she knows someone who died when doctors cut her breast…traditional medicine herbs too, I can get cured without removing my breast" (Sister Akos).

Similarly, Maame Tawia describes the lack of money to pay for breast cancer care following diagnosis as the reason that led her to choose traditional medicine, in this instance, herbal treatment. The herbal medicine was cheaper and more easily available where she lived.

"me too I don't have any husband to support me, it is my brother I go to for help and he too he is on pension, so going to him all the time for money was uncomfortable for me, so because I did not have money to come to the clinic and me too I did not want to sit doing nothing about it (the disease), I went to get some herbal concoction to apply on it…" (Maame Tawia).

HCPs recount that patients use traditional medicine before, during or after presenting to health facilities due to the trust the public have in them and the official recognition they get from policy makers. One consultant expressed his views about traditional medicine as follows:

"Umm, those people are our competitors, they are alternative to the care we give here but those people because of politics, policy makers are even fuelling it, they are making them thrive yes… the public trust them too, secondly, it is not like us healthcare workers that the law forbids us to go and make certain advertisements but them they can say anything they want they can say anything at all and their words are very persuasive so if you are ill you will not come to hospital you will rather go to them" (Doctor B).

The narration above further describes the role of the media in disseminating information about traditional medicine and cancer cure and thereby providing patients information about their treatment options, something that is rarely and inconsistently provided by HCPs at the breast clinic. The information provided by the traditional healers in the media (mostly via television and radio) may be misleading but nevertheless portrays traditional medicine as a cancer cure. This means traditional medicine is widely viewed as an alternative, and equally effective treatment modality for cancer. Some women may therefore be drawn towards this mode of treatment rather than biomedical treatment.

6.1.5 Anticipating high financial cost of biomedical treatment

The lack of information about the cost of treatment from HCPs means women do not know the amount of money they should expect to pay for treatment. However, as evident in chapter four, women make substantial payment towards breast cancer management as they need to pay for diagnosis and staging and would still be expected to make contributions and top-ups towards treatment. Since women are not informed of the total amount they will pay for treatment, a few of them interacted with peers at various phases of treatment at the clinic who informed them about the cost of treatment. For example, Sister Sara and Sister Adwoa were informed by peers that cancer injections cost over 500 cedis (£90) per visit. Similarly, Sister Akos was informed by a peer that the treatment has cost her close to 24000 cedis (£4000). As women learn from their peers about cost of treatment rather than HCPs, it is possible they receive misleading information, but, the reality (based on the evidence gathered at the clinic records) is that the treatment is costly for the ordinary Ghanaian.

When women were asked about their concerns, most expressed cost of treatment as their major challenge. Women anticipate high financial cost of biomedical treatment, and the need to mobilise funds in order to access it. The mobilisation of funds can deplete the family of its resources. Sister Akos for example describes how she utilised all her savings.

"…all the investigations I have done so far, it is around 17 million (~£300) that is my business capital, I have spent everything, now I don't have money…" (Sister Akos).

Women also anticipated other hidden costs of breast cancer treatment. For example, they will need to travel from their towns to the city where the hospital is located, so, for many of these women, there were concerns around transportation costs. For other women, following up with care at the breast clinic meant not being able to engage in economic activities, which led to a loss of income.

"money is my problem, since I started coming to clinic, I don't work anymore, so my daughter is the one supporting me, she gives me money to feed, they also do contributions to pay my transportation and come to the clinic, hm" (Auntie Serwaa)

"I used to buy goods and sell but since I started coming to the breast clinic I have not opened my shop" (Maame Abigail).

Most of the participants had no independent economic means, so, treatment and other hidden costs could be a barrier to the persevering with the recommended treatment. As this is a disease described as 'koankro' (incurable), a continued dependence on others for some form of financial support towards its care is implied for patients. Indeed, the study demonstrated that patients relied on family members and friends for financial assistance. One consequence of this financial reliance social networks is that patients may lose control over the choice between treatment options. For example, the analysis showed that for three women, there was tension between the family's choice and their own. Sister Foriwaa said her children supported her upkeep and added that her children have also paid for the investigations she has undergone thus far. However, she had also wanted to buy herbal drugs to treat the disease, but she had to listen to her son's advice to receive only the conventional treatment

"I will say it is my eldest child because he says he agrees to what the doctor says, so I should follow the doctor's treatment and I also said okay, because when I called him and said there is this drug they sell at the information centre, I am going to buy it, but he said Maa, don't go and buy any drug, I should listen to what the doctor is saying so I said okay and I stopped…Umm, you see this children they are my everything and me too I don't want to do anything that they don't like and they are good children they support me everything they pay for the photo and all the things the doctor requested so I don't want to do anything they won't be happy with" (Sister Foriwaa).

Similarly, Sister Sara's brother in the diaspora and Sister Lydia's brother cautioned their sisters that if they chose any treatment aside from the conventional treatment recommended by the breast clinic, they would not continue to provide financial assistance.

"umm my brother, the one abroad says I should agree if the doctor's say they will cut the breast, because he said nothing will happen to me if they cut my breast but if I make up my mind to do herbal treatment, then that one he will not bring any money for it" (Sister Sara).

6.1.6 Belief in God as the healer

All participants described themselves as belonging to a particular religious faith, mostly Christianity. Regardless of the faith, all participants have shared belief in God's providence, one of which is 'health'. Participants believed in God as the provider of health. Due to this belief, participants mentioned that their healing lies with God. Participants believed that without God, everything will be in vain. It is God that gives healthcare professionals the knowledge and skill to treat, which means if God does not intervene, then everything that is done will be in vain. Participants used expressions such as: ‘God does what he wants,’ ‘it is only when God intervenes that everything will work out well’; ‘even the doctor, it is God that will show him the way’; ‘as for me I tell God everything and he is the one taking care of me’. Patients believed in God for bringing healing regardless of whether they believed in spiritual or physical causality. The healing God brings is spiritual which needs to happen before it manifests physically. The general belief was that God is the end to all means without whom no healing will be achieved.

Belief in God as the overall healer helped women to cope. They believed that although the disease or treatment may shorten their lives and treatment may reduce their quality of life, with the help of God, that situation can change.

“…so, the treatment may affect it (fertility) but it is my prayer and faith that says I will just bring forth a baby right after the treatment” (Natasha).

Women were involved in all kinds of spiritual practices. ‘Asofo’ (pastors) and ‘Odiyifour’ (prophets) are consulted (before, during or after attending the breast clinic) who may uncover the cause of the breast cancer. The belief was that if there is any spiritual causality, then the pastors and prophets may uncover that and pray against it. Through prayers, they can invoke God to bring them healing. Following diagnosis, all the women have been involved in one spiritual act or the other. Most of the women attended prayer sessions and have been praying with the support of their pastors and prophets and also on their own at home, and with the support of their families.

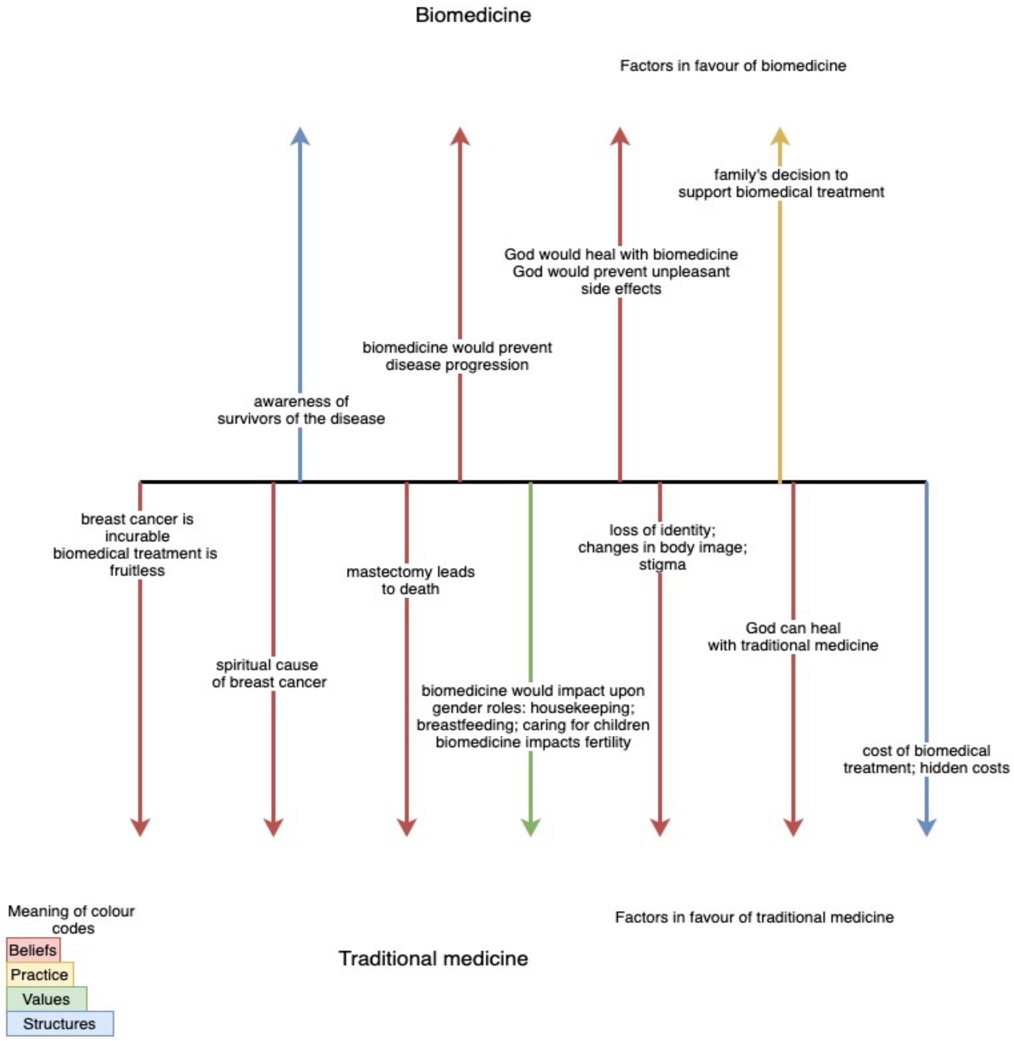
“I have been speaking to him, the pastor and going for prayers, and he said oh something that he saw and prayed against why did it manifest, so he said he will continue to pray with me, I go there on Fridays and sometimes on Sundays for him to pray for me” (Sister Lydia).

The belief in God for bringing healing may influence women to choose spiritual healing over biomedical treatment especially when women also believed the disease has a spiritual cause. Again, the belief in God as a healer working through care providers may influence women to choose both physical treatment (biomedical or herbal) and spiritual healing. Choosing spiritual healing in combination with biomedical treatment or herbal treatment illustrates the way medical pluralism is practised by women in southern Ghana.

6.2 How the cultural context influences treatment decision making

Within the context of Ghana, quality information about breast cancer and treatment is limited creating gaps in knowledge about the disease and its treatment. Women rely on friends, family, spiritual leaders, community and their own experiences for information and explanations about the disease and treatment including treatment consequences on themselves and their loved ones. These explanations, together with the structural factor of the high cost of biomedical treatment, influenced women's decision making regarding biomedical treatment. Some of the factors were positive and provided women with a reason to choose biomedical treatment, while others were negative and provided women with a reason to reject biomedical treatment in favour of traditional medicine. The positive factors are referred to as pull factors for biomedicine, pulling women towards biomedicine; the negative factors are referred to as push factors, pushing women away from biomedicine towards traditional medicine (see figure 6.1).

Figure 6.1: Factors in favour or against biomedicine



As indicated with the colour codes, the factors in figure 6.1 reflect the beliefs, values, practices and structural concerns that influence women's breast cancer treatment decision making. As can be seen, there were many more factors in the form of beliefs, values, practices and structures pushing women away from biomedicine and towards traditional medicine than there were pulling them towards biomedicine. This indicates a strong influence on women against receiving biomedical treatment.

The pull factors include an awareness of survivors of the disease. Knowledge of survivors increases trust of women in HCPs and biomedical treatment. Women believed that as other women have survived the disease with biomedical treatment, they could also survive the disease with biomedical treatment, hence their decision to choose biomedical treatment. The next pull factor is the belief that biomedicine would prevent disease progression. Women's prior negative experience with traditional medicine diminished their trust in traditional medicine. They subsequently believed that biomedical treatment would prevent disease progression. The third pull factor is the belief that God would heal them with biomedicine or prevent its unpleasant side effects. These women decided they would choose biomedical treatment, but they would combine it with spiritual healing in spite of the tension between the two.

However, although women may have decided to undergo biomedical treatment due to these pull factors, the reality was that patients also faced financial challenges with paying for biomedical treatment. Patients reported the financial burden of treatment, the fact that health insurance does not offer coverage for most of the cost of treatment, and transportation costs as they often needed to make long journeys to the hospital. Women felt this financial challenge may hinder them from persevering with biomedical treatment. These issues suggest that even for patients who decide to commence biomedical treatment (because they believed it would lead to cure or prevent disease progression), the associated costs are a potential structural barrier to them finishing prescribed treatment. Thus, within the cultural context of Ghana, the treatment costs disempower women who have low and uncertain incomes, in contrast, traditional medicine appears more affordable, accessible and with fewer unpleasant side effects.

Moreover, the last pull factor (figure 6.1), which is the decision by a woman's family to fund biomedical treatment, may cause conflict when what the woman wants and what their financially supportive relation wants differ. This represents an unequal power relationship. For example, since the option of having biomedical treatment is decided by the person with powerful influence on the woman (family member paying the treatment), should the woman have an alternative source of funding for treatment, there is uncertainty as to whether the woman will persevere with biomedical treatment. Moreover, should the family member's decision change or if that source of funding ceases, then there is a possibility that the option of receiving biomedical treatment may also change. This suggests a case of uncertainty in the future as to whether the woman will persevere with biomedical treatment.

6.2.2 The pull factors for traditional medicine

The study demonstrated several factors that can pull women towards traditional treatment. These factors include the description of breast cancer as an incurable disease. If the disease is incurable, it means biomedical treatment is ineffective. This can deter women from using biomedical treatment. Furthermore, the attribution of breast cancer to a spiritual cause questions the potential effectiveness of biomedical treatment, because there is an inherent conflict between faith and science. This belief can deter women from biomedical treatment. Also, the anticipated consequences of biomedical treatment such as death from mastectomy; inability to perform gender roles (housekeeping, breastfeeding and taking care of children's needs); changes in body image and stigma; and fertility issues can push women away from receiving biomedical treatment and to strongly consider the default treatment, which is traditional medicine. The availability of traditional medicine, and the publicity it gets from the media (television and radio) that it can melt breast lumps without the need for surgery, further encourage women to choose traditional treatment over biomedical treatment.

On the whole, as mentioned above, the fewer number of pull factors for biomedical treatment compared to those pushing against biomedicine suggest that within the context of Ghana, a woman with breast cancer is likely to be more strongly influenced by factors that prevent her from opting for biomedical treatment than facilitate or encourage her to do so. The reason for this is even if she decides to choose biomedicine as a result of the pull factors, the reality is that she will need to make payment before receiving care, and this can create a barrier for timely access to biomedical treatment. This, however, also implies that although the diagram is a representation of all the factors that have been identified in the data, nonetheless, at the individual level, each participant will experience these factors differently and not necessarily all of them. For instance, a woman may believe having mastectomy means she might not live long, she may still choose mastectomy to prevent the poor quality of life associated with disease progression. Similarly, another woman could choose traditional medicine not necessarily because she believed more in its efficacy, but because she does not have money to access biomedicine. Thus, at the individual level, the factor(s) influencing the uptake of biomedical treatment may vary from one woman to the other.

Chapter Summary

This chapter has demonstrated that information gleaned from women’s individual experiences, family and friends, community, the media and spiritual leaders strongly influence them against biomedicine. In addition, the cost of treatment is high. All these considerations push women away from biomedicine and towards traditional medicine.

Breast cancer treatment decision making is not a simple straight forward decision of having or not having biomedical treatment. Rather it is a complex inter play of beliefs, practices, values (e.g. gender roles), resource constraints, economic powerlessness and access inequalities. These issues will be conceptualised through the cultural lens and discussed in relation to the literature within the next chapter.

Chapter 7 Breast cancer treatment decision making: perceived through the lens of the cultural context

This study explored how the cultural context of Ghana influences treatment decision making for women who have been diagnosed and are considering whether or not to start treatment. The objectives set out in this study were to explore: (a) the beliefs, (b) values (c) practices and (d) structures that influence breast cancer treatment decision making. Participant observation and in-depth interviews were conducted at the breast clinic on women diagnosed with curative breast cancer, their self-nominated relatives, doctors and nurses. The findings from the study adds to knowledge by providing explanations that local contextual factors hide quality information needed for effective decision making and also push women away from biomedicine and towards traditional treatment. The findings go some way to explain why women in Ghana present later after diagnosis and consequently have poorer outcomes than other countries. This chapter discusses the findings in relation to the existing literature on factors influencing breast cancer treatment decision making among women in Africa.

When discussing the findings, it is important to reflect upon the extent to which the aim and objectives have been achieved. Chapter 4 was mainly about the behaviours (i.e., practices) and structural issues at the breast clinic impacting diagnosis and treatment recommendations. This included women's passivity and deference to HCPs; HCPs leading discussions; lack of involvement of women during treatment discussions and lack of communication around the cost of treatment. These practices prevent or obstruct the availability of the quality information needed for informed treatment decision making (objective c).

In chapter five, the factors (uncovered through interviews) underpinning these practices were outlined. For example, women's belief in passivity as a lay constructed role and HCP's belief in acting in patients' interest were some of the reasons provided for their behaviours (objective a). Other structural factors identified included resource constraints with resultant lack of privacy from simultaneous consultations; high cost of treatment and language deficiencies (objective d). Furthermore, a belief in a cause originating from a spiritual attack, and a belief that disclosure would lead to social exclusion and ridicule all contributed to the hidden nature of information around the disease and treatment (objective a).

Chapter six highlighted that patients fill this gap in available information with misconceptions and folklore widely accepted in their community. While some women believed treatment could potentially lead to a cure or longer survival, other women drew on prevalent beliefs about the incurability of cancer and a belief that mastectomy inevitably leads to death (objective a). These beliefs together with the values women had regarding continuing with their normal activities and roles (housekeeping; breastfeeding; taking care of children) (objective b); their faith in God and belief in spiritual healing (objective a), strongly influenced women in their decision-making about treatment. Many of these influential factors push women away from biomedicine and pull them instead towards traditional medicine. This chapter will highlight these influential factors under structures, practices, beliefs and values to provide a clearer understanding. The final section integrates the four contextual factors (beliefs, values, practices and structures) with the two overarching themes identified in chapters five and six.

7.1 Structures

This section discusses three structural factors- financial resource of individuals, resources at the clinic and issues around language.

7.1.1 Financial resources and impact on the individual and family

The decisions women make about breast cancer are impacted by women's wider socio-economic circumstances. Economic situations in the country are challenging. A majority of the women had limited formal education which means they had less opportunities for any formal employment. The women were either unemployed or self-employed as traders or farmers. Women earned irregular incomes from these activities that were barely adequate for them to be self-sufficient towards their daily upkeep, even without the cost of healthcare. Consequently, financial constraints were a major challenge for women as they influenced their decisions regarding uptake of biomedical treatment in this study.

The issue of financial barriers to uptake of breast cancer services have been reported extensively in the African literature (Egwuongwu et al., 2012; Clegg-Lamptey et al., 2009; Pruitt et al., 2014; Wright et al., 1997; Oguntola et al., 2011; Ukwenya et al., 2008; Anyanwu et al., 2011; Ntekim et al., 2009; Anarado et al., 2015; Mc Ewan et al., 2014; Sanuade et al., 2018). The similarities in findings suggest that financial difficulties continue to be a persistent problem influencing timely uptake of breast cancer treatment in the continent and this requires urgent attention. It is important to note that cancer services in the biomedical sense are a scarce resource in many developing nations. Aside from the cost of the cancer care services, transportation costs influenced decision making around breast cancer in this study. Although this finding contradicts O'Brist (2014), who reported distance to health facilities was not a significant problem impacting on women's uptake of cancer treatment, it does support that of Ukwenya et al. (2008). The reason for this is that all the available breast care centres are located in urban centres; therefore, the high cost of treatment coupled with the need to travel long distances and also pay for the cost of transportation is extremely challenging for the ordinary person already facing economic hardships. This suggests that biomedical care will exclude the poorer members of society, and also push them towards traditional treatments which are readily available and more affordable in rural communities.

Ghana does not have a developed welfare system, and as a result, patients have limited financial support towards receiving breast care that they will need to pay for treatment themselves. Also, the report from O'Brist et al. (2014) that breast cancer services are covered by the NHIS in Ghana is challenged by the findings of this study where women had to pay for this service before receiving treatment. This finding from this study also demonstrates that healthcare access is not necessarily a basic right in Ghana. One consequence was that patients often relied on families to support payment of breast cancer care with the result that families were key in the decision-making process; a practice very common in Ghana. Some family members decided the type of healthcare the patients should access, if they were to continue to provide them financial support. The role of the family in the decision-making process towards healthcare should never be under-estimated in Ghana as family members can decide whether patients could have biomedicine or traditional treatment. This implies that decision making power is under the control of whoever has the resources to fund care (which could be anybody e.g., husband, sibling, child or parent) which can lead to tension between the patient and family concerning the treatment option to choose. This finding has been reported in other studies from the continent where families decided against biomedical treatment or in favour of biomedical treatment (Clegg-Lamptey et al., 2009; Mc Ewan et al., 2014; Pruitt et al., 2014; Anarado et al., 2015; Wright, 1997). The reliance on family for support towards breast care may also have the effect of further impoverishing families who seek to support the payment of cancer services for their loved ones. In lower income countries like Ghana, experts have documented that chronic diseases propel patients and their families in a ripple effect of poverty because over 60% of healthcare costs are financed out-of-pocket (Sanuade et al., 2018; Coast et al., 2016). This makes the cost of breast cancer treatment, including associated hidden costs, an important factor in treatment decision making as it creates a significant barrier in accessing biomedical treatment.

7.1.2 Resources at the clinic

In addition to financial barriers impacting timely access to treatment, the few clinics that offer cancer care have limited or non-existent resources to effectively deal with breast cancer and this impacted on treatment decision making. This finding resonates with that of Sanuade et al. (2018) in another teaching hospital in Ghana and Pruitt et al. (2014) in Nigeria where limited resources influenced breast cancer treatment uptake. In this study, the teaching hospital where the breast clinic was located was a referral hospital for malignant cases for over 10 million people living in the northern, middle and some southern parts of the country (Ghana Statistical Survey, 2010). The clinic can hence be overwhelmingly busy for the limited number of staff at the clinic to effectively engage with patients.

Improving quality engagement between patients and providers requires time, facilities, appropriate education materials and expertise which this study found to be mostly lacking. The large numbers of patients meant HCPs at the breast clinic did not have sufficient time or resources to conduct extensive exploratory conversations with patients about their illness and treatment. The busyness of the clinic meant HCPs prioritise getting the work done, and also put patients under a degree of pressure to avoid being too demanding. Seeing many other patients in the waiting area can make it seem to a patient that it would be self-centred to take up what they feel to be disproportionate share of the doctor’s time. Patients were not able to adequately engage with HCPs to express their fears and concerns about the disease and this influenced their decision making.

The WHO (2010) has emphasised the needless suffering of patients with cancer in developing countries due to the almost absent response capacity in these countries. The WHO (2010) stressed that cancer burden in developing countries like Ghana is growing, but there is limited capacity response across the whole continuum of cancer control (prevention, public education, screening and early detection, diagnosis and treatment). They further added that the demand of diseases like cancer is huge (WHO, 2010) but most health systems in developing countries in Africa are designed to deal with infectious diseases. In many of these countries, there are no facilities, equipment, infrastructure, financial resources, staff or training to deal with cancer. For example, in this study, the limited resources resulted in HCPs conducting two or more consultations in the same room at the same time. The practice of simultaneous consultations means patients lacked privacy. Lack of privacy for patients with breast cancer has been reported in a previous study by Wright (1997). Clearly, across the country, policy makers are not providing adequate resources for cancer care, hence, staff at the clinic take on the burden and adopt measures to mitigate this challenge. However, this practice wherein patients lacked privacy contradicts professional ethics (Ghana Nursing and Midwifery Council, 1997). Therefore, although resource constraints are a clear issue that needs addressing at the policy level (e.g., improving staffing levels and number of consulting rooms), simple measures can be adopted by HCPs to improve privacy for patients. This includes partitioning a room with a screen so that one patient does not see the other during consultations.

The other resource factor is the lack of breast specialists at the clinic where only HCPs with generalist training care for patients with cancer. Since they are generalists, HCPs may not have the skills and expertise to be able to meet the needs of such patients, which are potentially complex. Indeed, it was often the case at the clinic that patients were not given any specialist attention particularly with regards to their psychological concerns including their fears and worries. This was also a finding of Clegg Lamptey et al. (2009) in a study of 89 women with breast cancer. The authors reported that although women reacted with shock, fear and devastation at their diagnosis, they did not receive any counselling support or opportunities to express their fears. It is almost a decade ago, yet, the similarities in findings highlight the continued neglect of women’s psychosocial concerns. When patients are not able to share their concerns, they will not be revealed, and the finding implies HCPs target the physical aspect of the disease, while the psychosocial aspect of the illness is overlooked despite its importance in the decision-making process. This pushed some women away biomedicine towards traditional medicine.

7.1.3 Language

The next structural factor that impacted decision making was language and this finding mirrors that of previous studies by Asobayire and Barley (2014) and Wright (1997). Patients and HCPs communicated in the local language, ‘Twi’ and when HCPs offered explanations about the women’s cancer stages and treatment, there were clear hindrances to this as a result of limited concepts to describe the disease and treatment. Although this finding is similar to Wright (1997), the latter found that ethnic differences between black patients and the White physicians in Groote Schuh Hospital in South Africa were such that both parties were not able to communicate about the disease in a way that both could understand. This differs from the study reported here in the sense that both HCPs and patients communicated in the same language (despite some differences in ethnic background), but there were nevertheless limited concepts in the local language to explain the disease and the various treatment approaches. Indeed, the way language masks patient-provider interactions and understanding of cancer in Ghana is a unique finding of this study. The limited concepts in the local language were exacerbated by the limited formal education of patients because they could not speak English well. For instance, in this study, three-quarters of the 16 women had either basic or no formal education at all. Although this finding contrasts with some studies conducted on the continent where many of the participants had at least high school education (Anarado et al., 2015; Adejoh and Olurunlana, 2016; Pruitt et al., 2014; Clegg-Lamptey et al., 2009; Ntekim et al., 2009;

Egwoungwu et al., 2012; Ukwenya et al., 2008), it nonetheless compares well with reports from the Ghana Statistical Survey in 2010. According to the 2010 census report, the literacy rate of people aged 15 years or more (both men and women) was 58%, but the rate for females is lower of around 49.8%. Limited formal education may impact on effective-patient provider interaction as it can limit understanding of medical matters by patients, and this finding supports that of Ukwenya (2008) in Nigeria and Dedey et al. (2016). In Ghana, the prevalence of people who can understand and appreciate effectively medical information concerning treatment, medication and disease aetiology (i.e. health literacy) is low (Amoah and Philips, 2018). Amoah and Philips (2018) used the Swedish Functional Health Literacy Scale with 779 rural and urban adults in Ghana and found that only 32% reported having sufficient health literacy. Indeed, in this current study, even among the six participants with formal education (four patients; two relatives), two mentioned they could not understand the information in their medical reports. Some of the underpinning health literacy issues are that in terms of access, health information materials are few and those available are written in English, which may not be accessible to patients who do not understand the language. Also, although some health information may be disseminated through television and radios, the medium of communication is sometimes in English (Norman, 2015), which suggests that many Ghanaian listeners who do not understand the language are excluded. Moreover, although the internet is increasingly becoming a medium for accessing health information, as at 2010, only 7.8% of the population 12 years and over had access to the internet (Ghana Statistical Service, 2010). Thus, the contextual issues are such that many patients have insufficient understanding of health and or medical information to engage with doctors to discuss their medical conditions and what the treatment will involve. Consequently, patients were less empowered with effective information. This impacted on treatment decision making as patients relied on information from other sources, most of which were misleading.

Overall, there is overwhelming evidence linking structural factors such as economic powerlessness; limited concepts in the local language and formal education; and inadequate resources at the breast clinic to quality engagement and uptake of biomedical treatment. This issue has implications for policymakers insofar as it is strong call to action to look at effective ways in addressing these barriers. One way is for policy makers to give cancer a higher place in development agenda both at the national and international level. The WHO (2000) has long called for developing nations to have cancer control programmes that are appropriately prioritised to meet the needs of the people. This is suggested to include a combined effort from both governmental and non-governmental experts and stakeholders to develop policies acceptable and affordable to the people for whom they are intended.

At the level of the clinic, HCPs would require more training to increase their awareness about the issues impacting breast cancer treatment decision making. Although some of the issues (financial barriers, formal education; accessibility to health information and language) are outside HCPs control, HCPs nevertheless need to be aware of the vulnerabilities of patients who visit the clinic and create an enabling atmosphere to engage patients and explore their concerns. HCPs could further collaborate with key stakeholders so that information in appropriate formats e.g., videos and pictures are provided to supplement information and enhance the description of the disease and treatment.

7.2 Practices

Two key practices were found to influence breast cancer treatment decision making. The first was a set of hierarchical behaviours and actions performed by women and HCPs as they interacted; and the second was the practice of traditional medicine.

7.2.1 Hierarchy and deference

The study demonstrated that women were passive and deferred to HCPs and this finding reflects previous findings from Nigeria (Adejoh and Olurunlana, 2016). Women's passivity and deference indirectly influenced treatment decision making because patients believed that they, unlike HCPs, did not have any expert knowledge about the disease and treatment and therefore assumed they had nothing to contribute. Consequently, they were not keen on being involved in effective discussions around breast cancer treatment (Adejoh and Olurunlana, 2016) and left them susceptible to misleading information from other sources. This finding is similar to and supports that of Anarado et al. (2015) where lack of information and support from nurses created gaps that threatened adherence to prescribed chemotherapy courses among women with breast cancer in Nigeria.

High levels of defence to authority figures reflects the Ghanaian hierarchical society (Norman, 2015). In hierarchical cultures, children and young people's responsibilities and behaviours are usually decided by others in the community, with the understanding that this is in both the child's and community's interest (Hofstede, 2001). Older people are esteemed within the community because they are regarded as superior to younger people and are reservoirs of wisdom (Norman, 2015; Hofstede, 2001). These traditional ideologies therefore hold that behaviours, norms and practices should be in agreement with hierarchical obedience and preference for harmony (Hofstede, 2001). Young people therefore need to be submissive to older people. In the family and in social circles, people show respect for seniors and seek their opinion when making decisions (van der Geest, 1998). Deference to HCPs, not least doctors, is an extension of deference to authority in everyday life. It is believed that doctors have acquired wisdom and expert knowledge from education (Norman, 2015). Consequently, there is an expectation amongst people that they should submit to the advice of doctors and allow them to make decisions that affect their interests (Norman, 2015).

This traditional practice limited patients' active involvement and participation in discussions about their treatment options and ensured they avoided voicing their preferences and priorities. This practice reinforced a hierarchical patient-provider relationship. Because doctors served as authoritative figures, they believed women did not understand the implications of their medical condition and hence decided the treatment for the women. In order for harmony to prevail during the clinic encounter, patients would acquiesce to doctors' recommendations about treatment (often by simply nodding) although patients sometimes expressed concerns about the treatment decision once outside the clinic.

There were other practices at the clinic that were clear signals of the hierarchical relationship. An example is the protocol and formality at the clinic which gave prominence to inter and intra-professional communication between doctor and nurse and between consultant, residents and house officers rather than between HCPs and patients. Consequently, even in the middle of consultations with patients, staff could be interrupted by their colleagues, sometimes, for quite considerable periods of time and this was found to be disengaging for patients to share their concerns.

Another practice amongst HCPs was conscious miscommunicating of the treatment intent to women with the aim of influencing their decisions; another finding unique to this study. It was evident in the study that the hiding of treatment intent (especially mastectomy), usually until the last moment (surgery phase of treatment), could be problematic as it could be shocking to the woman to realise the nature of an operation at the final moment. It could also mean the woman may not have had the chance to grieve (Kubler-Ross, 1969) the potential loss of the breast, which may impact on the woman's decision making.

Other hierarchical practices were that HCPs often did not provide adequate information about treatment consequences or the cost of treatment, which again limited the information available to women about the disease and its treatment. This finding contrasts those of Adejoh and Olurunlana (2016) who found HCPs provided patients with sufficient information about treatment effects, but it very much supports findings of Adewale et al. (2008), Egwoungwu et al. (2012) and Clegg-Lamptey (2009) and may explain why patients' knowledge about the disease and treatment were limited even after presenting to health facilities.

This finding clearly suggests that hierarchical practices, although they may be valuable within the community, have a detrimental effect on patient-clinician interactions and the sharing of quality information needed for informed decision making. This is a strong and unique finding from the study that needs addressing in order to improve effective treatment decision making regarding breast cancer. Although it may be difficult because it is engrained in the culture, but an awareness of its constraints is nevertheless an important initial step, and HCPs should be aware of the limiting and constraining effects of hierarchical practices on treatment decision making. HCPs should encourage patients to express their opinions, preferences and priorities by limiting the practices that obstruct such expression. One way this might be facilitated is by minimising interruptions at the clinic. Although junior doctors will still need to seek advice from clinicians about the patients they are seeing, such interruptions should be kept to a minimum in order to send clear messages that patients matter and that HCPs focus and attention is on them.

7.2.2 Traditional medicine

The second key practice that influenced treatment decision making is the practice of traditional medicine in the country. Traditional medicine offers a competing modality to biomedicine in terms of disease explanations and healing methods, hence, it influenced women in their decisions regarding treatment choice for breast cancer. Research conducted in Ghana and in other African countries has found that traditional medicine influences advanced breast cancer presentation and non-completion of recommended biomedical treatment (Aziato and Clegg-Lamptey, 2015; O'Brist et al., 2014; Clegg-Lamptey et al., 2009; Ukwenya et al., 2008, Wright, 1997). Traditional healers propagate concerns about cancer treatment and promote themselves as offering herbal or spiritual healing without the need for surgery. Advertisements for traditional treatments are conducted in the community and on radio and television, and their attractive message of cure without surgery draw women towards accepting traditional medicine. Traditional medicine enjoys the same legitimacy and popularity as Western medicine (Saleh, 2013), and is supported by claims that such practices enhance cultural continuity (WHO, 2013). The importance of traditional medicine to cultural continuity is evident in this study when women mentioned they have been successfully practising traditional medicine for all sorts of health-related problems. Additionally, their availability and affordability make treatment costs comparatively low and this was also evident from this study. The WHO (2013) has stressed that all medical systems fall short, therefore, in their quest for health people compensate for the deficiencies within the two systems by employing both traditional and biomedical healing services.

However, from a biomedical perspective, traditional healing practices have not proven effective against curing breast cancers (Aziato and Clegg-Lamptey, 2015; O'Brist et al., 2014). Moreover, traditional medicine has consistently been linked with advanced cancer presentations (Clegg-Lamptey et al., 2009; Clegg-Lamptey et al., 2015; Sanuade et al., 2018). Thus, there is an absence of evidence surrounding the cure of cancer with traditional medicine, and this should be made clear to women. The issues around traditional medicine and cancer control are complex, and to address these would require complex measures including, first and foremost, a political will from the government (WHO, 2013). This is particularly important because although traditional medicines have long been practised in Ghanaian societies, it is clear that structural factors/policies legitimise and strengthen their use in the country. From this perspective, improving cancer control would thus benefit from commitment from the government and the traditional and biomedical practitioners. A typical example is that of Komfo Anokye Teaching Hospital (KATH), which provides training for traditional healers in Kumasi to refer suspected cancer cases to KATH and not to treat them exclusively with traditional means (O'Brien et al., 2012).

7.3 Beliefs

Women's decisions about breast cancer treatment were influenced by a number of beliefs. This included a belief in a spiritual cause; belief in incurability and/or death from mastectomy; and belief in God.

7.3.1 Belief in a spiritual cause

The belief that breast cancer was caused by 'bayie' (witchcraft), 'ahonhom bone' (evil spirits) or 'ntoyare' (bought disease) reflects findings from several other studies conducted on the continent (Asobayire and Barley, 2014; Pruitt et al., 2014; McEwan et al., 2014; Wright et al., 1997). In the African belief system, illnesses, particularly those whose aetiology are less understood, or those that are intractable and unpredictable are ascribed to the direct actions of supernatural entities such as, gods, spirits or ancestors (Hellman, 2007). In this case, the poor breast cancer outcomes in the community help in forming this superstitious belief about the disease aetiology. Thus, biomedicine and traditional medicine offer contradictory explanatory models, which previous evidence has shown leads to misunderstandings, between patients and HCPs during consultations and to treatment non-completion (Pruitt et al., 2014; McEwan et al., 2014; Wright, 1997).

Secondly, the belief in spiritual causes means the woman would rather commit to the practitioner (spiritual healer; prophets; pastors) who can explain the illness in more familiar cultural terms involving the spiritual aspects of their lives which reflects and supports prior findings of Wright (1997) and De-Graft Aikins (2004). The authors of these two studies found that in traditional Ghanaian and other African societies, health is seen as a balance between people and their social, natural and supernatural environment. Physical symptoms can manifest when there is a disturbance of any of these environment, and divine healers (juju men or fetish priests) have traditionally been consulted because they were believed to know about the origin, significance and treatment of ill health. Their approach to healing was the calling on of deities (De-Graft Aikins, 2004; Wright, 1997) who were believed to be able to counter the evil forces causing the ill health. The women believed the diviners were best placed to provide healing for the breast diseases inflicted on them by supernatural forces (Wright, 1997).

In contemporary Ghanaian society, the divine healers have been replaced by Charismatic Pentecostal churches (De-Graft Aikins and Koram, 2016) who offer spiritual healing usually through prayer and fasting carried out in prayer camps. Based on this belief, a third of the women in this study consulted their spiritual leaders (prophets, pastors) because they believed these people possessed the divine spirit of God to counter the supernatural force causing the disease. These prophets also reinforce the spiritual causal theory and either advocate solely for spiritual healing or for a combination of spiritual and biomedical healing. A woman in this study declined biomedical in favour of spiritual healing and reflects findings from a Nigerian study where women similarly declined biomedical treatment for spiritual healing (Pruitt et al., 2014). Thus, belief in a spiritual cause of cancer supports earlier studies and influenced decision making by pushing women away from biomedicine.

The attribution of spiritual cause to breast cancer is a great challenge to cancer control. HCPs should be aware of their contribution to propagating the myths and beliefs around cancer and the fact that it pushes women towards traditional medicine. They should therefore engage more with patients and increase the knowledge base about the disease amongst patients. Evidence from Adejoh and Olurunlana (2016) in Nigeria suggest this might be helpful for effective and informed treatment decision making. Furthermore, there is a need for widespread public education and breast cancer awareness programmes to enlighten people about the disease.

7.3.2 Belief in incurability of breast cancer/death from mastectomy

When women were diagnosed with the disease, it aroused strong emotional reactions. The reactions were shock, confusion, fear and sadness. Some of the reactions were related to the belief that breast cancer is incurable and therefore they were going to die; a finding that supports those reported from Ghana, South Africa and Nigeria (Oguntola et al., 2011; Clegg-Lamptey, 2009; Wright, 1997). Indeed, in Ghana, this fear is not surprising considering that the study by Clegg-Lamptey et al. (2009) found that over 60% of breast cancer patients did not know of any survivor. When women believed the disease was incurable or that they would inevitably die, they questioned the need to pay huge sums of money to fund treatment that did not work and decided not to persevere with the recommended treatment. Not only did the incurability of cancer give women reason to decline treatment, but also the fear that cancer will lead to death especially after mastectomy.

Fear has been identified in several studies conducted in Africa as a dominant theme preventing the engagement, uptake and continuation of treatment (Meachem, 2016; Pruitt et al., 2014; Egwuongwu et al., 2012; Clegg-Lamptey et al., 2009; Ukwenya et al., 2008). Fear driven by anecdotal stories concerning other women who died from the disease after undergoing mastectomy resulted in mistrust of biomedicine and HCPs in treating the disease. This supports the findings of Oguntola et al. (2011) who reported that women in Nigeria who believed biomedicine aggravated breast cancer did not return to complete biomedical treatment.

A few of the women in the present study had their fears heightened following disclosure of their diagnosis to their trusted social network. The family of these women often reaffirmed this social belief that biomedical treatment involving ‘cutting of the breast,’ will necessarily lead to death. This reinforces the belief that it is the mastectomy that kills regardless of the stage of presentation. Five out of the sixteen women initially considered not to persevere with biomedical treatment due to fear that cancer is incurable and that mastectomy leads to death. However, of these, three returned later to the clinic to persevere with treatment after their symptoms worsened.

For a life-threatening disease, it is to be expected that women would react with fear, and this again highlights the need for quality engagement with patients to share their feelings. As fear strongly influences women’s decision making, structured counselling that explores women’s fears and concerns should be integrated into the clinic to provide appropriate support for women. This is indicated in studies conducted in Nigeria and Egypt where although women were fearful, information on hope of recovery with treatment allayed women's fears (Adejoh and Olurunlana, 2016; McEwan et al., 2014).

Knowledge of survivors was also found in this study to allay women's fears and gave women hope for cure and trust in biomedicine. This encouraged women to opt for biomedicine. This finding therefore supports previous evidence reported by Adejoh and Olurunlana (2016) and Mc Ewan et al. (2014). However, the difference between the current study and the previous findings of Adejoh and Olurunlana (2016) is that women in that study engaged in discussions with HCPs and shared their concerns and fears about the disease with them. Additionally, the women received follow-up contacts from HCPs where they were able to discuss their concerns outside the clinic. This increased their hope for cure and motivated them to take up treatment (Adejoh and Olunrunlana, 2016). In this study, survivors of breast cancer and women's family and friends provided patients with information (that was not forthcoming from HCPs) about the disease and acted as cues to the uptake of chemotherapy and mastectomy. This compares well with Anarado et al. (2015) in Nigeria where the absence of nursing support on information about chemotherapy was supplemented by survivors and peers which led patients to accept and cope positively with chemotherapy.

Aside from knowledge of survivors, previous experience with poor outcomes of traditional medicine reinforced beliefs in biomedicine for preventing disease progression, and this often persuaded women to decide in favour of biomedicine. This finding reflects and supports earlier studies on breast cancer treatment delay in Africa (Wright et al, 1997; Clegg-Lamptey et al., 2009; Ukwenya et al., 2008; O'Brist et al., 2014). When women used traditional medicine and found it to be ineffective, they modified their perceptions about biomedicine and returned to biomedical treatment (Agbeko, 2017; Aziato and Clegg-Lamptey et al., 2015; Clegg-Lamptey et al., 2009; (Sanuade et al., 2017; Aziato and Clegg-Lamptey, 2015). What this current study also importantly adds is that women who had witnessed a neighbour or relative experience disease progression with traditional medicine subsequently developed mistrust for it and consequently decided to choose biomedicine. Thus, firsthand experiences and information about other people's experiences are influential in women's decision making. This indicates that when newly diagnosed women share in the experiences of other women with the disease, newly diagnosed women can receive information and support regarding their fears and worries. A structured survivorship programme integrated into the care of women at the clinic therefore promises to be beneficial, although this is currently absent from the clinic. HCPs themselves acknowledge the need for a structured survivorship support group integrated into the care of women, but they seem to recognize challenges with this. The lack of time and resources on the one hand, and the issues of stigma on the other hand seem challenging for a successful survivorship programme. Nevertheless, evidence from this study demonstrates the strong influence of survivors' experiences on new patients' decision making. Consequently, there is an urgent need to engage stakeholders (care providers, patients, policy makers) to explore the concept of peer support and how it can be adopted and adapted as a model of supportive care at the clinic. The need for context specific adaptation is particularly important taking into consideration resource constraints and stigma issues.

7.3.3 Belief in God as healer

Belief in God as healer and controller of events strongly influenced women in their decision making by acting both as a pull factor towards biomedicine and as a push factor away from biomedicine and towards traditional medicine. Thus, 'belief in God' had an influence in either direction (i.e. traditional medicine or biomedicine) and this finding is congruent with findings from previous studies conducted in Ghana and other African countries (Aziato and Clegg-Lamptey, 2015; Anarado et al., 2015). Such strong faith in God is in line with the culture of Ghanaian and many other African societies where an interventionist God is perceived as a powerful interventionist Supreme. As reported in prior studies in Ghana, women believed God would heal them, provide them with a new breast or with money to continue with treatment (Aziato and Clegg-Lamptey, 2015; Opoku et al., 2012). Women in this current study, however, did not voice the belief that God would provide a new breast, nonetheless, they were hopeful that God would heal them, prevent them from experiencing the unpleasant and dreaded side effects of treatment or pave the way for a loved one to help with financial support towards treatment. Due to the strong faith in God, women were engaged in religious acts of prayers, fasting and singing following diagnosis. This finding mirrors other studies where a high prevalence of attendance of churches and prayer house and camps were found among cancer patients in Ghana and Nigeria (Anarado et al., 2015; Aziato and Clegg-Lamptey, 2015).

However, belief in God sometimes created tension between spiritual healing and biomedicine particularly when women believed that God would cure them without the need for surgery. Nonetheless, a consistent finding among all women (regardless of their decision for traditional medicine or biomedicine) is that it helped them to cope. Many studies conducted elsewhere have found improved psychological well-being (in terms of depression, anxiety and stress regarding potential recurrence) in breast cancer patients who engaged with God (Schreiber and Brockopp, 2011; Bjorck and Thurman 2007). The evidence that a belief in God helps women to cope with cancer diagnosis indicates that this aspect of women's lives should not be overlooked. Interventions at the clinic are unlikely to be effective if they are based solely on a biomedical perspective without recognition of this strong religious dimension. Addressing women's psychological issues and concerns relating to breast cancer diagnosis (fears, worries, sadness) within their worldview could allow for interventions that are culturally and religiously effective. For instance, integrating spiritual care as part of the support that women could receive at the clinic could be beneficial. This would require collaboration between HCPs and religious leaders. Thus, interventions aimed at supporting women at the clinic could be tailored to women's world views to allow for active participation of women and increased acceptance of the intervention.

7.4 Values

Analysis of the data demonstrated important values that women considered when decisions regarding breast cancer treatment were being made. This included the female body; health; and ability to fulfil female roles.

7.4.1 The female body

Women's concerns over the potential impact of treatment side effects (e.g., loss of hair and skin changes from chemotherapy; loss of breast from mastectomy) on their appearance were found to impact decision making. This finding supports those of Oguntola et al. (2011) and Clegg-Lamptey et al. (2009). This current study extends the findings of these studies by demonstrating that the stigma associated with biomedical treatment was a concern of women when deciding whether to commence biomedical treatment. In this case, the stigma associated with the side effects of treatment acted as a push factor away from biomedicine and towards traditional medicine and this finding has similarly been found in Kenya, Nigeria and South Africa (Meacham et al., 2016; Ukwenya, 2008; Wright, 1997). This means that women's concerns prior to initiating treatment may be that of stigma and this may change, or they may be more concerned about the distressing side effects during treatment. This suggests that both the physiological effects of treatment and the social consequences of treatment can have a devastating impact on women with breast cancer. The side effects of treatment including loss of hair and a breast conflicted with attributes perceived to be normal for females in the society. The fear that the side effects of treatment would be triggers of stigmatisation behaviours from the public such as being shunned led women to internalise stigma (Goffman, 1968). When women internalised stigma, their self-worth was diminished and they felt they would lose some of their identity. This consequently results in stigmatisation behaviours from the public and the internalisation of stigma on the part of the women (Goffman, 1968). For example, one woman who was supported by her husband to have mastectomy doubted her husband's true feelings about her having the operation and was concerned that losing a breast would diminish his perception of her as a woman. This reflects society's construction of the acceptable image of a woman as one with two breasts. This widely held ideal image of the female could compel women (with breast cancer and/or who have undergone mastectomy) to hide themselves from spheres of the society because of fear of rejection (Tettey, 2017).

Overall, although the side effects of breast cancer treatments threatened what was valued (the female body) and prevented the uptake of biomedical cancer services in previous studies (Meacham et al., 2016; Ukwenya, 2008; Wright et al., 1997), women in this current study did not consider avoiding biomedicine due to this threat. Nonetheless, the concept emerged strongly in women's narratives as a concern pushing them away from biomedicine and towards traditional medicine.

7.4.2 Health

Women considered health important when they were making treatment decisions. Women affirmed that it is when they are healthy that they can continue with their everyday lives. Some women were concerned that their health would be impacted negatively by biomedical treatment. For example, one woman was concerned that losing a breast will set her apart from other women and identify her as 'sick'. Being 'sick' meant she will become dependent on others for her daily livelihood and this perception acted as a push factor away from biomedicine. This finding supports that from Meacham et al. (2016) where women's concerns over dependency on others prevented them from engagement with cancer care services.

Within the African contexts, Tettey (2017) argues that the need for females to be healthy is valued because health and ill health are based on cultural standards submerged in gender roles. Women are expected to be strong and healthy to perform their high workloads of housework, childbearing, working in the farm alongside men (Okejie, 1994). Ill-health and/or being 'sick' (perceived to be caused by the removal of a breast) would be a challenge to working and providing for such basic needs. The consideration of breast cancer treatments as a threat to women's health pushed them away biomedicine. Nonetheless, there were other women who perceived biomedicine will rather restore their health and this pulled them towards biomedicine.

7.4.3 Ability to perform female roles

The ability to perform females' roles was found to be important to women and this impacted breast cancer treatment decision making. This finding is consistent with previous studies in Ghana (Tettey, 2017; Aziato and Clegg-Lamptey, 2015). In Ghanaian societies, there are accepted behavioural norms to which women were expected to adhere, which were socially and culturally sanctioned and learned through the socialisation process (Tettey, 2017). For example, in the African context, the female body is understood in terms of its core reproductive function as the bearer of children (Tettey, 2017; Okejie, 1994). Indeed, in traditional Ghanaian societies, the pride of a woman lies in their ability to accomplish this core role, hence, the ability to nurture others, and be fruitful is the foundation of womanhood. Again, the African view of a woman as one who can breastfeed her children with her own breastmilk elucidates the gendered role of women (Hellman, 2017). This view thus downplays the experience of women particularly when they needed to make decisions around breast cancer. In a study reported by Aziato and Clegg-Lamptey (2015), one woman was sorrowful, distressed and confused because she had no husband or child at the time of diagnosis. She was concerned she would not be able to get married and bear children following mastectomy. Similarly, two women in this current study were concerned that treatment would impact their ability to have their desired number of children.

Gendered expectations from women have been found to increase the time interval within which women seek medical care for breast cancer because they did not want to disrupt community life by being labelled as unable to take care of their families (Wright, 1997). This supports the findings from this study where women feared mastectomy would disrupt the everyday life of breastfeeding and acted as a factor pushing women from biomedicine and towards traditional medicine. In a study conducted in another part of the country, men were not very forthcoming to let their wives spend time on cancer treatment and diagnosis because they felt their wives would be unavailable to undertake house chores and livelihood activities (Aziato and Clegg-Lamptey, 2015). Tettey (2017), in her feminist analysis of the Ghanaian context, indicated that language is a way of learning about a society’s gender norms and values. In Ghana, the comparison of a woman to a mother hen symbolises the expectations of society from women. Behaving otherwise will show others how the woman is failing to meet those expectations and can consequently lead to shame. Three women hence decided against biomedicine in order to continue with housekeeping or care for their family although one woman later returned to accept treatment when her brother (who was supporting with payment) decided against traditional medicine.

The implication for the findings around women’s values is uncertain. On the one hand, professional ethics demand that women’s values be respected. On the other hand, when these values are the consequence of society’s demand on women and myths surrounding post mastectomy, they require some serious consideration. For example, body image and stigma concerns highlight the fact that breast cancer is not only a biological disease but also a social one which means treating the disease would require addressing both aspects. Women should be given the opportunity to voice their concerns, particularly how they perceive breast cancer might impact upon traditional notions of the female body and gender roles. It is when these concerns are shared that appropriate support (e.g. information about wigs, prosthesis; information about possible reconstruction) could be given. Also, as a society, there should be a continuous raising of awareness and health education within the community (e.g. by women's self-help groups and government health educators) about women's health and how it is influenced by discourses around womanhood and femininity. There should not be an over-emphasis on breasts, hair and skin tones as a defining characteristic of females in Ghanaian societies as these could silence women with breast cancer to hide their conditions and limit the strength, support and experiences that they could share with their peers.

Furthermore, cancer care services should take a holistic view of women's breast cancer experience. Considering the socio-cultural notions around the ideal female body and women's roles in the society, it would be naive for cancer services to focus solely on biomedical aspect of breast cancer, because it can obscure the realities of women's lives. Thus, cancer services should equally focus on the psychosocial aspects of women's lives in order to address the socio-cultural beliefs that serve as barriers.

7.5 Summary of how the contextual factors interact to influence decision making

The preceding sections have demonstrated how the contextual factors (structures, beliefs, values and practices) impact upon women's decision making. This section builds on these to show the links between the contextual factors and the overriding themes (see Table 7.1 below).

Table 7.1: How the contextual factors shape 'hiddenness' and 'filling in the gap'

Hidden information around breast cancer and its treatment			
Structure	Practices	Beliefs	Values
Language issues Health information materials; limited concepts in the local language Lack of resources	Deference/Hierarchical Practices Doctors miscommunicating treatment intent Lack of adequate information about treatment consequences and costs	Limited discussions due to belief in a possible spiritual attack and stigma concerns	

Filling in the gap			
Structure	Practices	Beliefs	Values
Survivors exist* Cost of treatment	Traditional medicine	Breast cancer caused by ‘witchcraft’; ‘evil spirits’; ‘bought disease’ Mastectomy inevitable leads to death God is the overall healer/would prevent side effects of treatment* Treatment would prevent disease progression*	Mastectomy would impact on strength and health (‘will become sick) Treatment would restore health* Mastectomy would impact upon housekeeping; caring for children Treatment would impact upon breastfeeding; fertility; female body and identity

*: The factors that influenced women to accept treatment

From Table 7.1 above, there are many structural issues, practices and beliefs that increase women’s vulnerabilities and lead them with inadequate information about breast cancer for effective decision making. As has been demonstrated, limited formal education impacted upon women’s ability to access and effectively utilise health information about breast cancer, particularly those materials in English language (WHO, 2020). This problem was compounded by the lack of terms in the local language to adequately describe breast cancer; and by the lack of resources at the clinic. HCPs were busy and had limited logistics, expertise and training to effectively engage with patients and provide the needed information around breast cancer and treatment. Perhaps more importantly, the culture of deference and conforming to hierarchical norms meant patients lacked the needed skills and motivation to actively request for information. Patients in this study looked up to their doctors to decide for them. The doctors, being members of the culture, also capitalised on their authority and attempted to influence the behaviours of women by intentionally miscommunicating treatment intent. These issues did not make quality information available to women in the clinic context. Outside the clinic context, the situation was no different. Beliefs in spiritual attack from cancer disclosure and concerns over stigma inhibited discussions about the disease in the communities. In the context of such limited quality information, the local beliefs, such as spiritual cause of cancer; incurability of cancer and that mastectomy would inevitably lead to death inform the choice of treatment which usually favoured traditional medicine. In addition to beliefs, women’s concerns over the threat that biomedicine posed to their values influenced their decision making. There were concerns that treatment would impact the female body, diminish their identity and lead to stigmatisation. One woman was concerned that mastectomy would impact her health by making her sick and unable to perform her daily activities. There were other women who were concerned that treatment would impact upon their ability to have their desired number of children, perform housekeeping, breastfeeding and/or care for their children. These roles conformed with societal expectations. Two women prioritised their caring roles (including providing food for their children) over their healthcare needs and this made them decline biomedicine at the end of the study. The decisions made by these two women were not surprising given that these women were single parents and were engaged in jobs that did not provide security. Their livelihoods were dependent on their day-to-day jobs, which meant they were more concerned about meeting their basic needs, i.e. feeding themselves and their children compared to attending clinic appointments for treatments that were rarely affordable and that was believed to lead to death.

The realities of women's lives highlight the need for HCPs to be aware of the socio-economic conditions of women and provide the needed support and information to help women think carefully about what is important to them as they make decisions around breast cancer treatments. Table 7.1 above, also provided highlights on the beliefs; values and structures (e.g., knowledge that survivors of the disease exist; biomedicine would prevent disease progression; restore health; God can heal with biomedicine) that influenced women to accept biomedicine. This suggests that there are individual differences in relation to women's informational and support needs. The implication of this is that HCPs should assess each individual woman's informational and support needs. Considering the busyness of the clinic, HCPs can prioritise and spend more time with the women who are likely to rely on misleading local and common beliefs in the community. This is not to say that women who had some trust in biomedicine would not require support from HCPs. Such women may also have their own concerns and HCPs should explore and provide the required support.

7.6 Chapter summary

Overall, this chapter has discussed the main findings of the current study through the lens of the cultural context and its relationship with the existing literature. The findings support those of previous studies, but it has also offered new perspectives that are different from the literature. For example, it has highlighted the absence of quality information as a result of the limitations in the local language, hierarchical practices at the clinic, limited staff numbers and expertise, inadequate logistics, stigma and superstitions. This novel insight has delineated the context within which the myths and misconceptions that influence breast cancer treatment decision making occur. In addition, the study has revealed the structures, practices, beliefs and values which are influential in breast cancer treatment decision making. These issues illustrate that breast cancer treatment decision making is impacted by many contextual factors, therefore, improving outcomes for breast cancer with regards to treatment decision making requires a holistic approach from all key stakeholders. This includes providing appropriate resources and required logistics for breast cancer care, removing financial barriers and improving economic development of women. It also requires understanding of women’s religious beliefs about health and healing; understanding folk beliefs about breast cancer causes, and anticipated consequences of treatment on themselves and their loved ones and incorporating these together in approaches/interventions designed to promote informed decision making for women in Ghana.

Chapter 8 Conclusions and recommendations

This chapter presents the conclusion of the thesis by providing a concise overview of the study. Next, it highlights the thesis' original contribution to knowledge with regards to the way the cultural context of Ghana influences women's breast cancer treatment decision making. Thirdly, the chapter offers a critique of the strengths and limitations of the study in terms of its aims and then recommends areas for future research. Finally, the chapter ends with practice and policy implications of the study.

Overview of the study

The study focused on breast cancer because it is one of the leading causes of cancer morbidity and mortality among women in Ghana. There is evidence to suggest that many women in Ghana diagnosed with breast cancer may not receive optimal treatment (Scherber et al., 2014; Clegg-Lamptey et al., 2009). This is quite concerning given that survival is linked mostly with stage of disease presentation and optimal treatment (Cancer Research UK, 2018). Although many women present with advanced disease, the reality is that even when they present with stages where they have a good chance of cure, some do not follow through with treatment. These women often later return with advanced disease, which has poorer prognosis and is more expensive to treat. This study was undertaken to provide an in-depth understanding of what influences women's decisions whether or not to proceed with a recommended treatment following diagnosis.

The study started with an initial review of the literature to provide insight on the issue, but this mostly concerned treatment non-completion. Even from the perspective of treatment non-completion, it appeared majority of the factors were socio-cultural. Consequently, the study explored these in more depth in terms of their influence on treatment decision making among women diagnosed with breast cancer in Ghana. The study employed an ethnographic methodology and purposefully selected participants from a breast clinic in a teaching hospital in southern Ghana. The study also utilised participant observation of the clinic and in-depth interviews of women diagnosed with curative breast cancer, nominated relatives and healthcare professionals.

This study focused on the processes that women went through as they navigated the breast clinic and interacted with HCPs to receive a diagnosis and a treatment recommendation. Since the decision on a choice of treatment may not necessarily occur at the breast clinic, interviews were also conducted to find out about women's lives outside the clinic. This approach, and being informed by a social construction theoretical perspective, placed breast cancer within the socio-cultural context of women, and subsequently allowed an exploration of how that influenced women's treatment decision making.

8.1 The study's unique contribution to knowledge

The findings of this study go beyond those reported in prior studies by highlighting that breast cancer treatment decisions are made in a context devoid of quality information. In so doing, it has demonstrated the influence of the cultural context as important in breast cancer treatment decision making. Not only has the study demonstrated its importance in understanding decision making, but it has also shown that the cultural context, including the beliefs, values, practices and structures, has a strong influence on women against the uptake of biomedical treatment. This advances existing knowledge on breast cancer treatment decision making in many ways.

First, this is the first study conducted in Ghana that has demonstrated that despite the objective of the Ministry of Health (2010) for women to make informed treatment decisions, for breast cancer, accurate and quality information around which women make these decisions is often hidden from them. The study demonstrated extensively the underpinning contextual factors contributing to this hiddenness. Lack of resources in the breast clinic meant there was limited staff numbers, expertise and facilities (including consulting rooms, information materials suitable for the needs of the women), and this impacted on quality engagement with patients. Poor engagement limited patients' ability to share their concerns and or receive appropriate information and support from HCPs. Likewise, poor formal education and literacy issues amongst patients and limited linguistic capital around cancer were some of the underlying roots of the hidden information. The study also revealed the inherent hierarchical cultural practices and non-participatory clinical encounters profoundly restrict the availability of quality information about breast cancer and treatment. Furthermore, there is data to suggest that belief in a spiritual cause of breast cancer, belief that God is the ultimate healer and that stigma acts to limit information about the disease and its treatment. These factors could increase how vulnerable patients felt which led them to rely on other sources such as family, spiritual leaders, friends and the media for information and support. The reliance on other sources for information and support created avenues for misleading information about the disease and treatment. For example, authority figures such as women's spiritual leaders reinforced women's suspicions about the spiritual cause of breast cancer, to fulfil their interest of providing spiritual healing. Also, common or shared beliefs that were prevalent within the community about the incurability of cancer and that mastectomy leads inevitably to death strongly influenced women against choosing biomedicine, and instead to consider approaching traditional medical practitioners who offered healing without surgery.

Additionally, the socialisation of women regarding females' roles and the ideal female image influenced them during decision making. Women were concerned that some of the things that were important to them will be impacted by the side effects of biomedicine. This included loss of a breast from mastectomy, which means their appearance would dramatically change or they would not be able to perform breastfeeding, housekeeping or care for their children. There were also concerns that breast cancer treatment would impact their ability to have their desired number of children. These concerns strongly influenced women against biomedicine.

The strong influence against biomedicine also stems from access barriers. For example, even when women are considering biomedicine because they have knowledge that survivors of breast cancer exist (from survivors, peers, family, friends, health educators); or believed that biomedicine will prevent disease progression; and or that God will heal with biomedicine, the reality is women needed to pay for the cost of treatment before receiving care. The high cost of treatment and of transportation means patients who are wanting to persevere with biomedicine are hindered from accessing this care or are delayed in reporting back to the clinic to start treatment. These contextual factors will pull women towards traditional medicine, which are readily available, more affordable and whose practice are legitimised in the country.

8.2 Strengths of the study

The strengths of the study relate to its methodological rigour; the extent to which it fulfils the trustworthiness criteria as a qualitative study. In this study, the study's strength will be related to Lincoln and Guba (1985) trustworthiness criteria consisting of credibility, transferability, dependability and confirmability. These terms are explained in table 8.1 below.

Table 8.1: Lincoln and Guba (1985) trustworthiness criteria

Credibility	Confidence in the truth of the findings
Transferability	The findings have applicability in other contexts
Dependability	This details how the study is consistent and could be repeated

Confirmability	A degree of neutrality or the extent to which the findings of a study are shaped by respondents and not the researcher's bias or interests

As proposed by Lincoln and Guba (1985), for a naturalistic study to be credible, it should be conducted in a natural setting. In this study, I immersed myself in the natural environment of participants, which is the breast clinic (southern Ghana) using participant observation and in-depth interviews. This allowed me to familiarise with participants during breast cancer diagnosis and treatment recommendation and explored from their own perspective, the role of the cultural context in influencing women's treatment decision making.

To further enhance credibility and present the participants' (emic) perspective, it required that the data collected is adequate to support the analysis presented. The implication for this study was that there was prolonged observation until data saturation was reached and detailed field notes were also kept. In addition, the study used more than one group of participants (i.e. patients, families, HCPs). This facilitated a broader understanding of the different contextual aspects impacting breast cancer treatment uptake. Moreover, the in-depth interviews which were employed were audio-recorded which enhanced continual listening of narratives during data analysis. Also, because interviews were conducted in the Twi Language, a validation check from a local expert was sought (appendix 12) as the researcher translated the interviews conducted in Twi to English. In enhancing credibility of the findings, it was also ensured that supervisors' input was offered by constantly consulting them throughout the research process and at the completion of each data generation. This allowed for other approaches and ideas for subsequent investigation, and appropriate interpretation of data (Shenton, 2004). Another essential issue was that attention was paid to negative cases during analysis. The study therefore derived its strength from these processes as they ensured that participants' perspectives underpinned the findings reported.

An additional means of enhancing the study's strength was through its confirmability. From an ethnographic perspective, this required me to be reflexive about how my personal influences, beliefs and assumptions (Huberman and Miles, 2002) may have impacted on the study. My status as both an insider and outsider was a strength for this study. For example, my understanding of the common local language and culture facilitated a trusting relationship with participants and allowed interaction with participants without any hindrance. On the other hand, as an outsider (because of exposure to UK education and culture), I was able to perceive the culture at the breast clinic with 'new eyes' and this facilitated insights into issues that would otherwise have gone unnoticed.

The strength of the study also lies in my being explicit about how my personal circumstances, such as my own belief in God, my nursing background and exposure to other health contexts, could influence the interpretation of this study. I ensured a plan was in place to manage the potential impact of these issues. One of the ways this was ensured was to be conscious of these and to note them down in a reflective diary. For example, during participant observation of patient-provider interaction at the breast clinic, one woman mentioned that financial challenge was a reason she would be unable to follow-up with treatment. My exposure to the UK health system where there are limited access barriers meant the woman's reason was very plausible. However, upon further probing, the data suggested the woman had more grave concerns including mistrust of HCPs and fears around mastectomy. Reflecting on this revealed that there may be more underlying concerns to what patients actually voice during interactions with HCPs. This experience allowed more probing during interviews to gain insight into participants' perspectives. Another way participants' perspectives were ensured was that in reporting the research findings, verbatim extracts were used. Also, findings were linked to existing literature in order to retain congruence between the theoretical perspective of the research and the research aim. This whole process allowed rich descriptions and the conclusion of the role of structures, beliefs, practices and values in keeping information and understanding about the disease hidden, and subsequently filling in the knowledge gap it creates. As a result, the study has the ability to inform healthcare practitioners working with Ghanaian women with breast cancer about the impact of the cultural context on their treatment decision making. This would allow the incorporation of the study's findings in culturally appropriate interventions to promote informed decision making for women with breast cancer in Ghana. The study should also inform policy makers about the challenges to breast cancer treatment uptake and would contribute to nursing scholarship.

The study's strength can also be evaluated from detailed descriptions of the context and the research participants. This relates to transferability (Lincoln and Guba, 2000). The study has provided an in-depth description of the phenomenon and the research background and also adopted a purposeful sampling approach to select key participants (Shenton, 2004). For instance, the study was conducted at a tertiary hospital which sees patients from diverse backgrounds, and this allowed the selection of participants from different ethnic groups and socioeconomic circumstances. The study provided a proper and clear record of the participants' characteristics, demographic data and study contexts. This makes the study poised to offer insights about breast cancer treatment decision making for readers to ascertain how the findings can be transferred to other similar contexts.

8.3 Limitations of the study

In ethnographic study, the aim is primarily an in-depth understanding of the role of people's cultures in relation to a particular phenomenon. This study sought an in-depth understanding of the role of the cultural context of Ghana on women's breast cancer treatment decision making. However, the study focused on a limited sample of participants from one teaching hospital in the country. The focus on one hospital is a limitation for this study as patients who were not able to attend this hospital could not be included. Also, although the study sought to reduce this limitation by including participants from diverse groups, it did not have women from all the ethnic groups across the country, particularly those who could not speak English or Twi. Therefore, the findings may not be representative of such women.

Statistics show that breast cancer is diagnosed predominantly in stages 3 and 4 (Wiredu et al., 2014), but this study was only limited up to stage 3 curative disease. It is possible that the study's findings might differ from the experiences and perceptions of women whose cancers were not curable.

Interviews were conducted in Twi and helped elicit rich data but translating the data from Twi to English raises the question as to whether translated versions retained the values, assumptions and feelings that were present in the original spoken language version (Temple and Young, 2004). Although this is a potential limitation, it was offset both by my insider status in the dual role of researcher/translator, and by employing back translation of transcripts from a local expert (Edwards, 1998).

8.4 Implication of study findings

8.4.1 Future research

The study has demonstrated the contextual factors influencing treatment decision making. Firstly, it has shown that although communication is in the local language, posters are written in English, which is less accessible to most of the women. Also, there are limited concepts in the local language to effectively describe the disease and treatment. Future research could develop informational tools in the local language supplemented with pictures and videos to accurately describe what breast cancer is, its treatments and aims of treatments. Future research could apply a systematic review approach to identify tested low literacy informational support interventions (Choi, 2012). A typical example in the literature is where pictograph-based tools were developed and tested amongst patients with low literacy skills to enhance breast care instructions. The drawings were perceived by participants as engaging and enhanced clarity of the intended health message. This approach could be adopted and adapted in future studies and the informational tools can subsequently be tested in a pre-test, post-test intervention study at the breast clinic.

The study also found that women had various concerns about the effects of treatments on themselves and their loved ones including inevitable death from mastectomy, body image, fertility, breastfeeding, housekeeping and caring roles. Other issues which were similarly of concern to women were treatment costs, but these concerns were hardly discussed. Future research can explore how clinicians who are involved in the care of women can provide targeted information and counselling to them during treatment decision making. Through an action-based approach (Hung et al., 2019), the study could involve HCPs, patients and survivors of breast cancer to develop a patient decision aid. This could be used by the nurses at the breast clinic to help patients think through the pros and cons of curative breast cancer treatment as they make treatment decisions.

The findings further indicated that women's treatment decision making is strongly influenced by the testimonials of other breast cancer survivors, but HCPs perceived that they do not have the requisite logistics and support for a survivorship program at the clinic. Action-based research with HCPs, breast cancer survivors, patients and policymakers is urgently required to identify and integrate an appropriate survivorship care programme at the clinic (Alfano et al., 2014). Future studies should also explore the feasibility and acceptability of such a survivorship programme.

The study sought to understand decision making from the perspective of women. It did not explore in-depth the factors influencing treatment recommendations by HCPs. For curative breast cancers, women could have benefitted from conservation as well as mastectomy. However, mastectomy was mostly decided by HCPs. Future research should explore factors influencing surgery treatment recommendations by HCPs.

This study was based on the time points from diagnosis to treatment recommendation i.e. after patients have attended tumour board meetings. The study did not follow-up with women whether they persevered with the treatment decision made. This study could therefore be adapted to explore whether women who decided to have treatment actually went through with the decision or not and the factors accounting for their decision.

8.4.2 Practice

The study has demonstrated that quality information needed for informed treatment decision making is inaccessible or hidden from women. In order to make decisions that are informed, a woman needs to know and understand her disease stage, the appropriate standard treatments, and the risks and benefits of these treatments. Attention to these specifics might lead women to make decisions that they can keep to. Although not all the patients in the study said they wanted information about the disease, most of them said they would have liked more information particularly around the potential treatments. Nevertheless, HCPs provided women with limited information about the disease and its treatment not least, the associated risks and benefits. This practice does not meet professional expectations. HCPs need to improve information provided to patients. Nurses can play a role in this respect. With the appropriate training, it is expected that nurses will develop skills and provide holistic care to patients. For instance, as mentioned above, the findings from this research could inform a decision support intervention. This potential intervention could be nurse-led at the breast clinic. Because patient education and counselling are within the roles of nurses, they are better placed to provide support, adequate information and counselling to patients to navigate their treatment journey. The information should incorporate effects of treatments on body image, fertility, breastfeeding, housekeeping and caring roles and treatment costs.

Women may be overwhelmed with the news of diagnosis and may fail to retain information from providers, therefore, other support including a phone line that women can call may be helpful. There is evidence that when patients contacted HCPs outside the clinic on a phone line, it helped them to ask questions they were unable to do so at the clinic (Adejoh and Olurunlana, 2016). This can be adopted by the breast clinic to provide support to patients outside the clinic.

The study demonstrated that patient-clinician interactions were dominated by physicians and women were passive as they interacted with HCPs. Some of the practices of HCPs including frequent interruptions by other HCPs; simultaneous consultations; lack of involvement of women at the tumour board meeting; miscommunicating treatment intent and withholding certain information around fertility and costs could both discourage women from being involved in decision making and leave them with gaps in their knowledge. This made patients susceptible to misleading information, myths and misconceptions about breast cancer and treatments. In addition to these practices, the uncomfortable chairs for patients at the clinic and their arrangements also reinforce existing social, cultural, educational and professional hierarchies at the clinic, which discourage patients from actively involving in treatment discussions. HCPs need to be aware of all of these issues and take practical steps to improve patient engagement. Firstly, they would require cultural awareness and communication training (explained under policy recommendation) in order to actively seek to draw and involve patients into discussions. Doctors for example could use communication prompt to invite patients into discussing issues and concerns that bother them. Secondly, HCPs should limit interruptions to a minimum during patient-clinician interactions in order to effectively engage with patients. Thirdly, HCPs should provide accurate information about the disease and treatment and involve women in treatment discussions. Finally, HCPs should collaborate with policymakers to address infrastructural issues e.g., screens to tackle simultaneous consultation and more comfortable chairs to boost patients' morale.

Stigma discourages women from persevering with biomedical treatment; a finding that concurs with studies conducted in other African countries. This demonstrates the need for an intervention to reduce stigma for women diagnosed with the disease. Stigma was associated with the side effects of treatment and its impact on women's self-image as well as the image others have of them and their perceived roles. Interventions levelled at these factors can be valuable in reducing stigma. At the practice level, there should be more engagement and counselling for women to discuss these concerns.

The study found that meeting survivors who had successfully completed treatment fostered hope and allayed women's fears and concerns. HCPs can collaborate with survivors and integrate cancer survivorship programs into the care of women. The more women hear positive stories of survivors, the less cancer would be associated with folk tales and misconceptions.

The finding that families have the tendency to influence women suggest that they should be more involved when HCPs are providing information and education about breast cancer to patients. It appeared that HCPs desired to involve families but there was a lack of commitment to this practice at the breast clinic. Families' involvement is important because when they better appreciate and understand the disease, it is hoped they will support women to make informed decisions.

This study acknowledged that faith in God is very important to Ghanaian women with breast cancer. The prevalence of women's belief in God is comparable with findings from prior studies. The strong faith in God helped women to cope with the cancer diagnosis. Some studies therefore suggest that prayers should be used to supplement hospital treatment for patients with cancer (Aranda et al., 2005; Cebeci, et al., 2012; Doumit et al., 2009). This study recommends that HCPs should provide women with holistic care and acknowledge women's religious beliefs. HCPs could work with the hospital chaplain or religious leaders to provide support for women upon request.

8.4.3 Policy

HCPs are not in a position to address structural barriers that inhibit women from accessing cancer care services. Nevertheless, it is important for care providers, both nursing and medical professionals who care for patients, to be cognizant of the socio-cultural and individual barriers and take these into account when providing information, advice and counselling. This would require more training for care providers to understand the needs of patients who receive a cancer diagnosis, so they can adopt improved engagement practices with patients. Policymakers should emphasise the need for and provide support for training programmes that promote socio-cultural awareness and communication skills amongst HCPs.

The underlying reason for a lack of appropriate psychosocial support stems from the lack of staff and specialist training in breast care and the under-resource nature of the breast clinic. The numbers of HCPs are too few to adequately engage with the many numbers of patients seen at the clinic. Policies should aim at increasing staffing levels and providing expertise training in cancer care. Policies to improve cancer control should look beyond the physical aspects of the disease. Care services must engage an holistic approach to the whole person in terms of the physical, social, spiritual, psychological and cultural aspects of the patient.

The policy should also provide cancer information materials. There should be more funding and support for the relevant research in health information so that breast cancer materials are translated into the local language and supported with pictures and videos. This would enhance an accurate description of the disease and treatment to women.

With regards to facilities, there were a limited number of consulting rooms to provide privacy to patients during patient-provider interactions. In the long term, policymakers should look at addressing this infrastructural issue. Meanwhile, in the interim, screens can be provided to divide the consulting rooms to ensure privacy for patients.

In terms of breast cancer care access, the study found that it can lead to serious healthcare expenditures for women. This relates to the breast care itself and then the associated hidden costs (transportation; loss of income). There is a need for a robust and proficient national health insurance scheme that is inclusive and able to tackle the financial barrier of cancer treatment (Sanuade et al., 2018). This would reduce the burden on individuals and families. In the long term, policies that aim at addressing transportation barriers are encouraged. For example, there can be liaison with the local government transport system (metro mass public transport) to provide free transportation to women who are unable to afford this. Also, since women's socio-economic situation has a bearing upon their engagement with cancer care services, it signals the need for polices from several sectors including education, employment, health, gender and social protection. When women's levels of education and socioeconomic conditions are improved, they can engage with breast cancer services (Ohene-Yeboah and Adjei, 2012). Currently, the government policy of free senior education for every Ghanaian child is a step in the right direction.

At the community level, policies should aim at culturally appropriate strategies to improve breast cancer awareness. For example, the limitations in the local language for cancer suggest that health educators should be provided with appropriate materials to supplement description of the disease (Asobayire and Barley, 2014).

Policies should also be targeted at reducing social stigma with regards to challenging the widely held perceptions about breast cancer for women to openly discuss breast problems without fear of stigmatisation. Policies that inspire community mentors to be drawn into breast cancer educational programmes and use of willing breast cancer survivors and advocates in eventful places such as durbars, festivals, and marketplaces are encouraged.

8.5 Chapter summary

Sub-optimal treatment is a challenge to breast cancer control in Ghana. This is the first research study that has utilised ethnographic methods to explore the contextual factors influencing breast cancer treatment decision making among newly diagnosed women at a breast clinic in southern Ghana. This ethnography has demonstrated that the decision to start or not start a recommended breast cancer treatment is complex, and this decision is shaped by the socio-cultural context within which women live. Structures, practices, beliefs and values hide quality information necessary for effective decision making and also fill in the gap. Many of the information available to women were misleading (belief in spiritual cause of breast cancer; belief that mastectomy leads to death) and pushed women away biomedicine. These factors, together with the financial access barriers, indicate that within the cultural context of Ghana, there is a strong influence against biomedicine. Several recommendations for research, practice and policy have been suggested, which could contribute to optimal treatment uptake and consequently improved survival outcomes.

Appendix 1: Summary of national strategy for cancer control in Ghana (Ministry of Health, 2010)

Objective	Strategy	Specific breast cancer control strategy
Document 50% of all cancer cases and establish a cancer registry to form the basis of delivery of cost effective interventions for research and surveillance	Develop cancer registry and research and strengthen routine data collection system to capture reliable information, undertake regular operational researches to provide evidence for decision-making	
Reduce the incidence and mortality of cancer by 30% through primary prevention, effective screening and early detection	Prevention i. reduce the promotion of unhealthy foods ii. increase awareness for healthy food to enable people make informed choices iii. provision of recreational centres to increase uptake of physical activity iv. encourage workplace fitness v. ban smoking at public places vi. increase taxation on tobacco and alcohol vii. control advertising of tobacco and alcohol and prohibit sale to minors Screening and early detection i. Establish cancer awareness and screening programmes ii. Employ both organised and opportunistic strategies	Early detection Promote breast self-examination through public education and awareness campaigns Train health professionals to offer clinical breast examination every three years to women below 35 years and once a year to women 35 years and over Use mammography as a diagnostic tool
Improve effective diagnosis and treatment of cancer by 30% through evidence-based cost effective interventions to reduce morbidity and mortality	Develop treatment protocols and guidelines for management of cancers Develop guideline for referral of cancers Establish tumour boards to oversee management of cancers Ensure pharmacovigilance as an integral part of management Treatment must be tailored to the best interest of the patient	Develop standard protocols for management of breast cancer Make basic standard treatment available to all women including surgery, radiotherapy, chemotherapy, hormone therapy and biologic therapies Equip all regional hospitals to have the capacity to treat breast cancer satisfactorily

	Patients shall be given all the information required about a procedure before it is performed Remove geographical and financial access barriers to care Make basic standard treatment available Form regional multidisciplinary oncology teams	
Objective	Strategy	Specific breast cancer control strategy
Improve the quality of life for those with cancer and their family members through support, rehabilitation and palliative care	Social, behavioural, environmental, psychological and health services research will be supported to determine effective methods and timely access to screening, diagnosis, treatment, palliative care, rehabilitation and supportive care Avoid unnecessary suffering by providing emotional support, symptom control, end-of-life care and bereavement care To provide palliative care to at least 25% of eligible patients by 2020 Train health professionals in various areas of cancer specialty Restructure training curriculum in all training institutions to reflect current knowledge of the cancer continuum Equip the national, regional, district and sub-district centres to promote prevention, screening, early detection, diagnosis, treatment, palliative care, rehabilitation and supportive care	
Improve the service delivery across the continuum of cancer control through effective planning and coordination linked to improved resources	Government to increase resource allocation toward cancer control Make available Magnetic Resonance Imaging unit, Computerised Tomography unit, specialised ultrasonography, Radiotherapy unit with brachytherapy and teletherapy Enhance collaboration with local and international partners Increase commitment towards research	Make available mammography as a screening procedure (for women above 40 years) and as a diagnostic tool

Appendix 2 Search strategy for CINAHL Database

Save Searches / Alerts

☐ Select / deselect all [Search with AND] [Search with OR] [Delete Searches] [Refresh Search Results]

	Search ID#	Search Terms	Search Options	Actions
☐ 0	S13	S5 AND S6 AND S9 AND S12	Search modes - Find all my search terms	True S13 View Results (306) View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE
☐ 0	S12	S10 OR S11	Search modes - Find all my search terms	True S12 View Results (4,818,916) View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE

☐ 0	S11	chemotherapy OR mastectomy OR "neoadjuvant therapy" OR "adjuvant therapy" OR "breast surgery" OR radiotherapy OR "hormonal therapy" OR "systematic therapy"	Search modes - Find all my search terms	True S11 View Results (605,725) View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE
☐ 0	S10	treatment OR uptake OR decisions OR decision-making OR delay OR adhere* OR nonadherence OR comply*	Search modes - Find all my search terms	True S10 View Results (4,547,896) View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE

		OR "non compliance" OR abscond OR incompletion OR acceptance		
☐ 0	S9	S7 OR S8	Search modes - Find all my search terms	True S9 View Results (5,167,868) View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE
☐ 0	S8	context* OR social OR ethnicity OR stigma	Search modes - Find all my search terms	True S8 View Results (982,133) View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE
☐ 0	S7	"socio-cultural"	Search	True S7 View Results (4,539,078)

		OR economic OR beliefs OR barriers OR facilitators OR knowledge OR provider OR interaction OR "patient-provider" OR information OR values OR cultur*	modes - Find all my search terms	View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE
☐ 0	S6	"breast cancer" OR "breast neoplasm" OR "breast malignancy" OR "breast tumor" OR "breast tumour"	Search modes - Find all my search terms	False S6 Rerun View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text

☐ 0	S5	S1 OR S2 OR S3 OR S4	Search modes - Find all my search terms	False S5 Rerun View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
☐ 0	S4	libya OR tunisia	Search modes - Find all my search terms	False S4 Rerun View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
☐ 0	S3	rwanda OR senegal OR sierra leone OR south africa OR swaziland OR sudan OR tanzania OR togo OR uganda	Search modes - Find all my search terms	False S3 Rerun View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text

		OR zambia OR zimbabwe OR morroco		
☐ 0	S2	guinea OR kenya OR lesotho OR ivory coast OR madagascar OR malawi OR mauritius OR mozambique OR mauritania OR namibia OR niger OR nigeria	Search modes - Find all my search terms	False S2 Rerun View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text
☐ 0	S1	africa or OR algeria OR angola OR benin OR botswana OR burkina faso OR cameroon OR OS	Search modes - Find all my search terms	False S1 Rerun View Details Edit Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Plus with Full Text

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Appendix 3 Critical Appraisal Guide

Critical Appraisal Skills Programme (2013)

10 questions to help make sense of qualitative studies.

Screening Questions	Yes No Can’t Tell
Was there a clear statement of the aims of the research?	
Is a qualitative methodology appropriate?	
Was the research design appropriate to address the aims of the research?	
Was the recruitment strategy appropriate to the aims of the research?	
Was the data collected in a way that addressed the research issue?	
Has the relationship between researcher and participants been adequately considered?	
Have ethical issues been taken into consideration?	
Was the data analysis sufficiently rigorous?	
Is there a clear statement of findings?	
How valuable is the research?	

Critical Appraisal Skills Programme (2013)

12 questions to help you make sense of cohort study

Screening questions	Yes No Can't tell
Did the study address a clearly focused issue?	
Was the cohort recruited in an acceptable way?	
Was the exposure accurately measured to minimise bias?	
Was the outcome accurately measured to minimise bias?	
Have the authors identified all important confounding factors?	
Was the follow-up of subjects complete enough? Was the follow-up of subjects long enough?	
What are the results of this study?	
How precise are the results?	
Do you believe the results?	

Can the results be applied to the local population?	
Do the results of this study fit with other available evidence?	
What are the implications of this study for practice?	

Appendix 4 Critical appraisal of included studies

Critical Appraisal of qualitative studies (CASP)

Study	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Total
Sanuade et al., 2018	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Can't tell	8/10
Adejoh and Olurunlana, 2016	Yes	Yes	Can't tell	Yes	Yes	No	Yes	Can't tell	Yes	Can't tell	6/10

Anarado et al., 2015	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Can’t tell	8/10
Mc Ewan et al., 2014	Yes	Yes	Yes	Yes	Yes	No	Yes	Can’t tell	Yes	Can’t tell	7/10
Pruitt et al., 2014	Yes	Yes	Can’t tell	Yes	Yes	No	Can’t tell	Can’t tell	Yes	Can’t tell	5/10
Wright et al., 1997	Yes	Yes	Yes	Yes	Yes	No	Can’t tell	Can’t tell	Yes	Can’t tell	6/10

Critical Appraisal of Quantitative studies (CASP)

Study	Did the study address a clearly focused issue?	Was the cohort recruited in an acceptable way?	Was the exposure accurately measured to minimise bias?	Was the outcome accurately measured to minimise bias?	Have the authors identified all important confounding factors?	Was the follow-up of subjects complete enough? Was the follow-up of subjects long enough?	What are the results of this study?	How precise are the results?	Do you believe the results?	Can the results be applied to the local population?	Do the results of this study fit with other available evidence?	Total
O'Brist et al., 2014	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Can't tell	Can't tell	Yes	8/10
Cubasch et al., 2017	Yes	Yes	Yes	Yes	No	Not applicable	Yes	Yes	Can't tell	Can't tell	Yes	7/10
Egwuongwu et al., 2012	Yes	Yes	Yes	Yes	No	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	7/11
Dedey et al., 2016	Yes	Yes	Yes	Yes	Yes	Not applicable	Yes	Yes	Can't tell	Can't tell	Yes	8/10

Oguntola et al., 2011	Yes	Yes	Can’t tell	Yes	Yes	Not applicable	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	6/10
Anyanwu et al., 2011	Yes	Can’t tell	Can’t tell	Yes	No	Not applicable	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	4/10
Clegg-Lamptey et al., 2009	Yes	Can’t tell	Can’t tell	Yes	No	Not applicable	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	4/10
Ntekim et al., 2009	Yes	Yes	Can’t tell	Yes	No	Not applicable	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	5/10
Ukwenya et al., 2008	Yes	Yes	Can’t tell	Yes	Yes	Not applicable	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	6/10
Adewale et al., 2008	Yes	Can’t tell	Can’t tell	Yes	No	Not applicable	Yes	Can’t tell	Can’t tell	Can’t tell	Yes	4/10

Appendix 5 Characteristics of included studies (quantitative)

Author and Year	Country and setting	Title/Aim of research study	Method	Period of data collection	Number and age of participants	Stage of breast cancer at diagnosis	Type of breast cancer treatment	Factors influencing treatment uptake	Comments on study quality + = Strength - = Weakness
Cubach et al., 2018	South Africa Hospital	Title Breast conservation Versus mastectomy among breast cancer patients in Soweto, South Africa Aim: To explore determinants of surgical treatment choice	Retrospective chart reviews Multivariate logistic regression model	January 2009- December 2011	445 participants Ages 18-70 years and over	Stage 1 (n= 17) Stage 2 (n= 195) Stage 3 (n= 142)	Mastectomy (n=354) Breast Conservation (n= 91)	Older age group (50-59 years) and ages greater than 70 years (p< 0.01); stage at diagnosis (Stage 2, p= 0.002); (Stage 3, p< 0.01); HIV positive status (p=0.13) were independently associated with total mastectomy.	Strength Attempted to include all women diagnosed with breast cancer except those whose cancers were not curable, hence, there was fairly large sample size which means the margins of errors associated with findings were reduced; used rigorous statistical analysis to control for confounding Weakness the study lacked data on socio-economic status which would have provided further insight as the choice of mastectomy over BCS because radiotherapy needed in addition to

									conservation was over 100km away hospital based study therefore subject to selection bias

Obrist et al., 2014	Ghana Hospital	Title: Factors related to incomplete treatment of breast cancer in Kumasi, Ghana Aim: To identify the patient and system factors related to incomplete treatment of breast cancer among patients	Retrospective chart reviews to identify patients who prematurely terminated treatment Face-to face interviews with structured questionnaire Statistical analysis with unconditional logistic regression model	2008-2010	117 participants1; 31 participants did not complete treatment (patients, n=5, next of kin, n=26) 86 completed treatment (53 patients, 33 next of kin) Age range: 24-99 years Mean 53.55 years	Stage 1 and 2 (n=28) Stage 3 and 4 (n=81) Unknown (n=8)	Chemotherapy Radiotherapy Hormonal therapy	Islamic faith, n=8/31 (25%) ($p=0.03$) Seeking traditional healing n=14/31 (45%), ($p<0.01$) Lack of awareness of health insurance cover for breast cancer treatment n=10/31 (32%) ($p<0.01$) Knowledge on health insurance provision led to treatment completion Women who completed treatment were more likely to know survivor ($p<0.01$) Did not complete treatment group more likely to perceive would not respond to treatment ($p<0.01$) Did not complete treatment group more likely that unavailability of chemotherapy drugs delayed treatment ($p<0.05$) Completed treatment group more likely than those who did not to be diagnosed as early detection ($p=0.01$) 31 (26.5%) did not complete treatment, 86(73.4%) completed treatment	Strength: Instrument used to collect data was derived from the literature and through participant observation Matched cases (nonadherent) to controls (adherent) which allowed determination of significant findings in the univariate analysis Used rigorous statistical analysis to control for confounding Weakness: Majority of ‘did not complete group’ were patients’ next of kin. This could have impacted on responses especially regarding healthcare system

Included quantitative studies on factors influencing breast cancer treatment uptake in Africa continued

Author and Year	Country and setting	Title/Aim of study	Method	Period of data collection	Number and age of participants	Stage of breast cancer at diagnosis	Type of breast cancer treatment	Factors influencing treatment uptake	Comments on study quality
Oguntola et al., 2011	Nigeria Hospital	Title: Nonadherence to the use of tamoxifen in the first year by the breast cancer patients in an African population Aim: To determine the rate and contributory factors to nonadherence to tamoxifen during the first year of usage in patients with breast cancer	Retrospective chart reviews Descriptive statistics	June 2001-June 2005	28/114 did not use tamoxifen at least one week continuously Age range: 45-65 years	Stage 1 (n=2) Stage 2 (n=2) Stage 3 (n=8) Stage 4 (n=16)	Tamoxifen	Advanced disease stage (not statistically significant, p=0.15) Younger age (not statistically significant, p=0.15) Unbearable Side effects: 9/28 (32%) Financial constraint: 6/28 (21%) Feel drug not working: 4/28 (14%); Spiritual (n=2) Co-morbid illness, diabetes, hypertension: 2/28 (7%) Non availability of drug: 2/28 (7%)28 (24.5%) did not follow treatment recommendation 86 (75.4%) followed treatment recommendation	Weakness: did not give much information on why non-use of tamoxifen for one week was considered significant; evaluated reasons for not following treatment recommendation based on self-report. No other means of verification. Therefore, it may have been under reported Did not provide adequate information on reasons for not continuing with treatment to allow in-depth evaluations Did not use appropriate statistical analysis to control for confounding

Included quantitative studies on factors influencing breast cancer treatment uptake continued

Author/Year	Country Setting	Title/Aim	Method	Period of data collection	Number and age of participants	Stage of breast cancer at diagnosis	Breast cancer treatment	Factors affecting treatment uptake	Comments on study quality
Clegg-Lamptey et al., 2009	Ghana Hospital	Title: Why do breast cancer patients report late or abscond during treatment in Ghana? Aim: To determine the causes of delayed presentation in breast cancer patients at Korle-Bu Hospital, and reasons for patients absconding before and during treatment	Face-to-face interviews with structured questionnaires Descriptive statistics	September 2007-July 2008	35/101 abandoned breast cancer treatment between 13 and 105 weeks, median 41 weeks Age range: 20-74 years	Stage 1 and 2 (n=14) Advanced disease (n=17) Unclear stage (n=4)	Neoadjuvant therapy Mastectomy Adjuvant therapy	Fear of mastectomy n=20 (57%), Alternative treatment n=28 (80%) Financial incapability n=11 (31%); clinical response n=4 (11%); Observing n=3 (8.5%) Exercising faith n=2 (5.7%) Side effect n=1 (2.8%) Family refused n=2 (5.7%) Family commitment n=1 (2.8%)35% did not follow treatment recommended, Early stages returning with advanced stages n=12 17 with advanced diseases returned with disease progression 1 who refused adjuvant therapy returned with chest ulceration	Convenience sampling: sample may not be truly representative Reported on side effect but unclear what side effect Inadequate reporting as study was unclear on how participants details were cross checked with previous case notes Descriptive statistics

Included quantitative studies on factors influencing breast cancer treatment uptake in Africa continued

Author and year	Country and setting	Title/Aim	Method	Period of data collection	Number and age of participants	Stage of breast cancer at diagnosis	Type of breast cancer treatment	Factors influencing treatment uptake	Comments on study quality
Adesawale et al., 2008	Nigeria Hospital	Title: Paradox of wellness and nonadherence among Nigerian women on breast cancer chemotherapy Aim: To highlight a group of women on chemotherapy for breast cancer who defaulted from their medications because they were improving	Retrospective chart reviews Descriptive statistics	January 1993-December, 2002	152 /188 defaulted treatment recommendation 101 patients record available as missing two consecutive doses of injectable chemotherapy 18/101 did not adhere due to feeling well with start of chemotherapy Age range: 31-50 years	Stage 1 (n=6) Stage 2 (n=10) Stage 3 (n=2)	Neoadjuvant chemotherapy Adjuvant therapy	Feeling well with start of chemotherapy, n=18 (18%) 152 (80.9 %) did not follow treatment recommendation; 36 (19.1%) followed treatment recommendation 5/9 on neoadjuvant chemotherapy returned after 6-12 months with metastatic disease, 4/9 lost to follow-up 3/9 on adjuvant therapy returned within a year with local recurrence 2/9 returned in good health but defaulted again, 1 out of the 2 returned with hepatomegaly and ascites	Did not give rationale why intentional nonadherence was pegged at missing two or more doses of injectable chemotherapy or taking less than 90% of oral chemotherapy Only analysed patients who stopped treatment because they were feeling well. There could have been other alternative reasons affecting adherence in addition to feeling well Mostly descriptive

Included quantitative studies on factors influencing breast cancer treatment uptake in Africa continued

Author and year	Country and setting	Title/Aim	Method	Period of data collection	Number and age of participants	Stage of breast cancer at diagnosis	Type of breast cancer treatment	Factors influencing treatment uptake	Comments on study quality
Ukwenya et al., 2008	Nigeria Hospital	Title: Delayed treatment of symptomatic breast cancer: the experience from Kaduan, Nigeria Aim: To investigate the factors associated with delayed treatment of symptomatic breast cancer	Face-to-face interviews with structured questionnaire Descriptive statistical analysis	July 2003 to June 2005	111participants; no delay (n=12), 99 participants were interviewed on reasons for delaying treatment for more than a month, median delay 9 months Median age: 43 years	Stage 1 (n=10) Stage 2 (n=18) Stage 3 (n=37) Stage 4 (n=46)	Mastectomy Neoadjuvant chemotherapy Systemic therapy	Refused consent for mastectomy from; i. family influence ii. Disfigurement, and fear of partner abandonment, n=18 (18.2%) Not aware biopsy confirmed breast cancer, n=4 (4.5%) Could not afford hospital treatment, n=13 (13%) Delay associated with advanced disease stage of breast cancer (p< 0.05) Alternative treatment, n=38 (38%) Low level of education (p<0.05) Distance to facility (p<.05) 12 participants received treatment within a month without delay 99 participants delayed treatment between 1month and 4 years, median of 9 months	Compared two groups: delay less than a month and delay more than a month. Justified that delay was based on Clinic guideline Clustered findings around symptoms perception and start of treatment which limit in-depth understanding of findings related to delay after diagnosis Did not provide much data on participants who had no delay to enable in-depth evaluations Did not use appropriate statistical analysis to control for confounding

Included quantitative studies on factors influencing breast cancer treatment uptake in Africa continued

Author Year	Country Setting	Title/Aim	Method	Year	Number and age of participants	Stage of breast cancer	Type of treatment	Factors influencing treatment uptake	Comments on study quality
Anyanwu et al., 2011 continued	Nigeria Hospital	Title: Acceptance and adherence to treatment among breast cancer patients in Eastern Nigeria Aim: To identify patient acceptance and adherence to medical treatment and to identify patient and system barriers to adherence	Retrospective medical chart review Descriptive statistical analysis	2004-2008	173 participants with confirmed diagnosis charts were reviewed for acceptance and adherence to treatment Age 18-80 years Mean age 45.2 years	Stage 3 or 4 (n=140) Stage 0 (n=4) Staging for the remaining not given (n=29)	Breast surgery Neoadjuvant treatment Adjuvant treatment	44 offered adjuvant chemotherapy, 17(38%) completed course Reasons for discontinuation were cost of treatment and transportation, lack of bed space, lack of relatives to care for them Number of participants declining any form of treatment (n=65) 140 offered surgery, n= 71(50%) accepted Declined surgery (n=69) 53 offered neoadjuvant chemotherapy 15(28%) completed 65(37.6%) declined any form of treatment 108(62.4%) accepted one or more treatment modality 71/140(50%) accepted surgery when offered 69/140(50%) declined surgery when offered	Used medical charts to assess acceptance and adherence to treatment, study is limited in providing explanations on reasons for declining treatment Did not provide adequate information on participants to allow for evaluations

Included quantitative studies on factors influencing breast cancer treatment uptake in Africa continued

Author/Year	Country Setting	Title/Aim	Method	Period of data collection	Number and age of participants	Stage of breast cancer at diagnosis	Type of treatment	Factors influencing treatment uptake	Comments on quality
Ntekim et al., 2009	Nigeria Hospital	Title: Breast cancer in young women in Ibadan, Nigeria Aim: To review records for further study of females aged 40 years and below with breast cancer presenting at a radiotherapy department	Retrospective chart review Descriptive analysis	2003-2006	221 participants 40 years and below reviewed age range 21-40 years	Stage 1 (n=5) Stage 2 (n=29) Stage 3 (n=102) Stage 4 (n=85)	Mastectomy Breast conserving surgery radiotherapy	6/221 participants delayed radiotherapy due to lack of funds 188 (85%) were income earners 33(15%) were unemployed 56(25%) earned above $100 monthly 132(60%) earned below $100 dollars monthly Financial support were from relatives towards treatment 6/221 participants who delayed radiotherapy presented with loco regional disease and distant metastasis	Gave background descriptions on socioeconomic status of participants Used retrospective data which have a possibility of recall bias

Included quantitative studies on factors influencing breast cancer treatment decision making in Africa continued

Author Year	Country Setting	Title/Aim	Method	Study period	Number of participants	Stage of breast cancer	Type of breast cancer treatment	Factors influencing treatment uptake	Comments on study quality
Egwuonwu et al., 2012	Nigeria Hospital	Title: Default from neoadjuvant chemotherapy in premenopausal female breast cancer patients Aim: To investigate some factors that may contribute to low rate of acceptance and adherence to neoadjuvant chemotherapy	Prospective study Face to face interview using structured questionnaires hematologic investigation reports Descriptive statistics	June 2009- May 2010	44 patients followed 17/44 did not follow treatment recommendation Age range: 26-51 years Mean: 42.1 years	Stage 3	Neoadjuvant chemotherapy	10/44 (23%) did not follow treatment recommendation from lack of funds 3/44 (6%) defaulted due to preference for mastectomy 4/44 (9%) refused surgery after achieving clinical response with neoadjuvant chemotherapy, 17 (38.6%) did not follow treatment recommendation ; 27 (61.4%) followed recommended treatment, Outcome of treatment nonadherence not given	Collected prospective data on reasons for low acceptance and adherence to treatment which is higher on methodological quality hierarchy compared to case reviews Gave report on all participants who discontinued treatment Weakness: were mostly descriptive report, lack of report on reasons for acceptance

Included qualitative studies on factors influencing breast cancer treatment decision making in Africa

Author Year	Country Setting	Title?/Phenomenon of Interest	Method of data collection Period of data collection	Number of participants	Culture of participants	Age of participants	Type of breast cancer treatment	Findings	Comments on study quality
Pruitt et al., 2014	Nigeria Hospital setting	Title: Social barriers to diagnosis and treatment of breast cancer Phenomenon of Interest: To use qualitative methods to understand health seeking behaviours of women presenting for care at a tertiary hospital	Face to face semi structured interview Interview guide Unspecified period of data collection Thematic analysis	31 women with breast cancer 5 resident physician	Southern Nigeria Mostly spoke Yoruba and Ibo	Age range of women: 28-80 years Median 51 years Resident physicians age range: 35-38 years	Radiotherapy Breast surgery	1.Denial of breast cancer diagnosis i. doubted accuracy of results, ii. Breast cancer is fatal 2. Fear of mastectomy: i. for loosing breast, ii. Mastectomy will lead to death iii. Husband refused surgery 3. Strikes by hospital staff: could not have surgery at appointment day 4. Non-functioning radiotherapy machine turned patient away 5. Cost of treatment: out of pocket payment for all treatment 6.Use of alternative treatment due to i. denial of diagnosis ii. Belief in spiritual causes of breast cancer Family support to have treatment	Used multiple sources Used verbatim quotes Represented women from different backgrounds, audio recorded, translated and transcribed Interview guide developed from McGill illness narrative but did not give detailed information on this and how it was adapted to conduct the interview Did not justify the philosophical approach Unclear

Included qualitative studies on factors influencing breast cancer treatment decisions in Africa continued

Author Year	Country Setting	Title/ Phenomenon of Interest	Method	Number of participants	Culture	Age of participants	Type of breast cancer treatment	Findings	Comments on study quality
Wright et al., 1997	South Africa Hospital setting Patient home setting	Title: An investigation into the causes of absconding among black African breast cancer patients Phenomenon of Interest: Explore the meanings that govern patients' attitudes, beliefs and practices regarding breast cancer	i. Participant observation of patient/healer interactions, patients' home setting ii. Interviews with Semi structured questionnaire data collected between 1991-1995 thematic analysis	women who had absconded (n=4) women who were complying (n=3) newly diagnosed women (n=3) indigenous African healers (n=4) black African lay person (n=4) biomedical cancer professionals (n=6)	Black Africans in South Africa	Unspecified	Breast Surgery radiotherapy	1. causes of breast cancer i. an angry or evil person who sends poison into their bodies to poison the breast ii. black healers seen as the only legitimate and knowledgeable healer for cancer 2.suspicious of biomedical treatment as inappropriate; surgery causes cancer to spread, radiotherapy scars the cancer rendering it difficult for herbs to cure the cancer 3.adopting sick role came with social stigma from cancer diagnosis (biomedical clinic will be made public) and economic cost 4.treatment decision made by social ties and provided emotional and instrumental support to patients, gave advise to patients, exert pressure on choice of treatment 5.unpleasant experiences with junior and technical staff at the hospital Participants who complied with treatment disputed that cancer is caused by evil person **Lack of trust for traditional medicine** Participants who accepted treatment recommendation were sceptical about competence of indigenous healers, church leaders discouragement from seeking traditional healing but to rely on both conventional treatment and prayers Aunt died from breast cancer after consulting traditional healers	Used multiple sources Used different data collection methods Gave reason for method chosen to reflect philosophical underpinning Did not show how themes were generated from participants quotes

Included qualitative studies on factors influencing breast cancer treatment decision making in Africa continued

Author year	Country Setting	Title/ Phenomenon of interest	Method	Number of participants	Culture of participants	Age of participants	Type of breast cancer treatment	Findings	Comments on study quality
Anarado et al., 2015	Nigeria Two Surgical oncology units	Title: Experiences and desired nursing assistance of women on out-patients breast cancer chemotherapy in South-eastern Nigeria Phenomenon of Interest: Patient experiences and nursing care needs during chemotherapy	Focus group discussion Thematic data analysis	20 women with breast cancer; 4 completed all active treatment, 2 about to begin, 14 at different cycles of neo adjuvant and adjuvant chemotherapy	Igbo-ethnic group	36-66 years old	chemotherapy	**Hope**: i. Drug efficacy to cure disease gave hope Family and friends offered instrumental support which served as motivation to continue treatment Religious beliefs motivated patients to cope and continue with treatment Peer support with information on chemotherapy helped to cope and continue with treatment Seeing a cancer survivor motivated patients to take treatment Side effects scared them from taking treatment but they still continued **Inadequate information**: i. Received information when side effects had already started ii. Was not told how drug will affect my body Lack of funds delayed treatment **Drug benefits** i. Received information that drug will help if not will die	Used constant comparative methods until data saturation was reached Maximum variability enhanced the exploration of patients experiences before, during and after chemotherapy Only sought information from a single source i.e. patients, this limits critical perspectives from other sources e.g. caregivers

Included qualitative studies on factors influencing breast cancer treatment decision making in Africa continued

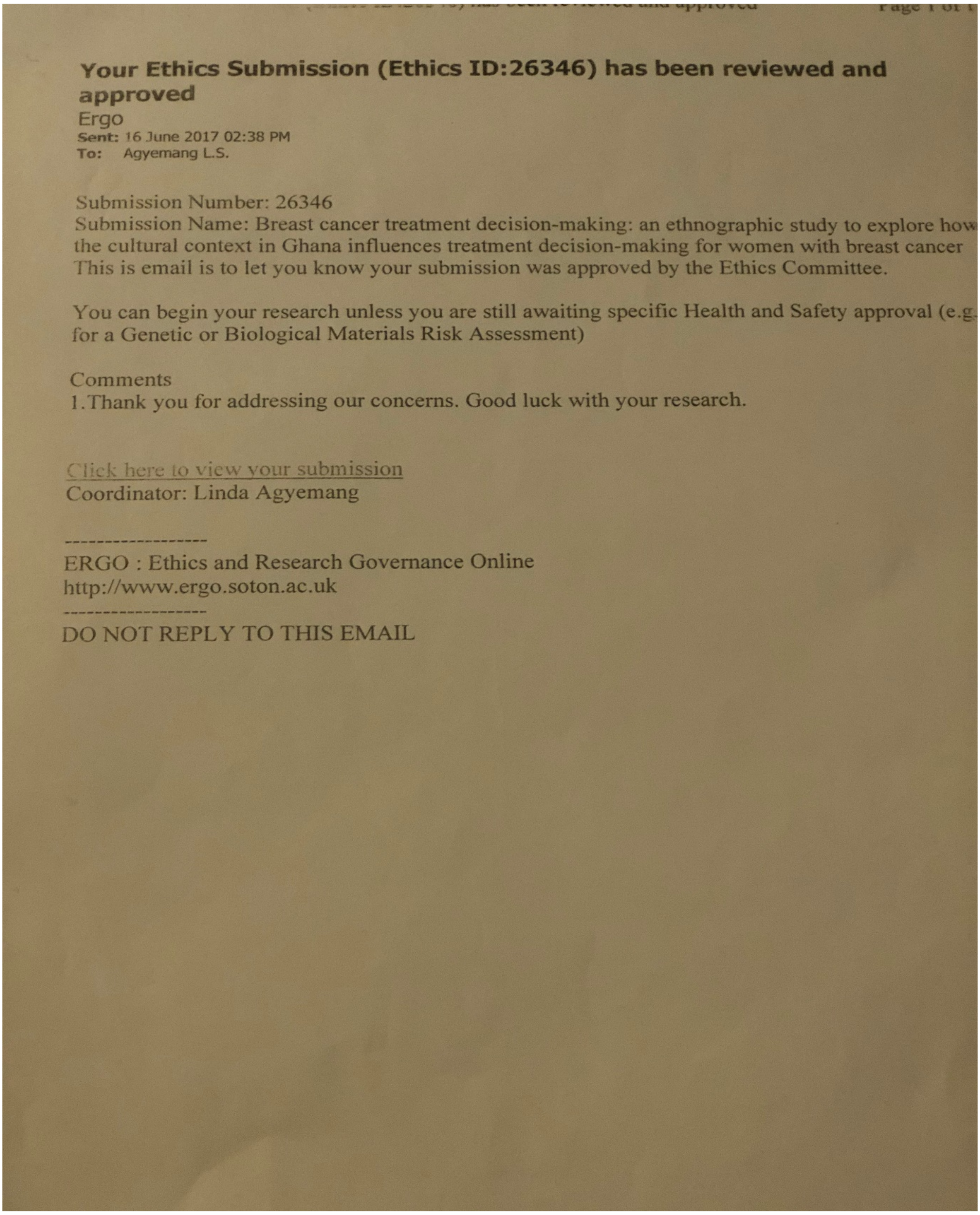
Author Year	Country Setting	Title/Phenomenon of Interest	Method	Number of participants	Culture of participants	Age of participants	Breast cancer treatment	Findings	Comment on study quality
Adejoh and Olurunlana, 2016	Nigeria Clinics	Title: Managing breast cancer: echoes from patients in Lagos, Nigeria Phenomenon of Interest: Examined the role of communication between patients and healthcare givers	Face-to-face interviews Telephone interviews Thematic analysis	20 women with breast cancer attending clinic for 6 months or more	Igbo Hausa Yoruba and others	21-61 years and above	Breast cancer treatment but did not specify which modality	**Information from healthcare givers**: Received information that helped in decision making Able to raise concerns and feelings and get response Fear of cancer diagnosis but information on hope of recovery through treatment made me less frightened Received information on breast cancer support groups that helped me share experiences with peers and cope with treatment Acquired supervision that enhanced treatment adherence Information on side effects which helped overcome fear and confusion Able to communicate on mobile phone when experienced side effect which facilitated action to take Received less information about treatment Doctor does not really tell much, no explanations **Passive control:** Doctors know best, so they decide for me **Emotional support** Received emotional support from caregivers	Purposively sampled participants to gain in-depth evaluations Used snowballing to get some participants to gain deeper insight into the phenomenon Relied on single source for data collection with no input from caregivers

Included qualitative studies on factors influencing breast cancer treatment decisions in Africa continued

Author Year	Country Setting	Title/ Phenomenon of Interest	Method	Number of participants	Culture of participants	Age of participants	Breast cancer treatment	Findings	Comments on study quality
Adejoh and Olurunlana, 2016 continued								Received less empathy from nurses Cordial relationship built confidence to take treatment **Financial concerns** to continue treatment **Communicatio**n with doctors helped and reassured me to overcome fear of death	
McEwan et al., 2014	Egypt Participants venue of choice	Title: A quality study of the social, economic and structural determinants of late diagnosis and treatment of breast cancer in Egypt Phenomenon of Interest: To understand women's experiences with diagnosis and treatment de	Semi structured interviews Thematic content analysis	15 participants with breast cancer purposively sampled from quantitative survey respondents	Unspecified	29-60 years	Mastectomy Chemotherapy Radiotherapy	Fear of cancer delayed treatment uptake Information on internets on possibility of survival made me go for treatment without delay Knowledge networks from friends and families raised awareness on the danger of the condition to seek help Mass media campaigns on breast cancer made me seek help Financial constraints and transportation costs delayed treatment uptake Poor communication from caregivers delayed treatment	Purposive sample from previous survey allowed in-depth evaluations Study clustered findings around operational definitions of delay, this limited understanding of findings around reasons for delay in uptake of treatment

Sanuade et al., 2018	Ghana Hospital Setting	Title: Understanding the causes of breast cancer treatment delays at a teaching hospital in Ghana Phenomenon of interest To explore the factors accounting for delay in initiating breast cancer treatment	Focus group discussions Period of data collection August 2013-September 2013 Theory-driven thematic data analysis	20 women with breast cancer	Akan, Ga Ewe	<40 years- 60 years and over	Breast surgery Radiotherapy	Four main patient factors including spiritual cause of breast cancer; fear; financial constraint and use of alternative treatment were found as reasons why women refused to seek definitive treatment following diagnosis (Otulobi et al., 2018). The provider and health system factors found include: healthcare workers attitude; corruption among healthcare workers; wrongful advice from health workers; long queues for treatment; unavailability of doctors; breakdown of machines; shortage of medicines and health workers. These factors delayed start of definitive treatment	Gave background description of participants Used a framework from the literature to explore concepts Used verbatim quotations in reporting findings Weakness Findings may not represent views of women from the northern part of the country

Appendix 6 University of Southampton Ethical Approval



Your Ethics Submission (Ethics ID:26346) has been reviewed and approved

Ergo

Sent: 16 June 2017 02:38 PM

To: Agyemang L.S.

Submission Number: 26346

Submission Name: Breast cancer treatment decision-making: an ethnographic study to explore how the cultural context in Ghana influences treatment decision-making for women with breast cancer

This is email is to let you know your submission was approved by the Ethics Committee.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment)

Comments

1.Thank you for addressing our concerns. Good luck with your research.

Click here to view your submission

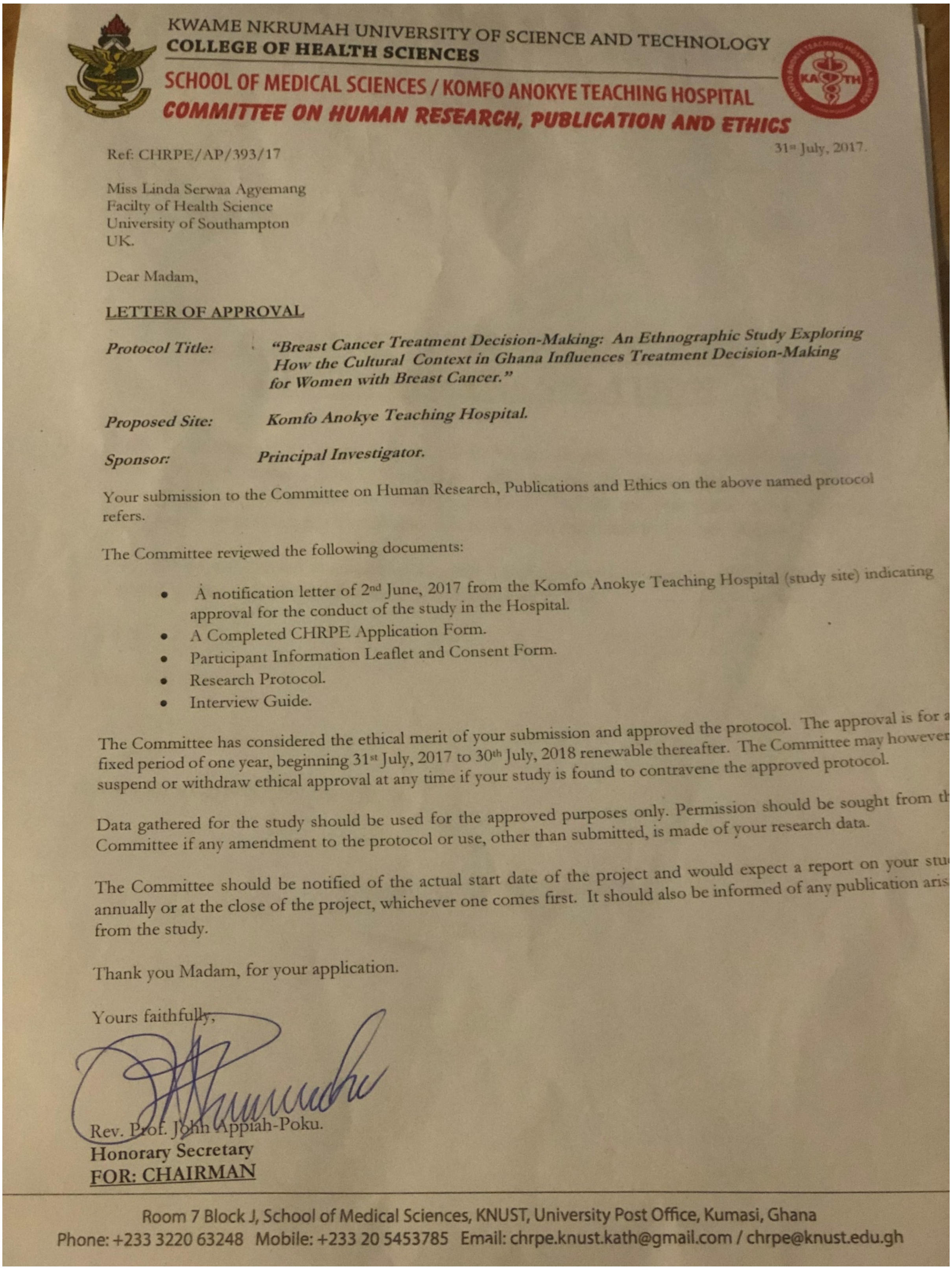
Coordinator: Linda Agyemang

ERGO : Ethics and Research Governance Online

http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

Appendix 7 Kwame Nkrumah University of Science and Technology ethical approval



KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL
COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS

Ref: CHRPE/AP/393/17

31st July, 2017.

Miss Linda Serwaa Agyemang
Facilty of Health Science
University of Southampton
UK.

Dear Madam,

LETTER OF APPROVAL

Protocol Title: *"Breast Cancer Treatment Decision-Making: An Ethnographic Study Exploring How the Cultural Context in Ghana Influences Treatment Decision-Making for Women with Breast Cancer."*

Proposed Site: *Komfo Anokye Teaching Hospital.*

Sponsor: *Principal Investigator.*

Your submission to the Committee on Human Research, Publications and Ethics on the above named protocol refers.

The Committee reviewed the following documents:

- A notification letter of 2nd June, 2017 from the Komfo Anokye Teaching Hospital (study site) indicating approval for the conduct of the study in the Hospital.
- A Completed CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Protocol.
- Interview Guide.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, beginning 31st July, 2017 to 30th July, 2018 renewable thereafter. The Committee may however suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from th Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your stu annually or at the close of the project, whichever one comes first. It should also be informed of any publication aris from the study.

Thank you Madam, for your application.

Yours faithfully,

Rev. Prof. John Appiah-Poku.
Honorary Secretary
FOR: CHAIRMAN

Room 7 Block J, School of Medical Sciences, KNUST, University Post Office, Kumasi, Ghana
Phone: +233 3220 63248 Mobile: +233 20 5453785 Email: chrpe.knust.kath@gmail.com / chrpe@knust.edu.gh

Appendix 8 Participant Information sheets

1. Participant Information sheet (Healthcare Professional)

Study Title: Exploring how the cultural context in Ghana influences treatment decision making for women with breast cancer

Researcher: Linda Serwaa Agyemang Ethics number: 26346(01)

You are invited to take part in this project exploring how the cultural context in Ghana influences treatment decision making for women with breast cancer. Before you decide, please read this information carefully to understand why the project is being done and what it will involve for you.

Please get in contact if you need more information or there is anything you do not understand. Thank you for taking time to read this information.

What is the research about and why is it being conducted?

I am a research student from the University of Southampton UK. This is a project towards a PhD degree and it is funded by Schlumberger Foundation.

Perceptions about breast cancer and treatment, cultural values and practices seem to influence treatment decision making for women with the disease in Ghana. These factors have been associated with suboptimal treatment use, yet there is limited understanding about the influence of these issues. The purpose of this study is to explore and understand how cultural beliefs, values and practices influence treatment decision making for women with breast cancer attending a southern Ghana breast clinic. I would like to talk to healthcare professionals (doctors and nurses) involved in the care of women with breast cancer, women who have recently been diagnosed and offered a treatment with curative intent and their nominated family members. I would like to explore your experience as a healthcare professional regarding breast cancer treatment decision making. I will also explore from women what matters to them as they make treatment decisions. It is hoped that the project could provide useful information on women's treatment decision-making at a breast clinic in Ghana.

Why have I been chosen?

You have been invited to take part because you are involved (as a healthcare professional at a Southern Ghana breast clinic) in providing care to women diagnosed with breast cancer. A total of six nurses, three doctors, 16 women with breast cancer (stage I to III) and 16 nominated family members (by women) will be invited to participate in the study.

What will happen to me if I take part?

The project will involve observing how healthcare professionals (nurses and doctors) talk to women who are receiving diagnosis and treatment recommendation at the clinic. Afterwards, I will arrange a time to meet with you individually, which is convenient for you and in a place you feel appropriate for an interview. There will be one interview with myself where I will ask you questions from an interview guide. The questions will be around your experience regarding treatment decision making for women with breast cancer. The interview is expected to last not more than an hour. When the project is completed, I will produce a summary of the findings, which I am more than happy to send to you if you are interested.

Are there any benefits in my taking part?

No, but information you provide may be useful in the care of women at breast clinics.

Are there any risks involved?

No, there are no anticipated risks involved. You may find it uncomfortable being observed or you may find that discussions may raise issues that you have not previously considered. You are free to stop being involved in observation or discussion if you do not want to continue.

Will my participation be confidential?

The study will comply with the University of Southampton's policy to ensure that the information provided will be stored and remain confidential. Your name will not be recorded to link you to the data. The data will be coded with pseudonyms and will be kept on a password –protected computer. The information you provide will be used for the purpose of the research and will not be disclosed to any unauthorised person. The information you provide may be disclosed when you provide explicit consent.

Do I have to take part?

No. Your participation in this project is entirely voluntary. You are not obliged to take part. If you do not wish to take part, you do not have to give a reason and you will not be contacted again. Also, if you do agree to participate, you will be asked to sign a consent form to show that you have agreed to take part in the project. You are free to withdraw from the study at any time without giving a reason.

What happens if something goes wrong?

Any complaint or concern about the study will be addressed; please contact

1. Chair of Ethics committee

Komfo Anokye Teaching Hospital

Kumasi

Ghana

Website: www.kathhsp.org

Telephone: 0322025252

2. Chair of Research ethics committee

University of Southampton

So17 Ibj

Southampton (United Kingdom)

Website: www.southampton.ac.uk

Telephone: 00442380595000

Any further information on the research; please contact

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United Kingdom

Dr Deborah Fenlon

University of Southampton

Southampton

So17 1bj

United Kingdom

2. Women Patient Participant Information sheet

Study Title: Exploring how the cultural context in Ghana influences treatment decision making for women attending a southern Ghana breast clinic

Researcher: Linda Serwaa Agyemang Ethics number: 26346(01)

You are invited to take part in this project exploring how the cultural context in Ghana influences treatment decision making for women attending breast clinic. Before you decide, please read this information carefully to understand why the project is being done and what it will involve for you.

Please get in contact if you need more information or there is anything you do not understand. Thank you for taking time to read this information.

What is the research about?

I am a research student from the University of Southampton UK. This is a project I am doing and it involves observing and talking to women attending breast clinic. The purpose is to find out who is important to you and what is important to you as you make treatment decision. It is hoped that the project could provide useful information about what influences treatment decision making for women attending breast clinic. The project is funded by an International Group called Schlumberger Foundation who funds women from poor resource countries to conduct projects.

Why have I been chosen?

You have been invited to take part because you are attending the breast clinic.

What will happen to me if I take part?

The study will involve observing how nurses and doctors talk to you about treatment at the breast clinic. Afterwards, I will arrange a time to meet with you, which is convenient for you and in a place you feel appropriate for an interview. There will be one interview with myself during which I will ask you questions from an interview guide. The questions will be about your views concerning the information you received from doctors and nurses about treatment. I will also ask you what is important to you during treatment decision making. The interview is expected to last not more than an hour. You can decide to nominate a family member to be part of the study. When the study is completed, I will produce a summary of the findings, which I am more than happy to send to you if you are interested.

Are there any benefits in my taking part?

No, but the information you provide may be useful for nurses and doctors to improve care for women at breast clinics.

Are there any risks involved?

No, there are no anticipated risks involved. You may find it uncomfortable being observed or you may find that discussions may raise issues that you have not previously considered. You are free to stop being involved in observation or discussion if you do not want to continue. You do not have to give a reason and it will not affect your treatment in any way. Please, ask me or your nurse if you would like extra support.

Will my participation be confidential?

The study will comply with the University of Southampton's policy to ensure that the information provided will be stored and remain confidential. Your name will not be recorded to link you to the data. The data will be coded with pseudonyms and will be kept on a password –protected computer. The information you provide will be used for the purpose of the project and will not be disclosed to any unauthorised person. The information you provide may be disclosed when you provide explicit consent.

Do I have to take part?

No. Your participation in this project is voluntary. You are not obliged to take part. If you do not wish to take part, you do not have to give a reason and you will not be contacted again. This will not affect your treatment in anyway. Also, if you do agree to participate, you are free to withdraw at any time during the project without your care being affected.

What happens if something goes wrong?

Any complaint or concern about the study will be addressed; please contact

1. Chair of Ethics committee

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Any further information on the research; please contact

Principal researcher

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Supervisors:

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3. Nominated Family Member Participant Information sheet

Study Title: Exploring how the cultural context in Ghana influences treatment decision making for women attending a southern Ghana breast clinic

Researcher: Linda Serwaa Agyemang Ethics number: 26346(01)

You are invited to take part in this project exploring how the cultural context in Ghana influences treatment decision making for women attending breast clinic. Before you decide, please read this information carefully to understand why the project is being done and what it will involve for you.

Please get in contact if you need more information or there is anything you do not understand. Thank you for taking time to read this information.

What is the research about?

I am a research student from the University of Southampton UK. This is a project I am doing and it involves observing and talking to women and nominated family member attending breast clinic. It is hoped that the project could provide useful information about what influences treatment decision making for women attending breast clinic. The project is funded by an International Group called Schlumberger Foundation who funds women from poor resource countries to conduct projects.

Why have I been chosen?

You have been invited to take part because you were nominated by a woman attending the breast clinic.

What will happen to me if I take part?

The study will involve observing how nurses and doctors talk to women and their relatives about treatment at the breast clinic. Afterwards, I will arrange a time to meet with you, which is convenient for you and in a place you feel appropriate for an interview. There will be one interview with myself during which I will ask you questions from an interview guide. The questions will be about your views concerning treatment at the breast clinic. The interview is expected to last not more than an hour. When the study is completed, I will produce a summary of the findings which I am more than happy to send to you if you are interested.

Are there any benefits in my taking part?

No, but the information you provide may be useful for nurses and doctors to improve care for women at breast clinics.

Are there any risks involved?

No, there are no anticipated risks involved. You may find that discussion raises issues you have not previously considered. Please, ask me if you would like to receive extra support.

Will my participation be confidential?

The study will comply with the University of Southampton's policy to ensure that the information provided will be stored and remain confidential. Your name will not be recorded to link you to the data. The data will be coded with pseudonyms and will be kept on a password –protected computer. The information you provide will be used for the purpose of the project and will not be disclosed to any unauthorised person. The information you provide may be disclosed when you provide explicit consent.

Do I have to take part?

No. Your participation in this project is entirely voluntary. You are not obliged to take part. If you do not wish to take part, you do not have to give a reason and you will not be contacted again. This will not affect you or the woman who nominated you in anyway. Also, if you do agree to participate, you are free to withdraw at any time during the project without you or the woman who nominated you being affected in anyway.

What happens if something goes wrong?

Any complaint or concern about the study will be addressed; please contact

1. Chair of Ethics committee

   Komfo Anokye Teaching Hospital

   Kumasi

   Ghana

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Any further information on the research; please contact

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Appendix 9 Consent form

Study title: Exploring how the cultural context in Ghana influence treatment decision making for women attending Southern Ghana breast clinic

Researcher name: Linda Serwaa Agyemang Signature ……………………….

Study reference: April 2017 version 1 Ethics reference: 26346(01)

Please initial the box (es) if you agree with statement(s):

I have read and understood the information sheet and have had the opportunity to ask questions abou ☐ the study and have had these answered satisfactorily

I agree to take part in this research project and agree for my data to be used for the purpose of this study ☐

I agree to tape recording during interview and agree for the data to be used for the purpose of this study ☐

☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected

I therefore consent to the University of Southampton UK retaining my personal details on a database, kept separately from the research data detailed above. The ‘validity’ of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details be removed from this database at any time. ☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant ……………………………………………………………………….

Signature of participant ………………………………………………………………………

Date………………………………………………………………………

Appendix 10 Observation guide and field notes

Field note seventeen

Observation guide

Participants involved	**Physical space:**
Date	**Time**
Activity	**Goal**
Objects	**Non-verbal behaviours**

Date: 20th September 2017

Time: 11:30am to 11:45am

Physical Space: Consulting Room Two

Activity and goal

Patient-provider interaction on diagnosis and management plan

Participants (actors) involved: Maame Mamuna; Dr A; Nurse A; (another Consultant)

Maame Mamuna wears a loose dark skirt and blouse attire and has a head gear hanging down her shoulders. She sits on a plastic chair adjacent Doctor A and places her bag on her lap. Doctor A in blue shirt tucked in trousers sits on a padded swivel chair. He lowers his head and glances through Maame Mamuna’s folder on top of his desk for a couple of minutes. Dr A raises his head and shoulders and turns to face Maame Mamuna and says, ‘is the report in?”. Maame Mamuna moves head up and down (nods) and looks into her bag. She places her right hand inside her bag and brings out a report and extends her right hand and gives it to the doctor who also takes the report in his right hand.

Dr A looks at the report and his eyes moves from left to right. He turns his gaze back to the table and looks at a particular page in the folder for about a minute. Consulting room door opens and Nurse A in blue uniform walks a few steps back to her seat, on the leather chair, and her gaze looks distant.

Dr A sits up straight in his swivel chair and gazes at Maame Mamuna directly and says, “the biopsy report from the excision biopsy, the first operation confirmed breast cancer. But before that the previous investigations did not state the breast mass was cancerous. So, at the tumour board meeting we decided to excise the scar and send a sample from the scar tissue for histology. The results here show that there are cancer cells still there (2) so now we will remove the whole breast".

Maame Mamuna looks at Dr A as he talks to her and she places her right hand over her left shoulder.

Dr A leans against his chair and gazes at Maame Mamuna and says, "so I will write some investigations for you to do and bring".

Maame Mamuna shifts a bit in her chair and replies, "where am I going to get the money to do these investigations you are asking me and the treatment?" ((her tone sounding irritated)). Nurse A turns her gaze towards Maame Mamuna ((obviously looking shocked)).

Dr A gazes at Maame Mamuna and says, "nobody nor any doctor is going to collect money from you"↑ ((looking angry, obviously not happy with Maame's line of questioning)). Maame Mamuna replies "but what you are telling me requires money, it is not free"↓ ((in a low tone)). She looks down and puts her hand in her bag and brings out something like papers from her bag. Maame Mamuna, "All these are receipts for the previous investigation and surgical procedure so money is involved. I do not have any money at the moment" ((in a sad tone and her gaze was more towards me than towards the doctor)).

Dr A looks up and sighs, "SHE JUST DOES NOT WANT TO DO MASTECTOMY" ((in a loud voice in English Language)). Maame looks down at her bag and puts the receipts inside the bag. The door opens and another consultant enters the consulting room.

This other consultant looks over at Maame Mamuna and comes to stand near the table of Dr A and says, "I have seen this particular woman in my consultation before".

Dr A gazes at the other consultant and says, "the current histology report says there are cancer cells in the scar tissue excised". Dr A flips through the pages in the folder noisily and shows a page to his colleague consultant and both of them look through. Dr A turns to a particular page and they began to read. For about four minutes the two doctors are engaged in flipping notes and reading Maame's folder. The other consultant still gazing at folder talks to Dr A, "this note I wrote it, so now the current histology report says there are cancer cells, so ok mastectomy is highly indicated". By this time, Maame Mamuna looks down and she wipes tears from her eyes with her head gear.

The other consultant looking at Dr A continues, “she will need to undergo investigations, abdominal ultrasound, chest CT and come along with the results on the next consultation, then we will take her to tumour board for discussion on treatment”.

The other consultant picks a folder on top of a pile of folders on Dr A’s table and walks out of the room closing the door behind him.

Dr A looks at Maame’s histology report and writes in Maame Mamuna’s folder for about two minutes.

Dr A closes folder and looks at Maame Mamuna and says, “you don’t need to do the investigations as you did some not too long ago. So, come on next Tuesday afternoon for tumour board meeting”.

Nurse A gets up and Maame Mamuna who was still upset also gets up and they both walked out of the consulting room.

Nurse A stands close to Mame Mamuna at the corridor of the nurses’ station and puts her hand on Maame Mamuna’s back shoulder and says, “it is alright for you to be upset so you can let out any built-up emotions”. Maame Mamuna, “I am not going to do any operation, thank you madam nurse” and she walks away.

Non-verbal behaviours

Maame Mamuna

Irritation is an emotion shown by patient after hearing doctor’s request about management Bringing out receipts of previous payments of breast care cost is a way to show patient is paying for care

Reducing tone of voice, looking in the direction of researcher other than HCP, looking upset →**powerlessness**

Crying is an emotion patient shows after hearing treatment [powerlessness?]

Looking down is a way patient behaved when two doctors discussed her case [less dominant?]

Dr A

Anger is an emotion doctor shows in response to patient who questions him over charges [authority?]

Leaning against chair and gazing at patient is a way doctors communicate with patient during treatment recommendation [authority]

Talking loudly to self in English is a way doctor responds to patient's defiance to treatment [authority]

writing in folder is a step in communicating treatment

Nurse A

Surprise is an emotion shown by nurse when patient questions doctor: unexpected behaviour/outside the norm?

Putting hand on patient's shoulder is a way nurses reassure patient

Objects (artefacts)

Breast cancer signs and symptoms poster

Xelodar pharmacology poster

Breast cancer markers poster

- There were two breast cancer 'signs and symptoms' posters pasted on the two sides of the wall and facing each other. The posters had a picture in a form of a drawing of the breast with content on signs and symptoms of breast cancer. There was a xelodar (pharmacology) poster and another poster 'breast cancer markers to look out for' also pasted on the wall next to the 'xelodar' poster. The content of the two-breast cancer 'signs and symptoms' posters were readable from where I sat, nonetheless, the 'xelodar' and 'breast cancer markers' posters were less readable because the writings were small.
- In this extension room is another poster on breast cancer signs and symptoms pasted at the head end of the trolley. This poster is similar to the one in the main consulting room. All posters are written in English.

Consultation table

Investigation request form

Prescription form

Patients' folders

- There was a desk (nicely polished) that served as a table for the doctor. On the table were investigation request and prescription forms which have been arranged. There was a pile of folders placed on the table in the order of person next to be called. There was no computer on the desk (this was the norm in most Ghanaian clinics).

Plastic chair

Wooden padded chair

Swivel chair

- Dr A sat in a swivel chair.
- Maame Mamuna sat on one of the two plastic chairs.
- Nurse A sat on the wooden padded chair

Analysis

Descriptive codes for woman's behaviour	**Doctor's behaviour**	**Nurse's behaviour**
Sitting on plastic chair	sitting on swivel chair	sitting on leather chair
Nodding is a cultural gesture for 'yes' and 'OK'	reading folder	looking surprised
Giving report to doctor	facing woman	
Listening	requesting histology report	
Questioning doctor about cost	reading histology report	
Showing emotion of irritation	giving summary of medical information	
Bringing out receipts as proof of payment	giving current diagnosis of cancer in breast scar tissue	
Having breast care requires money	deciding treatment, 'we will remove	
Raising concern of not having money	the whole breast'	
	requesting further investigation	
electing to refuse treatment		
	Showing emotion of anger	
	Shouting 'woman does not want mastectomy'	
	Speaking English Language	

Further exploration and reflections

I. What brings Maame to the clinic →explored with Maame during interview

J. Maame has breast cancer staging two i.e. T2N1M0 (factual information from folder), so why is mastectomy the only surgical treatment option→explored with doctor during interview

K. Conflicting core biopsy result and excision biopsy result: to what extent is core biopsy result reliable; what factors impact core biopsy result; what are the implications → explored with HCPS during interviews

L. Why is Maame sounding irritated and questions doctor where to find money for further investigation and 'removing whole breast' → will explore from interview

M. What are all the ways doctors communicate diagnosis and management plan→ more focused observations

N. What are all the ways other women respond when doctors communicate management plan→explored through focused observations

O. Why is doctor sounding angry following Maame's response→ implicit?

P. Why does doctor think Maame does not want mastectomy→ interview with doctor

Q. Why is Maame passive and does not ask question nor clarification on the conflicting diagnosis and current treatment plan

R. Why is Maame active in talking about cost issues and money concerns ; Is cost Maame's only concern or there are other concerns and why did she not raise them→ interview

S. What does Maame mean by 'I won't do any operation' → interview

T. Why is it that it is the nurse Maame talks to that she will not do the operation doctor talks about→ implicit

U. Why is nurse reassuring Maame outside consulting room? → further observation

V. Why did Nurse act surprised when Maame questions doctor→implicit

W. Why did doctor assume patient does not want 'mastectomy'?→ conversation/interview

X. If doctor assumes patient does not want mastectomy then why is there no attempt to elicit concerns/why no conversations around it→more observation

Y. To what extent do doctors explore patient's concerns after treatment recommendation; In what ways do doctors behaviour encourage or discourage active involvement of patient and why? →more focused observation

Reflections

The consultant in consulting room 2 had already seen several patients already. The nurse assisting the consultant had gone out (possibly to call the next patient although I did not hear the mention of any name). The common practice is for the nurse assisting the consultant to call patient by name by standing at the door of the consulting room.

I asked of her full name and cross-checked with that of the folder on top of the doctor's consulting table and it matched (performing the role of a nurse). I asked how Maame Mamuna was feeling. She responded that she was feeling fine. I placed the folder in front of Dr A (behaving like one of the nurses at the clinic; I felt like a member of the clinic team as I assisted the doctor in that role; on the other hand, I felt that this may have implication on the interview data I would gather from the patient; I wanted to be neutral but I guess I could not maintain that neutrality as I acted more like a nurse than a researcher.

Appendix 11 Interview guides

Interview guide for patient participant

Background information

Age	**Marital status**	**Menstruation status**
Parity	**Ethnicity**	**Place of residence**
Occupation	**Income**	**Religion**
Educational level		

1. Can you describe your thoughts about what the doctor and the nurse talked to you concerning breast cancer and treatment? Prompts:
2. Did you understand what you were told? What difficulties are you having making a decision? Did you want more information? Did you feel confident to ask questions or clarification? How clear are you about the pros and cons that are important to you concerning the treatment? Tell me more? Ask about behaviour the researcher observed; ask about meaning of behaviour observed; how does this experience influence your treatment decision?)
3. Who in your family makes decision about what to do when you or someone in the family is ill? (prompt: How is this decision made? Why?)
4. Show series of pictorial drawing (of social relations to woman, appendix 10) and let her point to those she thinks about as she makes decision about the cancer treatment
5. Probe further to explore what it is that she is thinking about (prompt: how is this influencing your treatment decision)
6. Let woman point who among the people in the drawing contribute to her breast cancer treatment decision making (prompt: in what ways; highlight the key people and factors influencing treatment decision-making; how is this similar or different to treatment decision making for other medical conditions? Why?)
7. Can you describe what values are important to you as you consider treatment (e.g. family commitment, family relationship, job, marriage, religion, childbearing and breastfeeding, can

you elaborate more on what makes it important to you? How does this influence your treatment decision?)

8. Can you describe how you considered this value in relation to survival, pain relief, treatment side effects or finances? (prompt: how does it influence your treatment decision?)
9. What does breast cancer mean to/for you?
10. What are your concerns about breast cancer and treatment? (prompt: have you shared these and with whom; how does this influence your treatment decision)

Interview guide for healthcare professional participant

Background information

Professional background	**Years of experience at the breast clinic**	
Ethnicity	**Religion**	**Age**

1. Can you describe how you provide breast cancer diagnosis to women with breast cancer attending this clinic?
2. Can you describe how you offer treatment recommendation to women with breast cancer?
3. Can you describe what patients' views are regarding consequences of breast cancer treatment?
4. Can you describe what you do when you find differences between your views and that of a patient regarding causes of breast cancer and consequences of treatment? What are their reactions?)
5. Can you share your experience of what patients think they need to do before taking up treatment (prompt: do they think they need to consult someone? Who do they normally consult? Why? What is the implication of that?)
6. What are your views on **who matters** to patients as they consider breast cancer treatment? (prompt: do you find differences among different patient groups e.g. age; educational status; income; marital status; ethnicity; religion; parity?)
7. What are your views on **what matters** to patients as they consider treatment? (prompt: do you find differences among different patient groups e.g. age; educational status; income; marital status; religion; parity?)
8. In what ways does this influence women's treatment decisional support?

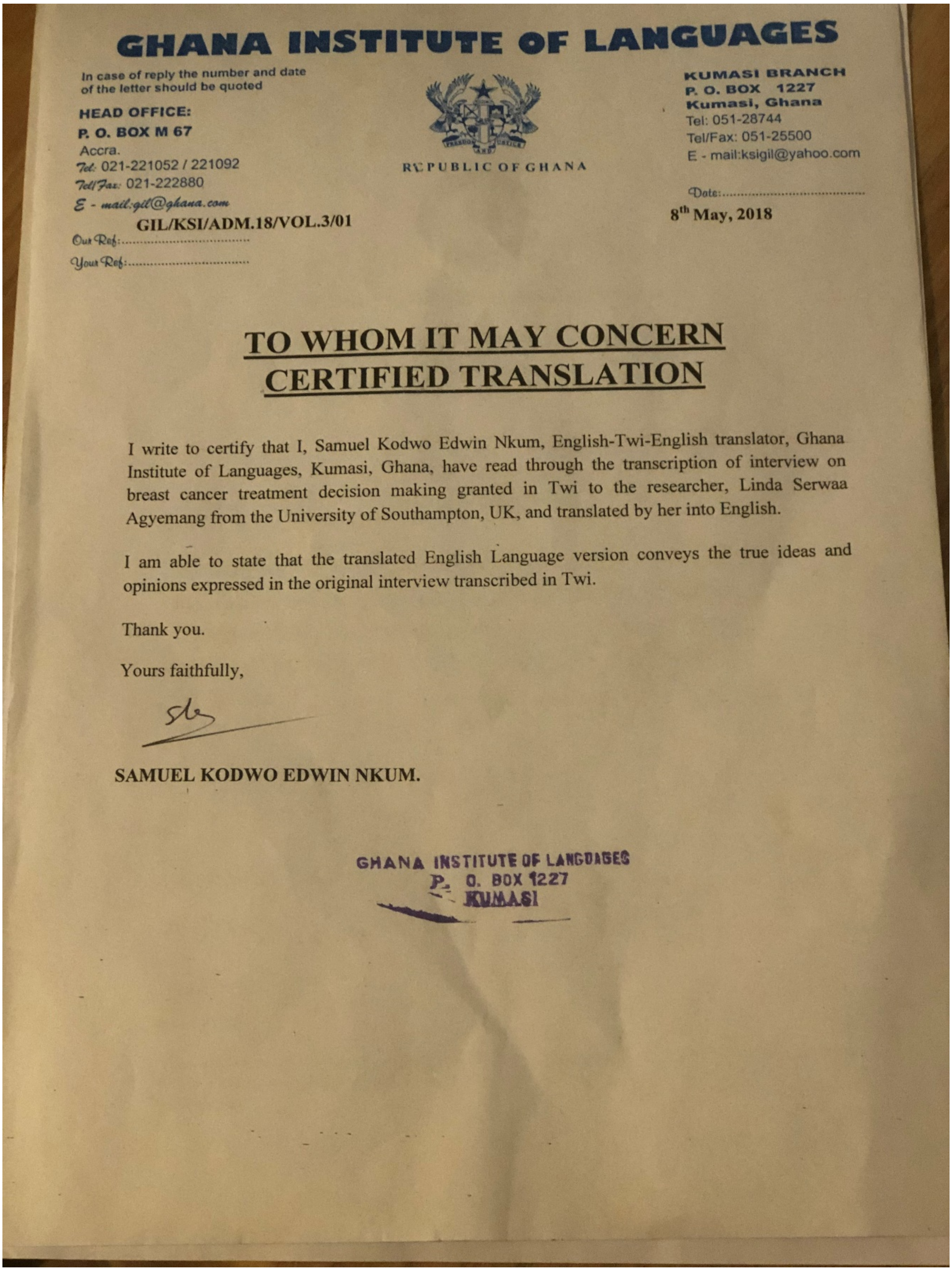
Interview Guide for nominated family member

Age	**Ethnicity**	**Religion**
Relationship to patient	**Educational level**	**Occupation**
Income		

1. What are your views on who Maame X normally consults when decisions need to be made about treatment for medical conditions? (prompt: Why? What do you think influence treatment decisions? What is the usual reaction of the woman to the treatment decisions?)
2. Would Maame X respond differently to different types of medical conditions? If so, what would those difference be? (prompt: In what way will her response be different?)
3. Can you describe how different or similar this is when compared with the treatment decision making for the breast cancer? (prompt: In what ways? Why?)
4. Can you share with me your views about breast cancer and treatment**?**
5. Can you tell me your concerns about breast cancer treatment (prompt: How do your views and concerns about breast cancer and treatment influence your support to the woman i.e. informational support, instrumental support, emotional support?)
6. How do you describe your role in the woman's treatment decision making?

An ecomap showing a woman (Maame X) and her social network

Appendix 12 Expert validation of translated transcripts



GHANA INSTITUTE OF LANGUAGES

In case of reply the number and date
of the letter should be quoted

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Date: **8th May, 2018**

Our Ref: **GIL/KSI/ADM.18/VOL.3/01**
Your Ref:

TO WHOM IT MAY CONCERN
CERTIFIED TRANSLATION

I write to certify that I, Samuel Kodwo Edwin Nkum, English-Twi-English translator, Ghana Institute of Languages, Kumasi, Ghana, have read through the transcription of interview on breast cancer treatment decision making granted in Twi to the researcher, Linda Serwaa Agyemang from the University of Southampton, UK, and translated by her into English.

I am able to state that the translated English Language version conveys the true ideas and opinions expressed in the original interview transcribed in Twi.

Thank you.

Yours faithfully,

SAMUEL KODWO EDWIN NKUM.

GHANA INSTITUTE OF LANGUAGES
P. O. BOX 1227
KUMASI

Appendix 13 Initial open codes

Initial open codes	
Steps to cancer diagnosis	Women’s daily lives
Women’s health seeking behaviours	Breadwinner
Illness perception	House chores
Participation in decision making	Children self sufficient
Self medication	Clinic structures
Illness severity	Posters and information materials
Contributing resources	Chairs
Social network input	Doctor-patient relationship
Support from family	Core biopsy
Knowing a survivor	Busyness of HCPs
Informational support	Diagnosis
Emotional support	Power
Financial support	Emotions and feelings expressed by doctors
Meaning of breast cancer	Patient history taking
Belief in supernatural cause	Management plan
Belief in physical cause	Doctors’ demeaner
Stigma	Misinformation
Reaction to breast cancer diagnosis	Tumour board meeting
Shock	Support from HCPs
Feeling sad	Nurses’ roles
Fear	Screening
Denial	KDK
Confusion	Reasons for accepting to take treatment
Inability to ask question	Treatment will prevent disease progression
Not wanting to bother staff	Prefers mastectomy due to side effects of chemotherapy

Doctor appeared tired Does not want to sound challenging Past experience Negative consequences for not following doctors’ recommendation Mastectomy leads to death Not know what cancer is Knowledge on cancer Presented because of pain in breast Presented because of lump Being cut with a knife weakens you Important things to women Womanhood Engaging in routine Family commitment Being able to work Belief in God	Desires more children but will have treatment Treatment will stop pain Concern over breastfeeding Significant other encourages treatment Prosthesis/reconstruction Reasons for not accepting treatment Uncertainty about treatment outcome Loss of trust due to past experience Significant other does not support treatment Treatment will lead to loss of income to take care of children Fear mastectomy will lead to death Loss of strength Prefers herbal treatment Financial constraints

Examples of codes and data extracts from NVivo

Participant	Codes	Data
Maame Mamuna	Inability to ask questions	Files\\coded transcripts\\maame mamuna with codes.1 (2) - § 3 references coded [0.20% Coverage] Reference 1 - 0.12% Coverage No I did not, when I decide to ask then I stop. I am not able to ask questions, if I say I asked about it I will be lying. At the clinic, I am unable to talk because I feel too sad. Reference 2 - 0.03% Coverage Every time i go to the clinic I will always be crying. Reference 3 - 0.05% Coverage this particular one I did not ask anybody how one gets it because I was feeling sad.
	Loss of trust due to past experience	Files\\coded transcripts\\maame mamuna with codes.1 (2) - § 10 references coded [3.86% Coverage] Reference 1 - 0.26% Coverage As for me, I know they are deceiving me. The first operation they did not remove it because they said they did not know it was cancer. With the second operation, why didn't they take it off because this time they knew it was cancer. I asked Dr A whether they were going to remove it they said no, why are they saying they are going to remove it now? What they said they were going to remove from my armpit is still there they did not remove it Reference 2 - 0.22% Coverage

		If they cannot remove it, they should say so. Every little time come and pay money so we can remove it for you, every little time come and pay money for us to remove it yet you are unable to remove it. The doctors are just deceiving me so I think if I stay at home with my condition, it will be better for me than to go to them for help whereas I wont get any help from them. Reference 3 - 0.10% Coverage he first operation, they did not take the thing out at that time when it was just here (points at a part of her breast to me) but now the thing has spread to my armpit. So I am saying I don’t think they can remove it for me. I don’t trust them to be able to remove it for me. Now they say they will cut the breast, I don’t think if they cut the breast they can remove the illness. This thing was small but they could not remove it, it was here (points at a particular spot on the right breast to me) they have let it spread to my armpit, so now I don’t trust them to be able to remove it, that is why I do not want them to cut it as even if they cut it, the illness will still be there, they cannot remove it. Reference 7 - 0.52% Coverage but what did they see previously that they did not remove it? That is what they said previously that they will remove it but they did not remove it. They asked me to come for them to do investigations; they did the investigations but they did not remove it. So now I do not trust them. Now they are saying they are going to cut the breast and remove it but why didn’t they remove it during the previous operations so I think even if they cut the breast, they cannot remove it. This is what I think. I don’t think they can do it for me again. I trusted them to remove it for me during the second operation because the first operation they said they did not know it was cancer, how

		could they remove something they did not know? They asked me what should they do for me and I said they should do whatever they think will help me so now if I think I cannot get help, why should I bother myself.
	Fear mastectomy will lead to death	Files\\coded transcripts\\maame mamuna with codes.1 (2) - § 6 references coded [0.78% Coverage] Reference 1 - 0.12% Coverage as for me, when they told me about the operation, I became nervous and what came to my mind was that if I do this operation and I do not wake up, I do not have a husband, who will take care of my children? Reference 2 - 0.12% Coverage the first operation, I did not have that thought but this particular one I have such thought.. I mean the operations are too many so if I go to do this and I do not come back, who will take care of my children. Reference 3 - 0.07% Coverage still think the same way because the doctors did an operation on the breast before and now they want to do another operation Reference 4 - 0.24% Coverage when the doctors told me I was very worried. The reason why I was worried is because I knew someone at Tek, when they told her she had cancer, she hid it from people and did not inform anyone. She then came to Gyii and the doctors said they will cut the breast. As soon as they cut the breast, within

		3-6 months the woman died. So when they told me, I felt that I am also going to die and leave my children. Reference 5 - 0.18% Coverage When she (the dead woman) was finally discharged home, she was at home for a while but she was taken back to the hospital for another operation where they took some things from her armpit. After this, it was not long and she died. So this woman's story made me scared when the doctors told me I had the condition.

Appendix 14 Data Extraction forms

Quantitative studies

Date of extraction …………………….

Author ……………………………………. …………. Year ………………………………… Country ………………………………

Setting…….

Study period……..

Number of participants ……

Age of participants …….

Method of data collection ……………………………………………………………………………………………………..

Method of data analysis …….

Stage of breast cancer	Breast cancer treatment	Operational definition of treatment (non) completion	Period of treatment (non)completion	Reasons for non(completion)	Outcome	Control	
						Number of participants	Number used in analysis

Authors' conclusion

Reviewer's comments

Data extraction form for qualitative studies

Date of extraction ………………………..

Author ………………………………….. …………. Year ………………………………. Country ……………………………

Setting……….

Culture ………..

Phenomenon of interest ………………………………………………………………………………………………………

Study period……….

Number of participants ……………………………………………………………………………………………………

Age of participants ……..

Method of data collection ………………………………………………………………………………………………..

……….

Type of data analysis ………………………………………………………………………………………………………

Findings ………

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………..

Author's conclusion

Reviewer's comments

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