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Impact of sociocultural factors on appraisal and help-seeking behaviour among Ghanaian women with breast cancer symptoms

By

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<u>ABSTRACT</u>

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<u>Doctor of Philosophy</u>

IMPACT OF SOCIOCULTURAL FACTORS ON APPRAISAL AND HELP-SEEKING BEHAVIOUR AMONG GHANAIAN WOMEN WITH BREAST CANCER SYMPTOMS

by Seth Agyei Wiafe

Breast cancer is a disease that continues to rise across the world, and it is now the leading cause of death among Ghanaian women. Currently, an estimated 85% of new breast cancer patients are diagnosed at advanced stages, resulting from delay in seeking modern medical help. Although it is generally acknowledged that early detection and treatment of breast cancer improves survival, it is unclear why the majority of Ghanaian women take longer to present symptoms than those in Western world. The aims of this study are; to ascertain how specific sociocultural issues influence Ghanaian women's appraisal of breast cancer symptoms, the meaning they ascribed to those symptoms, the significance of this experience on their timing and choice of healthcare utilisation, and whether these factors are different in Ghana from those identified in Western countries.

A qualitative design involving purposive sampling was used to recruit 35 patients awaiting their first medical consultation at two healthcare facilities in Ghana, 27 members of the patients' social networks, and eight healthcare professionals. The interviews were face-to-face audio recorded, semi-structured, and participants completed a demographic questionnaire. Additionally, field notes and a reflective diary were kept as supportive data. Thematic analysis was conducted to identify relevant themes. A computer software package was used for data management.

The study found four main influential factors that contributed to late presentation within the sample; these are patients' sociocultural backgrounds, specific manifestation of breast cancer signs, patients' emotional responses towards those signs and symptoms, and existing healthcare system. The study has deepened the understanding of appraisal and help-seeking behaviour of Ghanaian women who discovered breast cancer symptoms. These insights would assist healthcare professionals to implement interventions capable of encouraging early symptom detection and presentation for modern medicine treatment.

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Declaration of Authorship

I, Seth Agyei Wiafe, declare that the thesis entitled 'Impact of sociocultural factors on appraisal and help-seeking behaviour among Ghanaian women with breast cancer symptoms' 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:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- 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;
- where I have consulted the published work of others, this is always clearly attributed;
- 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;
- I have acknowledged all main sources of help;
- 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;
- parts of this work have been published or presented as:
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Definition of Abbreviations

ACS	American cancer society
AIDS	Acquired immunodeficiency Syndrome
BSE	Breast self-examination
CAM	Complementary and alternative medicine
CAQDAS	Computer-assisted qualitative data analysis software
CASP	Critical appraisal skills programme
CBE	Clinical breast examination
CHPS	Community-based health planning and services
CHRPE	Committee on human research publication and ethics
CINAHL	Cumulative index of nursing and allied health literature
CSB	Care-seeking behaviour
EPRC	Ethical and protocol review committee
GBHS	Ghana Breast Health Study
GDP	Gross domestic product
GHS	Ghana health service
GISP	Geographic information systems professional
GP	General Practitioner
HBM	Health Belief Model
HCP	Healthcare professional
HIV	Human immunodeficiency virus
IARC	International agency for research on cancer
IRC	Internet relay chat
JSS	Junior Secondary School

KATH	Komfo Anokye Teaching Hospital
KBTH	Korle-bu Teaching Hospital
LMICs	Low and middle-income countries
MEDLINE	Medical Literature On-Line
MeSH	Medical subject headings
MoH	Ministry of Health
MTPD	Model of total patient delay
NCD	Non-communicable disease
NEM	Network Episode Model
NHIS	National Health Insurance Scheme
NPC	National population council
OPD	Outpatient department
PsychInFO	Psychology Information
SCT	Social cognitive theory
SHS	Senior High School
SIM	Symptom interpretation model
SPSS	Statistical package for social sciences
TMPC	Traditional medicine practice council
TMP	Traditional medical practitioner
TPB	Theory of planned behaviour
TRA	Theory of reasoned action
UAE	United Arab Emirates
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Chapter 1:   Introduction and Background

1.1   Introduction

This thesis is an investigation into factors contributing to late presentation of breast cancer among patients in Ghana, who self-discovered symptoms suggestive of breast cancer. The aims were to conduct a rigorous and in-depth study to ascertain how specific sociocultural issues influenced patients' appraisal of breast cancer symptoms, the meaning they ascribed to the symptoms, the significance of this experience on their timing and choice of healthcare utilisation, and whether these factors are different in Ghana from those identified in Western countries. To shed more light on reasons for patients' delays in presenting to healthcare professionals (HCPs), this study set out to explore the delay-causing factors through the eyes of multiple sources including patients, members of their social networks, and healthcare professionals for their perspectives.

The study has included 35 patients from diverse backgrounds, 27 of their friends and family members, and eight healthcare professionals who completed in-depth face-to-face interviews and demographic questionnaires. The study took place at a time when late presentation of symptoms for modern medicine treatment is the characterisation of breast cancer, generating rising mortality amongst Ghanaian women. Therefore, this study significantly increases understanding of factors influencing the patient's delay from the time of noticing a breast change to presenting it for medical treatment.

This initial chapter sets the scene for this interpretive qualitative study. Beginning with the background of the research, I describe what motivated me to undertake this study. This is followed by information about Ghana in order to describe the context, breast cancer incidence and mortality in general, delayed presentation of symptoms, breast cancer control and prevention strategies, and the sociocultural impact of delayed presentation. Furthermore, the chapter presents justification for the research, the anticipated contribution of the study, and concludes with an overview of the subsequent chapters of the thesis.

1.2   Background

The focus of this research originated from my public health practice as a health geographer. Being a geographic information systems professional (GISP), conducting needs' assessments and creating spatial analysis to determine access to healthcare services were part of my responsibilities. In 2012, during one of my assignments to South Sudan, I encountered a woman with advanced symptoms of breast cancer at the hospital where I was working. This hospital had a capacity of 70 beds, and it was the only hospital within a distance of 50 miles radius. At age 45, the patient was very weak and unable to walk without help. There was an offensive discharge from her breast lesion. Due to the odour, she was left alone in the hospital courtyard while nurses attended to her on a stretcher.

Upon inquiry, I was told that the hospital usually receives a significant number of breast cases, but they typically present at the stage when the only treatment the facility could offer them is some form of palliative care. I understood from a nurse that this particular patient was seen at the hospital five years previously when the lump was small and not ulcerated. Although she was then referred to a specialist hospital, there was no record of any further follow up. Because of this experience, I became interested in learning more about what patients go through with a life threatening disease like breast cancer. I wanted to do this in order to understand how such patients assess their symptoms and their decision-making processes regarding treatment. This attempt to understand factors for delayed presentation is with a view to assisting healthcare providers to establish a more efficient prevention programme that encourages women to present breast cancer symptoms at an early stage for a definite diagnosis and treatment.

I chose Ghana as the location for this study for three reasons. Firstly, Ghana, like many African countries, is considered what the World Health Organisation (WHO) terms, an "epidemic of non-communicable diseases (NCDs)" including cancers, cardiovascular diseases, and diabetes (Alwan 2011). While the magnitude of these diseases continues to rise in Ghana, chronic conditions co-exist with the problem of communicable diseases. As a result, the double burden of infectious and chronic diseases constrains Ghana's healthcare

system, with significant proportions of healthcare budgets, human resources, and research focusing on communicable diseases, resulting in the comparative neglect of NCDs.

Secondly, my involvement with the Ghana Breast Health Study (GBHS) enabled me to gain useful professional and social contacts (GBHS 2013), as well as adequate geographical and public health knowledge of the country. Therefore, given the time constraints of undertaking academic research, where attention to logistics is crucial, it made practical sense to carry out this empirical study there. The third reason for choosing Ghana was my level of familiarity with the local language and cultural context. Since the focus of this study is to explore the links between sociocultural factors, appraisal of breast cancer symptoms, and choice of healthcare, language and communication are integral parts of the production, dissemination, and transformation of the knowledge generated (Easton 2001). Hence, with a good working knowledge of two major Ghanaian languages, Fanti and Twi, I felt a focus on Ghana would be supported by appropriate knowledge and skills to investigate the symptom appraisal and help-seeking phenomenon.

1.2.1   Information about Ghana

Ghana is one of the sixteen West African countries, and the first sub-Saharan country in colonial Africa to gain its independence in 1957(Drislane et al. 2014). Geographically, the country is situated on the west coast of Africa, off the Gulf of Guinea. It occupies a land area of 238,589 square kilometres, and is bordered in the west by Cote d'Ivoire, east by Togo, and the north by Burkina Faso (see Figure 1). The country consists of ten administrative regions that are subdivided into 170 districts (NPC 2011). The current population of approximately 26 million, which is made up of eight major ethnic groups, is very young; 38% are 0–14 year olds, 58% are 15–64 year olds, and only 4% are 65 years or older (World Fact Book 2014). While there are more than 250 languages and dialects spoken in Ghana, English is the country's official language, which dominates within government and business affairs (World Fact Book 2014).

Ghana's economy is mainly agricultural with crops produced for both local consumption and export. Minerals and timber also contribute to the country's earnings. A gross domestic product (GDP) per capita of US$1230, in 2010, classified Ghana as a lower middle income country (Osei-Ampofo et al. 2013). In 2014, it was estimated that the average monthly household income was GH¢1,400.00 (approximately 250 GBP) (GSS 2011).

Figure 1 Map of Ghana

The lower economic conditions make the choices of how to use Ghana's scarce resources to improve healthcare delivery difficult. Though the country is considered one of the fastest growing economies in the world, with higher per capita economy than most sub-Saharan African countries (NPC 2011), it faces economic challenges reflected in the poor state of health of Ghanaians.

The primary source of Ghanaian identity, loyalty, and responsibility is the institution of the family, based on a strong bond among its members and sustained through a series of kinship networks and marriages. Ghanaians emphasise communal values such as respect for the elderly, honouring traditional authority figures, and upholding social morals. Individuals attain recognition and social status through their extended family structure. To achieve good social standing, family members have to maintain a sense of harmony at all times, to ensure they do not cause anyone embarrassment (Lamar Soutter 2014). Family obligations take precedence over everything else in life. The family unit provides not only a sense of identity but also social, economic, and emotional support. For instance, the entire family shares any loss of honour. Wealthier members of the extended family are socially obliged and pressured to provide a safety net for poorer family members in a financial crisis, such as sudden unplanned health expenditure (Agyepong & Adjei 2008). All these features make the social structure in Ghana a collective one.

Whilst both matrilineal and patrilineal traditions co-exist in many ethnic groups, male dominance in gender relations is ensured through marriage customs and related institutions of lineage, polygyny, and the family (Lloyd & Gage-Brandon 1993). To emphasise strong family bonding and childbearing, Adongo et al. (1997) reported that women and children were considered as the property of the corporate family-kin and some communities strongly opposed reproductive control. Women were then expected to be submissive and obey their husbands at all times. Domestic power relationships, control over and use of family resources, and healthcare decisions for children and adults were all vested in males (Adongo et al. 1997). Gender roles were so rigidly segregated that men never did what was expected of women and vice versa (Avotri & Walters 2001). Most notably, Avotri and Walters (2001) indicated that the roles assigned to women placed heavy demands upon them, constrained them, limited control over their lives, and robbed them of access to health and economic resources.

Over the past decades, Ghana has made steady progress regarding the health of its population. This is exemplified by the fact that the median life expectancy is now 60 years, up from 45 years in 1957 (AHWO 2010),

compared to an average of 75 years in Western countries in 2012 (WHO 2013). Since the early nineteenth century, when modern medicine was introduced, Ghana's healthcare system has been organised under two main groups: modern and traditional (Tabi et al. 2006). While the Ministry of Health (MoH) licenses the healthcare facilities within the modern system, the practitioners of the traditional system are registered by the Traditional Medicine Practice Council (TMPC) (WHO 2001).

The modern healthcare system is further grouped into three categories: public, private-for-profit, and private-not-for profit. Public health services delivered by the agencies of the MoH include; the Ghana Health Service (GHS), the four teaching hospitals (Korle Bu, Komfo Anokye, Tamale, and Cape Coast) and other quasi-government operated health services, such as those provided by the army, the police, and some large corporations for their employees. The modern system operates as a three-tier referral model with primary, secondary, and tertiary levels. The teaching hospitals provide the highest level of care followed by the regional hospitals, district hospitals, clinics, health centres, and community-based health planning and service (CHPS) compounds, in that order. The private-for-profit system includes private doctors, midwives, and pharmacists who work in private healthcare facilities (Osei-Ampofo et al. 2013), constitute about one-third of Ghana's health facilities (IHME 2015). The private not-for-profit system are often religious missions (e.g. Christian and Muslim health services), providing approximately 40% of available healthcare (Salisu & Prinz 2009).

Despite improvements in life expectancy, the health status of Ghanaians still remains weak (Drislane et al. 2014). Several issues challenge Ghana's modern healthcare system. As previously noted in section 1.2, the country is confronted with the double burden of diseases, with increasing NCDs among the top ten diseases at outpatient departments (OPDs). In fact, Ohene-Yeboah and Adjei (2012) acknowledged breast cancer as the leading cause of cancer deaths amongst women, many of whom delay treatment. In addition to chronic diseases, malnutrition, parasitic and infectious diseases contribute to almost half of all deaths in Ghana (World Bank 2013).

Geographical access to healthcare continues to be a key challenge, despite the expansion of the CHPS initiative (Nyonator et al. 2005). The system is centred

heavily in the two largest cities; urban centres are relatively well served and contain most hospitals. As an example, treatment involving radiotherapy is only available at Accra and Kumasi, 250 kilometres (180 miles) apart, creating important geographical barriers to accessing radiation treatment for people who live outside those two cities. Since radiotherapy was introduced in Korle-Bu teaching hospital (KBTH) at Accra in 1997 and Komfo Anokye teaching hospital (KATH) at Kumasi in 2004, multidisciplinary approaches with some adjuvant treatments and limited palliative care strategies have enhanced cancer management (Vanderpuye 2012). Otherwise, according to Clegg-Lamptey and Hodasi (2007), surgery would continue to be the main form of breast cancer treatment in the country. As the healthcare system, and cancer treatments, continuously expand and become ever more available to the Ghanaian population, more women could potentially access care earlier, provided they take immediate medical action when experiencing a symptom that could signal breast cancer. However, the lack of accessibility to treatment centres as well as time loss and costs incurred from patients' transportation tend to present a huge barrier to seeking medical help.

In addition to the geographical considerations, patients might only have access to teaching hospitals through a well-developed referral system. However, a study on the status of referrals in Ghana revealed several barriers contributing to failure of patients' compliance with medical referral (BASICS II & GHS 1996). The deficiencies identified in the referral system include patient transport costs, fear of the hospital, and poor treatment received at the hospital. Other factors that could prevent patients from accessing the referral hospitals include costs unrelated to transportation that are associated with people who accompany patients, the need for permission from family members, and other unplanned financial commitments. Although parts of breast cancer diagnosis and treatments are covered by Ghana's National Health Insurance Scheme (NHIS), out-of-pocket costs per treatment course per patient are prohibitively expensive for the average working family (Agyepong & Adjei 2008).

Limited skilled health workers and inequity in the distribution of the health workforce further complicates the healthcare situation. As at 2010, there were only 2,306 doctors in the country. The doctor-patient ratio was 1:10,000, the

nurse-patient ratio was 1:1800, and the midwife-patient ratio was 1:7600 (NPC 2011). Radiation oncologists are scarce and are only concentrated in the nation's two teaching hospitals in Accra and Kumasi. These statistics contrast with the WHO's recommendation of a doctor to patient ratio of 1:1000 (Kinfu et al. 2009).

In the indigenous Ghanaian society, the approach to healthcare is centred on a personal understanding of one's health, life, and wellbeing (Tabi et al. 2006). Such health views influenced the development of the country's dual healthcare system. Based on the historical co-existence of several treatment modalities involving traditional as well as modern medicine, the MoH has formally recognised the role of the traditional healers within its healthcare system, an outcome resulting in medical pluralism (Twumasi 1979; Asante & Avornyo 2013). Currently, fifteen public hospitals operating modern medical system also have herbal medicine units (Modern Ghana 2015). Although both types of treatment regimens are accepted and used by Ghanaians, depending on their perception of the illness confronted, interpretation of symptoms, and types of healthcare available, traditional healing is still considered the dominant mode of treatment (Abel & Busia 2005).

The history of beliefs about illness and treatment can be traced back to the pre-colonial era, when traditional village priests were important in providing treatment for the sick. Illness was considered a departure from the natural equilibrium of an individual. In the Twi language, illness is "yadee" – "ya" meaning pain, and "adee" meaning a thing, so literally illness is a painful thing. A painful thing can be physical, psychological, emotional, spiritual, social, or environmental, and can be naturally or supernaturally caused (Abel & Busia 2005). The majority of instances of death, pain, suffering, and diseases were attributed to witchcraft. In the treatment of such illnesses, the usual process was for the priest to use divination to determine the source of the malady and to suggest sacrifices to appease the causal agents, before herbal medicine was prescribed for the patient. As a result, sick people were kept at home to receive various traditional treatments.

The role of village priests in the medical field reflected the belief that supernatural agents caused unexplained disease, misfortune, and premature deaths. Over thirty percent of Ghanaians believed that such supernatural forces

could be responsible for the spread of human immunodeficiency virus infection and acquired immunodeficiency syndrome (HIV/AIDS) or lymphatic filariasis (Gyapong et al. 1996). Supernatural beliefs differ according to ethnic group. Akans, the largest ethnic group, acknowledge many spiritual beings including the Supreme Being, the earth goddess, the higher gods, the ancestors, and a host of spirits and fetishes. These forces are believed to be spirits of mystical powers such as agents of witchcraft, magic, and sorcery, with the ability to cause harm. Some people also believed that illness could be brought upon someone by a maleficent curse. Therefore, one's health is dependent on the good relationship that is established between an individual and the chain of authority from the supernatural being.

The traditional healers are the most dominant providers of alternative therapy, with an estimated 70%–80% of Ghana's population using them as their frontline health service to help meet most of the primary healthcare needs (Abel & Busia 2005; Sato 2012). According to Sato (2012), traditional medicine is considered holistic and integrates the people's ethical, religious, moral, and cultural values. To illustrate, traditional healers are the first resort in mental disorders and they continue to be used, even after systems informed by modern psychiatry emerged in the country (Appiah-Poku et al. 2004). It is estimated that more than 100,000 traditional healers are uniformly distributed throughout the country (Abdullahi 2011), meaning there is one traditional healer for every 200 people, compared to one allopathic physician for 10,000 people.

While there are many types of traditional healers in Ghana, they can be categorised under four main groups (Twumasi 1988). First, there are the traditionally trained herbalists who usually operate herbal clinics; such healers often attribute their success to the particular herbs administered. Supernatural considerations are a secondary factor in their practice (Addae-Mensah 1989). Healers in the second group believe more in the supernatural causes and cures of diseases, than herbs. Usually, any herbal preparations they administer are employed as a means of destroying the supernatural powers responsible for any particular ailments. Traditional priests, priestesses, and cult healers are identified with this group (Addae-Mensah 1989).

The third group is an ill-defined hybrid of the first two categories. These are roaming herbalists, who conduct their trade either at street corners or from house to house, advertising cures for a broad spectrum of ailments. The final group is comprised of scientifically based herbalists. These are herbalists who combine herbalism and scientific methods in treating disease. Practitioners usually allow patients to visit modern scientific laboratories for diagnosis before herbal medicines are used to treat diseases (Tsey 1997). Given that an individual's interaction with the healthcare system may depend on how the health problem is perceived by the patient, and most importantly by relatives and close friends; this pluralistic healthcare system could create a situation where women may be confronted with a complex range of possibilities to consider when deciding what action to take upon the self-discovery of a breast cancer symptom.

1.2.2   Breast cancer incidence and mortality

Breast cancer is a major public health problem, the most frequently occurring cancer, and the leading cause of death in women worldwide (Ferlay et al. 2013). It is unique from other forms of cancer because it is associated with issues of disfigurement of body image (Helms et al. 2008). According to the most recent worldwide data from GLOBOCAN, published by the International Agency for Research on Cancer (IARC), Ferlay et al. (2013) estimated that approximately 1.7 million new cases of breast cancer were diagnosed, and there were 500,000 deaths, annually.

The WHO estimates that worldwide cancer mortality is projected to increase by 104% by 2020 (Rastogi et al. 2004). This surge is expected to be highest in LMICs, including sub-Saharan Africa, where a large proportion of breast cancer is usually diagnosed only when it has reached an advanced stage (Walker et al. 2004). Without any further action, the projected number of cancer deaths in Africa will have a severe impact on the health systems of the countries with deficient healthcare services and limited resources to improve them. In sub-Saharan Africa, breast cancer has now surpassed cervical cancer as the leading cause of death in women (Jemal et al. 2012). The most recently published data indicated that 133,890 new breast cancer cases, and 63,160 deaths, were estimated to have occurred in 2012, with the incidence and mortality patterns

varying remarkably across Africa (Ferlay et al. 2013). Although breast cancer crosses all demographic lines, affecting women of all ages, ethnic groups, socioeconomic strata, and geographic locales (Jones & Chilton 2002), the mortality ratio is much higher in LMICs than in Western countries (Ferlay et al. 2010). Studies from sub-Saharan Africa indicate that breast cancer in native black African populations is often severe with adverse prognostic features (Gukas et al. 2005; Ohene-Yeboah & Adjei 2012).

In Ghana, reported cases of breast cancer have almost doubled over the past 20 years. Since the 1953 report on malignant diseases of the Gold Coast (Edington 1956), a ten year (1991–2000) review of hospital mortality patterns showed an increase in breast cancer mortality of 17% (Wiredu & Armah 2006). Another study by Clegg-Lamptey and Hodasi (2007) has also reported breast cancer as the leading malignancy and the principal cause of death among Ghanaian women. Hospital based studies found that approximately 15% to 30% of all cancers were breast cancers, and the incidence appeared to be rising (Clegg-Lamptey & Hodasi 2007; Edmund et al. 2013). All these figures, which demonstrate an increasing burden of the disease in the country, are consistent with current statistics that show a growing trend in breast cancer mortality in LMICs.

Unlike the Western world, where it is frequently treatable and with lower mortality, breast cancer in Ghana is characterised by higher mortality. Clegg-Lamptey et al. (2009a) suggested that mortality is high because patients spend much time seeking help from other places besides the hospital, in their attempts to achieve a cure. Consequently, this patient behaviour allows the disease to metastasise beyond the breast to invade other organs of the body, such as the lungs, lymph nodes, skin, bones, liver, and brain (Breastcancer 2013). Delayed diagnosis and treatment of breast cancer is a problematic issue because it may result in emotional distress (Deane & Degner 1998), a more advanced disease at diagnosis, and the need for more aggressive and costly treatment (Richards et al. 1999).

While the median age at breast cancer diagnosis of women in the United States of America (USA) is approximately 62 years (Howlader N et al. 2013), the majority of women who are at risk, and often diagnosed in Ghana, are

relatively young, with a mean age of 48 years (Stark et al. 2010). Although the reasons for the difference in age at diagnosis are not yet apparent (Sighoko et al. 2013), multiple studies have documented a higher breast cancer incidence and death rate in pre-menopausal African American women than in non-Hispanic Whites (ACS 2013; Peter Boyle 2013). This suggests that it is likely the shared genetic background of indigenous Africans (e.g. Ghanaians) and African Americans has inherently aggressive biology contributing to the greater susceptibility to early onset of breast cancer in both groups (Gao et al. 2000; Adesunkanmi et al. 2006). Other studies have also indicated that the young average age at diagnosis among Ghanaian women could be partly explained by the low mean age of the general population (Gao et al. 2000; Olopade et al. 2003). Therefore, a greater focus is needed on understanding factors for delays in searching for, or accessing, breast cancer treatment in order to develop interventions that encourage early treatment, especially as the early ages at onset of many breast cancers result in highly associated disability and years of life lost (Soerjomataram et al. 2012).

1.2.3   Delayed presentation of symptoms

The stage of cancer is determined by the primary tumour's size, location, and the extent to which the cancer has spread at the time of diagnosis (ACS 2013). Defined as waiting time in the process of treatment, delayed presentation in breast cancer has been categorised into 'patient' and 'provider' delay (Bish et al. 2005). Patient delay has been defined as an interval longer than three months between symptom discovery and the first medical consultation (Arndt et al. 2002). Provider delay is determined as the period between the initial medical consultation and definitive treatment of cancer.

Variations in patient delay interval in the pathway to diagnosis and treatment have been reported between healthcare systems in higher and lower income countries (Weller et al. 2012). In Ireland, O'Mahony et al. (2011) reported that approximately 20% to 30% of patients with suspicious symptoms delayed for at least three months before seeking any medical help. In Ghana, a much higher proportion of patients with breast cancer was found to have delayed medical evaluation. A study by Ohene-Yeboah and Adjei (2012) reported that 85% of newly diagnosed patients presented with either stage III or IV cancers, and

delayed for a mean of 14 months. When breast cancer reaches stage III or IV, it is considered advanced, a point at which most conventional curative therapies are more likely to fail than succeed (Ramirez et al. 1999). The difference in the proportion of patients in the West presenting with late stage disease, as compared to that of Ghana could be attributed to several factors.

Factors contributing to late presentation have been studied extensively in Western countries since the 1930s (Pack & Gallo 1938; Bairati et al. 2006), revealing different approaches underpinning the explanations of the delay. Studies by Burgess et al. (1998) and Bairati et al. (2006) theorised delay around the patients' perceptions or the healthcare system without consideration of the social and cultural circumstances within which delay might occur. In Mexico, Unger-Saldana and Infante-Castaneda (2011) described delay as a result of the interplay between the patient's socio-cultural context, individual characteristics that influence symptom interpretation and decision-making, interaction with the social network, and aspects of the local health services. While this Mexico study identified significant factors for delay, it does not elucidate sufficiently on how the various dimensions involved integrated with each other to ultimately effect delay. To further understand factors contributing to delay, Scott et al.'s (2013) Model of Pathways to Treatment identified potential areas of delay. These include five events and four key intervals between these events. The 'patient interval' describes both appraisal and help-seeking components, as important aspects of the illness trajectory.

Breast cancer symptoms appraisal

Appraisal interval characterises the time from noticing a body change to perceiving a reason to discuss the symptoms with a healthcare professional (Scott et al. 2013). This interval may include symptom detection events, individual characteristics that influence symptom interpretation, aspects of the local health services, and decision-making processes. Identification of breast cancer symptom could also involve knowledge of cancer symptoms, emotional reactions to the self-discovery of symptoms, social support, and healthcare expectations. When symptoms are present, the most common complaint is a lump within the breast (Bish et al. 2005). The incidence of this sign ranges from 70% to 80%, indicating that the majority of women can identify a lump

that has reached up to one centimetre by correctly performing a breast self-examination (BSE) (Abuidris et al. 2013).

Research on breast cancer indicates that symptom appraisal is the most important stage in the process of seeking medical attention (Bish et al. 2005; Scott et al. 2013; Khakbazan et al. 2014). It is expected that following the detection of a symptom, it is appraisal that will drive the individual's decision to seek professional help. Therefore, a better understanding of the processes through which people interpret their symptoms during the appraisal interval, is significant in promoting early presentation. Although Scott et al. (2013) acknowledged that symptom appraisal is known to be an important stage in the decision to seek help, little is known about the process of symptom appraisal among Ghanaian women.

Help-seeking behaviour

Help-seeking, or why patients do or do not seek modern medical help early, is an important phenomenon in understanding breast cancer delay since a patient's potential for survival is reduced if she delays (Bish et al. 2005). Scott et al. (2013) described the help-seeking interval as the time from perceiving a reason to discuss symptoms with a healthcare professional, to a first consultation to discuss those symptoms. To throw more light on this phenomenon, it has been suggested that help-seeking is a problem focused, planned behaviour, involving interpersonal interaction with a selected healthcare professional (Cornally & McCarthy 2011). Interaction with others may not only bring the individual into treatment, but social networks can influence the decision to seek medical help in several ways (Leventhal et al. 2003).

A woman's decision to act, following the appraisal of a symptom, and the decision to contact a healthcare professional, can be influenced by attitudes to help-seeking. Such attitudes include concerns about the consequences of help-seeking, such as the effect of cancer treatments (Bish et al. 2005). Moreover, Bish et al. (2005) suggested that if women's attitudes to help-seeking are negative, it is more likely that they would delay contacting a healthcare professional in the event of a breast symptom. A study in the United Kingdom (UK) described multiple barriers and facilitators influencing help-seeking

behaviour for breast and cervical cancers, including community and social networks, health service characteristics, societal factors, and economic factors (Marlow et al. 2014). However, with breast cancer, which requires symptom appraisal and intention to act, it appears that the decision to seek help places women in a difficult situation. This is because, on one hand there is a problem that requires asking for help to be solved; but, on the other hand, such behaviour may come into conflict with specific cultural and social issues particularly modesty (Facione & Giancarlo 1998), dependence, obligation, damaged self-image (Kwok & White 2011), and factors impacting on the individual, such as stigma and fear of rejection (Facione et al. 2002), and overall helplessness (Goncalves et al. 2014).

The actual reasons why women with breast cancer symptoms do not seek early medical help remain unclear. Although attitudes toward seeking medical help for breast cancer symptoms have been widely studied among women in the UK (O'Mahony et al. 2011), Canada (Granek & Fergus 2012), China (Lam et al. 2009), and the USA (Facione et al. 2000b), relatively little is known about Ghanaian women's behaviour towards seeking help for breast cancer problems.

1.2.4   Breast cancer control and prevention strategies

There is a trend towards decreased mortality rate in most Western countries, where efforts and resources are devoted to combating the disease (Bray et al. 2004). Although many investigators attribute the decline in breast cancer mortality to mammography screening programmes (Chevarley & White 1997), others believe that much of the decline is due to improvements in treatment and earlier detection of palpable types of cancer (Jatoi & Miller 2003). However, Jemal et al. (2012) noted that the problem of breast cancer among populations in LMICs, such as Ghana, is further exacerbated by poor survival, which is among the lowest in the world. This low survival rate is due to the frequently advanced stage of the disease at diagnosis, combined with limited human resources and treatment options.

As the exact causes of breast cancer remain unclear, primary prevention is currently unavailable except by measures such as prophylactic mastectomy for

women who are genetically at high risk (Rebbeck et al. 2004). Therefore, secondary prevention, with the goal of detecting, diagnosing, and treating cancer at an early stage, is a major focus in the control of the disease (Remennick 1999). In their study, Khakbazan et al. (2014) recommended that symptom detection by patients and early response to self-discovered symptoms were important modalities to early diagnosis of breast cancer among Iranian women. This early detection approach requires women's participation in obtaining the recommended breast cancer screening measures, together with prompt diagnosis or treatment whenever any suspicious breast cancer symptoms occur. Hence, any change in the breast appearance and texture including a lump, nipple discharge, dimpling, and swelling can be a sign of breast cancer (ACS 2013).

The American Cancer Society (ACS) recommends that asymptomatic women aged 40 years and older should have a yearly mammogram screening. In addition, a clinical breast examination (CBE) is recommended every three years for women aged 20 to 39 years and every year for women aged 40 and over (ACS 2013). It is acknowledged that mammographic screening is expensive and requires considerable infrastructure and provider training. Zelle et al. (2012) asserted that due to the different economic, sociocultural circumstances, and healthcare system in Ghana, this important recommendation by the American Cancer Society would be nearly impossible to implement. As far as a strategy for breast cancer is concerned, Ghana lacks both a national breast cancer control policy and treatment guidelines (Zelle et al. 2012). Since Ghana has no standardised national guidelines for breast cancer screening, except minimum efforts in secondary prevention for detecting and diagnosing of cancer, public health attention to the disease is limited (Mena et al. 2014). Indeed, systematic CBE is not currently available in general healthcare settings and the majority of Ghanaian women do not practice BSE on a regular basis (Clegg-Lamptey et al. 2009a).

To determine how earlier detection of breast cancer symptoms could contribute to decreased mortality, a study in the USA reported that despite educating women on breast cancer symptoms and mammography guidelines, low screening rates and late stage presentation persisted (Facione & Katapodi 2000). A reason for delayed presentation was attributed to cultural beliefs and

culturally dictated behaviours influencing breast cancer screening and early detection. Although a focus on early detection of cancer increasingly calls for cultural competence in healthcare and education, in order to understand the impact of culture on early presentation, research in this area is limited in Ghana.

1.2.5   Sociocultural impact of delayed presentation

Culture has been described in various ways regarding its influence on human health behaviour, how the meaning of illness is constructed, and the way disease is interpreted (Kleinman et al. 1978; Leininger 1988). According to Leininger (1988), culture is the learned, shared, and transmitted values, beliefs, norms, and life practices of a particular group, which guides thinking, decisions and actions. The concept of culture can help to explain health beliefs, health behaviour, help-seeking, and treatment expectations for various health problems. Social and cultural factors also have a major effect on the individual in influencing early detection of breast cancer (Rajaram & Rashidi 1998). Fabrega's (1975) concept of ethnomedicine focuses on the importance and interrelatedness of culture and illness, and places emphasis on how social and cultural factors influence the perception, expression, and outcomes of medical problems. Ethnomedicine also involves how members of different cultures think about disease, organise themselves toward medical treatment, and the social organisation of the treatment itself (Fabrega 1975).

The concepts of health and illness vary according to place and social context as observed in various communities. For example, the populations within Western countries such as the USA and UK see disease as a result of natural scientific phenomena, and advocate or expect medical treatments that combat microorganisms or use sophisticated technology to diagnose and treat disease. Conversely, other societies, including Ghana, believe that illness is the result of supernatural phenomena; such societies promote prayer or other spiritual interventions that counter the presumed hostile forces of powerful spirits (Read & Doku 2012). Other cultural factors that may influence help-seeking include incorrect estimation of the consequences of delay, feeling vulnerable to breast cancer, and patients' attitudes about modern medical care (Facione et

al. 2000a). Moreover, patients' ability to understand, manage, and cope with the course of the illness, the meaning of a diagnosis, misconceptions about breast cancer (Facione & Katapodi 2000), and the consequences of medical treatment for cancer (Denieffe & Gooney 2011), have been identified. Furthermore, O'Mahony and Hegarty (2009) suggested that various factors, such as gender roles and socio-economic status, might also influence the decision making of women to seek medical attention.

The role of culture in breast health practices, including screening and early detection, have been studied, and is shown to influence women in several ethnic groups such as Chinese–Australians (Kwok et al. 2006), Latin Americans (Latinos) and non-Latino Whites (Anglos) (Betancourt et al. 2010), African Americans (Bradley 2005), and Chinese-Americans (Facione et al. 2000a). Hence, a sociocultural approach can be helpful when trying to understand better the impact of sociocultural factors that may contribute to increasing mortality rates among Ghanaian women.

1.3   Justification for this research

Delay in seeking help for breast cancer symptoms exists but it can be prevented. However, late presentation with increasing mortality has been the characterisation of breast cancer among Ghanaian women, making the disease a significant public health concern. In spite of the improvement in worldwide cancer treatment, the evidence that early diagnosis and treatment can reduce mortality, and the fact that 80% of breast cancer is found symptomatically by women themselves globally, the majority of Ghanaian women still report to healthcare professionals late with advanced stages of breast cancer with skin involvement (Edmund et al. 2013). Although reported breast cancer prevalence is increasing in Ghana, often late stage with a poorer prognosis, there remains limited understanding of the reasons why so many Ghanaian women delay presentation with advanced disease and what interventions could lead to earlier diagnosis.

Previous Western studies by Unger-Saldana and Infante-Castaneda (2011) and O'Mahony et al. (2013) have suggested that help-seeking for breast cancer symptoms involves complex behavioural interactions that are influenced by

external factors such as spouses, other family members, friends, and healthcare professionals. However, little is known about the sociocultural factors associated with symptom appraisal and help-seeking behaviour among Ghanaian women. Also, it is not clear what types of activities women engage in during the process of symptom appraisal, in making their decision to consult a healthcare professional, as well as what resources and constraints they identify in this process. Since one's culture is a patterned way of life that members of a society follow as part of their social interaction and managing their world (Bailey 1987), sociocultural factors can significantly influence both symptom appraisal and help-seeking behaviour of women who self-discovered breast cancer symptoms. In particular, culture could impact the decision as to whether an individual utilises or avoids the healthcare services available to them.

Although it has been suggested that late presentation of symptoms may be due to healthcare system factors, social barriers such as poverty, and cultural issues (Gerend & Pai 2008); knowledge regarding how these factors may contribute to delayed diagnosis of breast cancer among Ghanaian women is limited. However, in a country where traditional healing, as well as modern medicine, constitute integral components of the healthcare delivery system, the use of either or both traditional and modern medical systems could have significant implications for the help-seeking behaviour of women with breast cancer symptoms. In addition, the Ghanaian sociocultural structure of strong family ties and religious practices could also impact the choices made by individuals seeking healthcare services. This is because, depending on the symptoms experienced by a woman, she may choose to disregard the health problem, use known traditional treatment modalities, seek advice from her social network, or make a decision to use services of a traditional healer or a modern medical practitioner.

Furthermore, the external limitations imposed by the healthcare system's distribution and financial constraints could restrict the majority of the Ghanaian women from accessing adequate services. These, and many other considerations, mean that late presentation of breast cancer is a growing health problem. As a result of the literature reviewed, healthcare expectations,

strong family bonds, personal knowledge, stigma, economic, and emotional considerations are all identified as factors that seem to be important. Hence, my research question, which is focused on exploring sociocultural factors influencing delayed presentation, makes this a significant study as it attempts to understand the sociocultural context guiding the actions and beliefs of Ghanaian women, as they confront a potentially dangerous breast cancer symptom. Therefore, the purpose of this study is to explore those aspects of a woman's life that have been affected by the discovery of breast cancer symptoms, as well as to identify those factors that have an impact on her subsequent healthcare decisions. Coupling these issues with the limited diagnostic and treatment options, this study is expected to reveal rich descriptions of women's pathways to breast cancer treatment, beginning with the detection of a breast abnormality and culminating in the decision to seek medical treatment. This approach will encompass both the act of appraisal and the help-seeking intervals.

1.4   Contribution of this study to understanding delayed presentation

Since this study is uniquely designed to shed more light, through the eyes of multiple informants, on reasons why women present late, it is anticipated that the findings will contribute significantly to the existing body of knowledge on factors influencing late presentation of breast cancer. While previous studies have explored aspects of delayed diagnosis in sub-Saharan Africa, this study seeks to identify and explore features that impact in a comprehensive way, providing an in-depth understanding of the phenomena of delayed presentation and medical help-seeking in Ghana.

The findings of this study are not only important when advocating the use of Western world medicine for treatment of breast cancer in LMICs, understanding reasons for delay also help health researchers, healthcare professionals, health educators, and any individuals interested in planning and implementing innovative interventions to encourage early presentation that are uniquely adapted to the Ghanaian context. This research should also encourage women to present to mainstream medical practitioners in order to begin treatment earlier than is currently the case in Ghana. Finally, the outcome of this research

could produce a theoretical understanding of prolonged delays of breast cancer symptoms presentation among Ghanaian women. Such an outcome could be used as a framework for understanding symptom appraisal and help-seeking behaviour in other sub-Saharan African populations.

1.5   Structure of the thesis

This thesis comprises six chapters, and this chapter (Chapter 1) has provided the background to the study regarding information about Ghana, breast cancer incidence and mortality, delayed presentation of symptoms, breast cancer control and prevention strategies, and sociocultural impact of delayed presentation underpinning this research. The chapter also highlights the justification for this research, and offers this study's potential contribution to understanding delayed presentation.

The next chapter provides a detailed literature review on the issues of delayed presentation and help-seeking behaviour regarding breast cancer, focusing on sociocultural aspects. Finally, the rationale for conducting this research is offered, which leads to a focus on the overall research question, aims, objectives, and theoretical framework.

Chapter 3 considers the research methodology employed, the underlying philosophical assumptions, and the methods used to generate data. Specifically, details of the study design, recruitment process of the participants, interview process, data collection, and analysis strategy are presented. This chapter also outlines the ethical issues inherent in the study and approaches taken to enhance trustworthiness.

Chapter 4 reports the detailed findings of the study obtained from all the participants including patients, members of their social networks, and healthcare professionals. It also includes the demographic details of each group. Then the themes and sub-themes, which emerged from the data are introduced; finally integration of the findings will be explained.

Chapter 5 provides a detailed discussion of the study within the context of existing theoretical and empirical literature. The discussion is followed by the development of a conceptual framework in help-seeking explaning the

sociocultural determinants of delay in medical help-seeking amongst women in Ghana who had self-identified breast cancer symptoms.

Chapter 6 provides the conclusion to this study. It will also offer the strengths, limitations, and directions for future research. The researcher's personal reflections on the entire research process are also included.

Appendices, which include the relevant documents related to this study, followed by a glossary of terms, and references are listed at the end of the thesis.

Finally, regarding the presentation of this thesis, using the suggestion for writing in the first person (Webb 1992), I have complied with this with the aim of making my role and position as the researcher and author clear and transparent within this thesis.

Chapter 2:   Literature review

This chapter presents a comprehensive literature review to identify the evidence base and gaps in the current knowledge about delayed presentation of breast cancer symptoms, in order to explore the reasons for delayed presentation and the help-seeking behaviour in women who self-discover such symptoms. Particular consideration has been given to the social and cultural influences of symptom appraisal, help-seeking, and methodological issues that may inform the development of the current study. The final section of this chapter provides a rationale for conducting this research, as well as presenting the research question, aims, and objectives for the study.

2.1   Strategy

The review drew on a range of literature sources including peer-reviewed articles, book chapters, reports, and on-line resources. A five-stage process was developed based on previous personal experience of conducting both qualitative and quantitative literature reviews. The process involved a search strategy, selection of papers, synthesis of themes, critical appraisal, and presentation of results.

2.1.1   Search for literature

As there is a large body of evidence about help-seeking behaviour and cancer, the search for literature relevant to this study was centred on breast cancer. The search was conducted using three databases, namely the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medical Literature On-Line (MEDLINE), and Psychology Information (PsychInFO). The electronic searches were supplemented by manual searches of the bibliographies of original reports and major review articles.

The main search terms were "breast cancer", "patient delay", and "help-seeking behaviour". In addition, related search terms were developed to further refine the search and were combined, using the Boolean operators AND and OR and truncation represented by "*". For example, (breast cancer OR breast neoplas*)

AND (patient delay OR delayed presentation OR delayed diagnosis OR late presentation OR late diagnosis OR delay) AND (help-seeking behaviour OR help-seeking behavior OR care seeking OR care-seeking behavior OR health-seeking behaviour OR help-seeking behav* OR health seeking behaviour OR health-seeking behav*) (see Table 1).

2.1.2   Selection of papers

The inclusion criteria for the publications cited in this review were studies that focused on help-seeking behaviour and patient delay in women with self-discovered breast cancer symptoms, written in the English language, with no restrictions regarding date of publication. Studies with an inadequate focus on patient delay or identification of symptoms by a doctor or screening procedures were excluded. Due to the extensive number of hits obtained, search terms were mapped to medical subject headings (MeSH), when appropriate, to ensure relevancy of identified publications. The parameters set for this review helped to focus the search process in order to develop a critical discussion. Selection was not limited by study design, since it was considered appropriate to include evidence derived from quantitative, qualitative, and mixed method studies, thereby reflecting the heterogeneous nature of presentation delay and help-seeking behaviour research.

The search strategy resulted in the identification of 131 studies from the databases: 42 from CINHAL, 52 from MEDLINE, and 37 from PsychINFO. In addition, manual searching yielded five further papers from journals. Table 1 shows the search results from the traditional databases. Throughout the process, a number of studies were excluded at each stage if they were not deemed relevant to the subject. By merging the results of all individual search strategies, and excluding duplication and titles not relevant, the total number of hits was reduced to 42. Upon screening of abstracts, 30 papers qualified for full text screening. This stage led to the selection of 16 relevant papers from electronic searching plus five papers obtained through manual searching. Eventually, 21 articles that met the inclusion criteria were identified. The stepwise selection of articles by the selection criteria and outcome is presented in Figure 2.

Database searching:

Language: English

Keyword screening: breast cancer, patient delay, help-seeking behaviour or related search terms

Titles and Abstracts Reviewed: 131

CINAHL = 42, MEDLINE = 52, PsychINFO=37.

Reasons for Exclusion

Titles screening:

Included = 42, Excluded = 89

- Duplicates removed manually – 5
- Titles not relevant – 84

Abstracts screening:

Included =30, Excluded =12

- Symptoms detected through screening –10
- Articles not in English – 2

Full text screening:

Included =16, Excluded =14

- Less than 50% focus (not exclusively on breast cancer) –10
- Symptoms not self-detected – 2
- Dissertation (embargoed) –2

Manual search:

Retrieved =5

Total eligible included:

N =21

Figure 2 Flowchart of the search and selection process

Table 1 Search results from the databases

Southampton University catalogue of electronic databases	breast cancer OR breast neoplas* (S1)	patient delay OR delayed presentation OR delayed diagnosis OR late presentation OR late diagnosis OR delay (S2)	help-seeking behaviour OR help-seeking behavior OR care seeking OR care-seeking behavior OR help-seeking behaviour OR help-seeking behav* OR health seeking behaviour OR health-seeking behav* (S3)	S1 AND S2 AND S3
MEDLINE (2/2/2015)	202,782	112,333	7,170	52
PsychINFO (2/2/2015)	8,902	28,260	9,768	37
CINAHL® (2/2/2015)	53,639 (S5)	17,995	5,403	42

2.1.3   Synthesis of themes and critical appraisal

Appendix A shows the baseline characteristics of the included studies. Out of the 21 selected studies, three used a quantitative approach and thus the majority (18) adopted qualitative designs. In order to eliminate poor studies and facilitate the identification of any weaknesses when interpreting the findings, these 18 qualitative studies were appraised using the Critical Appraisal Skills Programme (CASP) tool (NHS 2006). The CASP tool presents a number of questions that deal very broadly with principles or assumptions characterising qualitative research. To accommodate the criteria of ten questions being assessed, the CASP tool was modified to determine the contributions of each paper and describe their methodological qualities.

Following analysis of the included studies, relevancy was assigned to the papers according to their overall contribution to help-seeking behaviour and reasons for patient delay. Assessing relevance revealed two general types of papers: those that were highly relevant [1-3, 6-10, 13-18, 20, 21] and those that were moderately relevant [4, 5, 11, 12, 19]. *(These numbers in brackets "[ ]" refer to the article numbers in Appendix A).* Highly relevant articles were entirely focused both on help-seeking and delay in breast cancer, whereas in moderately relevant articles, help-seeking or delay in breast cancer was only one of the concepts included, rather than the core focus of the article. Irrespective of their relevancy, literature from both groups was considered eligible to be included in the review.

Based on the CASP appraisal criteria, all of the qualitative studies possessed a favourable quality score, hence no study was rejected. It was observed that in all studies, the research objectives, sampling strategy, and data collection methods were clearly described; however, reflections of researchers on their thoughts and ideas and their relationships with participants were not clearly described in half of the studies [2-4, 7, 8, 12, 15, 20, 21]. The limited information on reflexivity does not neccesarily mean that the research is not robust. This observation could be explained by the fact that journal articles usually have a word limit and commonly reflections of researchers are left out as, editorially or otherwise, being considered of lesser importance. All studies described their analytical methods, research findings, and discussed findings in relation to the relevant literature.

The three quantitative studies were critically appraised using the evaluation tool developed for critiquing quantitative research studies by Coughlan et al. (2007).

Comprising critical elements influencing believability and key questions to assist the process, the tool provides a step-by-step approach to evaluating research (Coughlan et al. 2007). The studies were assessed for their reliability and validity, the two crucial aspects of the quality of quantitative research (Polit & Beck 2006). As validity is used to describe the ability of the tool to measure what it is supposed to measure, the reliability of a quantitative research study is associated with its consistency, repeatability, reproducibility, stability, and agreement (Brink & Wood 2001). In order to synthesise and translate the concepts into categories, each of the selected studies for the review was read repeatedly and items recorded in a table (see Appendix A).

2.2   Presentation of results

Appendix A summarises the characteristics of the included studies, providing author(s) names, year of publication, country where the research was conducted, aims/objectives, sample size, sample strategy, study design/method, setting, and main findings.

2.2.1   Study location

The 21 included studies varied geographically, with the largest number conducted in the USA (n=5), followed by Canada (n=3), Malaysia (n=3), Ireland (n=3), Iran (n=2), Mexico (n=1), Hong Kong (n=1), UK (n=1), Netherlands (n=1), and Taiwan (n=1). By regional distribution, the studies indicated that 38% were conducted in North America and the rest distributed across Asia (24%), Europe (24%), Middle East (9%) and Latin America (5%) (Appendix A). The distribution of the studies reflects the considerable amount of research exploring help-seeking behaviour and patient presentation delay of breast cancer in Western countries when compared with LMICs, perhaps creating an imbalance in understanding the global impact of the problem. Conducting similar studies in different population groups, such as in Africa, where the healthcare system and sociocultural factors are more likely to affect the choice of treatment using traditional, modern, or a blending of both modalities. The findings of such studies could enhance the understanding of women's decision-making processes in different communities experiencing a similar delayed symptom presentation problem.

2.2.2   Methodology

The studies were explored extensively to determine how the research design, data collection techniques, sample population and setting, data analysis, and use of theoretical models impacted the study (Appendix A). A qualitative approach was the most predominant research design used within the literature in this review. Despite the limited number of quantitative studies selected for detailed review (i.e. three), they yielded valuable information. In addition, all the studies were retrospective in nature, which may be associated with certain limitations such as recall bias.

The type of approach used in the qualitative studies included ethnography [1, 5], grounded theory [7, 10, 19], narrative [4, 12], and phenomenology [9]. None of the qualitative studies described their design as that of case study. The majority used purposive sampling as a way of identifying participants for the study. Face-to-face audio recorded semi-structured interviews were the predominant method of data collection employed. Various analytical methods were used, including narrative analysis [1, 4,12], content analysis [6, 8, 11, 15, 17], thematic analysis [19, 21], framework analysis [2, 3], Leininger's phases of ethnographic analysis [5], and Colaizzi's analysis [9]. Two types of qualitative data analysis software were used for data management and analysis. These were NVivo [1, 6, 10, 12, 19, 21] and MAXQDA [8].

All three quantitative studies [14, 16, 18] used a descriptive, cross sectional, and correlational survey design. All studies adopted non-probability convenience sampling, and data were mostly collected using mailed questionnaires. Participant recruitment occurred at various places including breast clinics, churches, obstetrics/gynaecology groups, a surgeon's office, and by various methods including newspaper advertisements and informal contact. Two studies [14, 16] used the Statistical Package for Social Sciences (SPSS) software for analysing the data with descriptive and inferential statistics. Pearson's correlation was adopted to explore relationships among variables, while in one study [18], regression analysis was used to test the effect of a factor on delay in medical help-seeking.

There were two types of studies that could also be categorised into two groups, depending on the primary focus of the study. There were studies that investigated the individual, usually the person with or suspected of having breast cancer [1- 6, 8-19]. Then there were also those that aimed to explore a broader perspective from the point of view of other family members [7, 20, 21].

A few of the studies included theoretical models in attempts to understand delays in disease presentation in different populations and to help explain symptom appraisal processes and help-seeking behaviour. Two of the qualitative studies used four behaviour theories: Health Belief Model (HBM) [21], Theory of Reasoned Action (TRA) [21], Theory of Planned Behaviour (TPB) [21], and Model of Total Patient Delay (MTPD) [3]. Among the quantitative studies, a psychosocial theory of care-seeking behaviour (CSB) was used as a guide in one study [18].

The Health Belief Model, the Theory of Reasoned Action, and the Theory of Planned Behaviour were used to explain the experience of symptoms regarding how a health threat can influence a woman's preference of behaviour. These frameworks allowed women to use their own terminology to interpret the symptoms during the appraisal process. Additionally, the Model of Total Patient Delay, which offered a framework to study and improve understanding of help-seeking behaviour, was adopted to understand the patient pathway leading from the detection of a symptom to consultation with a healthcare professional and subsequent treatment. Furthermore, the theory of CSB incorporates psychosocial variables, which are affect, utility, norms, and habit, as well as facilitators for care seeking behaviour were applied to cancer symptoms.

These models have been widely used to recognise identifiable stages relating to the detection of a symptom, from presentation to a healthcare professional, diagnosis process, and initiation of treatment. However, the majority of models were developed according to Western world studies, where cultural influences on symptom experiences do not feature prominently. While it may have been appropriate to consider using such a framework to test its applicability in the context of Ghana, the desire within this research was to be less constrained by any one perspective. Therefore, it was decided to adopt a more eclectic approach to the methodology and research design, in order to develop a theoretical understanding, which can then be contextualised within existing knowledge, rather than to test or expand upon existing theories. This choice of approach does not, however, prevent the insights gained from the above studies informing the focus and the areas of questioning to be pursued in this study.

2.2.3   Theoretical framework

Although this research was not designed to test a theoretical position and was not hypothesis driven, examining the reference lists of the literature reviewed found Scott et al.'s (2013) Model of Pathways to Treatment (MPT) (Figure 3) to be useful, in terms of understanding patients' processes of symptom appraisal and decisions-to-consult healthcare professionals for treatment.
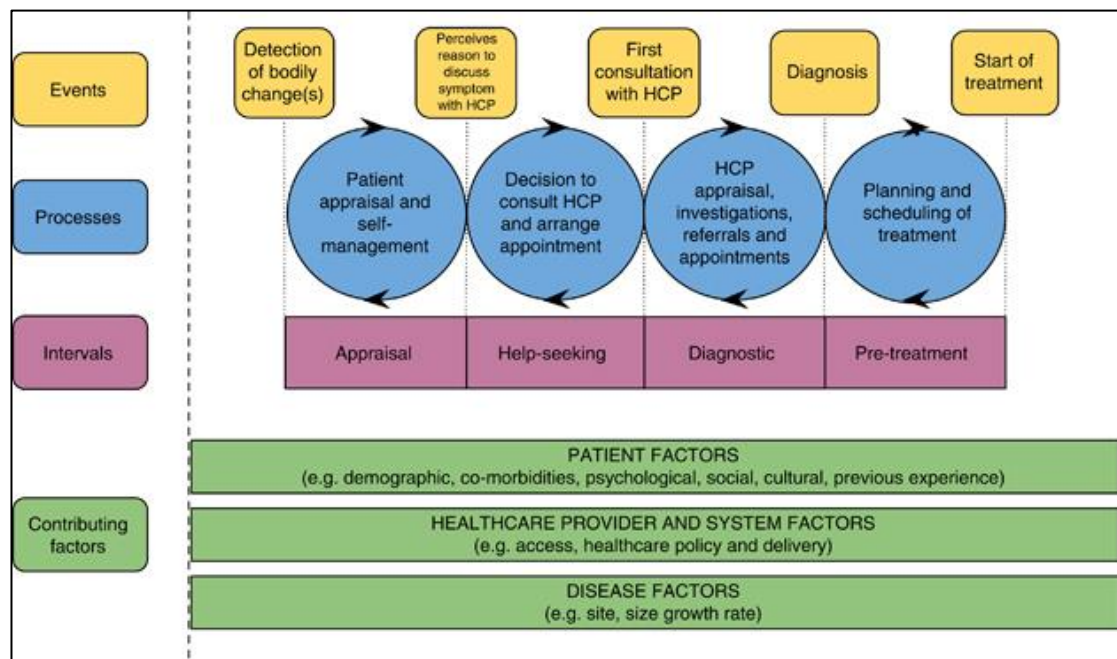
Figure 3 The Model of Pathways to Treatment. Used with permission from John Willey and Sons (see Appendix L)

The model (Figure 3) provides a useful research framework to explore and understand patients' journeys, as it takes into account the complex and dynamic nature of help-seeking behaviour. This model describes two intervals between a person detecting a body change and their first consultation with a healthcare professional: the 'symptom appraisal' interval and 'help-seeking' interval respectively. The 'diagnostic' interval is the time from the first presentation until cancer diagnosis. 'Contributing factors' that influence the duration of these intervals relate to the patient (e.g. previous experience, social and cultural factors), healthcare system factors (e.g. access) and tumour (e.g. location and rate of growth).

The Aarhus statement on improving design and reporting of studies on early cancer diagnosis, recommends the MPT as the standard model to describe events and processes underpinning the pathway to symptomatic cancer diagnosis and treatment (Weller et al. 2012). The MPT has been used effectively in help-seeking

studies as a framework in which existing psychological theories of appraisal and help-seeking can be integrated (Whitaker et al. 2015; Moodley et al. 2016). Therefore, in order to understand Ghanaian patients' help-seeking decision making for breast cancer alarm symptoms, the MPT was selected as the useful guiding framework for presenting a synthesis of the literature reviewed, exploring and interpreting breast cancer symptoms, and factors influencing patients' decisions to seek medical help in the present study.

2.2.4   Stage at presentation

In the review, the time from detection of symptoms to seeking medical help varied from a few days [2-4, 7, 9-16, 19-21] to several years [4, 9, 11-16,19, 20]. As mentioned before, by O'Mahony and Hegarty (2009) and Arndt et al. (2002), in Western countries, approximately 10% to 30% of patients with suspicious breast cancer symptoms delay for at least three months before seeking any medical help. In Ghana, Ohene-Yeboah and Adjei (2012) reported that an estimated 85% of newly diagnosed women delayed for at least fourteen months before seeking medical evaluation. The literature described patient delay as comprising delay in both appraisal and help-seeking intervals [1,3,6,7,8,9,10,14,16,18,19,20,21].

According to the General Model of Total Patient Delay (Andersen & Cacioppo 1995), and the Grounded Model of Help-Seeking Behaviour by Unger-Saldana and Infante-Castaneda (2011), the appraisal interval is the time from first noticing a body change to deciding to consult a healthcare professional. The help-seeking interval is the period between deciding to consult and actual consultation. A wide range of methodological and theoretical approaches have been used to measure time points and intervals of pre-diagnostic patient pathways to treatment (Weller et al. 2012). For example, Andersen and Cacioppo (1995) divided delay into five different linear stages within the General Model of Total Patient Delay, which comprise appraisal, illness, behavioural, scheduling, and treatment. While this approach has been widely used, it does not adequately describe the complex and dynamic nature of pathways to diagnosis and treatment (Scott et al. 2013).

As there are variations in the definition and measurement of key time points and intervals of the appraisal process (Weller et al. 2012), there has also been a wide range of methodologies to measure the time it takes to seek medical help. The most commonly used method of determining patient delay is the use of retrospective recall data [10]. In this way, the estimation of patient delay could be affected by two factors: faulty recall and false reporting by women (Burgess et al.

1998). In faulty recall, symptomatic women would be asked when the self-discovery of the breast cancer symptoms occurred. In answering, there is the possibility that the women would mistakenly recall the incident, especially in situations where they have had the symptom for significantly longer periods. Since this faulty recall could pose a threat to the validity of the study, attempts have been made to avoid retrospective falsification in the estimation of delay.

In some studies, women were helped in dating the onset of symptoms with specific memory probes and anchor points; whenever possible, dates were verified using hospital records. Studies by both O'Mahony et al. (2011), and Unger-Saldana and Infante-Castaneda (2011) have interviewed symptomatic women while the patents were waiting for their first consultation with the healthcare provider, in an attempt to minimise recall bias. Other studies have successfully used a guided recall procedure consisting of a set of questions designed as cues to help women recall accurately when they first noticed their breast symptoms (Bradley 2005; Kadmon et al. 2012). For example, women were asked about their activities at the time and about major events such as holidays, birthdays, or significant events that occurred around the time of symptom identification. Studies by Burgess et al. (1998), and Facione, and Giancarlo (1998) have also reported that women accurately marked the place and time the symptom discovery occurred, possibly because the occurrence of a breast symptom, which may be seen as a threat to women, may make it a significant and memorable event.

As a strategy, help-seeking can also be used to refer to the behaviour of an individual who is actively seeking external assistance from people to deal with a health concern. A review of the literature on help-seeking behaviour was shown to be a complex decision-making process instigated by self-identification of potential breast cancer symptoms that challenges personal coping abilities. By studying relationships between knowledge, interpretation of symptoms, and the decision to consult a general practitioner (GP) about breast cancer symptoms among women in the Netherlands, De Nooijer et al. (2001) described help-seeking as a necessary ingredient in an individual successfully coping with the perceived disease.

As a form of coping that relies on other people, help-seeking is based on social relationships and professional skills. The reviewed studies indicated that although help can be sought from a diversity of sources, including both individuals who provide advice and emotional support and healthcare professionals who provide

modes of treatment; support varies in the level of formality and experience. These sources of support include looking for help from social relationship sources such as spouses, friends, and other family members [5, 9, 11, 12, 14-16, 18-21], alternative medicine, which uses religious faith/indigenous healing [1,5,9-13,12,15,18, 19, 21], and the mixed type that uses Western therapy as a complement to indigenous healing [11,13,15]. In contrast, formal professional help is obtained from healthcare professionals who have a recognised role and appropriate training in providing help and advice at all levels of healthcare delivery such as GPs, oncologists, nurses, and other allied healthcare professionals [1, 2, 3, 17].

2.2.5   Major reasons for delay

The literature reviewed identified factors such as social support, symptom appraisal, emotional, culture, and healthcare system as variables contributing to late presentation. These have been categorised as major reasons for delay and presented in Table 2.

Table 2 Major reasons for delayed presentation and help-seeking

Reasons for delay	Key variables
Social factors	Lack of support, receiving wrong information, multiple social role obligations and competing priorities
Symptom appraisal	Lack of knowledge and experience of symptoms, misinterpretation of symptoms, nature of symptom (painless lump and non-lump), beliefs, perception of not being at risk
Emotional factors	Lack of concern, denial, fear (cancer diagnosis, death, consequences of treatment, abandonment)
Cultural issues	Health and illness beliefs, stigmatisation, religiosity and spirituality, complementary and alternative treatment, fatalism
Healthcare system	Lack of insurance services and financial difficulty, limited access to healthcare services, unpleasant experiences related to health providers, frustrating referral process

2.2.5.1   Social factors

Recognising the importance of social networks and cultural considerations, the act of women disclosing discovered symptoms to others, was identified as a significant predictor of shorter delay, was a common concept in some of the reviewed articles [2, 3, 5, 10, 11, 15, 20]. Since an individual's decision-making process was partly influenced by others, the majority of the studies focused not only on how symptom disclosure supported the participants [2, 3, 6-8, 10, 11, 15, 16, 19], but also noted a potentially negative effect of discussing symptoms with others [5, 17, 19, 20]. Although some women did not disclose their symptoms to anyone else, due to their concern of bothering others [3, 15, 20], most of the women talked about their symptoms with a layperson and received various kinds of social support from them [2, 3, 10, 15, 20]. Among studies conducted in China by Lam et al. (2009), and in Mexico by Unger-Saldana and Infante-Castaneda (2011), women used their social networks to determine the significance of breast symptoms, and for seeking advice on further action.

Disclosing their symptoms to others allows individuals to evaluate body changes against the views of others, thereby reducing and possibly modifying utilisation delay, if others also offer advice about the availability of health services. Utilisation delay describes the time from the decision to seek care until the person goes to the clinic and uses its services (Safer et al. 1979; Andersen & Cacioppo 1995). According to De Nooijer et al. (2001), Taib et al. (2011), and Lam et al. (2009), symptom disclosure and receiving social signals from others were often used by patients to evaluate, confirm or develop the interpretations of their symptoms. For example, women who initially ignored their symptom reinterpreted it differently after getting new information from others. Conversely, in studies from Malaysia [19] and Iran [17], receiving misinformation and reassurance messages from laypersons, which led to a wait-and-see approach, could act as a barrier to help-seeking.

The initial interpretation of symptoms may change across the help-seeking pathway because of the progression of the symptoms being monitored. From the literature reviewed [2, 3, 10, 19, 20], disclosing symptoms to others also led to self-management in terms of self-regulation and self-reappraisal of the symptoms. Both Burgess et al. (2001) and Lam et al. (2009) recognised that women who initially dismissed their symptoms often monitored them for any further development. In most cases, the persistency and worsening of the symptoms such as the enlarged size of the breast, skin changes, and breast

discharge [3, 10, 11, 20], prompted women to reappraise their initial interpretation. In addition, the presence of unbearable pain [2, 3, 10-12, 17, 19] and physical discomfort, especially if they interfered with women's daily activities [12, 20], were the most common triggers to help-seeking across different cultural contexts.

As breast cancer is largely a cancer of women, with some women holding multiple roles including being a mother, wife, and employee, the kinds of social support received by symptomatic women varied significantly. These include emotional support regarding the nature of the symptoms [11, 20], fear of the consequences of medical help-seeking, and fear of cancer as an incurable disease; financial support [9, 20]; reassurance [20]; and encouragement to seek treatment [2, 3, 20]. Lam et al. (2009) and Taib et al. (2011) indicated that constant reminders by significant others such as a spouse, children, colleagues, and other relatives resulted in timely medical help-seeking behaviour. Social constraint resulting from unsupportive social interactions and lack of family commitments, which leads to problem resolution, was indicated as a facilitator to help-seeking [15, 16].

Two studies by Lam et al. (2009) and Burgess (2001) found that perceived multiple social-role obligations and competing priorities were identified barriers to help-seeking, due to conflicting events that were prioritised above personal health. In support, Taib et al. (2011) recognised that although women were aware of how serious their symptom might be, they felt too busy to arrange for a medical appointment. Since the women's role obligations were associated with other family members, O'Mahony and Hagarty (2009) upheld that, for some women, helping others first seemed to reflect the tendency to place the needs of others over their own. Nonetheless, according to Reifenstein (2007), social support and problem solving strategies had no relationship with delay in medical care-seeking of African American women with breast cancer symptoms.

While no studies have been conducted on perceived culturally gendered role demands and delayed medical presentation of breast cancer symptoms in Ghana, it is anticipated that women may have several responsibilities in their daily lives, which may interfere with their ability to seek a breast evaluation. This expectation of gender roles could be explained in two ways. Firstly, as the majority of Ghanaians appreciate the extended family system, women are expected to support their spouse's decisions regarding childcare, household chores, and taking care of parents. Secondly, although an increasing number of spouses

currently share the breadwinning role in their families, gender inequality still exists (Sossou 2011).

2.2.5.2   Symptom appraisal

From the literature reviewed, symptom appraisal includes identification, interpretation, and monitoring of symptoms. The majority of women became aware of a body change in their breast, which was considered an abnormal or a serious health condition. The women first detected different symptoms including a lump [1-21], which was observed as the most frequently detected symptom, followed by pain [1- 4, 6- 8, 10-21], nipple discharge [8,10, 14, 15, 18], inverted nipple [3, 6-8, 17], axillary mass [6, 17,19, 20], arm pain [17], and weakness and dizziness [8, 12]. Symptom identification occurred under different circumstances. Women mostly detected these symptoms by chance while involved in activities such as showering [1, 2, 4, 6-11, 15, 17], breast feeding [15], and washing of clothes [19].

In some cases, symptoms were discovered by active detection through a BSE [2, 3, 5, 14-16]. Although women's active participation in breast cancer screening using BSE was identified as impacting help-seeking behaviour, O'Mahony et al. (2011) found inconclusive evidence that BSE use for breast cancer reduces mortality. Despite the absence of reliable evidence on the benefits of BSE, O'Mahony and Hegarty (2009) argued that the less often women performed BSE, the more likely they were to delay help-seeking. In contrast, Facione and Dodd (1995) suggested that by providing education to women about breast cancer symptoms, the limitations of BSE would better prepare a woman to respond to the first symptoms of the disease. Equally, O'Mahony et al. (2013) indicated that while the debate on the appropriateness of available breast cancer screening methods continues, the best strategy for reducing breast cancer involves a combination of early detection techniques, such as breast awareness and early help-seeking behaviour.

Although the majority of women with breast symptoms reported a palpable lump, the experience of a non-lump symptom was a common cause of delayed presentation [2, 16, 19]. While non-lump symptoms such as an indrawn nipple and breast pain could also be signs of breast cancer, women who experienced symptoms other than a lump may attribute them to other, less threatening breast diseases rather than breast cancer. Therefore, such women are less likely to report for medical attention, thinking that prompt medical help may not be

necessary. Burgess et al. (2001) highlighted that, due to a lack of psychological response to symptom discovery, non-lump symptoms could be a risk factor contributing to both patient and healthcare professional delay.

Despite the overwhelming evidence suggesting that long delays are associated with poorer survival, a rapidly growing lump may suggest cancer to both doctors and patients, while a slow growing lump could be less obvious to them. Burgess et al. (1998) explained that while women with non-lump symptoms were unlikely to recognise their symptoms, they were less likely to associate their circumstances with the possibility of getting breast cancer. Should that be the case, then one would expect to see less delay in the women with the symptoms that are more suggestive of breast cancer.

Symptom interpretation was identified in some studies [2, 3, 10, 19, 20], as the most important step in the help-seeking trajectory. During symptom interpretation, Scott et al. (2013) observed that women assess and respond by attributing their symptoms to a cause, rather than seeking help. From the literature, identified symptoms were labelled as signifying normal, ambiguous, or serious conditions. Symptom interpretation was influenced by the nature of the symptoms [1-3, 8, 10, 12, 14-17, 20], women's knowledge about the symptoms [2, 3, 10, 15, 17, 19, 20], and women's perceptions on being at risk of breast cancer [3, 11, 15, 19, 20, 17]. The women who interpreted symptoms as normal also attributed them to a variety of factors such as hormonal changes [8, 10, 13], trauma [8, 10-13, 20], and breastfeeding [11, 19].

In other studies [2, 3, 5, 10, 12, 17, 19, 20], women interpreted their symptoms as normal physiological changes or changes that were less serious or more ambiguous [10, 15, 19]. In the study by Taib et al. (2011), poor symptom interpretation in Asian women, who experienced both non-lump symptoms and painless lumps, delayed presentation. In contrast to associating non-lump symptoms to delay, a study among Chinese women with symptoms of breast disease by Lam et al. (2009) reported that non-lump symptoms were not associated with delayed presentation. However, findings from a study among Irish women by O'Mahony and Hegarty (2009) highlighted that delay occurred, regardless of the nature of the presenting symptom.

Hopefulness related to the nature of the symptoms, or the outcome of breast cancer, had different consequences. According to Taib (2011), while people hold an optimistic view about the nature of their symptoms, they tend to evaluate their

unexplained symptoms as less serious than a life-threatening condition. However, according to several of the studies [2-10, 13, 14, 17, 19, 20], women who attributed the symptoms to a benign or non-malignant lesion were more likely to delay seeking medical evaluation. Therefore, misinterpretation of symptoms, resulting from lack of knowledge of breast cancer, was identified as a key factor in delayed presentation.

While assessing 449 women attending the breast clinics of two large urban hospitals in Ireland for their Knowledge of breast cancer symptoms, O'Mahony et al. (2013) found that, more than half of the women were unaware or unsure of the association between non-lump symptoms and potential breast cancer. This finding highlights the issue of limited knowledge of non-lump symptoms among women. The knowledge factor influencing help-seeking behaviour involves identifying and interpreting the cause of the disease symptoms, risk attribution, perceived severity of the symptom, and impact of illness. Taib et al. (2011) regarded knowledge as a prerequisite for interpreting symptoms correctly. Additionally, both Lam et al. (2009) and Taib et al. (2011) found that a woman's help-seeking behaviour was based on her ability to interpret her symptoms correctly, by intuitively matching the prevailing symptoms against known breast cancer symptoms to determine the likelihood of cancer. These studies seem to suggest that help-seeking was defined by correct symptom appraisal.

According to De Nooijer et al. (2001), lack of information can cause misinterpretation of breast cancer, in the sense that patients who delay are probably unaware of cancer signals or misinterpret symptoms, particularly the non-specific complaints. Additionally, patients who may have misconceptions about the consequences of the disease, for instance such as 'once you have cancer, you will certainly die' will therefore delay. Likewise, among Iranian women, Khakbazan et al. (2014) reported that the women delayed presentation because they based their assumptions on optimistic attitudes, inaccurate knowledge, misinterpretation, and did not consider themselves at risk, in other words, they were in denial. Furthermore, O'Mahony et al. (2011) explained that women with limited knowledge about their relative risk of developing breast cancer are more likely to delay seeking an evaluation, than those who consider the symptoms to be a sign of a serious disease.

The lack of knowledge, and the tendency to attribute symptoms to common illness, increases the probability of delaying taking action. Nevertheless, symptoms that were compatible with the women's previous knowledge and

expectation of breast cancer usually resulted in prompt action. In one study, Lam et al. (2009) associated knowledge about correct symptom identification with prompt help-seeking behaviour. This might in part be explained by the fact that these women were so knowledgeable that presenting the symptom of a breast lump required immediate evaluation by a healthcare professional to achieve early treatment. This notion was confirmed by several other studies [1- 8, 11, 13- 20].

In the literature, family history of breast cancer [1, 3, 5, 8, 9, 10], and knowing friends who suffered from the disease [3, 5, 9, 10, 15, 20] not only influenced the interpretation of symptoms; such factors affected the women's decision making process. Although women who promptly sought help for their past illnesses are inclined to do the same thing for their suspicious breast cancer symptoms, Taib et al. (2011) reported that since symptom recognition was largely constructed from the woman's existing lay knowledge of breast cancer, any symptoms that were incongruent with the women's pre-existing knowledge were more likely to be dismissed as insignificant, thereby delaying help-seeking.

Several studies [3, 11, 15, 19, 20] also showed that women's perceptions of being at risk of breast cancer had a greater impact on symptom interpretations than reported knowledge. In addition, some of the studies reviewed [5, 10, 15] reiterated that having a family history of cancer had different and conflicting effects on the women's perceived risk of the disease, shaping their beliefs and experiences about its management and treatment. Moreover, in other studies [20, 17], it was observed that women with a family history of breast cancer had a greater awareness of the disease, considered themselves at higher risk, and experienced greater fear in dealing with the prevailing symptoms.

In contrast to the above notion, women who did not have a family history of breast cancer perceived themselves at low risk and delayed seeking medical help. O'Mahony and Hegarty (2009) also detected that women with less knowledge regarding family history and risk of breast cancer, over-estimated their risk of developing cancer due to their perception of being at a higher risk. Although Unger-Saldana and Infante-Castaneda (2011) concluded that prior negative experiences about the curability of breast cancer deterred some women from seeking help, it prompted others to seek medical help sooner. Conversely, while the personal history of breast disease has frequently been reported to influence breast cancer screening, Nosarti et al. (2000) found no significant relationship between this factor and delayed presentation.

In their respective studies, Facione et al. (1997) and Burgess et al. (2001) concluded that women who failed to perceive negative consequences with identifying and labelling the initial symptoms they discovered, were associated with delaying help-seeking. To substantiate this notion, both Lam et al. (2009) and Taib et al. (2011) validated that inadequate symptom knowledge and recognition may render a painless lump more likely to have poor symptom interpretation leading to delayed presentation. For example, a painless lump was perceived as a non-serious condition in Mexico [20], China [10], Malaysia [19], Iran [17], Taiwan [11], and USA [12]. Arguably, while increasing knowledge about correct interpretation of symptoms may lead to a shorter time between symptom detection and seeking medical help, knowledge alone may not necessarily lead to preventive health actions, as very little knowledge may delay women's screening decisions while the disease advances. Though the literature review and syntheses of Western world studies have identified how knowledge and symptom interpretation, the role of others, and fear of cancer risk, might all influence help-seeking, sociocultural factors did not feature prominently in these studies.

The source of women's knowledge of illness arises from a variety of sources including direct experience, self-education, media, and family sources. Besides the fact that women with a family history of breast cancer may receive recommendations about healthcare providers from friends who had previously gone through the same experience, they may witness their loved ones suffering or even dying from the disease. For these reasons, it is suggested they are more likely to be frightened and delay seeking help for their own symptoms. In China, Lam et al. (2009) found that the media were effective through heightened awareness of the seriousness of breast cancer symptoms, particularly if influential figures were involved. However, the majority of published studies reviewed were conducted in developed countries, where dissemination of information through television, the internet, and magazines is widely available for communicating personal experiences of breast cancer. Hence, it is not known if the type of local media used in Ghanaian settings for publicising disease awareness messages are effective (Panford et al. 2001).

2.2.5.3   Emotional response to symptoms

As the self-discovery of a breast cancer symptom could be perceived as a health threat or stressful event for most women, emotional reactions after discovering symptoms were highlighted in nearly all of the reviewed studies. However, whether a woman decides to seek professional medical evaluation depends on

how she responds to the symptom cognitively, emotionally, and socially (Kagawa-Singer 2000). Despite women who did not perceive the seriousness of the symptom possibly dismissing their symptoms without any emotional reaction [3,5, 10, 19], nearly all of the women who recognised the seriousness of the symptoms, experienced different types of emotional feelings such as anxiety, uncertainty [3,5], depression [11,15], hopelessness [11], and fear [11, 17].

Generally, lack of concern about the nature of the symptoms [3], denial [3, 15, 17,19, 20], fear of confronting a cancer diagnosis [3, 10, 17,19, 20], fear of cancer as an incurable disease [3, 10, 12, 19], and fear of the consequences of treatment [2, 5, 10-12, 20] were associated with delayed help-seeking. Specifically, a variety of fears that were reported included fear of abandonment by a male partner [5,13], fear of being given a cancer diagnosis [4, 13], mastectomy [4, 13], side effects of chemotherapy such as nausea, vomiting, and baldness [5, 9, 11], and fear of death [8, 9]. According to a study by Unger-Saldana and Infante-Castaneda (2011), fear seemed to provoke one of two opposite actions in the women who experienced it; either it delayed medical help-seeking in order to avoid confirmation of a cancer diagnosis or accelerated it.

As a common coping strategy, denial was influenced by symptom progression. Unger-Saldana and Infante-Castaneda (2011) indicated that among Mexican women who delayed seeking help, due to denial in accepting the possibility of cancer, the development of pain or nipple discharge triggered action. Hence, how knowledge of the extent to which emotional distress might facilitate or hinder a delaying behaviour that might interact with other factors, such as cognitive responses to influence the patient's action, is still unknown. Psychological responses often caused conflicting outcomes in the help-seeking process. Most of the women who understood the seriousness of their condition tried to seek medical care to confirm the diagnosis [2, 3, 8, 10]. A study in the UK by Burgess et al. (2001) about women's beliefs and fears about the consequences of medical help-seeking explained that some of the women who delayed seeing their doctor, reported past experiences of cancer in which a loved one had died a painful death. Although this event may have occurred many years ago, and the woman may acknowledge that things have changed since, the memory remained with them.

2.2.5.4   Cultural issues

A society's culture has imbued within it specific values, beliefs, attitudes, and habits (Leininger 1988). As previously discussed in Chapter 1, it is well documented that culture influences how health is viewed, how symptoms of illness are expressed, and when and how help is sought. The impact of culture on help-seeking behaviour has been documented (Bailey 1987; Kleinman 1988; Kleinman 1992; Helman 2007). Kleinman (1988) acknowledged that culture plays a significant role in women's health and their illness experience, which influences their health beliefs and practices. In fact, Kleinman (1988:p.22) specifically described breast cancer as:

> "A culturally marked illness, a dominant societal symbol that, once applied to a person, spoils radically the individual's identity and is not easily removed".

In some parts of the world, such as North America (Viladrich 2006), South Africa (Crawford & Lipsedge 2004), and East Africa (Weisz 1972), studies of the relationship between culture, illness, and healing have supported the idea that illness is thought of as disharmony between the individual and his or her environment. The environmental factors include social relationships, relationships with the natural world, as well as relationships with the spirits. Therefore, one's cultural belief system and interpretations of the meaning of illness have important effects on which treatment approaches are sought when illness strikes (Struthers & Eschiti 2004). In support of this notion, Bailey (1987) acknowledged that the culture of an individual is of special importance in health-related situations because it influences whether a person utilizes or avoids available healthcare services.

Women's personal factors such as socioeconomic status and cultural beliefs were identified as influencing individual help-seeking behaviours. There was limited and conflicting evidence about the impact of socio-demographic variables such as age, marital status, and educational status on help-seeking behaviours in the reviewed studies. However, according to two papers [10, 11], women who had lower socioeconomic status or had recently emigrated from LMICs to Western countries, were more likely to delay the seeking of help, a prediction especially relevant to older Chinese [10] and Taiwanese women [11]. Though these Western studies have identified the role of both professionals and social networks in help-seeking for breast cancer, cultural factors did not feature prominently in these

studies. In addition, while prompt help-seeking activity may be triggered by an emotional response to physiological changes, what triggers the decision of Ghanaian women to switch treatment modes from traditional medicine to modern medicine, and vice versa, is unknown.

Although less emphasis was placed on the cultural dimensions of the help-seeking behaviour, Yusoff et al. (2011) acknowledged that help-seeking behaviour is formed to correspond with the local cultural context. Expanding on the influence of culture, Kleinman (1992) explained that the way people define and think about illness is heavily dependent upon their social and cultural environments. According to Angel and Thoits (1987), culture determines what is considered normal behaviour and what is seen as symptomatic of an illness. Consequently, the experience of illness itself including how it is interpreted and what meanings are attached, and the way individuals approach help-seeking for what has been identified as a disease, are all shaped profoundly by culture (Kleinman et al. 1978; Angel & Thoits 1987; Bagley et al. 1995). Furthermore, Angel and Thoits (1987) agreed that culture also influences how people experience illness and how their distress is communicated to others. Therefore, social disclosure facilitates women's help-seeking behaviour.

Cultural beliefs about cancer

General and specific cultural beliefs about breast cancer, which caused women to ignore early or late signs, were found to be significant predictors of delay in the literature reviewed. For example, a common belief amongst African-American women is that 'if a lump is not bothering you, you shouldn't bother it, and it will probably go away' [12]. Additionally, 'if your body has no pain, it means that it is not harmful' in Mexican women [20] or 'a wound, which opens up, heals by itself, little by little' among Iranian women [17]. In the UK, O'Mahony et al. (2013) explored women's beliefs relating to breast symptoms and help-seeking behaviour and found mixed results. The study reported that more than half of the women believed that their breast symptom occurred by chance. Additionally, the study revealed women's belief that ignoring the symptom and hoping it would go away, contributed to longer delays. Conversely, a study by O'Mahony and Hegarty (2009) confirmed that women's belief in "the earlier I got it seen to the better" facilitated help-seeking, whereas considering the symptom as "harmless" both facilitated and deterred medical help-seeking.

Religiosity and spirituality

Both religiosity and spirituality were identified as important factors in healthcare decisions among women in the literature reviewed. While spirituality may incorporate elements of religiosity, these are not the same thing, nor are they entirely distinct from one another. Religiosity generally refers to the role that a particular religion plays in society, including the extent of people's beliefs, identity, commitments, and levels of engagement with their particular religion. On the other hand, spirituality is more of a personal practice that has to do with having a sense of peace, and a way of coping with change or uncertainty. Essentially, spirituality refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred to establish a greater purpose (Puchalski et al. 2009).

Amongst the literature reviewed, several studies were identified in which many of the respondents used religion as a way to address their fear of cancer. However, in the process of practicing their faith, medical help-seeking could be delayed. In other studies, the participants' relationship with God was one of the main support systems that allowed them to get through the difficult times of being diagnosed with breast cancer. Bottorff et al. (2007) reported that some of the Punjabi women who migrated to Canada drew on the support of their religious beliefs and became confident that everything was in God's hands and accepted their cancer diagnosis. The women drew strength from their religious belief that God would protect them. Similarly, while studying the experiences of Taiwanese women facing a new diagnosis of breast cancer, Lu et al. (2010) acknowledged that during the diagnosis and treatment phases, patients felt alone and full of mental pain. Therefore, the most commonly used strategy among them was reliance on their religious beliefs, which often made them feel calm and peaceful inside, reducing their sense of loneliness. Thus, the power of religious beliefs eased not only patients' physical and mental pain but also increased their confidence in facing the necessary treatment. In addition, O'Mahony et al. (2011) observed that some women were of the view that religious beliefs, and having a positive attitude, were helpful to the final outcome in the event of a breast cancer diagnosis.

While religious beliefs were important to some women, giving them the confidence to delay help-seeking, a study in the UK by O'Mahony et al. (2011), which explored women's beliefs around the use of prayer, revealed that some

women were of the view that religious beliefs helped them to have a positive attitude, to seek help promptly and were helpful in the outcome of the breast cancer diagnosis. This finding, about praying to God about the breast symptoms, was similar to that of another study in the UK by O'Mahony et al. (2013). However, in a study by Yussof et al. (2011), spirituality prevented women and their husbands from functioning at a level of psychological deficit, an emotional performance that is below average, due to breast cancer. Elements such as acceptance and positive thinking helped the couples to defend or protect themselves from any negative psychological element that may diminish their overall well-being. A study conducted in Malaysia by Taib et al. (2011) reported that religious beliefs about God's role in curing cancer influenced women's intentions to watch the lump for changes, because of denial that God would allow this thing to happen to them. In contrast, Norsa'adah et al. (2012) reported that some women believed they had breast cancer as a punishment for previous sins and their symptom was in a way, a lesson from God.

Fatalism is the belief that all events are predetermined; therefore, women with breast cancer who subscribed to this perspective either expected to die or, alternatively, expected that God will save them. This life-view was expressed in different ways; among the religion-oriented literature reviewed [9, 10, 12, 15, 16, 19], fatalistic views of cancer were expressed based on prior negative experiences in the family [19], and/or cultural beliefs about cancer [12]. Although curability was related to prompt help-seeking, and a fatalistic view was linked to delayed help-seeking behaviour, it was noted that women's views about the curability of breast cancer varied between societies. Fatalistic beliefs were prevalent in Ireland [15], Malaysia [19] and amongst African American women [12]. The study by Taib (2011) demonstrated that there was a strong association between fatalism and delayed help-seeking. Fatalistic beliefs dominated the women's decision-making process, indicating their sense of hopelessness and lack of self-efficacy.

In USA, Mathews et al. (1994) found that African American women with breast cancer delayed seeking evaluation because they believed that having a breast disease is God's will and their fates are placed in the hands of God. In Malaysia, Norsa'adah et al. (2012) explained that there were patients who believed that they had breast cancer because of their view that all events are determined in advance by divine will or fate, and therefore people have no control over disease, life or death; thus some submitted to God's will and refused treatment. Moreover, Lackey et al. (2001) studied those African American women's experiences who

had been recently diagnosed with breast cancer in which participants referred to their reliance on God as a demonstration of their spirituality. Initially, most of the women saw the diagnosis of cancer as a death sentence. Based on their perception, participants discussed how they had fallen away from God and how their breast cancer experiences brought them back to a closer relationship with God.

In addition, Mathews et al. (1994) also reported about the belief amongst African Americans, that cancer is always ultimately fatal, medical treatment is degrading and hopeless, and that there is nothing a person can do to prevent cancer. However, this belief did not prevent them from seeking and continuing prompt treatment, indicating that as they progressed through the breast cancer trajectory, their sense of fatalism seemed to decrease. There was a shift from a fatalistic acceptance of the inevitable outcome of death, which led them to yield to God and a spiritual cure, to an acceptance of the biomedical understanding of cancer. It is not known, however, if Ghanaian women would experience the same thing or whether this perceptual change might be reflected in their switching from traditional to modern medicine.

Spirituality, and its effect on help-seeking behaviour, has been noted in some studies. According to Lackey et al. (2001), African American women viewed reliance on God as a form of self-management and a mission to get other women to seek spiritual treatment early. In the same study, spirituality also helped African American women to deal with stress and uncertainty, following a primary diagnosis of breast cancer. Although in some studies [9, 12, 15, 19], religiosity was suggested as a facilitator to seek medical care among women with breast cancer symptoms, results were inconclusive. Therefore, due to inadequate information regarding the role of religiosity on help-seeking, there was limited understanding of how total dependence on spirituality and religiosity could influence help-seeking processes amongst women with breast cancer symptoms. On the other hand, O'Mahony et al. (2011) showed that although religious beliefs had a positive effect for some women in Ireland, those who relied on their faith had delayed seeking help. While fatalism may help explain healthcare decisions among Ghanaian women (Mayo et al. 2003), the influence of fatalism on delayed presentation and medical help-seeking in breast cancer among Ghanaians has not been well understood.

Complementary and alternative therapies

Although women had a strong belief in conventional treatments for breast cancer in the studies reviewed, participants in several studies considered alternative therapies as well, hoping that they would help with body and mind, but not necessary kill the cancer cells. In their studies, both Lu et al. (2010) and Rastad et al. (2012) found that some women who attributed their symptoms to less serious causes, or those women who were frightened of medical confirmation, initially sought alternative therapy as an easy way to deal with the symptoms before medical help-seeking. Based on the recommendations of their friends, relatives, and other patients, participants in these studies used the therapies such as Chinese medicine, herbal-nutritional supplements, and health foods in order to find a possible cure and to prevent the cancer's recurrence. They also believed that those alternative therapies could decrease the adverse effects of cancer treatments and promote their body comfort.

Likewise, O'Mahony et al. (2013) reported that women's beliefs in ignoring the symptoms and hoping that they would go away were associated with the increased likelihood of delay. According to Taib et al. (2011), due to uncertainty about the ability of conventional medicine to combat the fatal outcomes of cancer, some Malaysian women used alternative medicine instead. In other studies, some women applied alternative therapies as additional treatment for decreasing the adverse effects of conventional medicine [3, 11]. According to O'Mahony et al. (2011), while these studies acknowledged the use of alternative medicine in women, no compelling evidence that its use facilitated early presentation was identified.

Stigma

Stigmatising behaviour from others can take many forms, including social distancing, discrimination, and loss of social status. Social stigmatisation of breast cancer was seen in some of the studies, as a reason precluding women from openly discussing their experiences with individuals outside their family units. Women in identified ethnic groups perceived that social stigma was associated with breast cancer diagnosis, particularly among Punjabi women in Canada [1], Asian women in Malaysia [19], and Arab women in Iran [8]. Taib et al. (2011) observed a cultural situation in Indian women, where parents were not able to marry off daughters due to the stigma of cancer. Concerns around body image did not allow South Asian women to disclose their symptoms with the

public although some women suspected it might be cancer [19]. Likewise, in Iran, Khakbazan et al. (2014) identified that individuals with cancer disclosed their symptoms selectively.

In addition, Granek et al. (2012) indicated that embarrassment, humiliation, and the shame of being diagnosed with cancer were due to misconceptions, such as 'the only people who got mastitis were women who didn't bathe well' or often, 'homeless women were likely to get cancer'. Furthermore, Lam et al. (2009) and O'Mahony et al. (2011) identified women's preferences to be examined by a female doctor, as well as the shame and embarrassment of breast examination as a private organ, were reported in some studies in China [10] and by older women in Taiwan [11]. In these studies, fear of stigma of breast cancer caused delayed help-seeking. Although, it has been reported that one of the reasons making it difficult for mental health practice is the traditional stigma associated with mental health issues in Ghana (Salisu & Prinz 2009), there is only limited evidence linking stigmatisation to delayed breast cancer presentation in the country.

2.2.5.5   Healthcare systems

Healthcare provider and system factors constitute aspects of the healthcare services that influence the behaviour of both the patient and professionals when decision-making (Nosarti et al. 2000). These aspects include access to the generalist and/or specialist, availability of healthcare professionals, and choice of diagnostic procedures. Women who made the decision to seek medical help considered financial constraints, structural factors, and previous healthcare experience as informing their action. Based on the literature reviewed, personal financial constraints [10, 20, 13], lack of insurance services [20], difficulty accessing healthcare services for a number of reasons such as distance [19, 20], and lack of knowledge of breast clinic locations [10], were identified as factors that directly impacted the ability to seek timely medical consultation. Unpleasant previous experiences related to health service providers [20], and women's levels of trust in the knowledge and competency of the physicians [2, 3, 15], were identified as factors negatively affecting women's help-seeking behaviours. On the other hand, De Nooijer et al. (2001) acknowledged that women who did not delay in finding help, appeared to have more confidence in their doctor to handle their problem.

Structural factors related to health services, such as the long process of admission [3, 20] and challenges with referral systems, resulted in frustration and

fatigue in women while they attempted to follow their treatment plans. In addition, medical error and the assurances some women received from their physician, resulted in patient delay in seeking medical help [5, 17, 20]. Moreover, some women had concerns about issues such as unnecessary presentation, wasting the time of or bothering the physician [2, 3, 5]; these were issues which became barriers to receiving care. Other studies, including Norsa'adah et al. (2012) and Unger-Saldana and Infante-Castaneda (2011) have shown that a woman's decision to seek medical attention for breast cancer symptoms is made within an integration of personal, social, cultural, and healthcare system contexts. Few studies have explored extensively the complexities of sociocultural factors on sub-Saharan African women's reasons for delayed presentation of breast cancer symptoms.

2.3   Rationale for conducting the research

The literature reviewed revealed important insights into women's appraisal and help-seeking experiences with breast cancer symptoms. However, there is still relatively little knowledge about Ghanaian women's experiences between when they initially identified breast cancer symptoms and the time they first consulted a healthcare professional for medical evaluation. Although the reported studies have provided understanding into factors related to delays in help-seeking behaviour, the majority of the studies were conducted in Western countries with different sociocultural backgrounds, socioeconomics, and healthcare systems from those of Ghana. As a result, it is not known whether Ghanaian women have different cultural beliefs about breast cancer from women in Western countries impacting delay. If so, it is important to consider whether these beliefs and other factors are associated with the prevailing tendency to late presentation. This raises questions such as could women's roles in a patriarchal society, like that of Ghana, contribute to longer delays in presenting symptoms? Does the pluralistic healthcare system contribute to delayed presentation? Very few studies have examined these factors within the Ghanaian population.

The literature also highlighted theoretical frameworks pertinent to aid understanding delays in help-seeking in Western countries. However, there were limited number of theoretical models available for understanding delayed presentation of breast cancer symptoms to HCPs for West Africa, particularly in Ghana. Therefore, this proposed empirical research seeks to fill this gap by exploring the impact of sociocultural factors on appraisal and help-seeking

behaviour among Ghanaian women with self-detected breast cancer symptoms. The outcome of this research could produce a theoretical understanding of delayed presentation of breast cancer symptoms among Ghanaian women, which can be used as a framework for understanding other West African populations or to compare evidence with other models developed from Western countries.

2.4   Research question, aims, and objectives

To respond to the gaps within the literature, this qualitative study was designed to answer the following research question and address the subsequent aim and objectives.

Research question

The research question, which was initially generated from my professional curiosity, and refined by this literature review, is:

"How do sociocultural factors impact the interval between appraisal and help-seeking among women who self-discover breast cancer symptoms?"

Aims

The aims of this study are; to ascertain how specific sociocultural issues influence Ghanaian women's appraisal of breast cancer symptoms, the meaning they ascribed to those symptoms, the significance of this experience on their timing and choice of healthcare utilisation, and whether these factors are different in Ghana from those identified in Western countries.

Objectives

1. To explore the cognitive, emotional, and psychosocial impact of symptom appraisal amongst Ghanaian women.

2. To understand how the women interpreted symptoms and the sociocultural factors that informed that interpretation.

3. To describe how this interpretation informed their choice of healthcare utilisation and identify the steps in their decision-making pathway.

4. To explore how a symptomatic woman's social networks and social support system impact on her decision to seek help.

5. To explore reasons why Ghanaian women may delay seeking care for breast cancer symptoms from the healthcare providers' perspectives.

2.5   Literature review post 2014

Using the same literature review strategy previously described in section 2.1, literature searches since 2014 identified five papers that were published between January 2015 and June 2017 and are consistent with the aims of this research. The studies were geographically diverse, being undertaken in Japan (Oshiro & Kamizato 2017), Malawi (Kohler et al. 2017), United Arab Emirates (UAE) (Elobaid et al. 2016), Singapore and Malaysia (Lim et al. 2015), and United Kingdom (Jones et al. 2015). Even though all the studies adopted a qualitative approach with semi-structured interviews to collect data, only one study, by Elobaid et al. (2016), used a conceptual framework to guide analysis. The Model of Understanding Delayed Presentation by Bish et al. (2005) and a grounded model of help-seeking behaviour by Unger-Saldaña and Infante-Castañeda (2011) informed the development of the conceptual framework used in that study.

The first paper by Oshiro and Kamizato (2017) aimed at identifying factors influencing help-seeking behaviour by comparing delayers with non-delayers among Japanese female patients with breast cancer. This descriptive qualitative study interviewed twenty-one female patients recruited from two hospitals in Okinawa, comprising nine "delayers" and 12 "non-delayers". The participants revealed eight barriers to help-seeking, which were specifically associated with the delayers. These were: i) appearance of symptoms that cannot be definitely linked to breast cancer; ii) anxiety and fear; iii) necessity to prioritize immediate needs of daily life; iv) non-disclosure of the situation; v) the view that medical care is a nuisance; vi) desire to surrender to the natural course of things; vii) confidence that participants would not develop cancer, and viii) inaccessibility of medical facilities. The study also found that a common trigger for both the "delayers" and the "non-delayers" was the presence of other people who encouraged help-seeking. Thus, among the barriers to help-seeking presented, emotional reaction and economic hardship have also been identified as common barriers worldwide (Jones et al. 2014; Khakbazan et al. 2014); nonetheless, maintaining a positive relationship with family and friends was identified as a strong facilitator to help-seeking among Japanese persons.

The second paper by Kohler et al. (2017) explored the views of breast cancer patients in Malawi about their diagnosis and ability to access care, in order to

identify help-seeking behaviours and describe factors influencing delay. In-depth interview were conducted with twenty patients who were purposively sampled at Kamuzu Central Hospital. The patients were largely unaware of breast cancer and did not immediately notice potential symptoms. However, as symptoms progressed, women assumed illness and sought help from social networks, traditional remedies, and medical care. These practices delayed presentation. Although low awareness of the breast cancer symptoms delayed women's decisions to seek medical help in Malawi, other factors such as interpersonal issues, particularly social support, cancer-related experiences among peers, family roles and responsibilities, and the healthcare system greatly affected women's behaviours and access to care.

The third paper was a study conducted in UAE by Elobaid et al. (2016), which aimed to explore factors influencing delayed presentation for treatment after self-discovery of symptoms, and to investigate facilitators and barriers of women's treatment seeking behaviour in that country. Nineteen breast cancer patients aged 35–70 who experienced delayed presentation for treatment after symptomatic recognition of breast cancer were recruited and interviewed. Key themes that emerged from the interviews included varying responses to symptom recognition, fear of societal stigmatization, and concerns regarding abandonment by spouse due to breast cancer. The study also recognised that besides participants' lack of awareness about signs and symptoms of breast cancer, routine screening affected symptom appraisal and subsequent decisions on available treatment options.

The fourth study by Lim et al. (2015) explored and compared barriers to early presentation of self-discovered breast cancer in Singapore and Malaysia. Sixty-seven patients recruited from a University hospital with self-discovered breast symptoms were included in the study. In both countries, patients revealed barriers to early presentation as poor quality of online information about breast symptoms, financial issues, and negative influence of relatives. However, in Malaysia, perceived poor quality of care and services at the state-run hospitals and misdiagnosis by healthcare professionals were reported as barriers to help-seeking. In spite of their differing economic status, Singapore and Malaysia did not show any significant differences in the pattern of presentation and in the reported barriers to seek medical care.

The last paper by Jones et al. (2015) reported a study conducted in the UK to understand barriers to early diagnosis of symptomatic breast cancer among Black

African, Black Caribbean, and White British women. Ninety-four women aged 33–91 years encompassing 20 Black African, 20 Black Caribbean, and 20 White British women diagnosed with symptomatic breast cancer were interviewed at eight cancer centres/hospital trusts in London, Somerset, West Midlands, and Greater Manchester. Additionally, fourteen Black African, 20 Black Caribbean women with (n=19) and without (n=15) breast cancer participated in six focus groups. First generation Black African women experienced most barriers comprising conservative attitudes and taboos about breast cancer awareness, which contributed to their delaying the longest. Second generation Black Caribbean and White British women were similar and experienced fewest barriers. Absence of pain was a barrier for Black African and Black Caribbean women. All women viewed themselves at low risk of the disease, and voiced uncertainty over breast awareness and appraising of non-lump symptoms.

In summary, these studies published after 2014 were conducted in different countries. However, they shared a common complex array of factors (facilitators and barriers), which influence women's decisions on symptom appraisal and medical help-seeking. Such factors range from emotional reactions (particularly, anxiety and fear), to financial issues, issues relating to the healthcare system, social factors, and interpersonal issues (e.g. knowledge of symptoms). Nevertheless, these new papers do not add any further issues/themes to the ones already presented in section 2.2.5 of this thesis.

2.6   Chapter summary

This chapter has described the literature review that was undertaken to inform the study. The literature search strategies included the use of traditional databases accessed through the University of Southampton's Library, search terms, Boolean operators, and truncation to discover the relevant studies cited above. The search yielded some 21 relevant published articles, which revealed useful information related to delay and help-seeking behaviour of women upon self-discovery of unusual breast cancer symptoms.

It is apparent from the literature that a woman's decision to seek medical evaluation for self-discovered breast cancer symptoms is based upon multiple networks of personal, social, cultural, and healthcare system factors. Knowledge of a disease and a past history of medical help-seeking were identified as stimulating factors. However, some personal beliefs, competing priorities in life, and lack of access to health facilities were found to impede help-seeking

behaviour. On the other hand, fear and anxiety, use of complementary and alternative medicine (CAM), and the level of social support enjoyed were identified as both motivating and limiting factors when linked to the women's help-seeking. Nevertheless, information about which part of Ghanaian women's experience most informs their decision to seek help from a healthcare professional is limited. Therefore, it is argued that developing an understanding and gaining knowledge of pre-diagnostic breast cancer symptom experience of Ghanaian women, in terms of symptom appraisal and help-seeking behaviour, is necessary for guiding healthcare professionals in supporting patients through their decision making process. Such an understanding would also shed more light on the barriers and facilitators towards early diagnosis of breast cancer. This requires an approach that is flexible, open to modification or change if necessary, and would recognise patients as socially constructed. Therefore, knowledge of this relationship would benefit from the type of investigation that employs qualitative research.

Chapter 3:   Methodology and methods

Chapter 2 presented a critical review of the relevant literature on delayed presentation and help-seeking behaviour of women with breast cancer symptoms. Based on the gaps identified in the literature, this study aims are to ascertain how specific sociocultural issues influence Ghanaian women's appraisal of breast cancer symptoms, the meaning they ascribed to those symptoms, the significance of this experience on their timing and choice of healthcare utilisation, and whether these factors are different in Ghana from those identified in Western countries. This chapter provides a detailed account of the methodology chosen to undertake this research. A coherent design for the study that ensures quality, integrity, and is consistent with the research question, aims, and objectives would be presented. The chapter begins with a discussion of the research paradigm and the rationale for the approach adopted for this study. Subsequently, specific details regarding the identification of study sites, ethical approval, methods of data collection, data analysis, and the measures taken to ensure rigour and quality in the research process, will be addressed. Throughout Chapter 3, I try to reflect on my role in collecting and analysing interview data from participants.

3.1   Research design

Research design is a logical process that connects the data to the research questions and then to the findings and conclusions (Maxwell 2012). As a life threatening condition, breast cancer can bring about a life changing experience for the affected woman and those around her. To gain an in-depth understanding of the symptom appraisal and help-seeking patterns of these women requires an understanding of how members of a culture pay attention to the meanings and life experiences that people ascribe to an illness, as well as the intricate interrelationships that these meanings have on their behaviour (Bailey 1987). Therefore, to follow a systematic and precise process of gaining insight through discovering in-depth meanings of the appraisal and help-seeking phenomenon, several issues were considered to ensure the best investigative strategy was selected, consistent with the aims and objectives of this study.

3.1.1   Research paradigm

According to Patton (2005), the process of research design is of considerable importance. I began my research journey by defining the purpose of the study as the intention to explore those aspects of a woman's life that have been affected by the discovery of breast cancer symptoms and those aspects that have an impact on her subsequent healthcare decisions. The study focuses on each patient's story while using her social network, particularly friends and family members, and the healthcare professionals, as complementary sources of information. Creswell (2007) recommended that the exploration of multiple perspectives contributes to knowledge creation and provides a greater understanding of the issue under investigation than gained through a single perspective.

Following the defined research question stated in section 2.2.4, it was necessary for me to identify how quantitative and qualitative research differ at a philosophical level, as well as the nature of the evidence which each research model can generate (Patton 2005). Creswell (2003) suggested two paradigms that are widely used in research: positivism and constructivism. Quantitative research draws on the positivist paradigm, in which there is a perception that there is an objective reality, which can be measured. Knowledge is discovered and verified through direct observations or measurements of phenomena (Krauss 2005). In contrast, qualitative research draws on the constructivist paradigm in which there is a perception that reality is not fixed but comes from generating knowledge and meaning from personal interactions with others in a social context (Patton 2005). Within this paradigm, the phenomena of interest are explored from the points of view of the participants in their everyday lives (Denzin & Lincoln 2000).

Since this study is driven by the need to understand the meanings that women with breast cancer symptoms assigned to their decision of choice of healing, interpretivism was selected as a way of gaining knowledge and understanding of the social reality, through the participants' perspectives. This approach aims to understand the context and then make an interpretation that is shaped by experience (Ritchie & Lewis 2003). Interpretive researchers maintain that people usually give meaning to their environment and themselves, and the way

they do this is shaped by the particular cultures in which they live. Moreover, those who believe in this method argue that one cannot understand why people do what they do without grasping how those involved interpret meanings and make sense of their world, and without understanding the distinctive nature of their perceptions, beliefs, and attitudes. The research stance taken in the current study views reality as a social construct and places paramount importance on the experiences of individuals and the meanings that they assign to them (Snape & Spencer 2003). This approach contrasts with the positivist tradition, which takes reference from an objective concept of reality (Benton & Craib 2010). Hence, it requires openness on the part of the researcher, by suspending his or her prior cultural assumptions and adopting a willingness to learn the culture of the people being studied.

Studies involving qualitative approaches are regarded as being subjective, where the researcher's understanding of the events is paramount to address research questions that require explanation of social phenomena and their contexts (Snape & Spencer 2003). Due to the desire to study human behaviour and social interaction, qualitative methods of data collection, such as in-depth interviews with open-ended questions are recommended. Thus, the use of interpretive research can facilitate the exploration of help-seeking behaviour in women with breast cancer symptoms. In the process of the study, this research paradigm provided opportunity to explore the explanatory potential of existing theories as well as offering the potential to generate new theory through inductive analysis of the study data collected (Murphy et al. 1998). Adopting this approach supported the research objectives and underlying values of the study, by acknowledging that differing translations of the help-seeking behaviour of patients with breast cancer symptoms may exist among multiple participants.

3.1.2   Using a qualitative approach

Although the literature review identified both quantitative and qualitative methodologies, a quantitative design was not selected because it does not provide an in-depth understanding of experiences of this real life situation being studied (Creswell 2003). Qualitative research explores the social world, providing meaning and explanation for complex phenomena through an in-

depth examination aimed at understanding human experience, perceptions, motivation, intentions, and behaviour (Spencer et al. 2003). Data can be obtained through a variety of methods, particularly interviews, focus groups and observation, and analysing such data involves examining the words that are articulated during these interactions. Such a research approach is usually appropriate for understanding complex life experiences that are under-researched, and about which relatively little is known (Creswell 2003). Since the qualitative research approach is concerned with meanings people attach to their experiences of a situation, and how they make sense of that event (Burns & Grove 2003), qualitative research seeks to answer questions about the "What", "How", and "Why" of a phenomenon (Green & Thorogood 2009). Therefore, qualitative research constitutes a primary source of sociocultural behavioural data providing evidence of a person's cognitions and attributions regarding life experiences that are likely to influence future behaviour in similar situations (Baumeister & Newman 1994).

Adopting a qualitative methodology therefore supported consideration of the cultural and social context for symptom appraisal and help-seeking behaviour of patients, their social networks, and the views of healthcare professionals, in a way that would have been difficult to achieve using a quantitative approach (Tones & Tilford 2001). The choice of a qualitative methodology for the current study reflected the underlying assumptions associated with an interpretative research stance and provided a good fit for the research question. Qualitative studies facilitate the making of meaning through personal experience, by way of a process of reflection using storytelling as an essential element, where metaphors and folk knowledge have their place (Connelly & Clandinin 1990; Holloway & Freshwater 2007).

Additionally, a qualitative approach provides an opportunity to explore personal experiences beyond the boundaries of a questionnaire, while offering insight into decisions involving screening, diagnosis, treatment, various health practices, and a guide as to how healthcare services are provided (Overcash 2003). Indeed, the qualitative approach has been used effectively in several cancer studies to explore women's pre-diagnostic experience of breast cancer symptoms (Lam et al. 2009; O'Mahony et al. 2011; Granek et al. 2012). Based on the issues raised above, a qualitative approach, centred on the participant's

personal experiences, was adopted to elicit in-depth information about how a woman appraised the symptoms and the factors that informed her help-seeking decisions on whether the individual will use or avoid available modern healthcare services.

Among the five qualitative designs recommended by Creswell (2007), four were considered as potential approaches for this study: i) ethnography; ii) narrative; iii) phenomenology, and iv) grounded theory. A brief description of each of these designs is presented in Table 3.

Table 3 Summary of four qualitative research approaches

Research approach	Purpose	Focus	Data collection
Ethnography	To understand how people's actions, interactions, experiences, and feelings reflect the culture of a group	Specific field site(s) where group(s) of people share a common culture	Participant observation, structured or unstructured interviews with informants, and document collection, usually over an extended period
Narrative	To consider potential of stories to elicit meaning regarding people's lives	Individual experiences and sequences of events, shaped through stories	Unstructured interviews and conversations with individuals; oral histories; diaries and documentary analysis
Phenomenology	To understand experience from the participants' point of view	Descriptions and/or interpretations of everyday human experiences (the lifeworld) as sources of evidence	In depth, unstructured interviews, and purposive sampling
Grounded theory	To develop a theory from data collected in a natural setting	A process of examining the interaction of data collection and analysis, with theoretical sampling and constant comparison	Interviews, documents, observation, record review, or combination of these methods

Ethnography involves the recording and analysis of a way of life among groups of people and understanding their lifestyles and behaviours. Ethnography is usually based on participant-observation over often an extended period of time and results in a written account of people, place or institution. Adopting ethnography for this study would require that I immerse myself in the culture of the participants over a long period of time, engaging in observation and conducting interviews and conversations. As such it would have been inappropriate, given that the intention was to interview a large number of participants at a given point in time, rather than longitudinally.

Narrative inquiry is a means by which people's stories of personal experience and cultural context over time are systematically gathered, analysed, and represented as told by them. Narrative was not selected for this study because it is based primarily on a relatively unstructured approach whereby stories are elicited from participants and the way in which those stories are told is paramount. Phenomenology emphasises the meaning of individuals' experiences as they live them. Whilst the nature of the experiences, and the perceptions and views of individuals were sought in this study, an overtly phenomenological stance was not adopted. In turn, a grounded theory approach was not selected as, in this, the researcher attempts to enter the field with no prior theoretical assumptions and seeks to generate concepts and theory purely from the data.

Although this study was designed to develop insight and theory that could help to understand why women presented late with symptoms, it was initially informed to some extent by theoretical perspectives and prior knowledge of what the important factors may be. These could then act as a focus in the fieldwork. Since my study sought to explore a range of potential issues, within a society which is known to have a close-knit family system and where some *apriori* theoretical perspectives could have been relevant, no one of these four approaches was considered to be the methodology of choice for this study. Nevertheless, aspects of them proved helpful and thus a design was adopted, which combined in-depth semi-structured interviews at a single point in time with a range of participants (the women, those in their networks, and professionals) with the encouragement of story-telling about their experiences of appraisal of symptoms and factors concerning the help-seeking intervals.

Since the elicitation of personal experience, with a particular focus on the stories told by individuals, was the basis for collecting data, this study has drawn upon an aspect of Creswell's (2007) qualitative approach to inquiry, in which personal experience stories are collected. According to Baumeister and Newman (1994), stories allow the individual to reflect on both their past personal experiences and how that person has interpreted and internalised the meaning of those experiences. Holloway and Freshwater (2007) affirmed that the principal reason for using stories is to facilitate participants' understanding of their experience, legitimising their behaviour, and allowing them to share holistically their emotional experience with others. This approach is regarded as a particular research strategy that considers how the re-telling of events and experiences reveals more about personal experiences than just identifying a factual account of the individual. Such an approach allows a person to communicate through both the thematic content and the structural organisation of the interview (Labov & Waletzky 1997).

Indeed, this research design is commensurate with the oral tradition in Ghanaian communities, regarding the common use of storytelling among women to share knowledge and experiences related to health and other sensitive real life issues (Agalic 1978). Storytelling usually occurs in the early evenings, after the people had taken their meals. The venue is either an interior yard or in front of a compound house. During the performance of storytelling, the tellers are hardly interrupted until they finish their tales, allowing everyone the freedom to tell what they like (Schott 1994).

3.1.3   Data collection strategy

The knowledge of help-seeking and sociocultural factors that can impact healthcare choices, could be obtained through dialogue only with symptomatic women. To broaden the understanding of this particular issue, different types of participants, including members of the women's social network, and healthcare professionals, were interviewed to produce their own perspectives on the phenomenon. Interviews can be undertaken locally to the participant, they sustain a person-centred approach, and give the participant the full attention of the researcher to facilitate the re-telling of their experiences of finding breast cancer symptoms. The researcher in such a context will require

significant sensitivity to support the individual through their interview process (Ritchie & Lewis 2003). A consideration of these points, particularly the one-to-one approach, storytelling, and allowing for participant's preferences and expressed needs led to the conclusion that interviews would be the most appropriate method for information gathering in this study.

Besides the fact that in-depth interviews are integral to interpretivist research, it is a well-established research technique in social and health sciences (Mays & Pope 2000), and the most common form of data collection that produces rich text data in qualitative research (Holloway & Wheeler 1996). An interview is a conversation with a purpose, in which the interviewer aims to gain the perspectives, feelings, and perceptions of the participant being interviewed (Holloway 1997). It is also a verbal interaction between the researcher and the respondent for gathering data to answer particular research questions (Dicicco-Bloom & Crabtree 2006).

Interviews can take a variety of formats including telephone, face-to-face, email, and Internet relay chat (IRC) (Langdridge 2007). While there are many ways interviews can be conducted, a face-to-face interview permits the interviewee and the interviewer to develop a relationship that provides the interviewee an opportunity to react to non-verbal responses to judge the level of understanding to avoid misinterpretation (Dicicco-Bloom & Crabtree 2006). By interacting with the participants, the researcher attempts to seek answers, gain deeper meaning, clarification, and obtain evidence about participants' personal stories of experiences regarding the phenomena being studied. Therefore, interviews provide the opportunity for the researcher to explore ideas or concepts when asking questions as opposed to information gained by the researcher when directly observing from the participants' point of view (Patton 1990).

The single face-to-face interview that was used in this study had two parts. The first part was a narrative in which the patient was asked to tell a story of how she became aware of changes to her breast, together with how she interpreted the sign and the steps she undertook to seek appropriate medical help. This strategy allowed respondents to tell their story in their own way, how they perceived what had happened to them, and permitted them to speak uninterrupted until the story ended. The second part of the interview was semi-

structured, in which follow-up questions were asked in order to cover areas of interest and gain clarification of meaning of what had been said. To facilitate the interviews, a preliminary topic guide was developed from the themes evident in the existing literature on women's experiences of having breast cancer symptoms and delayed presentation. The aim of these questions was to ensure a degree of standardisation across the interviews on the topics covered, to explore important areas that were not brought up in the initial narrative, and to clarify any areas of ambiguity arising from the narrative.

Due to the flexibility of the semi-structured interview, it is particularly suited for studies investigating new ideas (Robson 1993). Such interviews permit neutral and non-leading questions and guidelines, which provide the opportunity for the interviewees to offer greater explanations and answers to the questions, as well as allowing interviewers to ask for clarification and probe for further information (Dicicco-Bloom & Crabtree 2006). This interview format also attempts to facilitate rapport, allows a greater flexibility of coverage, permits venturing into novel areas and tends to produce richer data than other formats (Smith 2007). It is therefore preferable to a more structured interview, which deliberately restricts participants' responses and tries to ask the same questions in the same way, thus attempting 'objectivity' and 'comparability' of responses.

Depending on the participant's convenience, the interviews took place either at the researcher's office, participant's home, or participant's office or workplace. Whilst the duration of the interviews was scheduled to be approximately 45 to 60 minutes, it did not fit within the exact period estimated. The interviews were also fully audio recorded when consent was given. The interviews facilitated the development of a bond with the patients, their social network, and the healthcare professionals. It also allowed the interviewer to delve deeply into social and personal matters, to gain information from the eligible participants, and receive a wide range of experiences. The rapport developed between interviewer and interviewees was also the means of establishing a safe and comfortable environment for the interviewee's personal experiences and attitudes. The rapport also provided immediate clarification and support when there was a lack of understanding regarding some issues or answers.

To prevent any problems related to the interviews with participants, a well-planned research and management process, including the building of a relationship of trust and respect, was applied. In this regard, the researcher protected the anonymity and confidentiality of the participants at all times. Given the diverse experiences of the women interviewed, different questions arose during each interview session. As the interviewing programme progressed, additional topics raised during previous interviews were also used in subsequent interviews. Therefore, the wording and order of questions were not the same for all participants. By using open-ended questions, participants talked freely about issues, without having their responses constrained by a structured set of questions.

3.2   Ethics

Ethical issues are important to consider when doing research with human subjects to safeguard their rights and ensure their safety. There are three main ethical issues to consider when undertaking qualitative research. The first is anonymity, whereby the use of pseudonyms protects the identity of the study participants through the process of data collection, analysis, and publication. A second issue is confidentiality, where the information gathered from participants must be kept private. The last issue is informed consent, indicating an agreement to take part in research without threat or persuasion.

3.2.1   Ethical approval

Ethical approval is a mandatory requirement for undertaking any human research project. To meet the University of Southampton's guidelines for studies conducted by students, an ethics application was submitted, and approval was granted by the Faculty of Health Sciences Ethics Committee of the University of Southampton (Ethics number: 9247) on March 25, 2014 (Appendix F). In addition, since the study was conducted within healthcare facilities in Ghana, separate ethics approval was acquired from each institution. The entire approval gathering process lasted approximately six months. While I followed the useful published guidelines describing the principles and approaches for submitting application for ethical merit review of my research, there was no organised institutional structures to implement the review

efficiently. Navigating through the bureaucratic system was complicated and time consuming. Although at times, the process was incredibly frustrating and challenging, eventually all required permissions were granted. Approval from the government hospital was granted by Kwame Nkrumah University of Science and Technology (KNUST) Committee on Human Research, Publication and Ethics (CHRPE) (Ethics number: CHRPE/AP/245/14) on July 14, 2014 (Appendix G) and that of the private hospital by Peace and Love Ethical and Protocol Review Committee (EPRC) (Ethics number: EA005/PLH on April 4, 2014 (Appendix H).

3.2.2   Informed consent

To ensure both the quality and integrity of the study, all participants were given an information sheet explaining the purpose of the research in clear and simple terms. The information sheet also addressed issues of data protection, confidentiality, study benefits, and contact information. Although there was essentially one version of the information sheet, each of the three participating groups had a slightly different version (Appendix B). All components of the study were fully explained to the participants, who were given time to ask any questions they might have. I answered any questions raised.

There was no coercion to participate in this research. There were no changes to their healthcare should any potential or actual participant choose not to participate or to withdraw from the study. Once eligible participants agreed to join the study, they were asked to give their consent to participate by checking appropriate boxes, signing, and dating at the bottom of the sheet to reinforce their verbal consent before being interviewed (Appendix C). I also signed the informed consent form, which was available in both English and Twi languages.

3.2.3   Anonymity and confidentiality

Due to the personal nature of qualitative research, anonymity and confidentiality present unique challenges. These were ensured in different stages. In the first stage, each participant was allocated a unique code so that any personal information collected could be held separately from the interview and demographic data. The second stage was to provide each participant with

a research pseudonym that would be used during transcription of the interviews. Also, other places, names, and immediately identifiable information were changed at the point of transcription. Transcription and early organisation of the data remained confidential. To protect the participants further, all raw data and all interpretations have been kept within the supervision team. Any data presented to an external audience will be removed from its individual and friend/family context to ensure anonymity of the members of the social network.

3.2.4   Data protection

All written information is secured in a locked filing cabinet in a locked office. The recorded interviews, transcripts, and field notes are kept in a securely locked cabinet. Digital files stored on a computer are password protected. Raw and coded data in the form of electronic files have been kept on the researcher's computer laptop with a security password and in electronic hardware at the University of Southampton. Only the researcher and his supervisors can access these data by using a security password. Data will be stored securely in the University of Southampton for ten years according to the University's policy.

3.3   Selection and location of participants

Different groups of participants were interviewed to contribute to the understanding of how women detected breast cancer symptoms, how they interpreted them, and the factors that impacted their decisions to seek medical help.

3.3.1   Selection of study sites

The research was conducted at two hospitals in Kumasi from where the total study population was recruited. As the Ashanti regional capital, and the second largest city of Ghana, Kumasi has a population of approximately two million people (World Fact Book 2014). One of the hospitals was a public facility and the other was privately managed. The Ministry of Health fully registered both hospitals. Hospital selection was determined by the criteria in Table 4. It was

anticipated that being the only two facilities offering specialised medical services in the northern half of the country, the majority of cancer patients who seek modern medical help in this vast area of the country would be seen at either of these selected sites.

Table 4 Inclusion criteria of the hospitals

Inclusion criteria	Description
Public hospital	It represented a typical public healthcare facility with a teaching hospital status
Private-for-profit hospital	Registered by the MoH but managed by a private entity
Hospital access	Practical reasons such as geographic access with transport links to facility
Hospital capability	Ability to assess, diagnose, and treat breast cancer

3.3.2   Participants and sample

Due to a lack of understanding of the relationships between different aspects of appraisal and help-seeking for breast cancer symptoms from the patient, members of their social networks, and the healthcare professional, it was expected that the collaborative explanations of the accounts from these different perspectives would help to gain insight into various aspects of the women's choice of healthcare. To answer the research question and increase scientific rigour of the study, different perspectives of the phenomena were requested from the participants. Figure 4 illustrates how the individual study groups are linked to the overall objectives of the study.

The importance of collecting information from close friends and family relations was because there are situations where the decision to seek medical help is led by someone other than the patient (Taib et al. 2011; O'Mahony et al. 2013). Granek et al. (2012) suggested that since the help-seeking trajectory of breast cancer includes the role of the healthcare professional, and the fact that the hospital may be the first place a woman goes to discuss breast related concerns, healthcare professionals are an especially important group from with

to elicit viewpoints on why patients may delay medical consultation. Regarding the social networks, since friends or family members are expected to be intimately involved with the patient's symptom experience, the social networks would be in a position to give their perspective of the patients' symptom experience.
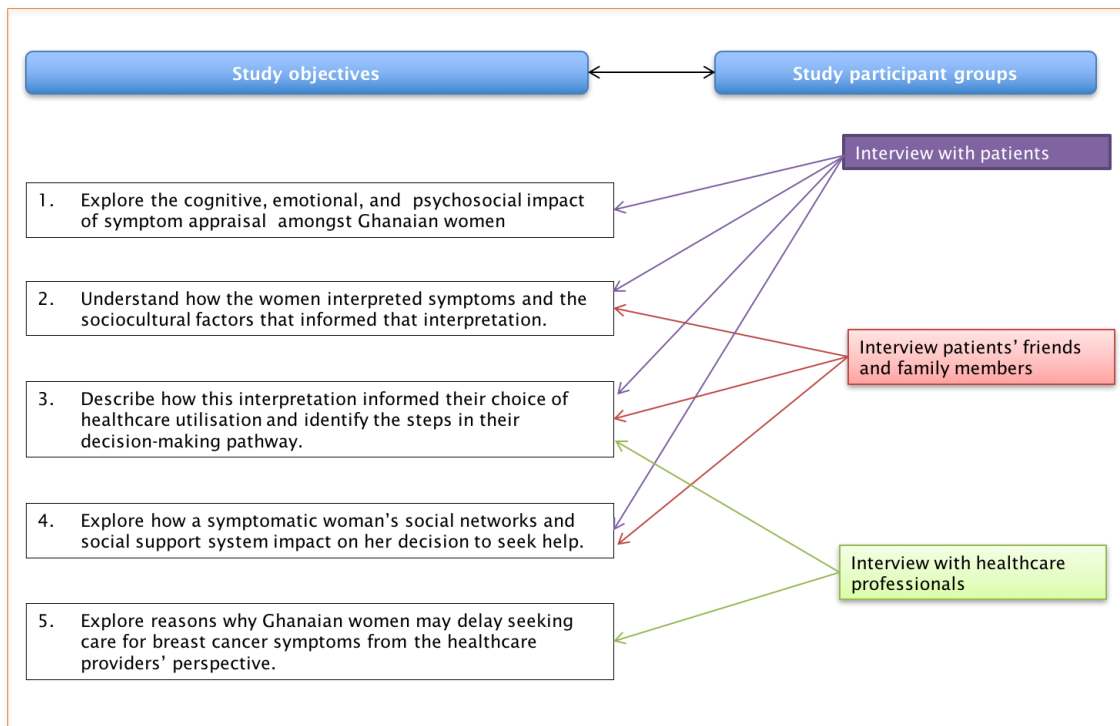
Figure 4 Linkage of study groups to research objectives

To reflect more on who to target for the interviews, purposive sampling was used to identify eligible patients to enrich the range of perspectives of experiences for the study. Purposive sampling is a deliberate and non-random identification of a group of people to ensure that all the key constituencies of relevance to the phenomenon being studied are covered (Ritchie & Lewis 2003). As a result, different age groups, diverse ethnic/racial backgrounds, the range of educational achievement, and socioeconomic status were considered during the recruitment process.

3.3.3   Access to participants

Access to symptomatic women was negotiated with the hospitals over a continuous period of contact with the clinic staff. Early discussion with the nursing directors' in charge of the clinics established the criteria of women

patients who would be eligible for inclusion in the study. After gaining permission to conduct the study, I proceeded to seek formal administrative approval from the respective directors of the outpatient clinics, by explaining the purpose of the research and asking for their help in identifying potential study participants. Access to participants was accomplished in the form of a letter to each of the nurses in charge of the clinics (see Appendix K).

I also arranged a follow up face-to-face meeting with the nurses in charge, to confirm their willingness to help with the patients' identification process. The nurse in charge at each study site agreed to serve as the central point of contact to supervise and share research information with the other staff nurses working at the out-patient clinics, where the actual recruitment of the women occurred. Patients who agreed to participate in the research suggested names of friends or relatives to be approached and invited to participate in the study. Access to the healthcare professionals was facilitated by obtaining the list of attending physicians and other clinicians, which was publicly available via each hospital's administration.

3.3.4   Identification and recruitment of patients

Upon arrival at the respective hospital, all patients must first report to the general outpatients' department for registration before they are redirected to the clinics. The clinics are headed by registered nurses who, by using the recruitment guidance sheet provided, were instrumental in identifying women with breast changes attending the clinic for the first time to me. This approach was adopted in order to minimise the potential for suspicion and mistrust of researchers that has been identified in previous research involving cancer patients. Then I described the study to the women, distributed a study information sheet, and invited them to participate after they had had the chance review the information sheet with the reply slip and to discuss it with their family. Since the women were most likely to return to the hospital for following up their investigations, I suggested at least 48 hours to allow them read and consider whether to participate in the study. They signalled if they were willing by submitting the return slip below the participant information sheet to me. Ultimately, I determined eligibility for recruiting into the study based on the criteria in Table 5.

Table 5 Symptomatic women inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Women 18-74 years	Women age below 18 or above 74 years
Self-detected symptom	Symptom detected through screening
No prior history of breast cancer	Previously diagnosed with breast cancer
First time clinic attendance	Returning patients for medical review purposes

The exclusion criteria were centred on removing eligible cases but ones that did not promise rich data, to ensure that women who have the greatest potential to share their experience on the phenomenon were identified. Although men can be affected by breast cancer, they account for only 1% of all cancer cases (Ying et al. 2005), and thus the study focused exclusively on women. Since the process of identifying the symptoms, interpreting the symptoms, and identifying what informed the decision to seek medical care, was central to this study, it was decided to exclude patients whose symptom was discovered by any other means than self-detection, as well as those patients who were previously diagnosed with breast cancer and had returned for a medical review.

After submitting the return slip indicating their willingness to participate in the study, I collected the patient's telephone number in order to set up an interview appointment later, if eligible. I contacted them within a week after receiving the return slip to check if they are still willing to participate and arrange a convenient time and place for the interview. Out of the 45 eligible patients, 38 agreed to be contacted. Eventually, 35 consented to be interviewed. Reasons for those who were eligible but declined to be interviewed, included problems with travelling out of town, spouse refusal, and not being interested.

The women who agreed to participate in the study were also asked to identify friends or relatives they would like to take part in the research. If the patients nominated them, the friends or relatives who accompanied the patient to the

clinic were invited by the researcher to join the study. Although every effort was made to recruit patients who could identify a friend or family member, those unable to identify anyone were not excluded from the research. Figure 5 provides a summary of the identification and recruitment process of patients for the study.
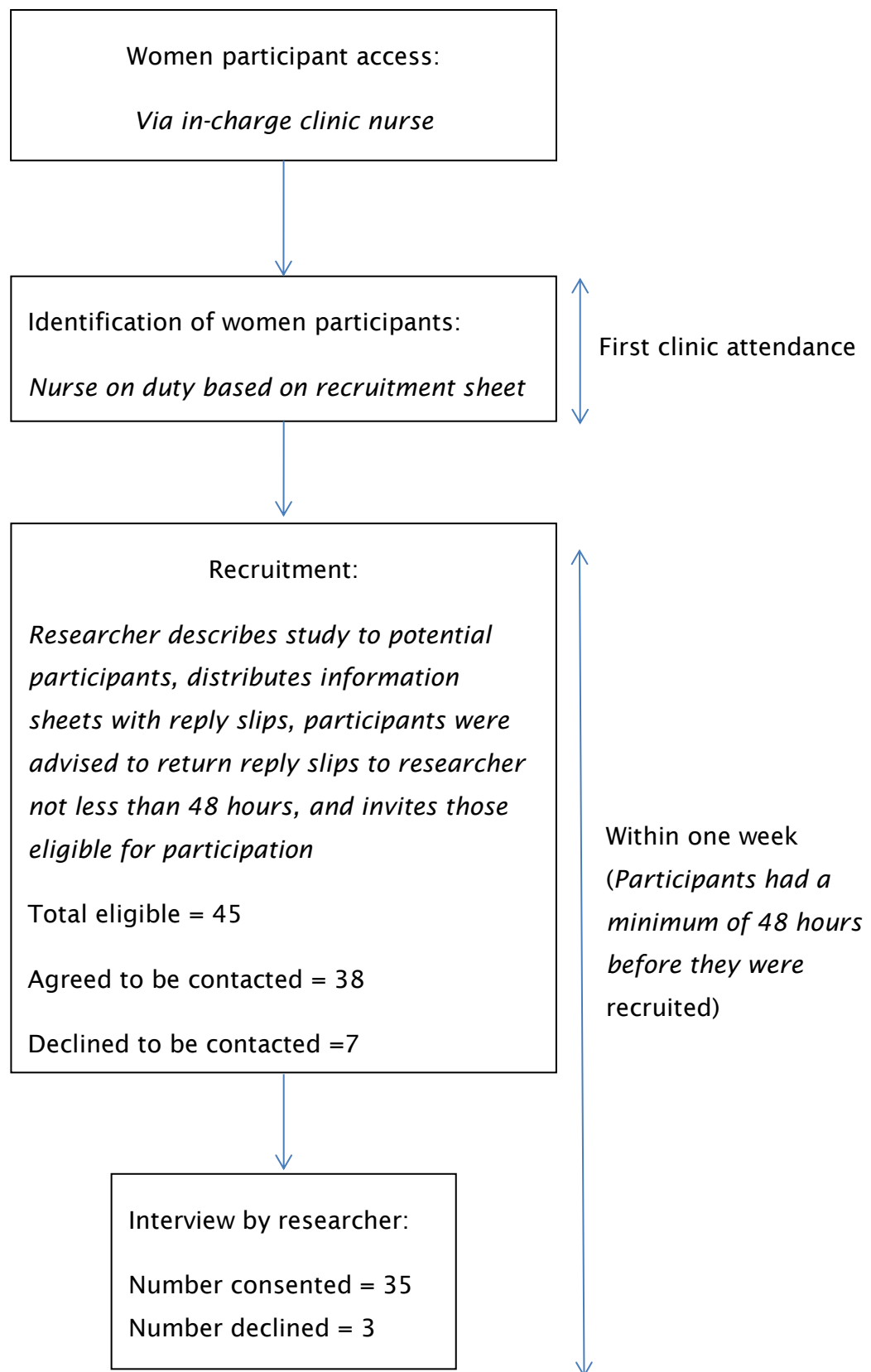
Figure 5 Identification and recruitment process of patients

3.3.5   Identification and recruitment of members of patients' social networks

Members of the patients' social networks, such as friends or family members, were eligible to participate in the research if they were above the age of eighteen years old and if they were suggested by a patient as being involved in her life at the time of symptom discovery and through the appraisal process. Such network members were included in the study, irrespective of whether the patients did or did not disclose their feelings to them. Upon agreement, I arranged to speak separately with the members of the social network suggested by the patient, to inform the members directly about the study and screen them for eligibility.

3.3.6   Identification of healthcare professionals

To identify the healthcare professionals, I obtained a list of physicians and other clinicians, which was publicly available from each hospital's administration. The eligibility criteria for healthcare professionals was that they must have been involved in breast cancer diagnosis and treatment with at least one woman, who presented three months or more after the onset of a breast cancer symptom, within the past two years. Separate letters were sent to the healthcare professionals at each study site outlining the purpose of the study and inviting them to participate. A follow up call and face-to-face meeting were used by the researcher to recruit those interested in joining the study. All but one of the fifteen healthcare professionals approached were eligible for the interview.

While this approach initially appeared to be successful, after recruiting eight healthcare professionals into the study, an outbreak of the Ebola virus in the West Africa region occurred. Although Ghana did not record any positive cases, the seriousness of Ebola placed the country on the highest emergency preparedness alert (WHO 2014). Due to their involvement in planning for the potential Ebola threat, the healthcare professionals were too busy to respond to the invitation to participate in this research. In trying to overcome this problem, another strategy was engaged by implementing the snowballing

approach. Snowballing sampling involves identifying potential participants by asking those already included in the study if they could identify individuals they anticipate would be able to give an opinion on the topic. Unfortunately, this recruitment strategy was unsuccessful and no additional participants in this group were recruited as a result.

3.4   Data collection

Data collection involves activities of gathering information for research purposes (Creswell 2003). In addition to the interviews, a reflective diary, and field notes were used to support the descriptions of the phenomena and information offered. Each participant was individually interviewed face-to-face at a convenient venue of their choice to obtain the desired information. Due to the difficulty in determining the sample size in qualitative research, the process of data collection continued until a saturation point was reached, after which no new information was added from any additional interviews. The interview was conducted in English with the participants who felt comfortable with this language, as the English language is used for all official means of communication in Ghana. Otherwise, Twi, the predominant Ghanaian dialect was utilised for those who were not fluent in English or those who preferred to be interviewed in the local language.

I was aware of my personal and professional experiences, cultural background, social position, and public health principles that could influence the questions being asked throughout the interview process. As a native of Ghana, I could relate to some of the potential issues addressed by the participants. Particularly, I was conscious about a potential situation in which being a male investigator, interviewing women on such a sensitive topic might be difficult for some patients to disclose to anyone other than her immediate family or medical practitioner. To deal with this situation, an alternative interview arrangement was put in place to address the sensitivity of this situation. Training two female nurses who were not involved in patient care management, and who were willing to volunteer for this study at no cost accomplished this. These nurses were recruited as assistant interviewers to conduct the interview alone with participants without the presence of the researcher in situations where a female participant may not be comfortable

with a male interviewer. The assistant interviewers were expected to follow all
other interview protocols such as audio recording and taking of field notes.

3.4.1   Completing the interviews

Once a participant had agreed to take part in the study, an appropriate date,
time, and place for the interview was decided. For some, this was in their
homes or workplace, as this was the most convenient for them, and for others
the interview was conducted at the dedicated office assigned to me. Lewis
(2003) stressed the importance of the environment for those participating in
an interview in order for the interviewee to feel confident, comfortable, and
able to concentrate. Such places include those that are private, quiet, and
physically comfortable so that the respondent is overwhelmed neither by the
researcher nor by the environment. When in their home or workplace,
participants control the environment, which helps them to feel more in control
and helps balance the power between the researcher and the participant (Lewis
2003).

At the interview, I discussed the study briefly and gave the participant the
opportunity to ask any questions. All participants were assured that taking part
was voluntary and that they could withdraw at any time. Additionally, I asked
whether they were happy with the interview being audio-recorded. If they
agreed, a small digital recorder was put between participant and me. They
were also informed that if at any time throughout the interview they would like
the recording to be stopped, they were just to inform me. The recorder was not
turned on until consent to record was given. All participants who agreed to
take part signed the consent form (Appendix C). All interviews were audio
recorded; otherwise, I would have discontinued the interview for those who
had not agreed to be recorded.

The interviews were conducted in such a way that allowed participants to talk
freely, enabling the researcher to explore specific areas of interest. To ensure
consistent and comparable data were obtained, using a loosely structured
format, each interview was guided by a set of questions and prompts,
providing a structure and consistency while allowing flexibility to the
participants to elaborate on their thoughts and feelings at each stage of the
process. I developed an interview guide for each participating group. The

study's objectives defined the topics, which were derived from the literature review. The interview guide for the patients is available in Appendix D. Although, I started by interviewing the patients, interviews of members of their social networks, and that of the healthcare professionals occurred concurrently.

During the interview, field notes were written in the field notebook. Field notes are records of observations made during or immediately after data collection (Corbin & Strauss 1998). The field notes helped me to remember the behaviours, activities, events, and other features of the settings being studied. Also field notes allowed me to gain more information about the phenomenon I was researching. Notes taken during data collection were primarily used for posing follow-up questions as part of the interview itself. However, those notes made after the interview were to describe the events that had taken place, were reflections on those events, and were to identify any particularly pertinent issues.

A reflective diary was also used to record my thoughts, emotions and feelings, and anything unexpected, surprising or unusual about the interactions during the fieldwork. Moreover, the critical issues that needed to be followed up, solved, discussed or organised were recorded. Thus, the reflective diary assisted the researcher in monitoring the research process. It was initially expected that the interviews would take approximately 45-60 minutes; however, in reality, the time needed ranged from 30-90 minutes. Although I planned to interview patients before a definite diagnosis for the symptoms had been offered, the participants were made aware that the subsequent diagnosis from their hospital records might be verified, if necessary, with their consent. At the end of each interview, the participants completed a structured demographic questionnaire. Subsequently, they were offered a summary of the main points discussed in order to safeguard accuracy from their own viewpoints.

3.4.2   Completing the demographic questionnaire

For this research, it was important to identify personal factors such as income, age, marital status, and educational achievement that may influence help-seeking. Therefore, a short self-completion structured questionnaire about

demographic data and other personal information was administered at the end of each interview (see Appendix E).

3.4.3   Support for participants

Participation in this research had no impact upon the treatment patients received and there were no invasive procedures involved. The participants giving a narrative of their personal experiences initially led interviews. Having participants recount their experiences through the interview process was emotionally laden for some, if not all. Therefore, the issues raised were dealt with sensitively. Although professional counsellors affiliated to the study sites were available, no situation reached a point where their services were needed by the respondents to address any emotional problems that arose.

The participants were reassured that they could stop the interview at any time and they could withdraw from the study entirely if they wished. Participants also had the option of choosing not to respond to a question if they found it uncomfortable or private. Furthermore, due to the length of the interview, participants were allowed to take a break if they felt tired or fatigued. The researcher, who has extensive experience with patients who have a chronic disease, conducted all the interviews.

3.4.4   Support for the researcher

I anticipated that interviewing participants would be personally difficult and therefore useful support mechanisms were put in place; however, I did not realise how much the respondents' experiences and lives would impact upon my own. Support mechanisms included regular emails to my supervisory team regarding how to address specific issues; regular reflection in a research diary was also helpful. The staff at the study sites also provided support, such as allowing me to use an office. While the interviews were quite challenging, especially in the middle of a potential Ebola outbreak in the country, the situation did not reach a point where the overall process was significantly disrupted.

3.4.5   Data collection summary

Face-to-face qualitative interviews, followed by a short structured demographic questionnaire, were used to collect data for the study. The interviews were chosen as a means of exploring in-depth individual accounts and the structured questionnaire provided a particular measure of each participant's demographics. Data collection occurred between April 2014 and October 2014.

3.5   Data analysis

The interviews, which were collected by the same method, produced high quality data. Having completed data collection from each of the participants at the study sites, I prepared a database to assemble the data from the three groups (patients, social network members, and healthcare professionals) in advance of data analysis. Qualitative data analysis involves the examination, categorisation, tabulation, and the combination of evidence to draw empirical conclusions, provided they are methodically appropriate (Boyatzis 1998). The thirty-five women, twenty seven members of the social network, and eight healthcare professionals were included in the analysis. The task of qualitative data management and analysis was robust and time consuming due to such processes involving transcription, coding, and time and effort to think about categories and themes. This section presents the stages of analysis of all interview data, which have generated the findings presented in Chapter 4.

3.5.1   Preparing the data for analysis

To make them more easily accessible and manageable, the raw data were divided into four parts in one database: the audio interviews, demographic questionnaire, field notes, and reflective diary. Putting the raw data into the study database involved two steps, the first of which was to turn the raw data into a format that was amenable for analysis (Lichtman 2012). To become familiar with the data, I transcribed it personally. Holloway and Wheeler (2013) recommended that transcribing the interviews personally allows the researcher to immerse themselves in the data.

Before transcription, I referenced each audio-recording file by assigning a unique code number. All audio files were transcribed verbatim by myself using

a transcription software called Transcribe! (SeventhString 2015). This software allows playback at variable speeds, fast forward, rewind, loop, word processing, and overall management of digital audio files. Alongside these transcripts, I also added my thoughts about the interview as well as any other relevant details. Where transcription was not possible due to interference on the tape, or if the dialogue was not audible, I re-listened to the tape to try and establish what was being said. Additionally, field notes about participant details were transferred into each interview. Although a word processing module was embedded in the transcription software, it was limited in text manipulation.

To facilitate the transcription process, I created a Microsoft Word document template, which was used for each participant's transcript to allow computerised storage and organisation of the data in a standardised way. The front page was set for recording the date, time, unique identification code, pseudonym, and location of the interview. See Figure 6 for an example of the front page and transcription page layout. Other relevant information on the first page included biographical data that was useful such as marital status, religion, age, and income.

Participant: Emily

Interview Group: Patients

Participant Code: 702_001

Interview Date: July 02, 2014

Time: 10:35AM – 11:37 AM

Location: Hospital Research Office

Biographical Details:

This is a 29 old single never married. Educated with a college degree. Observed lump two years ago but did not see it as a problem to see a doctor.

Time REF	Attendant	Transcript	Notes
60:07:50	SW	Good morning madam	
	Emily	Good morning sir.	
	SW	Have a seat here.	
	Emily	Thank you so much.	
	SW	I am so glad that we could meet today and talk about your health.	

Figure 6 Front page of transcription template

Additional pages were designed to incorporate a margin at both the left and right hand side for notes, indexing, and page numbers inserted in the footer (Holloway & Wheeler 2013). This protocol can be used as a form of indexing so that lines of text can be traced back to their origins within the data set. The transcription was written to represent the raw data as authentically as possible. Where appropriate, pauses, sighs, and emotional responses were included to ensure the original emphasis was not lost. To preserve the anonymity of the settings and participants, all references to names of places and persons were changed into pseudonyms.

The second step involved translation. Since some of the patients and their social networks preferred to be interviewed in the local language, the interviews conducted in Twi language had to be translated in order for me to be able to write my thesis in English. Translation refers to the transfer of meaning from a source language (in this instance Twi) to a target language (English) (Esposito 2001). The translation of qualitative transcripts raises many issues and difficulties, in particular because of a lack of availability of equivalent words or concepts and the different grammatical aspects of the two languages (Twinn 1997). In addition, the accuracy of translated data may also be influenced by errors made during translation, which are significant issues given their potential to influence the trustworthiness of the study and its findings.

To minimise errors and maintain trustworthiness of the study, Twinn (1998) recommended that transcripts should be analysed in the language in which the interview was conducted. However, this was not possible in this instance as the analysis had to be available in English in order to allow it to be scrutinised by the supervisors. As a result, all transcriptions from interviews conducted in Twi were translated into English and then the English version was used for data analysis. To maximise the consistency of the translated data, I translated all the data by myself (Twinn 1998). Ten of the patients' interviews and five of the social network interviews were conducted in Twi, and were then translated into English. Although the process was time consuming and challenging, engaging in it myself not only allowed me to demonstrate a clear audit trail from the original data, but was also a means of addressing the criterion of confirmability within this study (Tobin & Begley 2004).

The process of translation began with my reading of each transcript (in Twi) line-by-line. Sentences and paragraphs were then translated into English, word-for-word, to reflect the actual words used by the participants. During translation from Twi to English, I encountered the following problems. Firstly, there were many occasions when there were no equivalent words between the Twi and English languages. In such cases, I considered the context of the statement, rather than its literal meaning. In other cases, I developed a phrase to explain the sentence to make it understandable. Secondly, Twi proverbs were not easy to translate word-for-word. For example, one patient said that "okoto nwo anoma" literary meaning: "the crab does not give birth to a bird". In English it is similar to the apple does not fall far from the tree, which may not appear to have any particular meaning in English language. However, the patient used it in the context of describing how she had used traditional medicine as her mother had done before her, and that this was partly because she had inherited aspects of her mother's character.

To validate the accuracy of the translation and ensure that nothing was lost in translation, a back translation technique, the most commonly recommended procedure for translating research materials was employed (Behling & Law 2000). Esposito (2001) suggested that different researchers should check the accuracy of the translated data. To comply with this recommendation, the English transcriptions were checked and compared sentence–by-sentence with the original Twi transcriptions by an academic fluent in both Twi and English languages who was a former Ghanaian English teacher and PhD student in University of Southampton. During the process of checking for accuracy of translation, the translation checker suggested some changes to pronouns and tenses. Also, some English words were revised. The translation checker's conclusion was that the raw data, now translated into English, was an accurate representation of the original data gathered in the Twi language.

To manage large amounts of qualitative data in a systematic way, and to ensure efficient retrieval of that data, some computer-assisted qualitative data analysis software (CAQDAS) packages have been developed (Green & Thorogood 2009). Whilst such packages help to assist with the data analysis, they are not an alternative to a researcher's time, effort, and skills. Such software is viewed as a means of enhancing the rigour of qualitative studies

(Bazeley 2009), and can encourage proximity of the researcher with the data (Pope et al. 2000). For these reasons, NVivo™ 10 computer software package was utilised to facilitate data management, data retrieval, and analysis in this study.

Once a transcript had been finalised, I re-read all transcripts several times to further familiarise myself and to gain an overview of the information while making notes of initial thoughts, impressions, and potential themes identified. The first few interviews were summarised with my thoughts on the emerging themes and recorded in a notebook. After reading these early interviews, I developed a coding strategy to incorporate the areas of interest included in the topic guide with the new emerging themes. The coding strategy was reviewed after each interview and adapted to include emerging themes. See Appendix I for the coding strategy for patients' data.   Subsequent interviews and analysis took place side by side, allowing new and emergent themes to be incorporated into the interviews (Bryman 2012). To establish the most appropriate analytic strategy, I needed to consider the methods of qualitative data analysis.

3.5.2   Methods of analysing qualitative data

Since this study is built upon a qualitative research approach, and has collected data from interviews, the analytic process was guided by the nature and focus of the study to investigate issues, and to understand the phenomenon being studied. While there is a vast amount of literature that provides guidelines for undertaking qualitative data analysis, such as (Miles & Huberman 1994; Ritchie & Spencer 2002; Braun & Clarke 2006), each offers a different approach. This suggests that there is no one particular form of qualitative data analysis that is favoured above all others (Eisenhardt 1989). I therefore considered thematic analysis as the best strategy, which would allow me to analyse qualitative data in order to make sense of the data collected, and to present the findings from each interview so as to draw definite conclusions and generate new knowledge.

3.5.3   Thematic analysis

Thematic analysis, which is often used in qualitative research is one approach available to facilitate analysis of the development of themes or patterns within data. Braun and Clarke (2006) described thematic analysis as a method for

identifying, analysing, and reporting patterns within textual data. In addition to organising and describing datasets in detail, Boyatzis (1998) proposed that thematic analysis assists the researcher in the interpretation of various aspects of a research topic. Thematic analysis also aids the researcher to describe the phenomena being studied, and to condense the data, thereby giving rise to categories, or themes that are used to explain the phenomena. Themes add more weight to the voices and experiences of the individual, exemplifying the emic perspective of qualitative research, that of understanding the personal experience. Furthermore, the process of thematic analysis is flexible and has been detailed in various forms, for example by Miles and Huberman (1994) and Braun and Clarke (2006). Another significant benefit of utilising thematic analysis is its direct representation of an individual's point of view and descriptions of experiences, beliefs, and perceptions (Luborsky 1994). Ultimately, thematic analysis involves the search for and identification of common threads that extend across an entire interview or set of interviews (DeSantis & Ugarriza 2000).

While it is a widely used approach in analysing qualitative data, thematic analysis has been criticised by some researchers. Braun and Clarke (2006) suggested that what distinguishes thematic analysis from other approaches such as grounded theory or discourse analysis, is based on the fact that it is not devoted to any pre-existing theoretical framework. This 'theoretical freedom' indicates that thematic analysis is a more accessible form of analysis with the ability to be used with a wide variety of frameworks. In fact, Braun and Clarke (2006) clarifies that thematic analysis does not require the same detailed theoretical and technological knowledge of approaches, such as grounded theory and discourse analysis. Using thematic analysis assists with this study by providing clear links between themes and the aims of the study so as to guide the development of analytical claims. Therefore, the selection of thematic analysis lends itself to providing a rich thematic description of the entire data set. It is for these reasons that thematic analysis is recommended as a useful approach when exploring new or under-researched areas, across the whole social sciences including health.

Throughout the thematic analysis process, some interpretive decisions were made that influenced the final findings of the study. Data analysis was

conducted alongside data collection while identifying analytical themes and uncovering meaning from the informants' viewpoint, as those themes emerged from the data (Thomas 2006). Hence, the analysis was an inductive iterative process that commenced after the first interview; a process that proceeded through a series of steps described below, following the six-stage recursive process outlined by Braun and Clarke (2006). See Figure 7 for the thematic analysis process described by Braun and Clarke (2006).
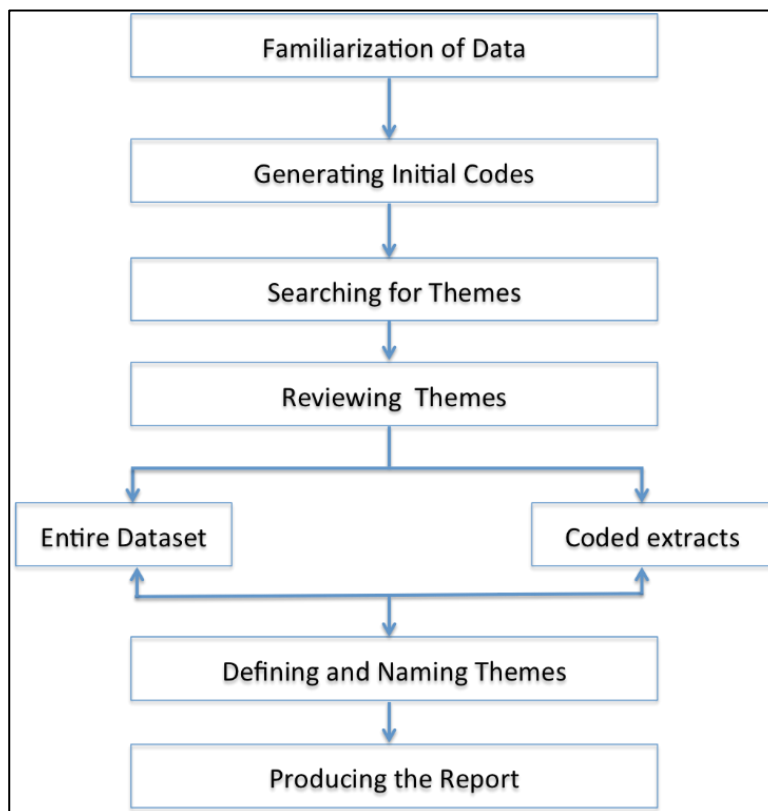
Figure 7 Thematic analysis process

These stages involved familiarising myself with data, generating initial codes, searching for themes, reviewing themes, defining and naming them, and producing the report. Inductive analysis holds that patterns, themes, and categories of analysis emerge from the data rather than being imposed before data collection and analysis (Srivastava & Hopwood 2009). The thematic analysis process involved developing a detailed understanding of events or phenomena based on concrete observations and paying careful attention to the meanings underlying lay constructs or terminologies. The data were then collated systematically into a matrix that facilitated an open and transparent account of the analysis undertaken.

3.5.4   Data analysis procedure for all participants

The data analysis involved information from the 35 patients, 27 members of the patients' social networks, and eight healthcare professionals. Using the same analytical steps below, I began with the patients' interview data in order to gain an understanding of the phenomenon of the appraisal and help-seeking among this particular group. This was followed by the data for members of the patient's social networks, and ended with the healthcare professionals. The process involved is detailed as follows:

Step 1: Familiarizing myself with the data

After finishing the processes of transcribing and translating the data, I had become familiar with the raw data through listening, repeated readings to gain an overview of the data, noting down initial ideas, and looking for early key ideas and potential meaning, as suggested by Braun and Clarke (2006). This initial step also involved sketching ideas, writing notes in the margins of the transcripts so that I could return to these at a later stage, and summarising field notes; these ideas are supported by Miles and Huberman (1994).

Becoming immersed in the data was also helped by constantly returning to the audio data to check the accuracy and appropriateness of what had been written as a representation of the account (Gibson & Brown 2009). This process also acted as a means of becoming further familiar with the data, and helped me not to lose sight of the individual's whole experience. This process also helped me to develop a general understanding of each dataset, by providing me with details of what patients said, what role the social network played, and the healthcare professionals' points of view about the phenomenon under investigation.

Step 2: Generating initial codes

The next step was to work through the transcripts to identify aspects of the accounts that were relevant to the research question, in order to move from description to a more conceptual level (Corbin & Strauss 1998). At this stage, codes were assigned to the transcript to identify where in the account this important aspect was. By definition:

> "*Codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes usually are attached to the "chunks" of varying size words phrases sentences, or whole paragraphs, connected or unconnected to a specific setting. They can take the form of a straightforward category label or a more complex one (e.g. metaphor)*" Miles and Huberman (1994: p.56).

The process of coding required that I read through the transcripts line-by-line, within given paragraphs and then reduced the selected data into one or two phrases by writing codes that were meaningful to me. Therefore, code words were written in the right hand margin of each data sheet, which had been analysed by using coloured pens, to indicate potential themes. An example of interview coding is presented in Table 6.

Table 6 Example of an interview coding

Data extract	First phase coding	Second phase coding
The only thing is that whenever I gave birth the breast swells and when it swells I just apply some of the man's herbal medicine on it and then it reduces so when I was saying that my breast was paining me my friend said that it maybe that because the breast was never sucked by a child that is why my breast milk that was supposed to come out did not and stayed inside till now that it's becoming a disease. (Akyea)	Using herbal medicine — Advice from friend	Preference for traditional healing — Influence of social network

To minimise any potential loss of meaning when coding, I also included data sections related to the codes so that the actual spoken words of participants, including complete sentences were maintained. I also read again any data that were not coded again to ensure that I had not missed any vital information (Coffey & Atkinson 1996). I generated an initial list of codes about the list of key issues, ideas, or themes that were emerging.

To develop codes that best fitted with the content of the segment of text, the code words were developed in two phases, as suggested by Bryman (2012). The first phase involved developing a basic code that emerged, more or less directly from a participant's words, or from my summary of what that participant seemed to be referring to. Following this, I continued to the second phase, which aimed to develop a code by re-reading the section of text related to the preliminary code. While some basic codes did fit with the segment of text, other codes did not, and were required to be changed to ones that are more appropriate. A schematic diagram of the coding process is presented in Figure 8.
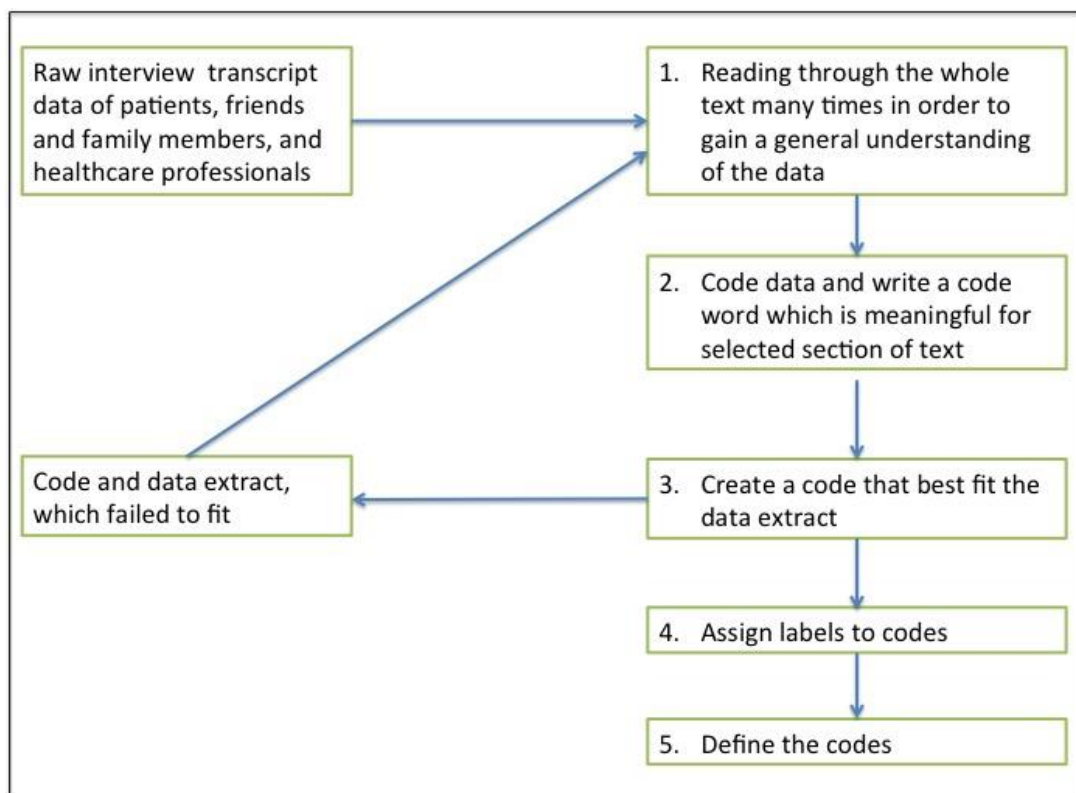
Figure 8 Coding process

A key complexity in the coding process was that I found it difficult to establish the term which best represented the actual meaning of the data within each segment of text. I had to read through the text several times to develop an accurate code. Another challenge was deciding what to code because to code everything can create too much information that may cause a reduction in decision quality, and to code too little would risk a superficial analysis (LaRossa 2005).

To address this potential problem, Miles and Huberman (1994) recommended that before commencing the coding process, it is useful to return to the research question and ask questions of the data that relate directly to it. Therefore from my primary question: How do sociocultural factors impact the interval between appraisal and help-seeking among women who self-discover breast cancer symptoms?, I came up with a series of questions such as 'What are the social factors?' 'What are the cultural factors?' 'What medical choices do patients have?' 'What names did patients give to their breast signs? A comprehensive list of factors is presented in Appendix J. Asking these questions during data analysis acted as a means of foregrounding certain issues without engaging an early interpretation of the texts.

To support coding and storing texts having the same codes of each transcription, the interviews were uploaded into NVivo 10 software, which was used with all the data, and across all participants (see Figure 9). Using the coding strategy developed (Appendix I), the transcripts were coded within NVivo as nodes and organised into emergent themes. Then I continued to read each transcription, line by line, to identify key words or meaningful concepts, which corresponded to the research question and aim of the study, generating initial codes in NVivo as free nodes.
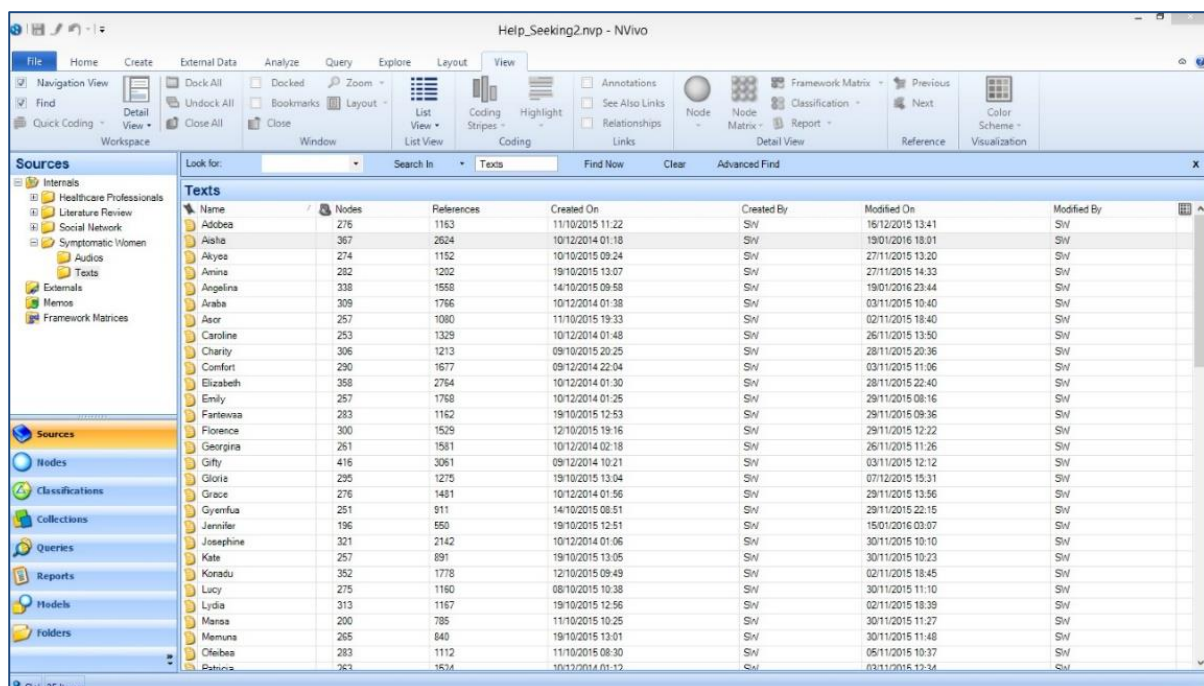
Figure 9 NVivo software with transcripts loaded

This process allowed me to code interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. Key words or concepts were then assigned codes or indexes to signify a particular segment through open coding, which allowed the key words to emerge from the raw data. At this point, I went straight into detailed coding, making nodes as needed; this was followed later by combining and grouping the nodes into related categories (Figure 10).
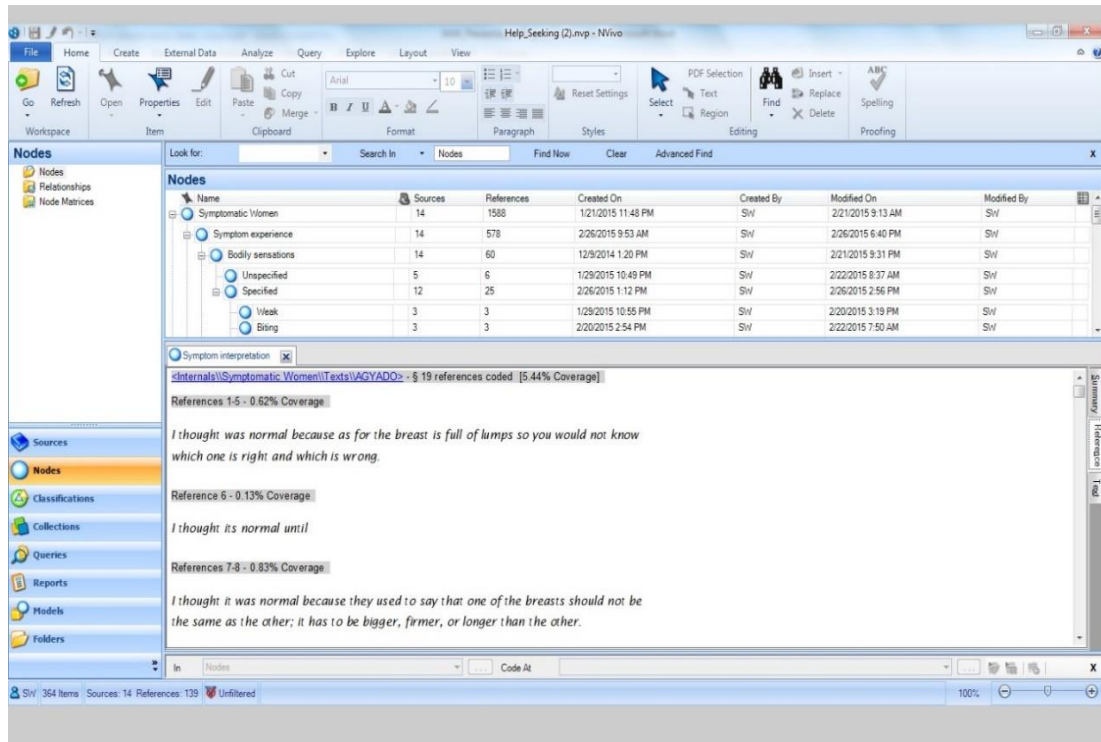
Figure 10 Coding in NVivo

The interviews provided a large amount of data; organising this initial coding into broad themes divided the data into more manageable sections that could then be further analysed. Information from the research diary was transferred to NVivo as a memo. Memos are ideas and thoughts about the data, reasons for patterns, and recording assumptions (Corbin & Strauss 1998). The research diary was maintained to enhance the trustworthiness of the final findings by recording an audit trial of the origins of any interpretations made (Creswell 2007).

It was possible to do further analysis within the NVivo software; however, at this stage a coding frame was developed for each node. The coding frame

facilitated the organisation and classification of data into emerging themes, while remaining close to the raw data and its meaning. To concentrate on the coding of all the qualitative data, I spent a total of eight months coding data collected from the 35 patients, the 27 members of the women's social networks, and eight healthcare professionals' interviews.

Step 3: Searching for themes

At this stage, a theme was generated by considering the meaning behind the codes and the emergent themes. All the open codes of the transcriptions were listed, sorted into potential themes, and all the relevant coded data extracts within the identified themes codes were collated. The theme was named and checked by considering the coded data extracts to ensure that the themes fitted with the coded data. I created a table to display the data and help sort the different codes into themes. Sorting the data by theme was done in a logical manner to enable data of similar content or properties to be collated with NVivo. While thinking about the relationships between codes, themes, and different levels of themes, the table was gradually refined to reduce overlapping and redundancy among the categories of codes. As new themes emerged from the data, I reviewed the coded transcripts to ensure that no relevant data were overlooked. Table 7 presents initial themes and codes for patients.

Table 7 Initial themes from patients' data

Theme	Category/Code
1. Symptom experience	Symptom variation Nature of symptoms (pain, non-pain) • Symptom type (lump, enlarged breast, discharge) • No lump Attribution • Minimise seriousness • Normal Recognition • Low perceived risk

Theme	Category/Code
2. Knowledge	No knowledge • Symptoms • Treatment Incorrect knowledge or beliefs • Not a hospital disease • Misunderstanding about the cause of breast cancer • No survivors
3. Emotional reaction	Fear of • Death from surgery • Blame or stigma • Spousal abandonment • Reduced womanhood • Side effect of chemotherapy
4. Cultural	• Patriarchy and deference • Evil spirits cause cancer • Preference for traditional medicine • Religiosity
5. Social network	• Protecting family (keeping secrets) • Sanctioning help-seeking • Taking action on patient's behalf • Inadequate social support
6. Healthcare services	• Perceived quality • Accessibility and availability • Financial limitations • Unfriendly attitudes of HCPs

Step 4: Reviewing themes

Following the previous step, on numerous occasions I returned to further reviewing and refining the initial themes generated with the entire data sets, until I was satisfied that the themes signified the meaning evident in the

interviews. Further refinement allowed themes to be presented in a more organised hierarchy, with the grouping of broad themes under those considered to be the main themes. A theme was generated by considering the meaning behind the codes and the sub-themes. The theme was named and checked, by considering the coded data extracts, to ensure that the themes fitted with coded data and the initial thematic maps of data analysis were gradually refined. The outcome of this refinement process can be seen in the thematic map presented in Figure 11.
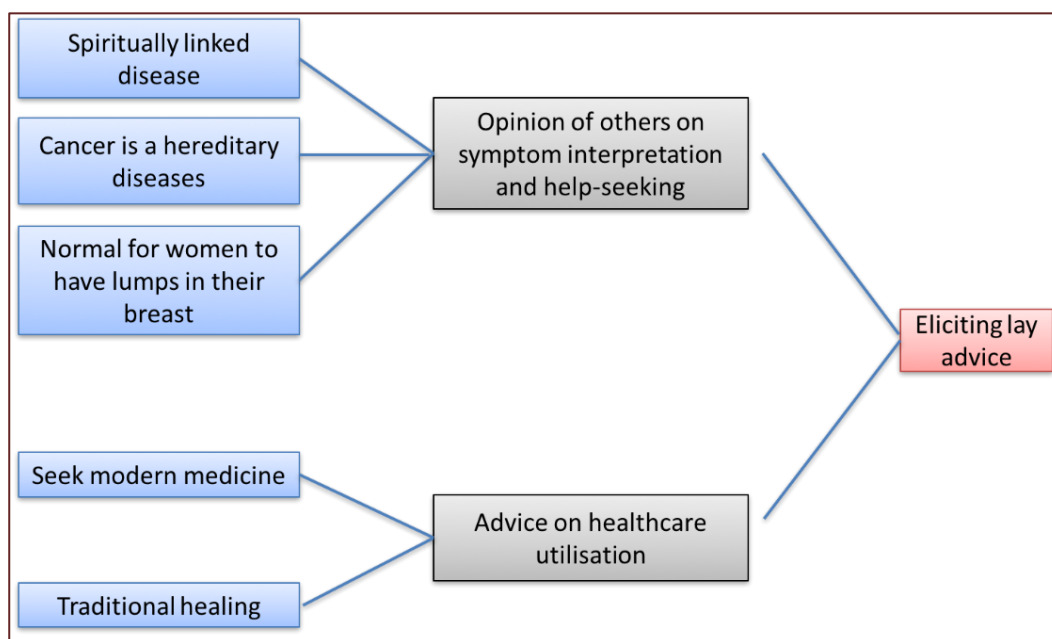
Figure 11 Thematic map showing eliciting lay advice theme

Step 5: Defining and naming themes

Following the previous step, I looked through the thematic maps to gain a broad view or conceptualisation of what is seen in the data. Ongoing analysis continued to refine the specifics of each theme, and the overall story the analysis tells. If necessary, similar themes were grouped to create the new categories. On completing the final thematic map for each group, I proceeded to the next stage in order to produce the report of the analysis.

Step 6: Producing the report

This stage is the presentation of the analysis by relating it to the research question and literature, and ultimately producing a scholarly report of the findings. The coding strategy for patients involved four themes with thirteen

sub-themes; three themes with eight sub-themes for the patients' social networks, and four themes with eleven sub-themes were identified for the healthcare professionals producing intricate thematic maps.

3.6   Quality of the research

Maintaining rigour and quality is a significant component of research (Tobin & Begley 2004). However, in qualitative research trustworthiness has been identified as an important concept for establishing rigour; it relates to truth-value, applicability, consistency, and neutrality (Guba & Lincoln 1994). In pursuit of trustworthiness within this study, I complied with certain criteria and developed key techniques to meet those across all phases of the study. Major criteria for ensuring trustworthiness, which comprised credibility, dependability, confirmability, and transferability, were applied (Guba & Lincoln 1994; Ryan-Nicholls & Will 2009). Each criterion, and the techniques employed to establish trustworthiness, are now presented.

3.6.1   Credibility

Credibility addresses the issue of 'fit' between participants' views and the researcher's representation of them (Schwandt 2007). It further describes the extent to which research findings represent accurate interpretation of the original data (Ryan-Nicholls & Will 2009), and poses the question of whether the findings faithfully reflect the phenomena being studied, as perceived by the participants (Ritchie & Lewis 2003). Within the current study, three strategies were adopted to demonstrate credibility at different stages. These included; a) peer scrutiny by supervisors and fellow postgraduate students, b) prolonged engagement and extensive observation in the field, and c) respondent validation or member checking.

Credibility and methodological rigour were enhanced through peer review of the study protocol prior to commencement of the study. The revised protocol was subsequently approved by the University of Southampton's Ethics Committee to ensure that the study was ethically conducted. Ethical approval was also gained from both study hospitals in Ghana. To mediate researcher bias in the interpretation of study findings, these were subjected to review with

supervisors who were able to challenge the analysis. Additionally, preliminary findings of the study were presented to fellow postgraduate students who were undertaking similar research. Suggestions and critiques gained helped to further refine the conclusions that had been drawn.

Another strategy of credibility occured through prolonged engagement with study institutions and participants. The multiple trips to Ghana and collaboration with the Ghana Breast Health Study (GBHS 2013), facilitated adequate understanding of the healthcare system, and established a relationship of trust necessary to overcome the difficulties in acquisition of permission from the respective institutions to conduct the research. Moreover, I spent six months in the Kumasi area while collecting data. The prolonged involvement allowed time to contact the participants individually, which enabled them to become familiar with my presence, and enhanced the identification of any potential discrepancies between the meanings presumed by the researcher and those understood by the participants. Since I was fully immersed in the interviews seeking a deeper meaning of the phenomenon being investigated, my shared language and culture with the participants lent further depth to the interpretation of their help-seeking experience.

Respondent validation or member checking, as recommended by Ritchie and Lewis (2003), is a further strategy used to heighten credibility. This involved gaining feedback from participants to determine whether the researcher's account mirrored participants' perceptions of the phenomena being studied. While some researchers view respondent validation as a useful attempt to maintain a study's credibility, others have questioned whether it is always an appropriate method of assessing validity of a finding from a qualitative study (Long & Johnson 2000; Mays & Pope 2000). For example, Long and Johnson (2000) argue that if validation is to be undertaken more than two years after a study, the time lapse is unlikely to be sufficient to demonstrate stability of findings in a meaningful way. In those instances, there would be considerable problems associated with such an attempt, particularly, participant morbidity, lack of access, and change of the participants' situation and views (Mason 2002). Given the dearth of standards against which to test validity in qualitative research findings, Long and Johnson (2000) support cautious use of respondent validation.

Since member checking may take place instantly in the course, and at the end, of data collection (Shenton 2004), two strategies were employed to seek feedback from participants within this study. First, all participants were offered a summary of the main points discussed at the end of their interview in order to establish their own perspectives. Second, three months after data collection have been completed, the researcher travelled back to Ghana to meet five of the participants who were interviewed, and shared a summary of the preliminary findings with them to verify if they considered the findings to be a reasonable account of their experience. Checking with participants ensured that the research findings were developed from the data that came from the viewpoints of participants (Tobin & Begley 2004), rather than from my points of view. This approach not only provided an opportunity for participants to confirm or refute the researcher's interpretation, it helped to reduce error in reporting findings, and preserved the relationship that had been established (Silverman 2013).

3.6.2   Dependability and confirmability

Dependability emphasizes the need for the researcher to account for the ever-changing context within which research occurs. This entails that the research findings would be deemed consistent and trustworthy, if other researchers examined the data collected and established similar findings (Murphy et al. 1998). Subsequently, confirmability refers to the degree to which the findings of research could be confirmed or corroborated by other external researchers (Guba & Lincoln 1994). Since confirmability involves the extent of consensus in relation to the findings, processes used in research should be sufficiently transparent so that others can evaluate its quality. The close association between dependability and confirmability has resulted in some strategies that are capable of addressing both criteria.

Three specific techniques were employed to meet the criteria of dependability and confirmability. First, an audit trail that provides a detailed description of the research process from the beginning of the study through to its conclusion was developed (Tobin & Begley 2004). This log of activities allows an observer to trace the course of the research step-by-step via the decisions made and procedures described. Field notes and a reflective diary were kept and they

provided a source of contextual data that assisted in the monitoring of the research process. Second, the detailed description of methods of data collection, together with the process of data analysis, are made clear in this chapter to determine how far the data and constructs emerging from them, may be examined by other researchers. Additionally, the key decisions made throughout the research have been explicit, so that other researchers can review the quality of the research. Such in-depth description of the research design allows the reader to assess the extent to which appropriate research practices have been followed.

Third, as indicated previously, the study was conducted using three different participant groups and data were gained from two sites. Integration of findings from the three participating groups was accomplished through thematic synthesis (Thomas & Harden 2008), to confirm and ensure that findings were corroborated and expanded from the data; the meanings were not overlooked, and data interpretation was consistent with the data collected. Extracts from the interviews and key documents have been included to provide evidence for the conclusions reached.

3.6.3   Transferability

Transferability refers to the extent to which findings of one study may be applied to other contexts or groups (Murphy et al. 1998). Since the findings of qualitative research are specific to the particular environments and the individuals involved, the issues of representativeness and generalisability, to other situations and populations, are problematic (Shenton 2004; Ryan-Nicholls & Will 2009). Thus, any attempt to apply findings from a qualitative study to the general population requires caution. Careful description of the process, findings and conclusions reached can enhance transferability. Considerable detail regarding all aspects of the research along with the findings and conclusions have been presented to allow readers to develop their own understanding of the insights generated. This facilitates comparison with other settings (Holloway & Wheeler 2013).

3.7   Chapter summary

This chapter has presented the methodology and methods used for the study, which has been designed to gain an in-depth understanding of symptom appraisal and help-seeking behaviour among Ghanaian women who self-identified breast cancer symptoms. The understanding of phenomenon under study goes beyond the patient, expanding to the viewpoint of members of the patients' social networks and also of healthcare professionals. Interpretivism is used to understand the context and interpret what was shaped by the participants' experience. Details about the population, sampling, data collection procedures, and ethical considerations were all addressed. Procedures for data management and analysis were described.

Two hospitals in Kumasi were selected, from which participants were recruited. Semi-structured interviews and a questionnaire were the main methods of data collection, while field notes and a reflective diary served as supportive data. The choice of interviews for information gathering allowed the participants the opportunity to discuss their experiences as they recalled them, to feel comfortable telling them, and to talk about what was important to them. Possible anticipated hurdles when interviewing the women, such as their resistance to discuss sensitive issues, or with a male interviewer, were unfounded. Data from interviews were analysed using thematic analysis. The computer software package NVivo 10 was used to aid data management and analysis. To ensure rigour and quality of this study, the importance of trustworthiness was identified and applied. The findings of the study are presented in Chapter 4.

Chapter 4:   Findings

As explained in Chapter 3, interviews were undertaken to explore perspectives on factors influencing patients' help-seeking behaviour. This chapter presents the findings of these interviews from the different sources, that is patients with breast cancer symptoms, their friends and family members, and healthcare professionals. In each of the sections 4.1, 4.2, and 4.3, there are two parts: contextual information on the study participants followed by a description of themes and sub-themes. To protect the identity of the participants, pseudonyms have been used. Finally, the fourth section (4.4) presents an integration of findings from interviews with all three sample groups to provide a full picture from all perspectives of how factors influence delayed presentation of breast cancer symptoms in Ghanaian women.

4.1   Findings from interviews with patients

This section presents the findings from patients who identified unusual breast disease symptoms themselves and then presented at a hospital for medical evaluation.

4.1.1   Characteristics of the patients

The patient respondents were 35 Ghanaian women from a variety of backgrounds who met the inclusion criteria and were happy to take part in the study. They came from eight of the ten administrative regions of Ghana (Figure 13), representing a large area of the country (see Table 8 for detailed characteristics of the patients). Additionally, Table 9 presents a summary of the individual characteristics of patient participants. Although some still lived in their village of family origin, others had moved to cities when they became sick. Although the patients' ages ranged from between 18 and 70 years, nearly two-thirds (n=23) of the sample were between 25 and 54, with approximately a quarter (n=9) aged 55 and over. Though mostly Christian (n=30), four patients were Muslim, and one patient had no religious affiliation. Approximately a third of the patients (n=14) had no formal education, 4 of the 35 attained only primary level education, and just over a quarter (n=8) completed secondary school education. Fifteen of the patients were married, four were divorced, seven had never married and seven were widowed. Two-thirds (22 of the 35) patients were self-employed and were involved in either small scale trading or peasant farming activities; the others

constituted full-time employees, students, and retirees. Almost a third (n=11) earned less than 100 cedis (approximately 20 GBP) a month. Thirty patients (86%) delayed for more than three months between when they identified suspicious symptoms of breast cancer and when they presented themselves to a healthcare professional for the first time. The median patient interval was 24 months. A breast lump without pain was the most commonly reported symptom among the patients, accounting for 80% (n=28) of all the symptoms presented.
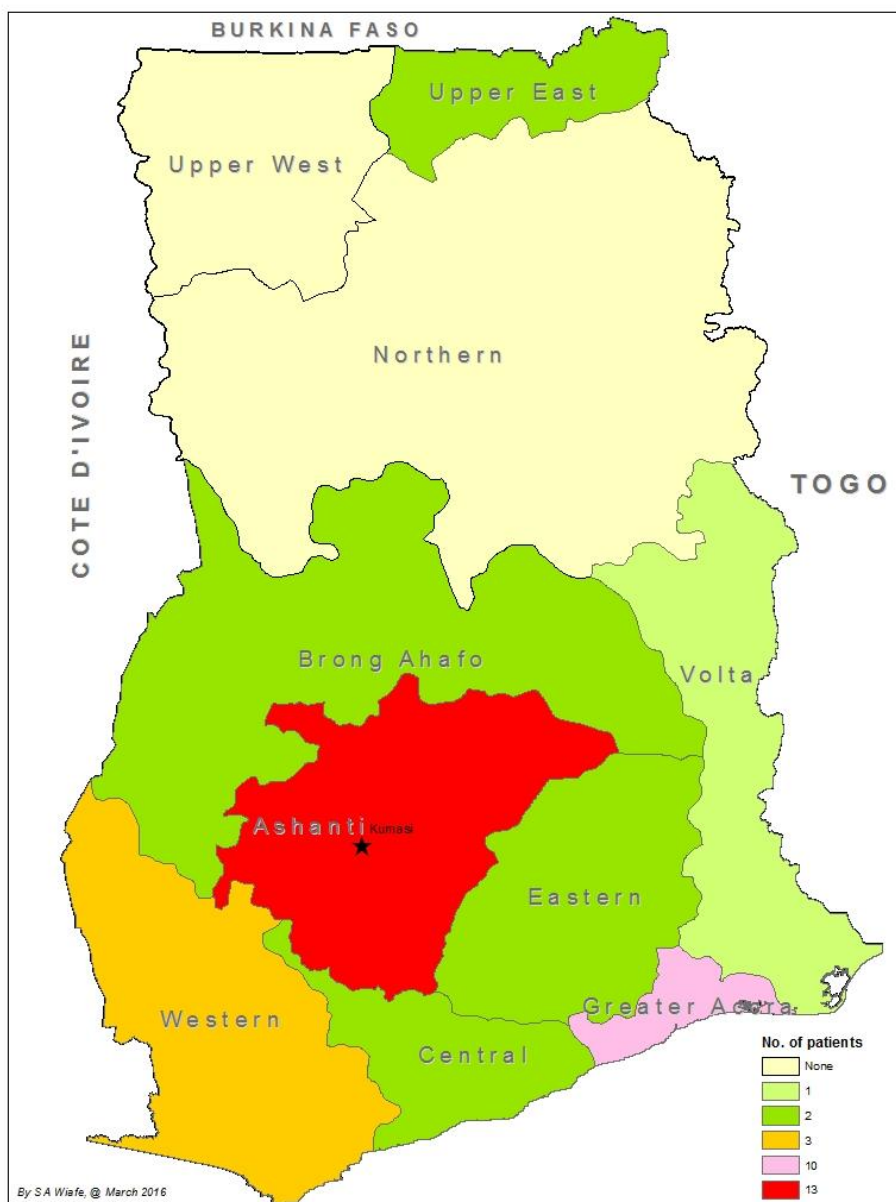
Figure 12 Geographic representation of patient participants

Table 8 Characteristics of patients

Characteristics	n (%)
Education level	
No formal education	14 (40.0)
Tertiary education	9 (25.7)
Secondary school	8 (22.9)
Primary school	4 (11.4)
Relationship status	
Married	15 (42.9)
Never married	7 (20.0)
Widowed	7 (20.0)
Divorced	4 (11.4)
Separated	2 (5.7)
Monthly income (GHS)	
Less than 100	11 (31.4)
100-200	8 (22.9)
201-400	5 (14.3)
401-600	4 (11.4)
601-800	2 (5.7)
801- 1000	2 (5.7)
More than 1000	3 (8.6)
Religion	
Christian	30 (85.7)
Muslim	4 (11.4)
No religion	1 (2.9)
Time to presentation	
0-1 month	2 (5.7)
2-3 months	3 (8.6)
Over 3 months	30 (85.7)
Median (months)	24 (1-50)
Pathology report	
Malignant	29 (82.9)
Benign	6 (17.1)

Characteristics	n (%)
Region	
Ashanti	13 (37.1)
Greater Accra	10 (28.6)
Western	3 (8.6)
Eastern	2 (5.7)
Upper East	2 (5.7)
Brong Ahafo	2 (5.7)
Central	2 (5.7)
Volta	1 (2.9)
Ethnicity	
Akan	20 (57.1)
Ga-Adangbe	7 (20.0)
Mole	4 (11.4)
Ewe	3 (8.6)
Other	1 (2.9)
Employment	
Self-employed	22 (62.9)
Other (retired, student)	7 (20.0)
Full time	5 (14.3)
Part time	1 (2.9)
Age	
18-24	3 (8.6)
25-34	5 (14.3)
35-44	5 (14.3)
45-54	13 (37.1)
55-64	5 (14.3)
More than 65	4 (11.4)
Nature of symptom	
Painless lump	28 (80.0)
Lump with pain	3 (8.6)
Others (nipple discharge, inverted nipple, peau d'orange)	4 (11.4)

Table 9 Summary of individual patient characteristics

Pseudonym	Ethnicity	Age	Relationship status	Region	Religion	Education level	Employment	Income (GHS)	Time to presentation (months)	Pathology report	Nature of Symptom
Adobea	Ga-Adangbe	70	Married	Greater Accra	Christian	No formal edu	Self-employed	>1000	30	Malignant	Painless lump
Aisha	Mole	52	Widowed	Upper East	Christian	Primary	Self-employed	<100	36	Malignant	Painless lump
Akyea	Akan	70	Widowed	Ashanti	Christian	No formal edu	Retired	<100	36	Malignant	Painless lump
Amina	Other	50	Married	Ashanti	Muslim	No formal edu	Self-employed	<100	25	Malignant	Painless lump
Angelina	Akan	26	Never married	Greater Accra	Christian	Tertiary	Full time	801-1000	28	Malignant	Painless lump
Araba	Ewe	44	Never married	Greater Accra	Christian	Tertiary	Self-employed	201-400	3	Malignant	Painless lump
Asor	Akan	47	Divorced	Western	Christian	No formal edu	Self-employed	<100	25	Malignant	Painless lump
Caroline	Akan	50	Married	Western	None	Secondary	Full time	601-800	1	Benign	Lump with pain
Charity	Ga-Adangbe	51	Married	Greater Accra	Christian	Primary	Self-employed	201-400	35	Malignant	Painless lump
Comfort	Akan	45	Married	Ashanti	Christian	No formal edu	Full time	100-200	57	Malignant	Painless lump
Elizabeth	Akan	46	Divorced	Ashanti	Christian	Primary	Self-employed	401-600	24	Malignant	Painless lump
Emily	Ga-Adangbe	29	Never married	Greater Accra	Christian	Tertiary	Part time	100-200	1	Benign	Lump with pain
Fantewaa	Akan	34	Married	Western	Christian	Secondary	Self-employed	201-400	10	Malignant	Painless lump
Florence	Akan	60	Widowed	Ashanti	Christian	No formal edu	Self-employed	100-200	18	Malignant	Painless lump
Georgina	Akan	46	Married	Eastern	Christian	Primary	Self-employed	100-200	24	Malignant	Painless lump
Gifty	Ewe	48	Separated	Volta	Muslim	Secondary	Full time	201-400	30	Malignant	Painless lump
Gloria	Akan	45	Married	Greater Accra	Christian	No formal edu	Self-employed	100-200	60	Malignant	Painless lump
Grace	Mole	66	Widowed	Upper East	Muslim	No formal edu	Retired	100-200	15	Malignant	Painless lump
Gyemfua	Akan	57	Widowed	Ashanti	Christian	No formal edu	Self-employed	<100	13	Malignant	Painless lump
Jennifer	Ga-Adangbe	34	Married	Greater Accra	Christian	Tertiary	Self-employed	<100	3	Malignant	Painless lump

Pseudonym	Ethnicity	Age	Relationship status	Region	Religion	Education level	Employment	Income (GHS)	Time to presentation (months)	Pathology report	Nature of Symptom
Josephine	Akan	43	Married	Ashanti	Christian	Secondary	Self-employed	401-600	12	Malignant	Painless lump
Kate	Akan	54	Divorced	Ashanti	Christian	Tertiary	Self-employed	801-1000	2	Benign	Lump with pain
Konadu	Akan	38	Married	Central	Christian	Tertiary	Full time	>1000	18	Malignant	Nipple discharge
Lucy	Ga-Adangbe	67	Separated	Eastern	Christian	Tertiary	Retired	201-400	18	Malignant	Painless lump
Lydia	Akan	35	Widowed	Ashanti	Christian	Secondary	Self-employed	601-800	24	Malignant	Painless lump
Mansa	Akan	55	Married	Central	Christian	No formal edu	Self-employed	<100	10	Malignant	Painless lump
Memuna	Mole	60	Married	Ashanti	Christian	No formal edu	Self-employed	401-600	6	Malignant	Painless lump
Ofeibea	Akan	46	Married	Brong Ahafo	Christian	No formal edu	Self-employed	100-200	20	Malignant	Painless lump
Patricia	Ewe	22	Never married	Greater Accra	Christian	Secondary	Student	<100	24	Malignant	Painless lump
Pauline	Akan	23	Never married	Ashanti	Christian	Tertiary	Student	<100	84	Benign	Nipple discharge
Rita	Ga-Adangbe	28	Never married	Greater Accra	Christian	Secondary	Student	<100	23	Malignant	Inverted nipple
Salamatu	Mole	60	Widowed	Ashanti	Muslim	No formal edu	Self-employed	100-200	24	Malignant	Painless lump
Salomey	Ga-Adangbe	18	Never married	Greater Accra	Christian	Secondary	Student	<100	48	Benign	Painless lump
Sarah	Akan	48	Divorced	Brong Ahafo	Christian	Tertiary	Self-employed	>1000	36	Malignant	Peau d'orange
Vivian	Akan	40	Married	Ashanti	Christian	No formal edu	Self-employed	401-600	30	Benign	Painless lump

4.1.2   Themes and sub-themes for patients

Four main themes, with thirteen sub-themes, were generated to describe reasons the patients did not seek medical help sooner than they actually did, after they discovered the changes in their breast. Each theme and sub-theme, as shown in Table 10, will be presented separately.

Table 10 Themes and sub-themes in patients

Themes	Sub-themes
1. Cultural beliefs and practices	1.1. Patriarchy and deference 1.2. Perception of cancer link to evil spirits 1.3. Religiosity 1.4. Patient's preference for traditional medicine
2. Trust in the modern healthcare system	2.1. Accessibility and availability 2.2. Previous experiences with healthcare professionals 2.3. Financial limitations
3. Emotional reactions to symptoms	3.1. Fear of death from surgery and side effects of chemotherapy 3.2. Fear of social stigmatisation 3.3. Fear of spousal rejection 3.4. Fear of diminished womanhood
4. Eliciting lay advice	4.1. Opinion of others on symptom interpretation and help-seeking 4.2. Advice on healthcare utilisation

4.1.3   Theme 1: Cultural beliefs and practices

Cultural beliefs and practices featured prominently in the patients' interviews as factors that mostly led to a delay in seeking medical attention. Those cultural beliefs and practices that prolonged the interval, between the first appearance of symptoms and the first visit to hospital, include patriarchy and deference, the perception of cancer link to evil spirits, religiosity, and each patient's preference for traditional medicine.

Patriarchy and deference

The decisions and actions of people with authority in the patients' lives impacted on the patients' ability to seek medical help for their symptoms. Just under a third (n=6) of the married patients had delayed treatment as a consequence of the influence of a husband and his power and willingness to limit financial support.

The patients discussed how the authoritarian attitude of their husbands meant the men were unprepared to listen to their wives' concerns. To illustrate this point, one patient reported how her husband ignored her pleas for help:

> *"I was always telling my husband if he could feel it [the lump] and he would say, 'you are always saying can you feel this? Can you feel this?' He did not even bother to know what I was talking about, he would brush it off and not discuss it any further. If he had paid attention to what I wanted to show him, I would have come earlier"* (Konadu).

Similarly, some married patients described how their husband regarded them as "property" because as wives they have little personal autonomy in the family. Traditionally, some wives refer to the husband as a "lord", indicating their obedience and submission to him. The following illustrates constraints on the autonomy of women:

> *"When we met with the doctor, he also told my lord that the way my breast was developing, he would have to cut it off. He [my husband] did not tell the doctor that he was not in favour at that time, but when we went home, he told me that he would not agree to the surgery because he was afraid. So that was when we decided to go the traditional treatment way"* (Gloria).

Some patients had adequate moral support from their spouses, who encouraged them to seek modern medical treatment.

One patient describes the expression of a husband's support for medical treatment:

> *"My husband knew about the problem the day I felt it, I told him and he said I should take it to the hospital. However, because he had travelled to his workplace, I had to wait for him to come to support me"* (Caroline).

Perception of cancer links to evil spirits

The majority (n=20) of the patients strongly believed in the power of evil spirits as the cause of breast cancer. They presumed that evil spirits regarding witchcraft activities are the cause of the disease symptoms; various explanations of signs of breast disease and its manifestations as a spiritual discourse (interruption in the relationship between the individual and the spirit world), a curse on the family, or as a fault of the afflicted individual, were offered. This sub-theme describes how the patients' belief in evil spirits as the cause of breast cancer, delayed modern medical help-seeking.

Some of the patients believed that spirits have invisible eyes and minds that they can use to destroy an individual, especially if they hear the problem from someone else. This notion motivates patients to keep their symptoma secret and to seek a spiritual solution:

> *"What I want to say is that we should not publicize these breast problems too much even when looking for an appropriate solution. You see in this world, we are different and everyone thinks differently. Some people have an ancestral spirit that they use to worsen the situation if they get to hear from you"* (Sarah).

Other patients regarded breast disease as a result of disruption in the relationship between the individual and the spirit world. One patient described the importance of keeping the symptoms as a secret:

> *"Breast disease is a disease that evil spirits too can associate with, so if you get it you just have to be quiet about it and be searching for some treatment spiritually"* (Charity).

In addition, some patients believed that spiritual attacks on the breast are consequences of specific actions or inactions taken by the patient, resulting in the development of the symptoms.

One young patient, who thought that her sexual immorality worsened her symptoms, said:

> *"When I started with the herbal medicine, there was an improvement, ok. But the traditional healer told me that I should not sleep with any man while receiving treatment because, in the spirit world, the spirits work with only one blood, they can't work with two types of blood. This means that if I sleep*

with any male partner blood gets mixed up. Unfortunately, I could not avoid sleeping with my boyfriend, therefore, the herbalist stopped the treatment and my symptom became worse" (Patricia)*.*

The patients also thought that breast cancer was caused by an attack induced by a malevolent person through supernatural powers. Therefore, if somebody intended to destroy the patient's life, a spiritualist may help to protect the individual. One patient demonstrated how she linked her breast problem to a curse on the family.

"To be honest, I thought somebody was trying to damage me through some spiritual means. Since my mother died of breast cancer, I immediately associated my problem to ancestors in my family. I might have wronged them. Who knows?" (Lucy).

Other patients noted that their prosperity in life became sources of jealousy for others, prompting spiritual attacks, as explained by one patient:

"I don't even know what my family wants from me. I believe that because I am so successful in my business that my children are well educated, some of my family members could envy me. You know I had a dream twice that someone was sucking my breast, but I did not think about it until I saw something in my breast, which made me suspect that it was my sister who has given me this disease spiritually. I have been looking for a solution" (Elizabeth).

Religiosity

The patients' reliance on God was very clear as they referred to the extent to which numerous aspects of religious activity, dedication, and beliefs delayed medical help-seeking. Most of the patients described themselves as fully dependent on God through faith, hope, and trust. Seeking spiritual support, ranging from a simple act of personal prayer through attending regular prayer sessions to participation in specially organised prayer camps, contributed to delaying presentation. The fear of cancer and the strength of patients' belief that pastors and spiritualists can do something about their situation was evident in the interviews.

One patient demonstrated that because her relationship with God was associated with great optimism and hopefulness, she did not need any medical intervention:

"I didn't do anything but I was just asking God about what this could be? If it is cancer, I was just praying for God to let it vanish... I was just praying. I have anointing oil that sometimes I rub on it. ……. that is faith you understand? So I apply faith on my anointing oil. I pray and administered it on the lump believing that through the power of God it will vanish" (Araba).

Some of the patients related their situation to the experiences of others. They believed that God could heal them in the same way others were healed. This was demonstrated by one participant:

"I saw other patients whose diseases have been treated successfully and as those people have received their treatment, I believe God will help me also. Therefore, I think and pray to God about it so that it does not get any worse and that I will be healed completely" (Asor).

Some patients indicated that the best way of dealing with their symptoms was to submit everything to "Almighty God" through spiritual healers.

"This problem has been one of the prayer requests that I asked of God. So God spoke to one of the elders at my church who saw it in vision what was troubling me, so he approached me and held my hand. Since then, we have been spending time together committing it [the lump] to the hands of God through intense prayers believing that God will take this problem away from me" (Josephine).

Nearly half of the patients (n=15) believe that since breast problems are caused by evil spirits, there is no medical cure for it and the only option is intense spiritual healing at a prayer camp. By staying for a long time at the camp, one patient explained her ordeal:

"When I arrived, the spiritualist told me that someone in my family has shot my breast with a spiritual gun. So the man started treating me with traditional medicine and prayers. He said that even the Bible says that we should use herbs to treat our diseases. That is why I stayed at the prayer camp for a long time" (Charity).

On the other hand, some patients considered their religiousness as a way of coping with the stress of uncertainty following the identification of the mysterious symptom:

"I only say that it is God, I always pray to my God. I say it is God who will solve that problem but I have nowhere to go again so always when I dream, I get up to pray. I know my God is powerful, that's why I am still around" (Aisha).

Some of the patients believe they drew closer to God because of their experience with breast problems:

"Since I do not rule out spiritual connection at all, I participate in prayer meetings a lot. I go there every Wednesdays and Fridays. Especially now that my other daughter is at home to take care of my shop, I have more time to participate" (Elizabeth).

Patients' preferences for traditional medicine

The patients' traditional and spiritual beliefs and their related treatments featured conspicuously in the data as factors that contributed to delays in presenting symptoms for modern healthcare. Patients described traditional medicine as any form of belief and treatment that differed from modern medical interventions. These alternatives included herbal treatment, spiritual healing, and self-treatment using widely known treatment modalities. Reasons that motivated the use of traditional medicine include personal belief in its effectiveness, convenience of access, and low cost of use.

Some patients, who initially sought help at the hospital while undergoing diagnostic tests and chemotherapy, chose traditional treatment instead because they felt their symptoms were not getting any better with modern medicine and traditional medicine could be a better option.

"It got to a time when I looked at the thing [lump] and it was not going away and it was getting worse so I decided to stop going to the hospital. It was then that I said 'oh I will try and get local medicine and see whether it will go or not'. So I started using the herbs" (Aisha).

Other patients also thought their families preferred traditional medicine because they believed breast cancer could not be treated at the hospital due to its spiritual linkage. This is consistent with the fact that historically, a traditional healer was responsible for both prevention and treatment of disease. One patient suggested:

"My family said this was not a hospital disease; it's a disease that should be treated with traditional medicine so they would use traditional medicine. Within a short period, they found traditional medicine for me" (Grace).

The patients believed in the assurances given them by the other people and sometimes by the traditional healers themselves through the media. For example, one patient explained her perception of the efficacy of using traditional medicine:

"Some people advised me that it was better for me to use traditional medicine because with the traditional medicine, it will not only dissolve the lump but my breast will not be cut off. With that information, I was happy to start using local medicines" (Gloria).

The radio and television have become major medium of health information for some participants. The information advertised by traditional medical practitioners about radiotherapy, chemotherapy, and mastectomy discouraged patients from seeking help at a hospital. As an example, one participant describes the programme she listened to on the radio about medical treatment for cancer:

"Regarding chemotherapy, they say it is very poisonous and bad because it makes the patient sicker and lose the hair. Others also say that it makes the skin black. I listened to all these on the radio" (Araba).

Instead of consulting established traditional healers, some patients treated themselves using treatment modalities with which they were familiar. Kate explains how she had treated a previous breast problem with the same medicine and got well:

"I applied some local herbs I used many years ago when I had a breast problem. My mother showed these herbs to me so whenever anybody in the family complained of a breast problem I would prepare the herbs and apply [them] on it [the lump]" (Kate).

The potentially high cost associated with modern medical evaluations compelled some patients to consider traditional medicine as a cheaper option. One patient expressed her choice this way:

"Yes, as for the use of herbs, it happened when I did not have money to go to the hospital. It was then that somebody introduced me to the traditional treatment. I used it for many months and it seemed to be working until one day when I was removing the old herbal medicine to apply a new one, then

part of my skin was removed with the herbs. Since then, it has developed into a big sore on my breast but the lump is still there" (Georgina).

To demonstrate their ease of access, the patients reported that traditional healers are more readily available in their localities, rather than the much scarcer formally qualified healthcare professionals:

"In fact, there are many of these people [traditional healers] scattered throughout our communities. They use herbs and other traditional methods to treat all kinds of diseases. So it was easy to find one of them and receive treatment for a long time" (Gifty).

In some instances, friends and relatives would lead the patients to traditional healers known to them. One of them described how her sister got some herbal treatment for her without the healer assessing her:

"My sister thought it was a boil so she accompanied me to get medicine from a traditional healer in her area. It was a mixture of herbs, which have been turned into a paste. I used to apply it on the breast two times a day, morning and evening. I used it for about four months but my breast was getting heavier and more painful" (Lydia).

Some patients described how some traditional healers do house calls and deliver the medicines to their homes for their convenience. One patient explains this:

"He [traditional healer] told us that he has treated many people before me with worse problems than mine. I agreed to his terms and left the place. In the evening, the man came to my house, brought the medicine for me to use, and gave me instructions on how to use it. Since then he always brought the medicines to me at home, until he admitted that the traditional medicine has not been as effective as he expected so I should rather go to the hospital. To be honest, using traditional medicine has not helped me all this while" (Gloria).

4.1.4   Theme 2: Trust in the modern healthcare system

There was strong evidence from the data; suggesting that due to the affected patients' lack of confidence in the modern healthcare system, they preferred traditional treatments. Patients reported that accessibility and availability, previous experience with healthcare professionals, and financial limitations were

factors that contributed to the delayed presentation of their breast cancer symptoms.

Accessibility and availability

Accessibility issues such as the distance between a patient's home and healthcare facilities, transportation, the referral process, and systemic delays were reported as common factors that impacted or facilitated presentation delays. The patients described transportation problems associated with the distance to a hospital. Patients who live within the Kumasi area used a combination of walking, hiring a taxi, or taking a shared local minibus to reach healthcare centres. Due to the isolation of specialised hospitals, some patients travelled as long as 12 hours to reach the hospital. Subsequently, most of these patients had to arrange for accommodation while in Kumasi. To illustrate this problem, one patient shared her frustrating travel experience:

> *"Look, I come from a very far place. So to get here on time, I had to get up very early but it depends on how the transport would run. If it is the morning that we left, we will get to Kumasi around 3.30 PM or 4.00 PM. If the transport left in the night around seven o'clock, we will get to Kumasi around four or five in the morning the following day"* (Aisha).

The patients also described the cumbersome referral system, between the general hospitals and the specialised hospitals, as a reason for delaying. Ghana has a tiered healthcare system within the public sector, where local/community health workers provide first aid and refer cases to district hospitals, polyclinics, regional or tertiary hospitals, depending on the institution's proximity and the treatment required. However, due to the complexity of the referral system, the majority of the participants could not completely follow through the required procedure. As a result, before attending the specialised cancer clinic after they are referred, a majority of patients (n=21) attended multiple health centres and hospitals elsewhere, circumventing or unwittingly hindering the usual referral process.

As an example of Ghana's lack of a coordinated healthcare system, one patient described the different health facilities she was referred to, until she gave up and ceased to seek help from within the modern healthcare system:

> *"I used to attend the district hospital for a month and they gave me a referral to Sunyani. When I went to Sunyani, I did a scan, a mammogram, and lab tests. Later on, they did a biopsy for me and told me to go for the*

results in three weeks. When I went back for the results I was told that there was a situation in my breast so I should take it to Kumasi. It took about six months to reach that point and I could not continue the process any longer so I got fed up and stayed at home. I wish they [healthcare professionals] had told me to come to Kumasi earlier" (Ofeibea).

Upon arrival at the hospital and after being recorded into the system, patients complained about the challenges they encountered. As it was a new facility for them, they found it difficult to navigate their way through the unfamiliar system. As a result, some 'floated' within the system for a long period before they could meet a doctor or simply gave up on the process. This experience is exemplified by one frustrated patient:

"We spent eight months at the Teaching hospital before I was assigned to a doctor. They were tossing us up and down. We would make every effort to go to the hospital, but they would tell us to go home and return at another day because we arrived late or the doctor was busy that day. So I got fed up and did not return" (Sarah).

The patients described how the assessment process contributed to their inability to receive a definite diagnosis. In most cases, the diagnostic equipment is not available at the hospital, and if it is, it is usually inoperative. Also, some of the hospitals are not equipped for the proper diagnosis of breast cancer. Therefore, patients are required to find a private vendor somewhere in the city to complete the doctor's request for an investigation. When completed, the diagnostic centre would produce a report for the patient to take back to the doctor. Many patients give up on the process due to various problems such as the one shared by this patient:

"When I went there to do the scan, they said the machine was faulty so I told my husband that the way they were going about it [the diagnostic process], I didn't like it so we should go back home and think of a different strategy" (Mansa).

Previous experience with healthcare professionals

Previous experiences of the patients with healthcare professionals delayed their definite diagnosis and treatment within the modern healthcare system. Patients remembered in detail their previous unpleasant experiences related to modern healthcare services and described the process as "painful", "time-consuming", and

even "unbearable". Specifically, patients described the healthcare professionals as impatient and unfriendly.

Two examples of how the patients did not appreciate the attitude of the doctor, and their decision to abandon modern healthcare treatment as a consequence, are as follows:

> *"I got scared upon hearing that my breast will be cut off just like that. I felt like fainting. I wish there could be a better way of delivering such a message to patients who might have gone through a lot already. You see, I did not return to that hospital because of the way I was treated. The workers at the hospital were not friendly at all"* (Gifty).

> *"Sometimes when I go, they will tell me the doctor is not available and we had to return to our home. Finally, I met with this female doctor and the way she delivered the report scared me. As soon as I entered the doctor's office, she said, "Madam we have investigated your report and we will cut off your breast completely". She did not even tell me what I was suffering from. My soul left my body at that moment. I became numbed and I could not think anymore. So I left the hospital and that was it until now. I totally lost confidence in hospitals"* (Salamatu).

In some cases, doctors may not be available to see a patient when she has made a journey to the hospital and they are told to return another day. One patient explained how she tried several times to meet the doctor, but with no success:

> *"The doctor was too busy. Every time we went we would be told that he had travelled to Accra. So the doctors who have come to the regional hospital to cover him gave me a letter saying that I should go to Kumasi to do the surgery. You see, I wasted all my time for nothing"* (Sarah).

Some patients refused to go back to complete the diagnostic process. One patient, who delayed carrying out the assessments, was afraid to return to the hospital, thinking that the doctor would accuse her for not being serious about her treatment and she believed that her medical records folder could be thrown at her as she alleged had happened before:

> *"Later on, my husband got the money and told me to go and do the scan, but I said if I do the scan and go back to the hospital, the doctor would be annoyed and throw the folder at me because it has taken too long time to do the scan"* (Georgina).

Considering the distance they had to travel and the fact that they had to proactively track down their reports, one patient felt that the assessment process was time-consuming and she could not bear the pain anymore:

> "*I had to travel all the way from Tamale to Kumasi for the purpose of collecting the results but when I arrived at the lab, I was told that the results were not ready so I had to go back. When I returned to check the results and they said my folder was missing so I should go and come again, I became frustrated and decided to go for local medicine because of the pain and heaviness of my left breast that I could not bear anymore*" (Gifty).

Being misdiagnosed previously by a doctor was indicated as a reason for patients to delay care. Patients felt that if physicians had not taken their medical concerns seriously in the past, then they were more likely to avoid the modern medical system in the present. One patient who felt her situation had been mishandled made her point in the following way:

> "*I went to the district hospital two years ago. I used to go and they would say: Oh it is typhoid they will give me drugs and asked me to come back in a week's time. When I finished the drugs, I would go back they would just tell me to go and collect more medicines. That is the only thing they were telling me. So I used to collect the drugs while the thing was growing and I became fed up and one day I said would not go there again*" (Aisha).

The patients reported the conflict they had between their expectation at the hospital and medical options presented to them. They complained that they were not satisfied with the services they received from the hospital-based healthcare professionals because they were not given any medicines from the hospital. Describing her expectation on receiving medicines, one patient explained:

> "*I went there about three times before they made me lie down and they used some needle to take something out of the breast and that they said that they would only give me medication when the report is in. This meant they did not give me any medication while the lump was just increasing in size so I decided to look for help from somewhere else*" (Akyea).

Financial limitations

The anticipated cost of breast cancer care was a critical issue that was expressed by twenty-five of the patients, as a contributing factor to the delay in seeking help within the modern healthcare system. In addition to transportation costs affecting

each participant's access to a modern healthcare facility, fees for ultrasound scans, mammograms, biopsies, and pathology examinations are required from out-of-pocket payments at the point of service. The patients mentioned that despite the availability of a National Health Insurance Scheme (NHIS), other expenses involved were too high and many could not afford to keep up the payments. Describing the limitation of the NHIS, one patient shared why she could not afford to continue using services at the hospital:

"Although I had a national health insurance card, there were other expenses, such as the lorry fare and not all the diagnosis and treatments are covered by the insurance so I could not afford to continue using the hospital due to poverty" (Asor).

Similarly, another patient stopped the assessment process due to her shortage of money:

"The 'seed' was very small when I took it to the hospital. But if I go to the hospital, don't I need money to buy the drugs? Now I do not work. My husband and I developed some cocoa farming but when he died, his family took everything away from me. So I had to stop going to the hospital because I had no one to help me financially" (Akyea).

Patients also discussed lack of money as a reason for delaying healthcare due to other family obligations that required substantial financial commitment in addition to the cost of healthcare. One patient was not sure she could raise enough money to educate her child and treat the disease at the same time:

"If it were not a money problem, I would have come back a long time ago when the disease was not going away. I do not have any lucrative work, and my child is also in school so I barely go by with the little I get from my small business. My husband is not helping him so I am the only one supporting him. I was afraid that if I was asked to pay some money at the hospital, I may not have the money to pay even for the medicines so I had to stay away from the hospital and depend on traditional medicine" (Asor).

For some patients, it was upon hearing about the costs involved with other people who had previously used the medical healthcare system that discouraged them from making any attempt to go to the hospital. One patient said:

"She [the friend] said that she had her lumps removed twice or thrice but it was the expense involved that was the problem. So when she mentioned

about the expenses involved, I got scared and cried, because I don't even have any money to begin with in the first place. I ended up not going to the hospital at all" (Josephine).

Other patients reported that their husband's inability to provide the necessary financial support delayed symptom evaluation. One patient illustrates this:

"After my husband lost his job, finances became so tight for us that when I went to the hospital, the amount of money that I was supposed to pay, I did not have enough money so I did not do the scan and the lab tests. I just put them down somewhere until later" (Georgina).

Similarly, some husbands did not acknowledge the seriousness of their wife's breast problem and were therefore unwilling to provide the necessary financial support for further evaluation:

"Immediately I showed it to my husband, he asked if it was painful. When I told him that it was not painful, he said it is probably nothing to worry about. Later on, when I wanted to go to the hospital, he told me that he did not have money for me because he didn't think it's such a big problem" (Charity).

4.1.5   Theme 3: Emotional reactions to symptoms

Emotional reactions to the discovery of symptoms of breast cancer were highlighted in all the patients' interviews. Patients often initially believed that their body changes were nothing serious and they thought the problem would either simply go away, or it could be treated with traditional medicine. However, with time, and as their signs worsened, they described how their perception of the seriousness of the symptom and the potential consequences regarding fear of death from surgery and the side effect of chemotherapy, fear of social stigmatisation, fear of spousal rejection, and fear of reduced womanhood influenced their decision to seek modern healthcare.

Fear of death from surgery and side effects of chemotherapy

The patients' perception of cancer treatment led to delayed presentation. A majority of patients (24 of the 35) labelled breast cancer as an incurable disease, associated with painful symptoms, causing suffering for the patient herself and anguish for her loved ones before and after her death. As a result, patients

delayed seeking medical attention to avoid confirmation of a cancer diagnosis and subsequent adverse treatment outcomes.

One patient who did not see the importance of knowing the diagnosis of her symptom illuminated the fatalism associated with breast cancer:

> *"Breast diseases are very dangerous and I heard that it can kill at any time. Since there is no cure for it, if I am found to have contracted one, it will just kill me. So I asked, what is the point of going? Just to hear the news? They will just tell me to do a mammogram, do this and that, just be wasting limited time and the disease will be growing until it kills"* (Charity).

The majority of patients (n=26) were also aware of possible consequences of cancer treatment from the experiences of peers. The expressions of fear of breast removal were found in the words or phrases used by patients such as "chopping off the breast", "removing the breast", "cutting off the breast", and "amputating the breast". These words reflected an actual fear of treatment and potential consequences. The patients' concerns about what would happen to them if they undergo the surgical procedure, was considered an important contributor to the patients' delay in seeking modern medical help.

One patient who witnessed the death of a relative after breast surgery illustrated it in this way:

> *"So fear of death took over my mind after my cousin died of breast removal. After that, I did not have the peace of mind at all and wondered whether I should go (to the hospital) or not. I could not gather the courage to show it to the doctor until now"* (Elizabeth).

Some patients were worried that surgery would not cure their cancer and that their body would only suffer more due to the disease. There was a general perception that patients who allow their breasts to be removed at the hospital die as a direct result of the surgical procedure. This was articulated in the extract above and by another patient who feared the outcome of surgical treatment, so preventing her from seeking the necessary help at the hospital:

> *"The growth in my breast was very small when I decided to take it to the general hospital. It was then that my friend told me that it was very dangerous for me to allow the doctor to cut my breast because people who allowed their breast to be removed die quickly. Then I changed my mind and used other traditional treatments"* (Gloria).

Similarly, another patient saw a doctor first when she noticed the lump but when she was told that she would have her breast removed said:

> "So when the doctor told me that he has to remove my breast, I was scared and ran away. Then I called my sister who was in the city and told her the problem I was facing at the hospital. She told me to come back to her because she has someone there who would help me. Not knowing it is a herbalist, I spent one month there without seeing any improvement" (Fantewaa).

Though these patients had not actually been prescribed chemotherapy, by listening to others about the side effects, they were fearful themselves. Just under a third of the patients (n=10) described how it was anticipated fear of the severe side effects of chemotherapy that was the most burdensome for them. As patients assumed they might have chemotherapy, they worried about the unpleasant and negative side effects such as nausea, weight gain, and hair loss; these were all concerns based on the experiences of others. One of the participants exemplified this fear as a reason for delaying hospital attendance:

> "As for me, when I saw the lump, I went to the hospital earlier but heard that if it is cancer, they will give me an injection, which would make me lose my hair and my tongue will become dark. I got worried about this because I have so much hair and I don't want to lose it so I waited for a long time" (Jennifer).

Fear of social stigmatisation

The social stigma of breast cancer was seen in just over half of the patients (n=20) as a reason precluding them from openly discussing their experiences with other individuals. Some patients tried to hide their symptoms because they feared that they would not be free anymore to associate with people in their community, if others learnt that they had contracted the "deadly" breast disease. Consequently, the fear of stigmatisation prevented patients receiving the necessary support for medical help-seeking and therefore contributed to the women delaying taking positive action.

One patient imagined how she would be treated if she had her breast removed. She thought that if others looked at her, they would be looking at the side where her breast was removed and she would be embarrassed:

"What I am saying is, maybe if I should go back to school again and I have a roommate and then maybe when I am dressing up and the person sees that I have only one breast; may be that person may share it with others and when they see me, they will point fingers at me that I am a person with one breast… this is kind of not normal" (Caroline).

Being aware that a cancer diagnosis can also create shame for families in the community, the patients reported that keeping information within close family circles protected the family from societal ridicule.

"Initially, I was telling people in my house, mostly family members that I have a lump in my breast. But my older son warned me not to tell anyone because if people get to know that I have the same type of sickness that killed my sister, it will be a problem for the family" (Angelina).

Some patients felt uncomfortable about disclosing symptoms to others, due to their perception of an association of cancer with witchcraft. One patient feared that the community would think that the family has been cursed with cancer:

"My mother died a few years after her breast was cut and my cousin also passed away and now it will be me, so I didn't know what people will think on my mother's side of the family about the cancer cells that have suddenly come to the family" (Josephine).

There is a general perception that if someone has cursed a family member through 'black magic', an unexplained disease can indiscriminately fall on any member of the family. Therefore, a patient who is suspected of being cursed would withdraw from the society to avoid being accused of it being her fault, especially if the symptom had never happened to anyone in the family. One patient explained why she kept her problem a secret:

"I am surprised that I had to go through this because there is no one in my family with this type of disease. I have never heard about its history in my family and I am wondering where this disease came from. That is why remained alone in the room and kept it to myself" (Fantewaa).

Another patient also believed that telling people would stimulate fear and generate too much gossip:

"Eh, but how come the same disease that killed my sister has also come to me? I believe there is some black magic behind this. If my family is not

difficult, then how could this be? My mother passed away not of the same disease. My other sister also passed a way from something else. So if it is difficult for me to understand, how would other people take it? Therefore, I was afraid of what people will talk about me, so it was better for me to keep quiet and look for a proper cure" (Grace).

Fear of spousal rejection

Fear of ostracism contributed to delayed presentation. The expectation of being abandoned by their husband was evidenced in many patient interviews and would be a reason for delaying medical evaluation of symptoms.

One patient described how she was worried about losing opportunities associated with her marriage, if the husband abandoned her:

> *"The other issue is my husband, who supports our children and me. How is he going to manage the news if I am diagnosed with cancer? Whom do we turn to for support if he abandons us? So each time I think about the possibility of being diagnosed with cancer, I get afraid that he might leave me and go for another woman, so I have been hiding it from him"* (Josephine).

Another patient did not want her husband to know that she had a problem with the breast, in order to avoid possible abandonment. She said:

> *"My husband can even leave me because I have heard numerous stories like husbands abandoning their wives because of the same problem I have with my breast"* (Fantewaa).

A further patient demonstrated the fear of being disgraced in society because of her husband's rejection:

> *"As for him [my husband], he used to come closer to me but lately, he is slowly isolating himself from me when the thing was getting worse. I am afraid that if he moves out and marries another woman, it will bring disgrace on my entire family and me because he will be justified since I will be of no use for him"* (Gifty).

The patients feared that if their husbands leave them, they would be disgraced in society; no one would support them, and the outcome would be a total collapse of the family, including possible neglect of the children by their father in some cases.

Fear of diminished womanhood

Nearly half (n=16) of the patients described how they feared the potential impact upon their social identity if diagnosed with a breast-related disease, given prevailing societal perceptions on the importance of the breast as integral to womanhood. The respondents were implying that, as patients, they would no longer be able to function as a wife and a mother. The patients associated breast cancer with fear of a distorted body image and loss of femininity, because they believe that such cancer affects a body organ that symbolizes femininity and motherhood. Therefore, patients who are married tend to hide and avoid discussing their illness with other family members, since it is considered shameful for them not to function as such. These considerations contributed to their apprehensions about seeking early medical intervention.

The expression of fear of the social and cultural implications of breast abnormality was clearly described by a young patient of 26 years, who shared how she feared her chances of becoming a mother would end if it is known that she had contracted breast cancer:

> *"How many men will marry a woman with one breast and full of diseases? I think that I may not be able to marry and have children as a result of this sign if it becomes positive. All these are important for family stability. These are all important considerations to make in life. In my family also, I am the only lady among my siblings so my father also thinks about this very much; I am also worried that something like this is happening to me"* (Angelina).

Another young patient, whilst not being afraid to die, feared that her chance of getting married in the future would be diminished by any deformity on her breast because of a potential husband's disapproval of her body:

> *"As someone who is not yet married, I was not afraid that I was going to die but I was uncomfortable that I would be operated on my breast. I am afraid that not every man will feel comfortable with a woman with a breast that has stitches to accept me as a wife. So with that, I was worried to know even what was wrong with my breast"* (Emily).

4.1.6   Theme 4: Eliciting lay advice

Eliciting lay advice from the patients' immediate social network, especially friends and family members, about what the symptoms might be and what to do about

them, was a universal approach for all the patients. Although the patients purposely selected how and with whom to disclose their predicament, social interaction was based on trust and the type of support they expected to receive. Reflecting on their deep cultural preference, approximately two-thirds of the patients (n=22) informed their husbands and female friends within days or weeks; furthermore, just less than one-third (n=13) contacted other family members several months after discovering the body changes. The opinions of others on symptom interpretation, help-seeking, and advice on healthcare utilisation contributed to delayed presentation.

Opinion of others on symptom interpretation and help-seeking

When they recognised the unusual sudden changes in their breasts, patients sought advice to understand these alterations by drawing on their immediate social networks to determine whether the sensation indicated a normal physiological process or, alternatively, that something was wrong. During their discussion with the social networks, especially friends, patients gave specific examples of the changes they had identified in and around the breast. These changes include; "a lump", which was commonly described as something hard like a "stone in the breast", "seed in the breast", "knot in the breast", "growth in the breast", and "raised spot on the breast". A painless lump was the most commonly identified sign followed by others including nipple discharge, inverted nipple, and peau d'orange. Additionally, the most frequently reported sensations were body pain, itching, body weakness, burning, and pricking in the breast. The patients indicated that symptom disclosure helped them to evaluate, confirm or develop their own interpretations.

Based on their knowledge and experience with cancer, friends and family members played a supportive role in providing alert messages to indicate a serious symptom of a disease. Nearly one-quarter of the patients (n=8) said that social interaction helped them to realise the seriousness of their symptoms. The initial signs did not raise enough concern for prompt medical consultation until it was confirmed by trusted friends and family members and, at times, by the media. As an example, one patient described how the information received from her children confirmed her suspicion:

> "*For several months now since I accidentally touched a hard substance while bathing, I observed that my breast was gradually increasing in size but I ignored it because it was not painful. Then one day when I felt a slight pain,*

I showed it to my children. They agreed with me and added that since the nipple was also hard, it may be an early sign of a breast disease being talked about on the radio. Therefore, they insisted that I seek care as soon as possible" (Salamatu).

Despite the increasing size of the breast, the patient ignored the painless mass. Instead, it was the sudden appearance of the pain that provoked her to discuss it with her immediate family.

In a similar manner, receiving messages through the media influenced some patients' interpretation of their symptoms and the decision to delay seeking medical help. One fifth (n=7) of patients, took note of information from multimedia sources, especially radio and television. Some patients indicated that there was one famous radio presenter who was promoting 'natural remedies' as opposed to hospital treatment. He advised listeners to avoid hospital treatment for breast cancer completely because he believed medicines for cancer were toxic. To exemplify this point, one patient said:

"The presenter said that chemotherapy is poisonous and that is the reason why patients react so badly to it; therefore, anyone who identifies a lump should contact him on the telephone numbers he provided because he has a remedy for cancer without giving the bad medicine. I acted on the advice given by the FM station and stayed at home all this while" (Araba).

Beside the radio, some patients also gained information from the television. To illustrate what was broadcast on the television, one patient made her point:

"I also heard on the TV that we can even examine our own breast but if we identify some change such as a knot or any hard substance, we should not delay searching for traditional medicine because it works when the bump is small. They say at that stage it is time wasting to go to the hospital to find out whether it is cancer or not, so I obliged" (Salomey).

Another patient also reported what she heard from the radio:

"I heard on the radio that a woman normally has multiple lumps but those are not cancerous. It could be cancerous when there is a pain in the breast. So when I felt the pain around my breast, I rushed to the hospital immediately because I began to fear that it could be breast cancer" (Rita).

Although a quarter of the patients described how their interactions with friends and family members encouraged them to seek modern medical treatment, approximately three-quarters (n=25) received misinformation and inappropriate reassurance messages, causing additional delays. The individuals' knowledge and experiences about breast diseases played an important role in interpreting the symptoms. Some participants became relieved and relaxed after they were assured that it is normal for ladies to have lumps in their breast at a point in their life. Upon informing her mother about a change in her breast, one of the young participants received advice that the lump in her breast could be a normal female developmental change and this reassured her that there was no need to take any action:

> *"I told my mother about the lumps in my breast and she assured me that as a young lady growing up and not yet given birth, it was normal for me to feel a lump in my breast. So I relaxed for at least five months before I decided to do something about it"* (Rita).

Another patient whose sister reassured her that the lump was noncancerous painted a similar picture about knowledge of cancer signs. She said:

> *"When I told my younger sister about my lump, she said it wasn't cancer because cancerous tissues move upon touching so it might be a different disease"* (Ofeibea).

Although the patient seemed to know about the seriousness of cancer, she did not realise the importance of taking immediate action upon noticing physical changes.

When another patient identified a growth in the right breast while breastfeeding a baby, she showed it to her husband and asked him also to check it for her. She said:

> *"He touched it and he reassured me that I should not worry because it could be the breastfeeding or an insect bite, which would eventually go away. So with what my husband told me, initially I did not pay attention to it. But as time passed, I observed that the hard substance in my breast was increasing in size, becoming harder, and the skin around the breast was also thickening. As the pain was appearing and disappearing, it troubled me so much that I decided to look for treatment for it"* (Comfort).

Drawing on the reassurance from her husband, this patient waited and did not take any immediate action. While she initially dismissed the breast symptoms, she monitored the symptom for any future developmental changes.

Among some patients, disclosure was associated with receiving information that suggested that they might not have to do anything about the lump. One patient was reassured through her friend's testimony, and therefore underestimated the importance of the signs and delayed her presentation:

> *"Even one of my friends said that she has a sister who had a lump in the breast and nothing has happened to her for a long time, although so far she has not done anything about it"* (Angelina).

There was a general belief that patients without a family history of breast cancer, cannot be at risk of breast cancer. A recurrent statement in the interviews indicated that nearly a quarter (n=8) of the patients saw cancer as a hereditary illness; hence, its transmission is contingent upon being a blood relative of someone who has previously been diagnosed with cancer. If cancer was not found in their family then they wondered about the origins of their breast problems. To illustrate this issue, one patient said:

> *"When I told my mother about the bump in my breast, she said that since this sort of thing is not found in our family, I should not worry about it. That reassured me a lot and I relaxed"* (Konadu).

This patient tried to make sense of her body change based on her perception of potential risk. She used cultural expressions to explain the list of perceived illnesses that she had internalised, to which she considered herself at risk. Thus, she evaluated her identified signs in accordance with those perceived risks, which included having a boil, the food she ate, the air she inhaled, and the water she drank.

In some cases, the advice given was related to the person's religious beliefs. Therefore, some patients decided not to take any action based on the guarantee they received from their friends that God has the power to make the lump disappear.

> *"Since I told my friend about the lump, she was always telling me that it would go away; by God's grace, it would go away by itself"* (Josephine).

The majority of the participants reported that the people they contacted interpreted the unusual sign as something bizarre, which was associated with evil spirits. To illustrate, one patient said:

> *"When I first saw the lump, I thought it was strange but I didn't know where it came from. I discussed it with my best friend who informed me that lots of people believe that evil spirits act on the breast and cause such things"* (Ofeibea).

Instead of attributing cancer to other physical causes, the friend explained that the sign originated from an evil spirit bringing breast diseases upon women. Generally, patients who associate their symptoms with traditional beliefs may be reluctant to seek modern medical evaluation because they believe that modern healthcare lacks the insights to deal with spiritually linked diseases.

Advice on healthcare utilisation

This sub-theme describes how information obtained by patients, from friends and family members, regarding available healthcare options contributed to the patients' delays in seeking modern care. The data revealed that a person's beliefs, familiarity with the local healthcare providers, and knowledge regarding breast cancer symptoms, are important not only for symptom interpretation but also for information about the kind of healthcare to pursue. While some of the patients were advised to seek modern medical help promptly, most patients were guided to seek traditional medicine by various sources.

Knowing that the breast lump could be treated at the appropriate hospital, friends who had experience of a similar problem urged patients to gain treatment at the hospital. As an example, one patient shared her story:

> *"When I contacted my friend, she advised me that it could be cancer so I should be serious with it. She encouraged me to go to the hospital and if it is cancer, they will remove it for me to be well but I was scared so I did not go"* (Sarah).

Likewise, knowing the value of early treatment of cancer, another patient was advised by her friend to seek medical evaluation and possible treatment.

> *"One of my friends told me that I should report to the doctor to remove it because she said the earlier the better. I was worried"* (Georgina).

Although these patients received appropriate advice regarding modern medicine from their friends, the outcome of the advice was not to pursue it due to perceived fear of possible breast removal.

Though some patients were encouraged by their husbands to go to the hospital, the majority (n=23) reported that their friends recommended traditional ways of dealing with the problem. To conform to societal norms about treating common diseases, one patient reported:

> *"When I disclosed the raised spot on my breast to my friend, she thought it was a boil so she suggested that I should use the traditional medicine which everybody uses around where I live. I had no other choice but to use it for several months but it wasn't going away"* (Aisha).

In Ghanaian society, a lump is often mistaken for a boil, which is a fairly common occurrence in the general population. A boil is a localised swelling and inflammation of the skin resulting usually from a bacterial infection of a hair follicle and adjacent tissue, with a hard central core, and which forms pus; it can appear anywhere in the body. It did not occur to the patient above that the "boil in her breast" could be a symptom of cancer.

The perception that traditional medicine could treat breast cancer prompted some friends to recommend it, as demonstrated by one patient:

> *"When I told my friend about it, she told me that I should not to worry because it can be treated with traditional medicine and, if I use it, I would be well. So I looked for a traditional healer who gave me some medicines for drinking and applying on the breast"* (Gloria).

The patients who ignored their breast symptom often depended on advice acquired from their closest friends and family members. This indicates that a patient's source of information, which was influenced by culturally acceptable explanations, played a more important role towards delaying presentation than merely the knowledge of the individual.

4.2   Findings from the patients' social networks

This section presents findings from the interviews with members of the patients' friends and family members (social networks) to explore their roles in the patient's symptom appraisal and medical help-seeking. Given that, in Ghana, friends and family members are highly valued for socioeconomic and cultural

reasons, the patients turned to them not only in times of great need but also to maintain the tradition of a tight family structure. The traditional household structure in most parts of Ghana is based on male-headed units of extended families, with a clear division of economic responsibilities based mainly on age and gender. Because of this structure, there were situations where the decision to seek medical help was led by someone other than the patient, instead of it being the patient's exclusive responsibility.

Specific elements of the social system not only influenced patients' beliefs and behaviour, they also affected the women's financial and emotional situations, and the types of healthcare choices made during breast cancer treatment. Although family members were willing to support the patients, this was informed by their cultural beliefs and constrained by their financial status, and knowledge and experience of the disease. Interestingly, with increasing social change in the structure of the household, there were situations where patients and their social networks did not agree on their approach to seeking help. The resulting tensions and pressures from close friends and relatives brought about the delays in seeking modern medical help.

4.2.1   Characteristics of patients' friends and family members

Although, all 35 patients interviewed had the opportunity to nominate someone who was knowledgeable about their symptom, to participate in the study, eight were not able to suggest anyone. The remaining twenty-seven patients did however recommend a friend or family member who agreed to take part. Eventually, 27 friends and family members of the patients, fourteen males and thirteen females, were interviewed (see Table 11 for detailed characteristics of patients' social networks). Fifty-six percent (n=15) were daughters, 22% (n=6) were husbands, as well as two mothers and two son-in-laws. Their ages ranged from 20 to 65 years. Five of them attained primary school or lower education, eleven received a secondary school education and another eleven went on to tertiary level. Fifteen were self-employed and six were full-time employees. Fifty-six percent (n=15) were married.

Table 11 Characteristics of the patients' social networks

Characteristics	n (%)
Education level	
No formal education	3 (11.1)
Primary school	2 (7.4)
Secondary school	11(40.7)
Tertiary education	11(40.7)
Gender	
Male	14 (51.9)
Female	13 (48.1)
Marital status	
Never married	6 (22.2)
Married	15 (55.6)
Divorced	6 (22.2)
Employment	
Full time	6 (22.2)
Part time	1 (3.7)
Other (retired, student)	5 (18.5)
Self-employed (trading, farming)	15 (62.9)
Religion	
Christian	22 (81.5)
Muslim	5 (18.5)
Monthly Income (GHS)	
Less than 100	3 (11.1)
100-200	5 (18.5)
201-400	7 (25.9)
401-600	4 (14.8)
601-800	3 (11.1)
801- 1000	2 (7.4)
More than 1000	3 (11.1)

Characteristics	n (%)
Relation to patient	
Mother	2 (7.4)
Friend	1 (3.7)
Son-in-law	2 (7.4)
Daughter	15 (55.6)
Sister	1 (3.7)
Husband	6 (22.2)
Age	
Less than 25	4 (14.8)
25-34	5 (18.5)
35-44	7 (25.9)
45-54	4 (14.8)
55-64	4 (14.8)
More than 64	3 (11.1)

4.2.2   Themes and sub-themes from friends and family members

Information, advice, and support received as a result of patients' interaction with friends and family contributed to their decision regarding when and where to present the detected signs of breast cancer for medical evaluation. The three themes of: i) superstitious beliefs about cancer, ii) protecting the family from societal ridicule, and iii) inadequate social support had two, two, and three sub-themes respectively; data that explain how the role of the social networks contributed to the delay (see Table 12 for details).

Table 12 Themes and sub-themes from patients' social networks

Themes	Sub-themes
1. Superstitious beliefs about cancer	1.1 Evil spirits cause cancer 1.2 Curse on the family
2. Protecting family from societal ridicule	2.1 Keeping symptoms of loved one within close family circles 2.2 Denying the possibility of cancer
3. Inadequate social support	3.1 Providing inappropriate advice about the signs 3.2 Financial burden 3.3 Decision for healthcare choice 3.4 Tension between patients and family

4.2.3   Theme 1: Superstitious beliefs about cancer

Similar to the patients, the general belief of the social network is that breast cancer is a spiritual disease caused by evil forces. The respondents mentioned the idea of being cursed or bewitched and that witches can cause illnesses when angered. They described how illnesses and disorders were perceived to be linked to jealousy, spirit possession, and black magic. The social network explained that some people are believed to have inherent powers to hurt others through the use of invisible forces. The two sub-themes that emerged were; 'evil spirits cause cancer' and 'spiritual discourse by family'.

Evil spirits cause cancer

The family's belief that cancer originates from evil spirits contributes to delayed presentation. The majority of the friends and family members (n=18) related a patient's breast problem to the work of evil spirits based on dreams. As an

example, since one mother was convinced that her daughter had been bewitched, she looked for a spiritual treatment:

> *"The way she confirmed that she sometimes has dreams of somebody sucking her breast, I strongly believed that there was some evil spirit behind her breast disease. Whether it's from her workplace, from home, from school, I cannot tell. In this case, I suggested that we look for a very powerful spiritualist to help us"* (Mother).

Curse on the family

Although friends and family members did not know the main source of the patient's breast problems, they believed that there was some spiritual discord within the family. One husband suggested that the evil spirits were angry with his wife because she was still spiritually married to them; therefore, those spirits were attacking her fertility with this disease. He said:

> *"The secret is that my wife was a fetish priestess before I married her so before she stopped, she didn't perform all the necessary rituals to allow her to dissociate herself from them. That is the reason why we are having all these spiritual challenges. The spirits want to destroy her breast so that she cannot have any children. That is a way for me to leave her so that she can still be married to them"* (Husband).

The family members believed what the traditional healers told them, especially when the family had failed to find the cause of the disease. A daughter was made to understand that her mother's problem was clearly a curse on the family:

> *"When I heard of my mother's breast problem, I was so confused not knowing what to do. I didn't know why the same problem that sent her sister to the grave should attack my mother soon after her sister's burial. When I contacted the local medicine men, they told me that my mother has been cursed. We ended up staying at the shrine for months to avert the situation"* (Daughter).

4.2.4   Theme 2: Protecting family from societal ridicule

Keeping symptoms within close family circles and denial in accepting the possibility of cancer were evident from the data. Family members perceived it as their duty to keep the patients' breast symptoms a secret within close family circles for fear of societal stigmatisation and concerns regarding abandonment by

the society. They do not want their families to pay the social price of having a family member with breast cancer.

Keeping symptoms of loved ones within the close family circle

Keeping symptoms only within close family circles limited the patients' chances of seeking early treatment. In general, families were aware that breast cancer is a dangerous disease because of its potential to kill; this was an awareness gained through witnessing other people die of the disease in their communities. The family members indicated that they needed to show their love to support the patients by preserving the unblemished womanhood of other family members. This was done by keeping the issue among themselves. One family member described how the family wanted to preserve the sister's breast:

> *"My sister was advised for mastectomy some years ago. Family encouraged her not to undergo the procedure since she was young and it was going to affect both breasts. Instead, we kept the issue within ourselves and resorted to traditional medicine using herbs and prayer camps all to no improvement"* (Sister).

Some family members kept the disease only within the family circles to avoid social stigma from the community. One daughter described the reason for keeping the symptom a secret:

> *"As a family, we believe that this kind of disease should not be public because of the possibility of evil spirits that are associated with it. So we did not disclose it outside of the family. If we had informed other people about it, we could have gotten help from places like this one a bit earlier instead of wasting all that time at other places"* (Daughter).

Denying the possibility of cancer

Family members' denial of the possibility of cancer delayed the patients' help-seeking efforts. Religious belief and previous absence of cancer in the family played a significant role in helping to support a woman who was in denial that her breast changes might be cancer. Some family members used the belief that religious intervention influences the outcome of cancer rather than medical treatment. To illustrate this perspective, a husband used examples from the Bible to encourage his wife while the breast lump grew larger:

"When we are together, I use the Bible to encourage her that despite the problems several Bible characters like Job endured temptations. So we should face this with courage for with God, all things are possible" (Husband).

There was a strong belief that there would need to be a family history of cancer for someone to be at risk of the disease. As a result, a daughter found it difficult to understand what was happening to her mother because, according to her, cancer does not run in the family. She said:

"I have not seen such illness in my family so I don't know where this disease came upon her from. Several things have been associated with breast diseases so I don't even know if a curse has been passed on her. So I took her to the prayer camp to find out what was going on spiritually" (Daughter).

4.2.5   Theme 3: Inadequate social support

Social constraints resulted in patients feeling that they had inadequate social support. Inability of friends and family members to provide appropriate information about the potential symptoms, the financial burden of supporting family members with cancer, and tension between patients and family members, all hindered the patient's medical help-seeking.

Providing inappropriate advice about the signs

The lack of knowledge about symptoms and risk factors of breast cancer amongst patients and family members influenced patients' understanding of the nature of the symptoms and their subsequent help-seeking actions. As an illustration, a sister to one of the patients expressed her inadequate professional knowledge and experience that misled the patient in this way:

"As a retired nurse, the few breast lumps I have seen were the advanced ones, which were either very big or very hard, but hers wasn't like that, the lump was small and only on one side. Cancer did not cross my mind at all. I thought it would simply go away with time" (Sister).

A young participant had a view about breast disease being 'age' related. She said to her friend, one of the participants:

"You know … my friends are saying that these breasts problems are for old people and not for young people like us" (Friend).

The majority of family members encouraged the patients not to worry about the lump if it was not painful. A daughter explained that she thought the painless lump of her mother was not serious and there was no need to take any action:

"The reason is that the lump itself was not painful. The way I saw it, I told my mother that she did not have to worry about it because it would be painful if it was that serious. She continued with her normal duties until the pain started" (Daughter).

Nearly half of the family members (n= 12) mistook a lump for a mere boil, for which there are cultural interpretations and accepted traditional treatments. One daughter who thought a clot of breast milk caused her mother's lump showed this:

"I believed that it was the remnant of a breastmilk induced boil, which never came out after it ruptured and had developed into the lump. I thought there was no need to take it to the hospital but to use the locally known traditional medicine" (Daughter).

The daughter appeared to be trying to convince herself that her mother's breast problem was not that serious. From this and other stories, patients commonly assumed that in a situation where a woman is unable to breastfeed after giving birth, the accumulation of breast milk could lead to a clot that might later develop into a boil. Traditional medicine, which has been passed on from generation to generation, are commonly used to treat these kinds of ailments.

Upon learning about the discovered symptoms, family members provided information which comforted the patients and made them believe that the sign was not serious. Checking and providing reassurance by her husband led a wife to underestimate the situation and delay presentation:

"I had to check it even though I am not an expert in that field. After that, I tried to convince her that it could be normal because I felt that there were other bumps in the breast. I was trying to let her know that it was nothing to be worried and we believed in God that it was nothing" (Husband).

Financial burden

Although friends and family members were willing to support the patients, their lack of money was instrumental in the delayed medical presentation. The anticipated high cost of hospital fees was a deciding factor for the majority of the social networks when it came to supporting the patients through the modern healthcare system. While some family members were aware of modern healthcare, they did not have the money for an initial consultation. A husband illustrated this:

> *"I have heard of the breast care hospital but I didn't have money to take her; I told her that we should wait so that when I get some money, we could deal with it"* (Husband).

Some family members initially went to the hospital with the patient, but did not have enough money to pay the required deposit, which delayed treatment. A daughter expressed the dilemma this way:

> *"The hospital is about money; yes cutting off that breast is about money, taking medicine too is about money. Initially, she went to the hospital and they told her she should bring 600 cedis (approximately 120 GBP). Where were we going to get that amount of money? We didn't have it so she had to be in the house for a long time until my aunt brought her to the hospital"* (Daughter).

Similarly, a husband did not have money for his wife, who had presented early to hospital to complete diagnostic tests; this lack of funds resulted in delayed diagnosis:

> *"She came back from the hospital and told me that she did not have enough money with her to do all the tests. Since I too didn't have money, I requested a loan from somewhere and when I got the money, we realized that the thing has already grown so big"* (Husband).

In addition to the lack of money for hospital services, family members especially those who needed to travel long distances, discussed other related circumstances where the money would be needed such as transportation and lodging costs. A husband thought that if he and his wife knew someone in the city they could stay with, it would reduce their expenses. However, since they did not know anyone in the city, they had to wait until they could gather resources to do so, as explained by the husband:

"So I was waiting while looking for money before I could bring her to the hospital. Even going to the hospital, we needed to plan where to stay since we didn't have anyone in the city to stay with. Indeed, this disease has affected our livelihood, our family, and our future" (Husband).

Decision for healthcare choice

Friends and family members indicated that they were instrumental in deciding where their loved ones should seek care. However, the decision-making process regarding the choice of healthcare caused a delay in patients' medical help-seeking. Their choice of healthcare was influenced by a combination of factors including traditional beliefs, the cost of care, and trust in the modern healthcare system.

Friends and family members who believed that evil spirits originated the breast cancer symptom thought that since the hospital could not handle the disease, they preferred traditional medicine. As an illustration, a mother suggested herbal treatment to her daughter, based on her belief in its ability:

"So I told her that we should first take it for herbal treatment because I know a lot of people who have successfully used traditional medicine for treating these kinds of breast diseases" (Mother).

Due to their previous encounter with a hospital, the majority of patients' family members suggested that they were not sufficiently satisfied with the quality of care to recommend it to their loved ones. For example, a daughter decided that she would not allow her mother to undergo a suggested surgery, due to a lack of trust regarding the quality of care at that hospital:

"When she reported to me that the doctor would like to remove a piece of her breast for examination, I advised her not to go there again. Then I told her that we should look for a solution elsewhere because I did not know how that hospital operates" (Daughter).

Other family members also attributed the delay to the investigations and diagnostic process at the hospital. One daughter explained that her frustration at the hospital prompted the use of traditional treatment:

"In the three months that we were waiting for her results, we went there so many times and each time we went, they told us that the report was not

ready. So for this, I was not motivated to follow up at that hospital. Instead, we got help from elsewhere" (Daughter).

Instead of seeking traditional medicine from practitioners, some family members used known remedies that had been passed down over generations. A typical example is a husband who self-treated his wife at home for a long time:

"I called my father and asked him to tell me the type of medicine he used to treat his wife. My father gave me instruction on how to prepare the herbal medicine, which I used on my wife's breast. After applying the medicine for several months, we did not notice any improvement and it was increasing in size" (Husband).

Tension between patients and family

Family members often reported that if the patient had informed them earlier, they could have supported them sooner. According to the information from family members, the reasons why patients failed to confide in them included: fear of abandonment by their husbands, lack of trust among family members, anticipated pressure from families to seek modern treatment, and a concern not to be a burden on the children. This disagreement between patients and family members, around the time patients disclosed the signs to them, contributed to delayed presentation.

Perceived fear of spousal abandonment was one of the reasons some patients delayed disclosure. One husband illustrated how his wife feared that if she informed him of the sign, he might leave her for another woman:

"Since we got married, she has been having challenges with the inability to maintain the pregnancy to full term. As a result, she was always saying that I should not divorce her. Even though it was not my intention to do so, when she discovered this one [lump], she thought it would make me leave her, so she kept it away from me" (Husband).

Family members disclosed that patients could not trust them enough to share their personal problems. The women were afraid that their private information would be made public and cause embarrassment for them. One daughter described how her mother put more trust in her friends than herself:

"My mother did not help me. Why am I saying that? She was only discussing it with her friends and listening to their advice. If she had made me aware

at the early stage of the disease, it would not have gotten to this stage"
(Daughter).

Other family members pointed out that due to differences of opinion in healthcare use, patients withheld information from them for fear of being forced to the hospital to undergo possible breast removal. A daughter thought that fear associated with breast removal is what made her mother keep it to herself, as described below:

"She still had it in her mind that if she went to any hospital, her breast will be cut off and she would die. You see there is a general belief that when patients with breast problems are taken to the hospital they (Doctors) usually cut the breast and they (patients) do not survive long after that"
(Daughter).

Another family member showed that it was the difference in the opinion he had with his mother on the type of healthcare to use that prompted the mother to keep the signs to herself.

"Since she knows that I do not believe in those things and would never agree with her use of traditional medicine, if she had told me, I would by all means have forced her to go to the hospital. But, she kept it away from me" (Son).

Some family members were not informed about the problem because the patients did not want their problem to be a burden on the children.

"She kept it to herself because since it's not too long ago that we lost our father and we have taken over the running of the family; she was sympathizing with us and did not want to add more worries to our lives"
(Daughter).

4.3   Findings from interviews with healthcare professionals

This section presents findings from the interviews with the healthcare professionals. The interviews were designed to explore the beliefs of healthcare professionals regarding why patients delay seeking care for their breast cancer symptoms.

4.3.1   Characteristics of the healthcare professionals

The healthcare professionals' data were from eight participants: two males and six females (Table 13). There were three general practitioners (GP), two medical assistants (MA), one registered nurse (RN), one nurse oncologist (NO), and one surgical oncologist (SO). Their work experience ranged from 3 to 15 years. A medical assistant is an allied healthcare professional who supports physicians and other healthcare professionals, usually in a clinic setting. The nurse oncologist is a specialist cancer nurse who provides care for cancer patients.

Table 13 Characteristics of the healthcare professionals

Characteristics	n (%)
Gender	
Male	2 (25.0)
Female	6 (75.0)
Years of experience	
Less than 5	2 (25.0)
5-10	1 (12.5)
11-15	4 (50.0)
More than 15	1 (12.5)
Specialty	
Registered nurse	1 (12.5)
Nurse oncologist	1 (12.5)
Surgical oncologist	1 (12.5)
General practitioner	3 (37.5)
Medical Assistant	2 (25.0)

4.3.2   Themes and sub-themes from the healthcare professionals

The interviews with the healthcare professionals (HCPs) identified four themes regarding why they believed patients delayed presentation: cultural beliefs and practices; lack of trust in the modern healthcare structure; societal perception of breast cancer on patients, and; Knowledge and awareness of cancer amongst patients (see Table 14 for details). These, in turn, yielded eleven sub-themes. These themes were similar to those identified within the data from interviews with patients and members of their social networks, supporting those themes but also providing additional perspectives to them.

Table 14 Themes and sub-themes from healthcare professionals

Themes	Sub-themes
1. Cultural beliefs and practices	1.1 Submitting to decisions of others 1.2 Traditional beliefs about breast cancer 1.3 Religiosity 1.4 Patients preferentially seeking traditional healing
2. Trust in modern healthcare	2.1 Poor access to care 2.2 High cost 2.3 Concerns about patient-healthcare professional relationship
3. Societal perception of breast cancer	3.1 Lack of partner support 3.2 Avoiding social stigmatisation
4. Knowledge and awareness of cancer amongst patients	4.1 Insufficient awareness about symptoms and personal risk 4.2 Impact of cancer diagnosis

These findings are expanded upon below.

4.3.3   Theme 1: Cultural beliefs and practices

The healthcare professionals indicated that patients' cultural beliefs impacted on their knowledge of risk factors for cancer, as well as the meaning of the disease, which guided them to respond to the symptoms emotionally, cognitively, and socially, as demonstrated by their help-seeking practices. The cultural factors that were perceived as influencing the late stage at diagnosis were: submitting to decisions of others, traditional beliefs about breast cancer, religiosity, and patients preferentially seeking traditional healing.

Submitting to decisions of others

In Ghana, where husbands control most women's decisions and actions, this sub-theme explains how the decisions of significant others delay patients from seeking medical treatment. The HCPs explained how the patients tell them in the consulting room that sometimes it is the action of their husbands that delay them from the presentation. They become afraid that if they do not listen to them, they stand the chance of losing them and their livelihood as well. To illustrate, one of

the GPs talked about how the decision of a husband for one of his patients contributed to the delay of his wife's diagnosis:

> *"This patient initially attended a local clinic when she first identified the lump. She was referred to the regional hospital for further evaluation. When she informed her husband, he said he had no money for her to cover medical cost in the city. He believed that if his wife travelled to the city for medical evaluation, she stood the chance of losing the breast through surgery and die or it could be too costly for them. He insisted that they go to the prayer camp to see if prayers can help them in those ailments. At times also, they go to fetish priests to see if they can heal them because some people claim that those places can heal those diseases"* (GP).

The HCPs acknowledged that patients are not getting the right messages through media outlets. They identified the television and the numerous radio stations as a common place where some patients make their decision on healthcare for their breast symptoms. For example, there is an advertisement by traditional healers, which says that they have medicine that will dissolve the lump, hernia, and fibroid.

The oncology nurse clarified the impact of the misleading advertisements in the media:

> *"Patients who listen to these programmes develop a preconceived notion that there is medicine for dissolving the lump so if a health professional tells them that their lump can be removed by surgical means, they run away to look for that medicine, which can dissolve the lump"* (ON).

The intensity of media advertisements on promoting traditional healing for breast cancer confuses patients, as exemplified by one of the GPs:

> *"Yes at times, I think patients are caught in the middle not knowing which direction to take between traditional healing and the conventional way"* (GP).

Traditional beliefs about breast cancer

Factors that contributed to the development of this sub-theme include fatalistic thinking, evil spirit involvement, and patients preferentially seeking traditional healing. All the HCPs acknowledged that the view many patients have about breast cancer is that it is the kind of disease that has no treatment. Hence, once they develop it, their belief is that death is imminent. This fatalistic thinking can

be the basis for their decision to initially use traditional treatment and a reason for patients presenting with late-stage disease.

One medical assistant noted that it is a generally accepted concept in Ghanaian society, that breast cancer is associated with death.

> *"There is a general belief among Ghanaians that breast cancer is untreatable and once it is detected at the hospital the breast will be cut off and soon after that the patient dies"* (MA).

Similarly, there is also a common misconception that if the patient went to the hospital to be told that she has breast cancer, it would mean that she would die of the disease. To avoid the possibility of being told she has the disease, most patients would choose to stay away from the hospital as much as possible.

The majority of Ghanaians are highly superstitious and believe in the other types of healing rather than the modern form, because of the belief that if the hospital is not able to cure the problem then it must be spiritual. The oncologist clarified this point:

> *"When a patient comes to the hospital for a blood test, for example, and everything seems normal but the patient still does not feel well, then they start saying that it must be something not physical but spiritual"* (SO).

Some patients interpreted dreams as a spiritual revelation of their breast problems. In their minds, patients think they would have to undergo a spiritual process such as fasting for days in order to avert any calamity. One of the nurses shared her experience using a patient's story:

> *"The patient said that she dreamt that a dog was chasing her and the dog eventually bit the left leg, and when she woke up she felt pains in her left breast. This made her believe that her breast problem is spiritual. She contacted a prayer camp where she received prayers for nearly six months, to no avail"* (RN).

There is also the belief that women can experience breast cancer as a result of disruption in the relationship between the individual and the spirit world, or an attack induced by another person through supernatural means. One of the GPs described how a patient believed that her problem was a jealousy induced curse that warranted a spiritual remedy:

"The patient said that although she has given birth to seven children, she never experienced any swollen breasts while breastfeeding them, so why now? She thinks it is a curse from someone who is jealous of her. The patient did not see the hospital as the place to go because she believed there was a spiritual involvement and needed a spiritual solution" (GP).

Patients preferentially seeking traditional healing

This sub-theme describes how the HCPs recognised that the patients' persistent belief in witchcraft causing harm to their breasts requires them to take appropriate steps to ward off the activities of witchcraft. Key principles involved are the use of herbal treatment and spiritual healing. Thus, traditional treatments such as herbal preparations and prayer camps are the most frequently used sources of healing.

One of the nurses discussed how the treatment of one of her patients for what was suspected by a herbalist to be a boil prolonged the interval before she sought medical treatment:

"This patient was given a cream to apply on the breast. The herbalist told her that what she had in her breast was a boil so the cream will cause the abscess to come out. With time and as the lump was increasing in size, she thought that the cream was working. She spent about five months at this place applying creams till the herbalist confirmed that the cream was not working" (RN).

The HCPs were cognisant that patients' fear of surgery originated from the apparent fear of death from the modern medical procedure, thereby enhancing the position of traditional healers. Commenting on the current influx of traditional medicines, one of the GPs said:

"We have seen that the excessive use and preference of traditional medicine over conventional medicine is having a negative effect on patients presenting late for medical evaluation. They spend all the time visiting these places" (GP).

The healthcare professionals believed that many of their patients have a preconceived notion from the spiritualists that a breast disease symptom is spiritual, and linked to witchcraft or some evil spirit, therefore patients think they should go to a prayer camp and pray, instead of attending the hospital with their breast problem.

One of the nurses recognised that the large number of these spiritualists makes it convenient for the patients to go to them rather than travelling to the hospital:

"But you know now we have a whole lot of spiritualists appearing. I don't know where they are coming from and people believe in them that they can get their diseases healed rather than come to the hospital and go through all the troubles at the hospital" (RN).

Besides the many spiritualists, the HCPs admitted that the belief of her social network and the community can also influence a patient to prefer traditional healing over modern medicine. One of the GPs said:

"If the community where the patient lives have people that are used to going to the herbalist, there might be a lot of influences on her to make the wrong decision about healthcare choice such as the unorthodox system for breast cancer" (GP).

4.3.4   Theme 2: Trust in modern healthcare systems

Poor access to care, high cost, and concerns about the patient-healthcare professional relationship were factors that generated mistrust among the patients and contributed to their delayed help-seeking behaviour.

Poor access to care

The HCPs agreed that the lack of healthcare facilities, which are capable of diagnosing and treating breast cancer within reasonable distances of a patient's home, create a significant barrier to help-seeking. Accessibility issues such as the geographic distance between the patient's home and healthcare facilities, transportation, and the complicated and often frustrating referral system contributed to delayed presentation. In situations where the patient needs to travel for more than five hours to a hospital that is in a strange environment, with no relatives around to host them, moving around the city becomes a challenge for such patients. Many women facing such experiences give up and look for a more convenient traditional source of treatment closer to home.

One of the GPs described how some of the patients, who do not have accommodation, spend the night in the city:

"I have heard some patients even sleep on the benches at the hospital. The security allows them to sleep there for the night so that they continue with

treatment the following day till they finish and then leave. So it's not easy
for them but we have no choice" (GP).

Since there are only a few hospitals in the country with the necessary equipment
and personnel to manage breast cancer, all the other peripheral hospitals are
forced to refer breast disease symptoms to these specialised hospitals. As a
result, these hospitals are not able to manage all the cases referred from the
clinics, district hospitals, and regional hospitals. One of the nurses commented:

> *"The patients too feel that they are just wasting their time when they come*
> *to the hospital; there are far more patients than the doctors can handle. So*
> *patients don't come until they are unable to bear the pains, contributing to*
> *late stage presentation"* (RN).

High cost of care

There was a consensus among the HCPs that poverty is also a huge problem
among the patients who come to them. The HCPs confirmed that although many
of these patients were registered within the National Health Insurance Scheme
(NHIS), the scheme did not cover the investigations for breast cancer. It only
covers some treatment. One of the registered nurses shared the financial struggle
patients go through:

> *"Patients need to have access to some money to take care of out of pocket*
> *medical cost and other expenses such as transportation and meals. So when*
> *they think about all these expenses that they are not able to afford they*
> *would rather not go to the hospital"* (RN).

Although some of the patients know that medical intervention is preferable, they
may not have the financial means to fulfil what they believe may be the right
thing to do. One of the medical assistants illustrated this point regarding how
one of his patients, who was a peasant farmer, prolonged symptom presentation:

> *"She did not have enough money to go to the hospital by herself without help*
> *from external funding sources. With the little money she was able to raise,*
> *she attempted to seek medical intervention from at least two other hospitals*
> *but the money ran out quickly. She eventually left the hospital system and*
> *started using traditional medicine"* (MA).

Concerns about patient/healthcare professional relationships

The HCPs recognised that patients' lack of confidence in the modern healthcare system contributed to their delay in using it. Factors such as breast symptoms being previously misdiagnosed, limited diagnostic equipment, a limited oncology workforce, lack of skills amongst the oncology workforce, and unprofessional attitudes of some healthcare professionals, all contributed to the women's lack of trust in modern healthcare.

Half of the HCPs (n=4) reported that in most cases, patients lack confidence in medical professionals, due to breast symptoms being previously misdiagnosed. Telling the patient that nothing was wrong with her could also make the patient relax, and make her believe that she is alright and nothing serious would happen to her. Such patients think that as they have been to the hospital, and the doctor says nothing is wrong, they would not seek a second opinion for a long time.

To clarify, the oncologist reported a situation concerning a 34-year-old patient who presented with a huge breast mass:

> "*When I asked her the purpose of her consultation, she said she had gone to the hospital before but the doctors told her that they did not see anything wrong with her so she relaxed. But the tumour grew to the extent that she could not even go to church anymore until someone advised her to use herbal medicine, which has not helped her*" (SO).

Another area that the HCPs reported as causing frustration for patients was the assessment process, especially the lack of efficient diagnostic equipment in treatment facilities. For example, the majority of the hospitals do not have a mammogram machine and those that have experience frequent breakdowns. In such situations, patients are sent to private diagnostic centres to perform the procedure. Speaking about the status of the mammogram machine at one of the study hospitals, one of the nurses said:

> "*Since our mammogram machine broke down about three years ago, we tell patients to go outside in town. Therefore, we have to direct them to places where they have the mammogram machines to do them. This is not easy at all for those who travel from far places. Imagine a patient who comes from Tamale who has to do a mammogram in Kumasi. Since the mammogram report is not ready for at least three days, does she go back to Tamale and come back?*" (RN).

Even if she can complete the mammogram in three days, that third day will not be the day she is supposed to see the doctor again. That means she could collect the report, go back to Tamale, and then return to the clinic on the day she is due to meet the doctor again. Furthermore, if a patient met with the doctor on a Monday, she would be allowed to see the doctor only on Monday, meaning every patient has her specific day for seeing the doctor.

> *"So when a patient who meets the doctor on Mondays receives her diagnostic report on a Wednesday, she needs to wait until Monday before she could see the doctor and discuss the problem. What if the doctor does not show up? This experience, which is not convenient for many patients, turns them away from the hospital"* (MA).

All the HCPs recognised that there is also a lack of clinical specialists in the system to treat breast diseases; in particular, the health centres and clinics do not have the appropriately trained personnel for breast health issues. Due to the shortage of doctors in the country, nurses typically manage public clinics, and health centres. These nurses are normally the first point of call for all health issues and because no specialised oncology nursing school exists in the country, most nurses have little knowledge of breast cancer. One of the medical doctors said:

> *"For instance, even if a patient reports a breast problem to a healthcare professional such as a nurse, because the professional does not have the necessary knowledge, the healthcare professional will not put the patient on the bed to examine the breast to know if there is a lump somewhere in the breast"* (GP).

In addition, the HCPs asserted that in most of the tertiary hospitals, the general surgeon is the one taking care of breast cancer patients. It is the same doctor doing appendectomies and many other procedures. Thus, when a breast cancer patient comes to seek medical attention at the hospital, she is not given any distinctive service as a patient who needs to see a specialist. To illuminate this issue, one of the nurses said:

> *"…and breast surgery too, it is the same general surgeons who come here that perform it. We don't have specialist breast doctors at this hospital. Yes, they are all general surgeons. So they handle general surgery cases but they do come here to see breast cases. They are also not bothered about*

seeking training for breast something because they are general surgeons and are satisfied with it" (RN).

The HCPs were aware that the majority of the patients who present late with advanced cases were often untruthful about their experiences. They do not reveal all to the healthcare professionals, especially about the date when they initially identified the signs. When asked, patients present their stories eloquently to avoid a possible 'scolding' from the healthcare professionals. For example, the oncologist said:

> *"When patients narrate their stories, they try to associate the changes they have in their breast with some incidents they had some time ago, which may just be coincidental. For instance, one patient told me that a handbag hit her breast when she was lifting it from the wardrobe and after a while, she noticed the lump in the same breast hit by the bag. So it's always difficult for us to know whether they stayed for three months, six months, or one year to predict how long the disease has been there"* (SO).

One of the GPs who was talking about a colleague mentioned that unfortunately some health workers have the habit of shouting at patients, if they speak the truth about why they have delayed for so long before coming to the hospital:

> *"Why have you stayed too long in the house for this thing to rot before you brought it?"* (GP).

Under these circumstances, a patient who has been subjected to an aggressive treatment by a healthcare professional will most likely be reluctant to go back for further medical consultations.

4.3.5 Theme 3: Societal perception of breast cancer

The HCPs views about what patients believe about breast cancer include beliefs that it is an incurable disease, that evil spirits cause breast cancer, that it is a curse on the family, or the result of a person's failure, and that a woman will die from a mastectomy create societal stigmatisation. Consequently, patients felt themselves unable to inform anybody about their predicament. Lack of partner support and avoiding social stigma delayed patients from seeking medical attention.

Lack of partner support

Lack of partner support and concerns regarding being abandoned by their husband contributed to delays in seeking medical help. The patient's concern about being less attractive to their partners, as well as the anticipated fear of partner abandonment identified in interviews in the order two samples were explained further within the interviews with HCPs. The HCPs reported that patients regard the breast as a symbol of womanhood and beauty, and therefore any problem around it is detrimental to themselves and their families. As a result, their thought of a 'horror' of mastectomy, patients see themselves as deformed, thereby diminishing their social status on marriage, child bearing, and also creating a reason for divorce. Due to the severe reaction of some husbands, patients believed that losing the breast makes them incomplete as women. Therefore, the majority of the patients who observed any abnormality would do all they could to keep it a secret, and would delay help-seeking. One of the nurses made the following remark:

> *"The reason why patients who consult me avoid the hospital is that they don't want their breast to be removed. They see themselves deformed if their breast is removed. You see the woman's breast is very important for several reasons. For the woman, the breast is a sign of beauty; it makes the woman a real woman"* (ON).

This idea creates a perfect environment for traditional healers who claim they have powers that not only cure cancer but preserve the breast as well. Undoubtedly, their messages resonate well with the patients, diverting them from seeking modern medical care.

According to the HCPs, some patients also believe that breast cancer is a contagious disease that can spread from one person to the other through personal contact, so creating the fear that if their husbands know about it, they would abandon them. One of the nurses explained this:

> *"Some spouses have deserted their partners as a result of this belief. So patients who are mostly the victims would feel it's better for them not to tell anyone for fear of abandonment"* (RN).

Avoiding societal stigmatisation

Considering the importance placed on the breast and its role in Ghanaian society, patients feel obliged not to disclose problems regarding the breast to others. This

sub-theme describes what the HCPs thought about how societal stigma associated with breast cancer, contributes to a patient's delay in seeking medical help. The HCPs showed that traditional beliefs, such as evil spirits causing breast cancer, create a social stigma in the form of embarrassment, not only to the patient but also to her entire family. Relating to one of her patients, one of the nurses commented that:

> *"This patient heard about the evil spirit involvement with this disease and therefore thought it wise not to tell anyone about it. She was afraid that if people spread her story about the problem in her breast, that will be bad for her status and damage her political ambitions"* (RN).

To ensure that patients can keep the symptoms to themselves, and not inform anybody, the oncologist commented on how some patients have developed a strategy on how to accomplish this:

> *"When someone living in the city develops breast cancer, she would rather move to the village and nobody would know what happens to her again. She simply gets missed out from the system"* (SO).

The physical manifestation of the advanced stage of breast cancer, such as an offensive odour and enlarged breast that no longer fit clothes, also creates isolation for victims, thereby motivating them to seek help elsewhere, besides the hospital. One medical assistant used a patient's case to illuminate this point:

> *"She went and used the herbal medicine for a while and the mass in the breast was still growing to the extent that she could not even go to church or attend any social function anymore because she could not wear any of her clothes anymore"* (MA).

4.3.6   Theme 4: Knowledge and experience of cancer

Accurate symptom interpretation can be influenced by the nature of the symptoms, the patient's level of knowledge of the disease, and their perception regarding being at risk of breast cancer. Insufficient knowledge leading to misinterpretation of signs and the impact of a cancer diagnosis were identified as limiting factors for medical help-seeking.

Insufficient knowledge of symptoms

The healthcare professionals (HCPs) considered the patient's lack of knowledge on breast cancer symptoms and risk factors constituted a major reason for her delayed presentation. All the HCPs reported that they thought the painless nature of a developing lump does not usually raise concern for the majority of patients who do not have specific knowledge and experience about breast cancer in order to alert them to take the necessary action.

Commenting on a patient's ignorance of the symptom, one GP said:

> *"Her hard substance was not painful at all but she kept touching it constantly to see if it would go away. Because it was not painful she did not see it as a problem to worry until after four months when the breast started to increase in size"* (GP).

This patient lacked the basic knowledge about the signs and symptoms of breast disease. Although she observed that her breast was increasing in size, she could not understand why she should go to the hospital to seek help when there was no pain. Instead, she rather thought her condition was normal, or at least non-threatening, and would go away.

The HCPs acknowledged that, in Ghana, people do not usually go to the hospital unless they are very sick or have some severe pain somewhere in the body.

> *"To be honest with you, I have not encountered many patients who came to see me with typical breast cancer symptom within three months. Usually, patients come with breast diseases from other conditions early when there is pain and so normally those are abscesses or mastitis or maybe some fibrocystic diseases. But in cases of breast cancer, normally because there is no pain, they think there is no danger"* (SO).

The healthcare professionals noted that, in most cases, they meet patients who do not even know that they have lumps in their breast, a situation explained by a nurse:

> *"I had this patient who did not even know she had lumps but she came in with the complaint of pain in the breast. It is by performing clinical breast examination that I realised that there was a lump. When I asked her she said she did not know about any lump in the breast. She insisted that she never had any problem with her breast until now"* (RN).

Besides patients' lack of specific knowledge on cancer, the HCPs argued that patients who do not have formal education have limited exposure to risk factors and, more importantly, where to go for medical consultation unless they are directed appropriately. Describing a patient with an enlarged breast mass, who was not aware of the necessary steps to take for seeking healthcare, the oncologist said:

> *"She was looking for help but from the wrong places. The different places she has gone to, different towns and villages, different kinds of spiritual healings she has gone through made me feel sad for her"* (SO).

According to the HCPs, the level of exposure to breast diseases for most of the patients they encounter was very low, giving room for myths and misconceptions about the disease. Usually, patients who ignore their breast mass and delay medical evaluation, depend on the knowledge they acquire from their social network instead of getting an opinion from a professional. One of the medical assistants noted that:

> *"Peer pressure has a huge influence on the patients. They tell us in the consulting room that their friends usually advise them not to go to the hospital because there is the belief that if they go the hospital and be diagnosed with cancer, their breast would be cut and they will die within a very short time"* (MA).

Lack of knowledge creates denial of the possibility of cancer, which leads to ignorance of the symptoms. The registered nurse (RN) talked about one patient who presented a large lump in the breast with peau d'orange, consistent with the advanced stage of breast cancer. The patient appeared very ignorant of her personal risk of developing the disease, as demonstrated by the nurse:

> *"She did not know what was going on in her breast and denied she could have breast cancer because there was no one in her family with cancer. She did not know whether this was a disease that can be treated at the hospital or curse from an evil one"* (RN).

As this patient thought that her chance of getting cancer was low, she also lacked the motivation to check at the hospital regarding what was growing in her breast, a situation that influenced her delayed presentation.

Impact of cancer diagnosis

The anticipation of a breast cancer diagnosis is considered a very stressful event for patients and their families. This sub-theme explains how patients who were fearful of cancer diagnosis delayed presentation. As communities continue to experience premature death from cancer, among friends and family members, the fear of the disease remains with them. Evidently, the perception of fear of breast removal was the most common obstacle among patients for early presentation, as suggested by all the HCPs. Specifically, they described how patients expressed their fear of dying from mastectomy, as if the treatment was worse than the disease itself.

The HCPs reported that patients believe breast cancer is associated with death as a result of surgery. Patients think that once they take their symptoms to the hospital, their breast will be amputated, followed by their subsequent death. As a result, they equate breast cancer to a death sentence. In fact, in some communities, the term 'breast cancer' is almost considered a taboo for people to talk about. One of the nurses noted that since patients think that their breast would be removed if diagnosed with cancer, they were reluctant to seek modern treatment:

> *"About 70% of our patients run away from mastectomy because they believe that when patients undergo a mastectomy, the maximum time they can live is six months, thereby accentuating the misconception that patients die after a mastectomy"* (RN).

In support, the oncologist said:

> *"The fact of the matter is that about 80% of the patients that come here come at the stage when surgery may be the only treatment option to save their lives. Of course, in the process, some of them die not because of the surgery but because of metastases. At stage 3 or 4, patients have 50% chance of survival"* (SO).

Another GP showed that, in addition to a fear of death, fear of the unpleasant side effects of chemotherapy, discouraged patients from seeking treatment at the hospital:

> *"So I think it is the fear of death and fear of treatment side effects that make some patients avoid the hospital as much as they do to dodge the possibility of being told they have the disease"* (GP).

4.4 Integration of findings

To gain a comprehensive understanding of the delayed help-seeking phenomenon, findings from individual interviews involving experiences of patients, insights from the social network, and the perspectives of healthcare professionals have been brought together to provide a deeper understanding of the symptom appraisal and help-seeking behaviour of Ghanaian women with breast cancer symptoms. Thematic synthesis was used to integrate the research findings (Thomas & Harden 2008). This process entailed comparing codes used to generate the themes to identify recurrent concepts and patterns between themes, which were subsequently organised into a framework of descriptive themes (Table 15).

Table 15 Framework of descriptive themes

Themes	Description
Strong cultural and religious beliefs	• Patriarchy and deference • Preference for traditional medicine • Superstitious beliefs about cancer
Mistrust in the modern healthcare structure	• Poor accessibility • Concerns about patient-healthcare professional relationship • High cost of care
Influence of the social network	• Opinion of others regarding interpreting bodily changes and about the type of medical help-seeking • Providing advice on healthcare • Protecting family from societal ridicule • Inadequate social support • Media publicity
Emotional reaction to symptoms	• Fear of death from surgery and side effects of chemotherapy • Fear of social stigmatisation • Fear of spousal rejection • Fear of diminished womanhood

Themes	Description
Knowledge and awareness of cancer amongst patients	• Insufficient symptom awareness and personal risk • Impact of cancer diagnosis

All themes were discussed with supervisors and checked, so as to ensure that the themes from the synthesis represented the respective findings and described the delayed help-seeking behaviour phenomenon of 35 Ghanaian women with breast cancer symptoms. Based on the themes and sub-themes that emerged from the interviews, eight areas that showed up strongly as dynamic factors, contributing to the patients' delays in seeking treatment, are now described below.

Strong cultural and religious beliefs

Patients' responses identified cultural beliefs and practices central to the decisions and actions that were taken or, more pertinently, were not taken. The patients' understanding of the symptoms and treatment was found to be influenced mainly by superstitious beliefs about the origins of cancer, leading them to believe that the symptoms could not be thoroughly treated with modern medicine. The majority of the patients believed that their breast cancer symptom was a fatal disease and a curse from an evil spirit. In addition to agreeing with the fact that evil spirits cause cancer, their social networks expanded on the evil spirit idea to imply that breast cancer signifies a spiritual discourse within the family. Similarly, the healthcare professionals thought that since the majority of Ghanaians are highly superstitious and believe in the effectiveness of traditional healing, most patients that come to them report late. The patients do this because they think their problem is spiritually connected, and therefore the hospital will not be able to find the problem and treat it appropriately. Identifying these unique cultural beliefs and practices served as the basis for how participants responded to their breast cancer symptoms.

With a strong belief in the spiritual nature and causes of breast cancer, the patients thought it was appropriate to seek a spiritual intervention. This was in the form of spending time with a fetish priest or at a prayer camp. Although the members of the patients' social networks did not say how they were spiritually involved, the patients discussed how the social network supported their spiritual healing process. On the other hand, the healthcare professionals believed that patients spent precious time at these places believing that a divine miracle would

heal them. The HCPs shared their views on how these spiritualist practitioners prey on the vulnerability of patients, making them believe the disease is spiritually linked. Cultural and religious beliefs ignited fear among the patients regarding death, social stigma, spousal abandonment, and the side effects of modern medical treatments.

Although, data presented in Table 8 show that there are unequal proportions of religious affiliations amongst patients, with 86% declaring themselves as Christian and 11% as Muslim, patients were consistent with their belief that a spiritually linked disease could not be physically treated through modern medicine. Consequently, the majority of both Muslims and Christians spent considerable time seeking help with spiritualists at prayer camps. Age similarly did not appear to differentiate patients in their help-seeking behaviour. Most patients, irrespective of age, perceived spiritual causality of cancer as the main reason for its associated social consequences (e.g. spousal ostracism and stigma).

Preference for traditional medicine

Both the patients and the healthcare professionals highlighted preference for traditional healing over modern healthcare. Patients who believe in supernatural causality prefer to seek help from traditional healers instead of modern medical sources. For the patients, their main reason for avoiding modern medical treatment was the possibility of losing their breast through surgery, as mastectomy is seen as the most commonly available treatment for patients who seek breast cancer treatment at the hospital. Apparently this claim is largely true, being based on their experience with other people who previously developed breast disease and attempted to seek help at the hospital through surgery. Patients strongly perceived that the most common treatment option at the hospital is a mastectomy.

Related to losing a breast is the strong social stigma associated with cancer sufferers, as patients not only have to cope with the shock of having the disease but the hostile reaction from society at large. Ghanaian society perceives that when a woman's breast is removed, it would mean either death or reduced womanhood. The perceived 'deformity' resulting from a mastectomy has resulted in some husbands abandoning their wives and marrying other women. Therefore, fear of the adverse reaction of some men to the disease pushes the patients to seek help from non-medical sources, a choice that further prolongs modern medical treatment. The healthcare professionals mentioned that most of the

patients demonstrated their disapproval regarding mastectomy by abandoning the surgery treatment after discussing that option. The professionals believe that when the patients 'escape', by deliberately avoiding surgery, they do not go home and do nothing. Instead, they turn to traditional medicine, informed by the advice and support from their social network. However, in most cases these patients return to the hospital when the disease has advanced to its later stages.

Patriarchy and deference

Obedience to the authoritative social structure is a strong cultural element in Ghanaian society that the married patients indicated was a limiting factor to modern medical help-seeking. They suggested that the culture allows a married woman to be viewed by the husband as "property", with little personal autonomy to implement preferences that they may have as individuals. Apparently, they said that even minor decisions related to the household finances involved their husbands' approval and, as women, they were obliged to obey their husbands' decisions. In the course of the interviews, some patients mentioned that as much as they wanted to seek medical help, the husbands did not support this desire. The healthcare professionals confirmed that patients often discuss with them the disagreements they have with their spouses, regarding the type of healthcare to choose. Patients reported that they are culturally obligated to obey their husbands for fear of losing them to other women. Furthermore, the healthcare professionals revealed that the advice patients receive from friends, family members, and other patients or peers, which is based on personal experience, seemed to influence their decisions.

Media publicity

The healthcare professionals also emphasised that uncensored TV and radio programmes about breast cancer, which were often misleading as regards the effectiveness of traditional healing and encouraging patients to choose this treatment pathway, were influencing patients. Thus, such mass media material appears to have a considerable impact on the patients' late presentation of their symptoms. Moreover, using the influence of media advertising, especially radio and television, traditional healers can divert patients with breast cancer symptoms away from modern healthcare. The conflicting messages in the media regarding the benefits of traditional medicine, i.e. that it can dissolve breast lumps making surgery unnecessary, were likely to engender mistrust in the modern healthcare system. While the majority of older patients paid more

attention to the benefits of traditional healing messages from the TV and radio, younger patients depended more on the internet and social media for information about the symptoms detected.

Trust/mistrust in the existing modern healthcare structure

Mistrust in the existing modern healthcare structure was a consistent finding in both the patients' and the healthcare professionals' interviews. The patients talked about problems accessing the healthcare facilities regarding long distances between their homes and those healthcare facilities that have the capability to evaluate and diagnose their symptoms. In addition, they talked about the complicated and ad hoc referral system, which they were not able to fully follow. Patients who decided to use the modern healthcare system, either through referral or because they believed in its efficacy, experienced poor access to healthcare services due to difficulty arranging money for transportation and long distances between patients' homes and healthcare facilities. Patients identified these accessibility issues as important barriers for timely medical treatment seeking, and subsequent delays often created anxiety and mistrust of the modern healthcare system that led patients instead to seek traditional medicine.

Furthermore, the previous unpleasant experiences patients had with some healthcare professionals were also an important factor that discouraged them from considering modern healthcare as a first choice for their breast cancer treatment. Previous patient interactions with healthcare professionals, such as their lack of attention to patients' emotional concerns, unfriendly attitude towards patients, and poor quality of communication were identified as barriers to early presentation. Some patients also expressed mistrust of doctors, citing concern about possible misdiagnoses of their symptoms. Some patients who had initially sought help from HCPs about symptoms, had been told they were benign, and then sought help from traditional medicine due to the worsening of symptoms.

Finally, patients discussed their financial challenges in managing the cost of cancer care within the modern healthcare system. They reported financial burdens in terms of the affordability of healthcare and the limited health insurance coverage, which influenced their presentation of symptoms within the modern medicine system. Financial burdens that limited patients' healthcare access created anxiety and fear of death; since for most of the patients the hospital had become their last hope. Subsequently, all these issues created

practical and system barriers that influenced delays in choosing medical diagnosis and treatment.

The healthcare professionals provided valuable insights not only about why patients delay medical help-seeking, but about also how the healthcare system deters patients from using it. Long distance patients had to travel to the specialist hospital and often the professionals were general surgeons, and not specialists in performing breast surgery. The lack of oncology specialists, which is perceived to facilitate surgical complications and misdiagnosis, leading to a large number of cancer deaths, discouraged patients from seeking help from modern healthcare. In addition, patients were also limited by the use of use of modern drugs to treat the disease, because such drugs are costly and come with unpleasant side effects. All these issues contributed to the patients' lack of confidence in the modern healthcare system. Furthermore, these created a strong deterrent concerning the use of modern healthcare, thus resulting in patients choosing the alternative of traditional medicine.

The healthcare professionals acknowledged that the limited number of hospitals in the country with the ability to treat cancer was one of the reasons why patients struggled so much to access the specialised hospitals; which, in reality, put many patients off seeking modern medical attention. Consequently, patients strongly believed that it is the surgery that is dangerous and not the late presentation of the disease. Patients thought that when they took their breast symptoms to the hospital, the entire breast would be 'amputated', and result in subsequent death following removal. This cultural belief generated a lot of fear among the women who planned to use the hospital as the first point of call with the disease. In fact, most of the patients believed that cancer was a deadly and incurable disease and very few of those interviewed knew of women who had survived the disease in their communities. The underlying mistrust results from many years of witnessing loved ones die at the hospital after undergoing breast surgery. For those patients, breast cancer equated with death, generating a fear of modern treatment. In addition, some younger patients reported fearing the side effects of cancer treatments, such as hair loss. They consequently feared modern medicine and preferred traditional medicine instead. For these reasons, affected women were less likely to seek help for cancer symptoms, thereby contributing to delayed presentation.

Role of social network

In most Ghanaian societies, having relationships with other members of the community, and the interconnectedness between people, plays a dominant role in each person's identity. Therefore, by disclosing the symptoms to others and seeking their advice, patients gained knowledge that was socially constructed, influenced by cultural beliefs, and contained explanations that determined the next course of action. When the patients identified the body changes, they interpreted the symptoms from a sociocultural perspective by disclosing those changes and symptoms to close friends and family members. The patients used trusted friends and family members as a source of support, information to interpret symptoms, and advice for healthcare utilisation. Another belief among younger participants was that every woman develops lumps in the breast and as they age, the lumps would suddenly disappear. This belief reassures them, hoping that their lumps will dissolve with time. The younger patients are also very secretive about disclosing symptoms to others in the community, fearing that "if anyone ever found out"; they could be labelled as abnormal. These patients were very reluctant to reveal their symptoms to anyone, except their closest friends and relatives.

As mentioned before, those in the social network also believed that evil spirits caused breast cancer. Hence, based on their knowledge, beliefs, and experience of the symptoms, the social network provided information to patients that was erroneous and led the majority towards using traditional medicine. Although members of the patients' social networks tried to raise money to support the patients, their attempts were unsuccessful in raising the necessary funds. As a result, a majority of the patients chose traditional medicine, which was perceived to be a cheaper option.

Members of the patients' social network mentioned another area of contention regarding the stage at which they were informed. Family members felt that patients did not inform them in time, due to fear of abandonment by husbands, lack of trust among family members, and pressure from them to seek modern treatment, all issues that contribute to delayed medical help-seeking. To prevent societal stigmatisation, the social network kept the symptoms of the patient confined within close family units, while searching for an appropriate solution. Keeping the symptom a secret was to ensure that the reputation of other women in the family were preserved for future marriages, since it is believed that the disease can be a curse on the family. Many men would avoid marrying a woman

from a family that was cursed. Subsequently, some family members even denied the possibility of cancer in the family, especially if there was no known history of a breast disease. While the younger unmarried women below about 30 years old worried about their prospects of finding a husband, mothers were concerned that the potential for their children to be married would be minimized if the community learned someone within their family had a 'cursed disease' such as breast cancer.

The healthcare professionals threw more light on the cultural and social importance of the breast, and its role in the society, as a reason for members of patients' social networks wanting to prevent mastectomies. Healthcare professionals emphasised the serious prevailing societal stigma associated with breast removal, as women are then considered deformed. In addition, lack of partner support was also an issue brought up by the healthcare professionals. They mentioned that there were some husbands who believed that breast cancer was a contagious disease that can be spread from one person to another, when living together. This made some husbands abscond if they learnt that their wives had a breast disease. For this reason, wives tried to keep the disease a secret from their husbands, therefore limiting their ability to seek medical help.

Emotional reactions to symptoms

The belief of breast cancer's link to an evil spirit or spirits is so strong that the community sees it as a shame in the family, inevitably diminishing the family's social status regarding marriage, child bearing, and a reason for divorce. Emotional reactions such as fear of death from surgery and concern about the side effects of chemotherapy, fear of social stigma, fear of husband's rejection, and fear of reduced womanhood, were emphasised by the patients as factors that influenced their decision to avoid medical help-seeking. These emotional reactions motivated patients, with the support of friends and family members, to seek help from traditional sources that promise to cover both physical and spiritual dimensions of the disease, have fewer side effects, are cheaper than modern medicines and treatment, and which fall within their cultural belief system.

Interpretation of symptoms

The healthcare professionals indicated that a lack of knowledge and awareness of breast cancer risk contributed to patients misinterpreting the signs of cancer. The lack of knowledge of cancer risk was also exemplified in the patients' interviews.

Since the majority of the patients initially had no pain, the growth of a painless lump was ignored by most of them and no action was taken until they experienced pain or the physical manifestation of an advanced stage of breast cancer, such as an enlarged breast. This finally provoked medical help-seeking. Most of the affected women understood little about breast cancer and or how the condition was affecting their bodies. Therefore, they did not know whether this was a disease that could be treated at the hospital or a curse from an evil spiritual being. A significant proportion of the younger women believed they were not at risk of breast cancer because a widely held perception exists in Ghana that breast cancer is a disease of older women (above 60 years). Denying the possibility of breast cancer due to age contributed to delayed appraisal and subsequent help-seeking.

4.5   Facilitators for prompt help-seeking

It has been previously reported in Tables 8 and 9 that most of the patients (n=32) in the study presented with late stage disease after three or more months since they identified a symptom only when symptom progression became unbearable (delayers). However, only a few patients (n=3) sought medical help within three months upon discovery of initial symptoms (non-delayers). Common factors among the non-delayers were a painful lump, and higher level of education in which two attained tertiary education and one had a secondary school education. A further facilitator among the non-delayers was the patients' reported beliefs in the effectiveness of modern medicine. Although those who did not delay were educated, there were nevertheless educated women who did delay. Patients who believed their breast symptom could be a physical condition also perceived that earlier diagnosis would improve their chance of survival, and this facilitated prompt help-seeking for modern medicine. In both instances (delayers and non-delayers), the most common triggers to help-seeking were pain, fear of social stigma, and the influence of members of their social networks. Being under pressure by the closest members of their social networks triggered patients to reappraise their initial interpretation and motivated them to seek immediate medical help.

4.6   Chapter summary

This chapter has presented findings from the study of the impact of sociocultural factors on symptom appraisal and help-seeking behaviour of Ghanaian women

who self-discovered their breast cancer symptoms. The findings revealed that a patient's help-seeking behaviour in response to breast cancer symptoms is a complex process involving some influential elements that forcefully push patients away from seeking modern healthcare and point them towards traditional healing until they realise that the symptoms were getting worse. It is at this stage that they finally appear to seek modern healthcare solutions.

Since recognising, interpreting, and responding to symptoms usually happens at the personal level, the three most influential perceptions that were recognisable from the patients, and which were corroborated by both social networks and, healthcare professionals were: a) the patients' perceptions of the cause of breast cancer; b) having very limited options for medical treatment except mastectomy, and c) a large proportion of patients dying as a consequence of surgery. Central to these factors is the patients' perception of death being a direct consequence of mastectomy rather than cancer. This concept may explain why the majority of the patients presented late for modern medical treatment, having initially tried traditional, culturally acceptable healers.

In addition, even if patients wanted to seek help within the modern medical system, they were discouraged by the challenges they faced at the cancer hospitals, the potential removal of a breast, and the use of modern drugs to treat the disease, which is costly and comes with unpleasant side effects. The extended interval between identifying a suspicious symptom and consulting a health professional appears to be a consequence of the patients' misunderstanding of the disease coupled with myths and misconceptions that pervaded most of them.

Chapter 5:   Discussion

5.1   Introduction

This study was conducted to ascertain: a) how sociocultural issues influence Ghanaian women's appraisal of breast cancer symptoms; b) the meaning they ascribed to those symptoms; c) the significance of this experience on their timing and choice of healthcare utilisation, and d) whether these factors are different in Ghana from those identified in Western countries. Data were collected from three participant sources; patients, members of their social networks, and healthcare professionals (HCPs) through face-to-face semi-structured interviews. This chapter discusses the findings identified in Chapter 4 in the context of the existing knowledge of delayed presentation of self-discovered breast cancer symptoms.

The chapter begins by considering the patients' pathways to modern medicine that emerged within the 'patient interval'. This model relates to the theoretical framework identified in section 2.2.2 (Scott et al. 2013). A patient interval refers to a period of time in an individual's pathway to medical treatment, between the detection of a symptom, in this case a breast change, and presenting that symptom to the 'first' healthcare professional (Weller et al. 2012). Since the study focused on factors for delayed presentation of breast cancer symptoms to a HCP, this chapter is structured according to the concepts of appraisal and help-seeking intervals (Scott et al. 2013). These intervals incorporate what have been referred to as the 'contributing factors', identified as: the features of patients (e.g. socio-cultural and demographic), healthcare provider and system factors (e.g. access, policy and delivery issues), and disease characteristics (site, size, and growth).

Contributing factors inform both the processes of symptom appraisal, self-management and arranging consultations, and the timing of events such as detecting body changes, perceiving a reason to consult a healthcare professional, and the first consultation. Although the contributing factors influence both appraisal and help-seeking, each will be discussed separately in this chapter, with consideration of the findings relevant to each interval. As indicated in section 2.3, there is a paucity of theory used in help-seeking studies for breast cancer in Africa. As a result, two theoretical models used by Scott et al. (2013) as examples in their conceptualisation of the model of pathways to treatment, have also been

employed to assist an understanding of symptom appraisal and help-seeking behaviour in the present study. These are the Common Sense Model of Illness Self-Regulation Theory (SRT) (Leventhal et al. 1980; Leventhal et al. 1997), which was used to analyse appraisal interval, and the Social Cognitive Theory (SCT) (Bandura 1986), for analysing help-seeking interval.

5.2   The patients' pathways to modern medicine

Using the patients' self-reporting of time from their discovery of body changes to their first presentation to a healthcare provider, the study has identified an average patient interval of twenty-four months. A high percentage (86%) of women delayed medical treatment and presented symptoms to clinicians late, according to the widely accepted standard that a delay is a period in excess of three months (Bish et al. 2005). This finding compares with research conducted in Western countries (e.g. O'Mahony & Hegarty 2009; O'Mahony et al. 2011), where much lower proportions (10% to 30%) of newly diagnosed women presented late; such delays are therefore a cause for concern.

Based on the original findings from the current study, Figure 13 illustrates the journeys of female Ghanaian patients, from the detection of breast changes to their presenting of the symptoms to a modern healthcare professional for the first time. In Figure 13, Scott et al.'s (2013) model of pathways to treatment was adapted to include the pluralistic healthcare system that exists in Ghana; hence, it is referred to here as the model of patients' pathways to modern medicine. The adapted model depicts the help-seeking trajectory in a non-linear way, reflecting the interlinked and ongoing processes of symptom appraisal and help-seeking behaviour. The blue arrows in Figure 13 represent symptom appraisal and the red arrows, help-seeking behaviour.

The entire appraisal and re-appraisal process is shown by the dashed and dotted rectangle. Following the detection of breast changes and their interpretation, almost all the patients in the study first used traditional medicine, before eventually turning to modern medicine for treatment. However, due to the tiered healthcare system within the public sector, few patients had their first consultations with modern medicine, then moved to traditional medicine before switching back to the modern medicine system when they realised the former was ineffective. There is a point within the pathway when patients re-appraised

symptoms and decided to move from traditional to modern treatment modes; this was a moment, which was often associated with worsening symptoms, increasing pain, and even feelings of desperation. Whilst nearly all patients in the sample followed broadly similar trajectories, in which the majority of women's first course of action is to seek help from traditional medicine, the point at which the switch from traditional to modern medicine occurred for each, was experienced at different times in that trajectory. Nevertheless, a majority of patients made the switch once they viewed modern medicine as the last and only treatment option left to them.
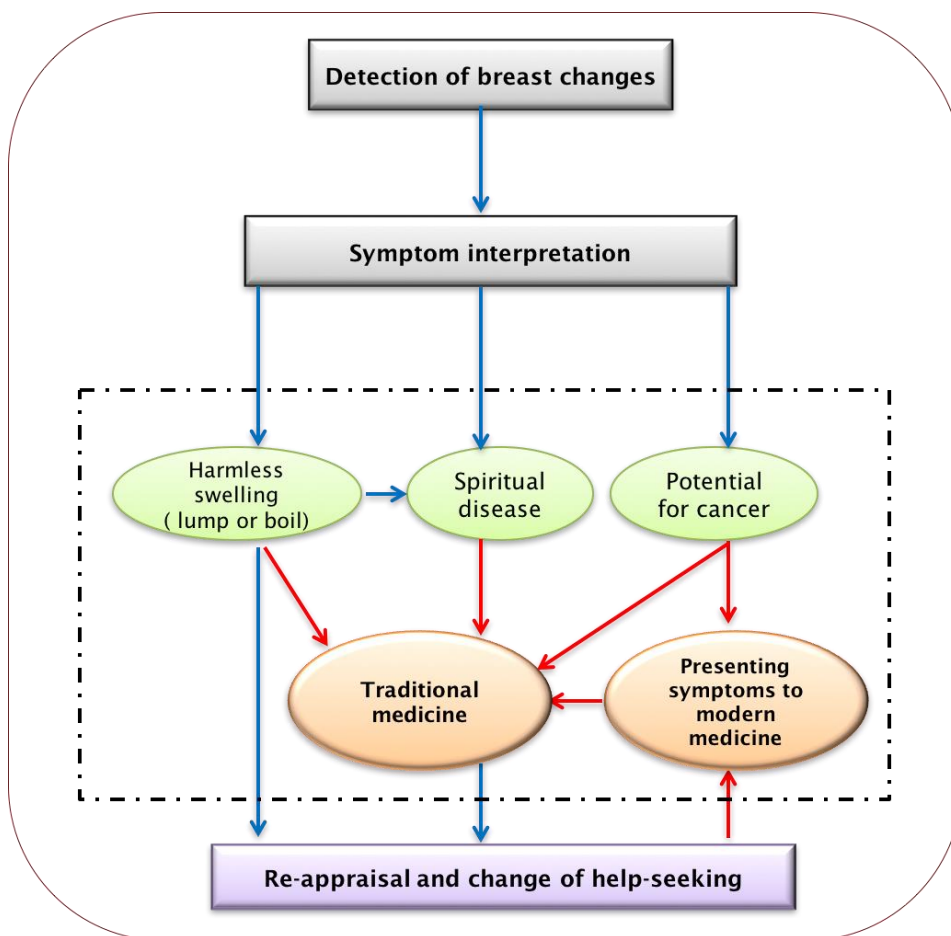
Figure 13 Patients' pathways to modern medicine

The study also identified factors that influenced the processes, timing, and type of healthcare decisions within the patients' pathways to modern medical treatments. Such factors are described as the contributing factors of symptom appraisal and help-seeking intervals.

5.3   Contributing factors of symptom appraisal and help-seeking

The contributing factors that emerged from the study included the social, psychological, cultural, and organisational contexts in which patients appraised their symptoms and then decided their help-seeking behaviour. These contributing factors can be categorised into four distinct groups: i) the sociocultural backgrounds of patients; ii) the specific manifestation of signs of breast cancer; iii) their emotional responses towards those signs and symptoms, and iv) options within the healthcare system. The contributing factors and the specific issues that comprise each group are illustrated in Figure 14.

Patients' sociocultural backgrounds

- Supernatural beliefs
- Preference for traditional healing
- Previous disease experiences
- Patriarchy and deference
- Socially accepted behaviours

Patients' emotional responses

- Fear of societal reactions
- Fear of medical treatment and prognosis
- Denial of possible cancer

Contributing factors

Symptom manifestation

- Painless lump
- Lump with pain
- Enlarged breast size
- Offensive discharge from breast

Healthcare system

- Modern healthcare
- Traditional medicine

Figure 14 Factors that contribute to appraisal and help-seeking intervals

The importance of the contributing factors was demonstrated by the fact that they determined the timing of how, and the direction in which, an individual progressed through the pathway to access modern medicine (Scott et al. 2013). Therefore, these factors help in understanding the prolonged intervals between symptom detection and initial presentation of symptoms for medical diagnosis and treatment. Similar to that described by Scott et al. (2013), the influence of the contributing factors in the present study sometimes preceded the detection of body changes and extended beyond when the patient's first medical consultation had taken place.

5.3.1   Patients' sociocultural background

The specific sociocultural characteristics that informed the appraisal and help-seeking of the study's participants comprised the following: supernatural beliefs; a general preference for traditional over modern medicine; previous experiences of illness and health workers in both modern and traditional medicine; the influence of patriarchy and deference on the attitudes of women, and the sociocultural meanings attributed to cancer or disease. Culture encompasses the shared beliefs, values, customs, social behaviour, attitudes, and characteristics of a particular social group (Peplau & Taylor 1997; Licqurish et al. 2016); all of this acts at both the community and population levels and influences the thoughts and behaviour of the individuals within that group.

The finding that many patients had strong supernatural beliefs involving evil spirits and divine powers, particularly witchcraft and "black magic", which they linked to the changes in their breast is in line with supernatural causation of other chronic illnesses such as mental illness (Read & Doku 2012). Based on a misguided view of the aetiology of the disease, the majority of patients used traditional healers who they felt were experts in healing spiritual diseases. The patients also believed that modern medicine was unable to interact with the spirits. Only traditional healers, most notably spiritualists, were thought to know how to interact with the spirits that caused the disease in the first place. Hence, patients reported using herbs, faith or spiritual healing, or a combination of these to treat their symptoms.

Socially accepted behaviours also constituted important contributing factors. Since patients belonged to a tightly knit social community, they had often experienced someone very close to them who had suffered and died at the hospital following mastectomy. Such previous experiences of the modern healthcare system were often negative. Patriarchy, and the deference it involves, was a sociocultural factor that primarily influenced help-seeking behaviour rather than symptom appraisal. Husbands were found to view their wives as their "property", who had little personal autonomy to decide the type of healthcare with which to engage. Asobayire and Barley (2005), which found that married women in Ghana were required to inform and seek authorisation from their husbands to visit a hospital, support this finding.

Symptom disclosure to members of the patients' social networks was based on each individual's perception of need, trust, and the ability of the friend or relative to offer the support they required. Family and friends that comprised an individual's social network provided advice regarding symptom interpretation and appraisal, whether or not to seek help, and from whom. Advice received from members of their social networks influenced the way in which patients managed the signs of their breast problems physically, emotionally, and socially (Bonsu et al. 2014). As found in previous studies (Scott et al. 2013; Whitaker et al. 2015), the influence of the social context including superstitious beliefs about cancer, protecting family from societal ridicule, and inadequate social support, is important to understand the processes involved within the appraisal and help-seeking intervals.

5.3.2   Patients' emotional responses to symptoms

The patients' emotional responses to the detection of breast changes were also identified as a key contributing factor to what is likely to happen to the symptoms with or without intervention (Figure 14). The consequences of accepting the fact that one might have or has cancer included social stigma as well as a fear of potential rejection and/or abandonment by spouses. Fear of discovering breast changes and the potential implications for patients was common. There was a perceived lack of emotional support within the modern healthcare system such as inadequate communication skills amongst healthcare staff, lack of counselling services, and lack of empathy. The modern healthcare system failed to address fears originating from the significance of the breast to women as well as the emotional and social consequences associated with its potential removal. This finding of scarce emotional provision is supported by a previous study by Clegg-Lamptey et al. (2009b), which found that the modern healthcare system in Ghana was not adequately equipped to deal with emotional issues related to breast cancer diagnosis and treatment.

5.3.3   Symptom manifestation

Symptom manifestation, and the changing nature of breast cancer symptoms over time, could influence both appraisal and help-seeking intervals. Breast lumps, either accompanied by pain or not, and other signs associated with breast cancer, were identified in the findings. Initially, the most commonly identified breast

cancer symptom detected by the patients was a painless lump. Since the lumps were untreated over a period of time, their condition worsened with the appearance of other symptoms, such as increasing pain, increasing breast size, and offensive discharges from breast lesions. These symptom manifestations provided part of the context that informed interpretation and re-interpretation and subsequent help-seeking behaviour.

5.3.4   The healthcare system

As described in section 1.2.1, the Ghanaian Health Service (GHS) promotes and encourages integration of both modern medicine and traditional medical systems (Sato 2012). In this respect, the healthcare system reflects the country's sociocultural context. Under this pluralistic system, patients may choose between traditional and modern medicine or a combination of both. Currently, the existence of public hospitals in Ghana with attached herbal medicine units is sparse, with only fifteen public hospitals to cover the whole country (Modern Ghana 2015). Taking advantage of this integration of herbal medicine and modern medicine, traditional healers have become increasingly sophisticated, adopting many of the practices of a modern healthcare system. The healers' innovations include: funding scientific research into plant medicine, prescribing and dispensing certified herbal medicines, and operating from modern clinical facilities (Abel & Busia 2005). Studies have indicated that herbal remedies can have a positive effect on anticancer activities relative to their suppressive effect on carcinogenesis and cancer metastasis (Cassileth 1996; Yin et al. 2013). These developments both confuse patients with regards to the difference between the two healthcare systems, and also reflect the increasing competition between traditional healers and modern healthcare providers (Asante & Avornyo 2013).

The use of traditional medicine in the present study is closely linked to cultural beliefs of supernatural involvement in illnesses (Twumasi 1979); these are beliefs that were held by many participants. A traditional healer was responsible for both prevention and treatment of disease. Spirituality is therefore an embedded ontology of healing in Ghana, indicating that whenever one gets sick, there is a requirement to examine the relationships that exist between the known and unknown, the spirit and the body, the visible and invisible, the natural and the supernatural (Darko 2009). Patients believe that due to its holistic nature, traditional medicine has the ability to completely cure the disease physically,

spiritually, and emotionally. Owing to the popularity of prayer camps, patients may stay for a length of time fasting and praying in close proximity to the supposed benevolent powers of a prayer leader, hoping they would be healed and avoid mastectomy. This overlap of religious and traditional beliefs is powerful in Ghanaian society, and has been previously reported by Tabi et al. (2006). Such a situation is rarely found in Western studies, though there was an element of this in the work of Gates et al. (2001) in USA.

Deficiencies in the modern healthcare system were a prominent finding in the current study. Patients reported difficulties accessing modern healthcare facilities as a consequence of several issues such as geographic distances between patients and healthcare centres, treatment costs not being covered by the insurance system, complicated referral processes between local and specialist hospitals, and a scarcity of competent healthcare professionals. As described in Chapter 1, there is an inconsistent geographical distribution of the few cancer treatment centres across Ghana, and this is exacerbated by poor road networks and an unreliable transportation system which together result in limited access to modern cancer treatment. Hence, if a patient lives in a village and discovers a breast symptom, the most likely scenario is for her to go to the closest clinic, which may not have the necessary equipment and personnel for proper medical evaluation. Furthermore, most rural areas lack hospitals and clinics as well as the doctors and nurses to staff them. In such cases, clinicians often refer patients who attempt to seek help at these peripheral healthcare facilities to Accra or Kumasi for further evaluation and possible treatment.

The lack of coordination of referral between community-level healthcare facilities and tertiary hospitals was also evident in the study's findings as patients talked about their frustrations. Doctors in Ghana see patients without any appointment system in place. Hence with only very few hospitals receiving a great many referrals from all the peripheral hospitals, tertiary hospitals can be, and often are, overwhelmed with too many patients to provide adequate care. The availability of highly skilled cancer specialists is usually inadequate at the referral hospitals, and such hospitals are unable to meet the increasing patient demand for cancer services. In Western countries high surgeon volume and specialization are associated with improved breast surgery outcome (Chowdhury et al. 2007). In contrast, the current study has found that some healthcare professionals, particularly general practitioners, have had to perform breast surgery despite not

being specialists. Often, therefore, when a patient with suspected breast cancer attends hospital, no special attention is given to her psychological concerns (Clegg-Lamptey et al. 2009b).

The desire of some patients to use modern medical services was challenged by limited resources and an inability to pay for other non-medical expenses associated with the help-seeking not covered by NHIS. Examples might include transportation costs to the hospital, accommodation, and other family financial commitments. Currently, breast cancer patients are also required to make out-of-pocket payments for screening, diagnosis and some treatment costs (Opoku et al. 2012). The high cost of medical care involving diagnostic tests, medication, and other miscellaneous expenses was beyond the financial capability of most of the patients in the present study. Therefore, with low-paying jobs, coupled with a limited insurance system and the high cost of medical care, modern medicine is likely to be inaccessible to many patients in Ghana who require sophisticated medical treatment.

Prior to their attendance at the specialist hospitals where they were recruited to this study, some patients had already consulted a HCP for their breast symptoms for months. The majority of those patients (86%) reported previous unpleasant experiences with the modern healthcare system, particularly regarding alleged unprofessional attitudes and poor communication skills amongst healthcare staff. The unfriendly attitude with which healthcare professionals sometimes communicated with these patients, and the insults they reportedly received during previous hospital encounters, did not enhance their motivation to seek help; such experiences actively discouraged those patients from returning to hospital. All these issues created frustration and mistrust among patients who were consequently disinclined to use existing modern healthcare services.

5.4   The symptom appraisal interval

The symptom appraisal interval (blue arrows in Figure 13), describes the time between when a woman first detects a breast change until she considers it sufficiently serious to warrant seeking Western style (modern) medical help (Scott et al. 2013). The processes and decisions within this interval were influenced by the following contributing factors: a manifestation of symptoms; patients' supernatural beliefs about the cause of breast changes; previous disease

experience of members of the patients' social networks, and; the emotional response patients experienced to the changes (Figure 14). As with the model of pathways to treatment (Scott et al. 2013), the present study incorporated both detection of breast changes and interpretation of symptoms within the symptom appraisal interval.

5.4.1   Detection of breast changes

The detection of breast changes by patients was the starting point in the symptom appraisal process (Figure 13). This activity was influenced by symptom manifestation regarding the magnitude of the change. Awareness of breast cancer symptoms can be achieved in a variety of ways, including mammographic screening and clinical breast examination (CBE) (De Nooijer et al. 2002). However, as indicated in the Findings chapter, most of the patients (80%) in the present study spotted the painless lump by chance, without any conscious action, such as breast self-examination (BSE) being undertaken. Since Ghanaian women do not normally practice BSE to look for changes in their breasts, the majority of patients did not notice the lump until it was very large. While BSE continues to be advocated for early detection of breast symptoms (ACS 2014), a Cochrane Review reported lack of evidence to support the use of breast screening by BSE or CBE of breasts in improving breast cancer mortality rates (Kosters & Gotzsche 2003). Nevertheless, BSE was recently identified as the only realistic approach in early detection of breast cancer in developing nations (Shrivastava et al. 2013).

With limited previous exposure to breast cancer symptoms, the finding of patients' accidental detection of the lumps occurred while they were cleaning around the breast or bathing or breastfeeding a baby. Inadequate knowledge of BSE could result in identification of breast lesion by chance. This has been previously reported (Aziato & Clegg-Lamptey 2015; Lim et al. 2015). Body changes detected accidentally reflect the lack of systematic CBE for women in Ghana; this highlights the fact that those at risk of breast cancer do not have access to free and routine mammography (Opoku et al. 2012), unlike the situation in many Western countries (Banning 2011).

Based on the findings from this study, patients often failed to recognise early symptoms identified as potentially indicative of cancer and perceived them as nothing to worry about, or else normalised them by attributing symptoms to

supernatural beliefs. In addition to lack of knowledge of signs and symptoms of breast cancer, some patients were not confident in their breast changes. Such patients consulted with trusted members of their social networks for support; they waited to be sure of the symptom identified, delaying presentation. Married women, in particular, reported they asked their spouses to confirm the lump they had identified before reporting to the hospital.

As seen in this study, another factor that contributed to symptom identification delay was attributed to perception of low personal risk. There was a strong belief among some of the patients that family history should be present for someone to realise they might be at risk of cancer. Thus, patients erroneously expected a strong family history to be associated with breast cancer. This belief led to denial among many patients, who admitted they were not ready to accept an expectant diagnosis of cancer.

Initial assessment of the accidental detection of a lump was made according to breast cancer characteristics such as size and rate of growth. Understanding the characteristics and significance of the lump can be explained by the Model of Illness Self-regulation (Leventhal et al. 1980; Leventhal et al. 1997), which describes how representations of illness are appraised and coped with according to self-regulation. Self-regulation theory is a system of conscious personal management involving the process of guiding one's own thoughts, behaviours, and feelings to achieve a certain purpose. The self-regulation model, illustrated in Figure 15, postulates that following the detection of a body change (i.e. breast cancer symptoms), there is an initial assessment by a patient of the likelihood of the symptom representing a serious illness, their perception of the treatments available to them, and the level of interference it will involve to their lives.
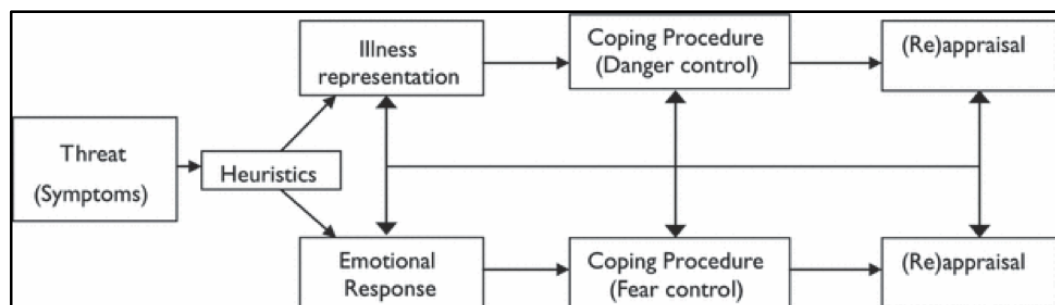
Figure 15 The Model of Illness Self-regulation. *Used with permission from John Willey and Sons (Appendix L)*

Chance detection of symptoms means the breast changes would be of sufficient size to be perceived by touch (Scott et al. 2013; Aziato & Clegg-Lamptey 2015), possibly signalling a late stage presentation of breast lumps. Indeed, several patients in the sample presented with lesions that were locally advanced with palpable mass, which informed their subsequent symptom interpretation and help-seeking decisions.

In the current study, the role of significant others in symptom appraisal were twofold: as a source of information as well as to validate the presence of a serious symptom (sanctioning). Denial in accepting the possibility of cancer in significant others also propagated delay in presentation to a medical facility. The impact of potential diagnosis on their loved ones also perpetuated delay. De Nooijer et al.'s (2001) study found that discussing body sensations with others stimulated early detection. Similarly, a review of help-seeking for lung cancer symptoms concluded that social networks influenced sanctioning of symptom seriousness in individuals who may otherwise be reluctant to perceive a reason to contact a doctor (Chatwin & Sanders 2013). However, in the present study, involvement of members of patients' social networks contributed to delay because there was often a misconception of the potential outcomes of breast cancer amongst the participants and their social contacts.

Due to the misconception of cancer by patients as being fatal (a sign of helplessness and hopelessness), it was easier for them to deny the fact than be confronted with a life-threatening disease. The fear generated depended on anticipated outcomes of treatment related to the cancer such as pain, social stigma, and even death. Since the majority of Ghanaian women present symptoms late, the poor outcome associated with patients with advanced disease suggests to women who identify any new breast symptom that it would be hopeless to treat it by modern medicine. Patients think that even when they may be at an earlier stage of disease and appropriate treatments might be different, they will have similar treatments to women they have known before who have not survived the disease.

5.4.2   Interpretation of symptoms

Detection of breast changes is followed by their interpretation (Figure 13). In the present study, symptom interpretation led patients to label what the identified

symptom meant to them, which eventually directed their decision to seek or to avoid confirmation of diagnosis from a HCP. The process of interpretation was influenced by the patients' supernatural beliefs of illness, by the views of members of their social networks, symptom manifestation of pain, and patients' emotional responses, such as fear. The cognitive illness representations in the 'self-regulation model' are organised into five sets of beliefs; these are: a) illness labels and associated symptoms (identity); b) the factors believed to have caused the illness (cause); c) the expected duration of the illness (timeline); d) the expected effects of an illness on physical, social, and psychological well-being (consequences), and; e) the extent to which the illness can be cured or controlled through treatment measures and behaviours (control/cure). These representations guide the selection and execution of specific behavioural reactions including symptom monitoring, self-medication, and visiting a healthcare professional; such actions are subsequently re-appraised regarding their impact on the symptoms over time (Scott et al. 2013). Additionally, the self-regulation model includes an evaluation component to determine whether implemented coping strategies are successful in achieving goals (Figure 16).

The 'self-regulation model' also suggests various 'heuristics' or 'rules' such as location, pattern, and symmetry that are used in forming interpretations, which could help in decisions relating to the meaning of symptoms, facilitating planning, and implementing ways of coping (Leventhal et al. 2003; Leventhal et al. 2007). However, in the context of Ghana, symptom interpretations are based on supernatural beliefs, knowledge of other people's past experience of cancer, and symptom manifestations, all of which inform patients whether symptoms deserve traditional or modern medical treatment. Due to the range of influences, different interpretations emerged in the present study. Three ways in which patients interpreted the changes were: a) as a harmless swelling such as a boil, b) as a spiritual disease, or c) as a potential symptom for cancer (Figure 13).

The first broad interpretation of breast changes, in the form of painless lumps, allowed patients to decide that no further medical action was necessary, in anticipation that it would naturally disappear. The patients' interpretation based on painless manifestation of lumps, which appears as a deliberate form of self-regulation, emerged from their deep cultural understanding of sickness as a "painful thing". Most of the patients subscribed to the influence of a fundamental sociocultural belief that if something is not painful, it is harmless until other

symptoms, such as bleeding and intense pain appear. In the self-regulation model, breast changes considered as harmless swellings are usually normalised by patients in order to maintain adequate physical and social functioning level, and then dismissed. Although normalisation of symptoms saves the cognitive effort of appraising body changes (Cacioppo et al. 1989), this adaptive process in which the breast changes were not considered as indicators of serious disease, coupled with late detection of a potentially dangerous sign, constitutes a major part of delay in seeking modern medical help (Kaur et al. 2006).

The finding of misattribution of painless breast lumps to harmless conditions, leading to delayed presentation to modern medicine, transcends cultures and has been consistently found in previous studies in the USA (Facione et al. 2000b), UK (Burgess et al. 2001), Saudi Arabia (Altwalbeh et al. 2015), and Mexico (Unger-Saldana & Infante-Castaneda 2011). The degree of pain associated with breast lumps has been shown by several studies to influence a woman's symptom appraisal, but in different ways. The absence of pain may contribute to appraisal delay, as was found with Black African and Black Caribbean women residing in the UK (Jones et al. 2015); however, other studies have reported that some women regard absence of pain as threatening and this triggered help-seeking (Unger-Saldana & Infante-Castaneda 2011; Jones et al. 2014).

Among those patients who considered their breast changes as a harmless swelling, the majority (60%) mistook those changes for a boil (Figure 13). Patients expressed a belief that the lump in their breast was a mere boil developed from the remnants of milk, which had stayed in the breast. This mischaracterisation of breast cancer symptoms by patients was based on their previous experience of boils, a diagnosis often mistakenly confirmed by family members. Cultural beliefs among the Ghanaian patients, together with a lack of knowledge of breast cancer symptoms, led to delay of medical help-seeking for painless lumps. Due to limited knowledge and misconception of the disease progression, some were not aware of cancer and the seriousness of the diagnosis regarding its metastatic potential. Previous Western studies of African Americans' beliefs about breast lumps include beliefs about the connections of impurities circulating in the blood and a breast lump formation, and beliefs that once air gets to a lump, the air will make it grow (Lannin et al. 1998). This finding, of associating breast lumps with breast milk, corresponds with a study in Ethiopia, where participants commonly

attributed the cause of breast cancer to problems with accumulated milk from breastfeeding (De Ver Dye et al. 2011).

Social influence on patients' self-regulation of the symptom was also recognised in the initial interpretation of the breast lump. Members of their social networks in the present study directly influenced and reinforced patients' appraisal decisions, particularly by providing reassurance that such manifestations were normal. This type of support comforted patients, reassuring them the symptoms were not serious or of concern. This approach allowed patients to maintain the regulation of their own thoughts about the meaning of their symptoms to suit their preference.

The second prevalent interpretation of breast lumps offered by the study participants was as a manifestation of a spiritual disease (Figure 13). This interpretation is based on beliefs that any strange symptom of unknown origin must be caused by evil spirits. In support of this notion, Andersen et al. (1995) acknowledged that since there is a link between detection of unexplained symptoms and the inference of illness, appraisal delay is most likely to occur as a result of misinterpretation. Some patients alleged that the appearance of a lump was a consequence of their failure to meet the needs of ancestors. Although deceased, ancestors are widely believed to maintain a relationship with, and care for, the living, and have needs just like their surviving descendants. Some patients also expressed the belief that the causation of their symptoms was the result of witchcraft conducted by neighbours, relatives, and friends who previously had unpleasant relations or were jealous of their successes in life.

Previous disease experience regarding poor outcomes of breast cancer by members of patients' social networks, helped form superstitious ideas about the cause of breast symptoms. Hence, many women with breast cancer symptoms around them would undergo traditional therapies. The finding that patients believed evil spirits might cause breast lumps and cancer reflects the fact that superstitious beliefs about diseases are deep rooted in West Africa. In the study conducted by Opoku et al. (2012) in Ghana, a high percentage of women believed that evil spirits could cause breast cancer through witchcraft. In Nigeria, also, many people believed that evil spirits can inflict breast cancer upon victims (Aduayi et al. 2015).

Patients in the present study who believed their symptoms were a curse on them are perceived to think about what has caused their symptoms and attribute them to things within their own control. Thus, patients sought to self-regulate interpretation of their symptoms as a spiritual disease. Adopting the control heuristic of the 'self-regulation' model, could explain patients' approach to control the danger of being cursed. The control rule suggests that deliberate thoughts regarding the meaning of a symptom affects decisions, and could be used as a coping response to reduce the threat itself (danger control) or the negative emotions associated with the threat (fear control) (Figure 15) (Leventhal et al. 2007). As a result, patients in the study are more likely to use traditional medicine than to seek modern medical help when they perceive symptoms to be manifestations of a curse. Although social support helped to motivate individuals to self-regulate their symptom interpretation, social outcome expectations (e.g. stigma and reduced womanhood) appear to be more important in motivating individuals to self-regulate their help-seeking behaviour of using traditional medicine over a lengthy period. In such circumstances, self-regulation of symptom interpretation was 'internalized' due to social pressure on patients who pretended as if nothing was wrong, as in the case of painless lumps.

Since the desire for women in Ghana to have children and childbirth is cherished within the sociocultural context (Nukunya 2003), the patients in this study bear similar characteristics to other women in Ghana. The cultural situation of Ghanaian women being concerned they may not able to marry off daughters due to the stigma of cancer in the family was reflected in this study, and was perceived as an appropriate reason for the majority of patients in this study to not disclose their symptoms to others about their possible cancer symptoms. The importance of validating symptoms with significant others to decide their breast symptom as non-serious were evident in this study. At times, particularly with painless symptoms, some patients considered symptoms in the absence of pain to be too minor and unimportant to disclose to others, who would not take them seriously.

The third interpretation of breast symptoms prevalent amongst this study's patients was the possibility that the breast lumps were indeed indicative of cancer (Figure 13), but not caused by evil spirits. Although some patients thought of the lump as a physical problem that could signal cancer, they hoped that this was not the case. Self-regulation stipulates that individuals, who interpret symptoms as a

serious condition or at least one that requires intervention by a healthcare professional to resolve them, are more likely to seek modern medical help promptly. Although, there was a strong belief among the patients that family history should be present for someone to be at risk for cancer, due to their fear of the disease, patients in the present study reassured themselves that, because there was no family history of the disease, there was no need to seek any modern healthcare professional help. As a way of fear control, the decision by some patients to deny the discovery of a symptom, which could confirm cancer, led to longer appraisal delays.

Irrespective of how patients interpreted their lumps, there seems to be an overlap regarding knowledge of interpreting the lumps as caused by evil spirits and realising them as the physical illness of cancer. Fear and denial are assumed to be common coping responses to the detection of breast cancer symptoms and are often responsible for patient delay in seeking medical help (Stiefel 2006). A study of breast health practices among South Asian women noted that while denial and avoidance can be considered coping strategies, they are counterproductive if the outcome leads to a delayed diagnosis of breast cancer (Bottorff et al. 1998). Although there is routine screening in Western countries and not in Ghana, the potential stressors influencing cognitive, emotional, and coping mechanisms are similar. Therefore, incorporating self-regulation theory (SRT) in the current study has been a useful explanatory tool within the appraisal interval to illuminate Ghanaian patients' initial interpretation of symptoms and subsequent attempts to control the perceived threat. At the end of the appraisal interval, the particular interpretation patients made of their symptoms informed their successive help-seeking behaviour.

5.5   Help-seeking interval

The help-seeking interval (shown by red arrows in Figure 13), describes the time from perceiving a reason to discuss symptoms with a healthcare professional to the first consultation with such a professional (Scott et al. 2013). The pluralistic healthcare system in Ghana allowed patients to make conscious healthcare utilisation decisions based on their perceptions about whether they should seek help from the modern or the traditional medical system. Evidence from the current study indicates that whether a patient sought help from either modern or traditional medicine, or from herbalist or spiritualist sources within traditional

medicine, depended upon the way in which they had interpreted their symptoms during the appraisal interval. The length of the help-seeking interval was influenced by symptom manifestation, patients' supernatural beliefs, socially accepted behaviours, patriarchy and deference, patients' emotional responses to detected body changes, previous disease experience, and the pluralistic healthcare system.

5.5.1   Motives for help-seeking

Whilst the pluralistic medical system permits different healthcare choices, some patients found it problematic when deciding whether their symptoms were purely physical in origin, and could therefore be treated at the hospital, or were a curse from an evil spirit that only needed spiritual attention. As indicated in Figure 13, within the dotted and dashed rectangle, at some point, nearly all the patients decided to seek help from traditional healers, before eventually turning to modern medical treatment. Initial interpretations of breast lumps by patients (e.g. as a harmless swelling or boil) did not remain static. Rather, re-appraisal of the symptoms and treatment options frequently occurred as patients' symptoms progressed. The strategy adopted by patients for dealing with their discovered symptoms was the means of self-management (or self-regulation).

Patients who initially perceived their lumps were harmless would then continue to appraise body changes until they decided it was either a boil or a disease that may or may not have a spiritual cause. Patients would then sometimes consider the possibility that their condition was spiritual in origin and switch to seek help from a spiritual or faith healer (Figure 13). Patients who believed that their breast change was a boil would treat it with traditional herbal medicine (Figure 13). Many patients believed traditional treatment could dissolve the boil spontaneously after a few applications of herbal treatment; however, they would then often use traditional medicine for a lengthy period, hoping that they would get well, albeit without success. Such investigations into, and employment of, traditional treatments resulted in significant delays in these women seeking modern medical help. Patients who interpreted their lumps as caused by evil spirits sought spiritual or faith healing because of their (erroneous) belief that only spiritual/faith healing could help them.

Eventually, as symptoms increased and traditional medicine proved unsuccessful, all patients thought their symptom could be cancer of a physical origin and subsequently sought help from modern medicine (Figure 13). Similarly, patients who associated their symptoms with boils applied herbal treatment until it became obvious the lump was not diminishing. Some patients commonly thought that if a woman is unable to breastfeed after giving birth, then it could lead to a swollen breast, which would further develop into a boil in the breast. In Ghana, people who suffer from such health conditions habitually consult traditional healers in their communities as the first point of contact. Due to historical and cultural reasons, some of the patients in the present study viewed traditional herbal treatment as being very potent for the cure of swollen breasts in women, which they consider the most common method of treatment. In these terms, patients expressed their belief in the efficacy of these traditional treatments. The unsuccessful outcome, as a result of using traditional medicine to treat the symptoms, led to patients revising cognitive and emotional representations of their symptoms and changes in the approach to coping with them. Such changes can be examined by the evaluation component of illness representation in the self-regulation model. Figure 16 depicts the model of illness representations.
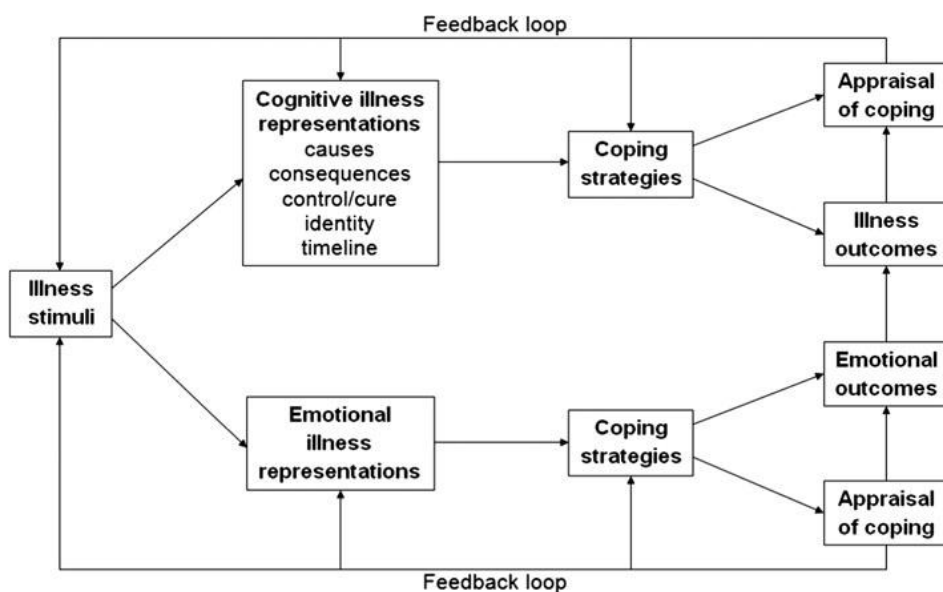
Figure 16 Model of Illness representations. *Used with permission from Taylor and Francis (*Appendix M).

The 'model of illness representations' proposes that illness perceptions directly influence coping strategies, which in turn influence outcomes. Illness perceptions represent lay interpretations of information and personal experiences the patient

has acquired. Leventhal et al. (1997) suggest that disease outcomes should be subsequently appraised to see whether the treatment mode being used have been successful. This self-regulation approach involves ongoing cycles of symptom appraisal and re-appraisal processes. Patients in the current study re-appraised their symptoms based on cultural beliefs and their perceived level of acceptability of either modern medicine or traditional medicine (Figure 13). This finding of re-appraisal of symptoms for patients who are already seeking help from traditional healers, adds to existing factors for inducing re-appraisal of symptom interpretation, particularly symptom development and persistence of symptoms (Scott et al. 2007).

Findings from the study also indicated there were both negative and positive factors that inspired patients to choose either modern or traditional medicine (Figure 17). These factors correspond with themes that emerged from the findings. Four themes that provided rationality for patients to choose traditional medicine are: i) strong cultural and religious beliefs; ii) mistrust in the modern healthcare structure; iii) influence of the social network, and iv) patients' emotional reaction to symptoms.
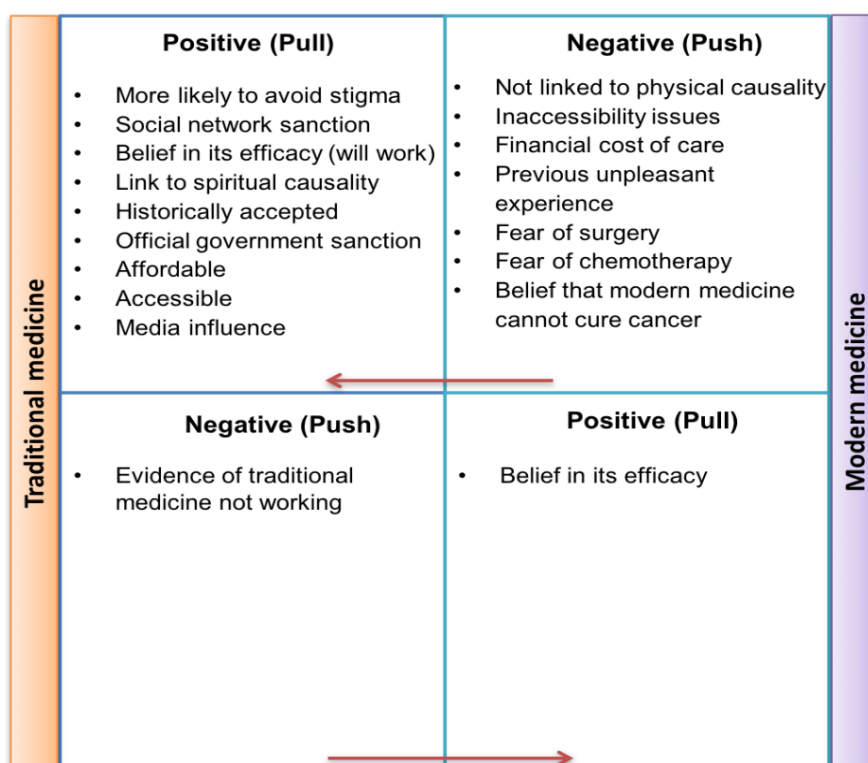
Figure 17 Factors for initial help-seeking behaviour

Positive factors are those that provide a good reason for selecting a certain mode of treatment. As presented in Figure 17, positive factors that motivated patients to seek help from traditional medicine, which are related to strong cultural and religious beliefs, include belief in the efficiency of traditional medicine, that the disease is linked to spiritual causality, and that it is a historically accepted treatment modality. In addition, factors that relate to mistrust in the modern healthcare structure include the official government sanction of traditional medicine, its affordability and accessibility. Moreover, factors linked to the influence of social networks involve social network sanction and the influence of the media. Finally, the assurance that using traditional medicine might avoid stigma was the one factor linked to the theme concerning emotional reactions to symptoms.

Negative factors push patients away from a mode of treatment, giving those patients a reason or reasons not to adopt a mode of treatment, thereby leaving the individual no option but to select the alternative mode. Three themes in the findings that could justify women choosing traditional medicine as a default included: i) mistrust in the modern healthcare structure; ii) emotional reactions to a symptom, and iii) knowledge and awareness of cancer. In Figure 17, negative factors that pushed patients away from choosing modern medicine related to mistrust in the modern healthcare structure, and included inaccessibility issues, the financial cost of care, previous unpleasant experiences, and a belief that modern medicine cannot cure cancer. In addition, factors that correspond to emotional reactions to symptoms were fear of surgery and fear of chemotherapy. Finally, a factor affiliated with knowledge and awareness of cancer is the perception that cancer is not linked to physical causality. Some of these themes are interrelated and/or co-existed among the negative and positive factors. For example, factors associated with mistrust in the modern healthcare structure, particularly accessibility and affordability, were positive push factors towards traditional medicine. Nevertheless, as illustrated in Figure 17, there were more push factors away from modern medicine in Ghana and more pull factors towards traditional medicine.

The consideration of additional influences to determine why the majority of patients used traditional medicine, and refrained from consulting modern medicine, is commensurate with the Social Cognitive Theory (SCT)(Bandura 1986) (Figure 18). The SCT describes a dynamic, ongoing process in which personal

factors, environmental factors, and human behaviour exert influence upon each other (Bandura 2004). The core determinants, which affect the likelihood that a person will change a health behaviour are: (1) their self-efficacy, (2) the goals they set for themselves and their plans of achieving them, (3) their outcome expectancies about anticipated costs and benefits of performing the behaviour, (4) their knowledge of health risks and benefits, and (5) perceived facilitators and impediments to making behaviour change.

Self-efficacy has been defined as the belief that one can successfully execute the behaviour required to produce the desired outcome, even when faced with obstacles (Bandura 1986). Hence, the patients' confidence in their control over a particular behaviour plays a central role in behaviour change. On the other hand, outcome expectancies, which are dependent on perceived consequences of action, contribute to an individual's intention (goal) to seek help. Three categories of outcome expectancies; physical, social, and self-evaluative have been identified. For example, the patients' belief in the efficacy of traditional medicine in the present study was regarded as a positive cultural incentive towards traditional medical treatment (Figure 17), increasing their desire for that kind of treatment. Patients' confidence in traditional medicine was developed through knowledge of other people's previous experiences, their prior negative experiences with healthcare professionals (mistrust in the modern healthcare structure), and persuasion from members of their social network (influence of the social network).
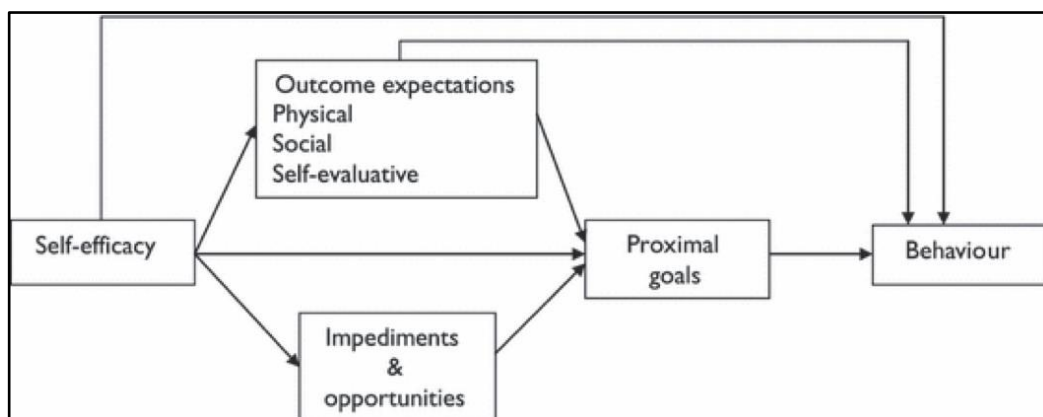
Figure 18 Social Cognitive Theory. Used with permission from John Willey and
         Sons (Appendix L)

Similarly, there are also a number of negative factors in the top right quadrant in Figure 17, which represent reasons that patients are 'pushed away' from using

modern medicine. Negative factors, including the perception that the disease is not linked to physical causality (knowledge and awareness of cancer), inaccessibility issues, financial cost of care, previous unpleasant experiences and belief that modern medicine cannot cure cancer (mistrust in the modern healthcare structure), fear of surgery and fear of chemotherapy (emotional reactions to symptoms), further encouraged patients towards the use of traditional medicine. These negative push factors do not necessarily mean patients had a strong belief in traditional medicine; the factors only show what is drawing people towards traditional medicine. Although, both traditional and modern medicines are options for patients during the help-seeking interval, there are many more positive reasons, or 'pull' factors in the top left quadrant in Figure 17; these factors influence patients to select traditional medicine rather than modern medicine.

There are very few factors in each of both lower left and right quadrants, which are either pulling patients towards modern medicine, or pushing them away from traditional medicine. For example, patients' beliefs in the efficiency of modern medicine to treat physical illnesses, motivated them to seek help from that mode of treatment (Figure 17). Nevertheless, during re-appraisal, when symptoms become progressively worse, some of these factors will have a different impact on that patient's journey, depending upon the severity of her symptoms. Thus, the occurrence of progressively worse symptoms pushing patients away from traditional medicine to modern medicine happens quite late in the disease progression.

Patients, who initially suspected that their symptoms could be cancer, and sought help from modern medicine (Figure 13), sometimes reported that they abandoned that type of treatment and consulted traditional healers, due to sociocultural factors and modern medical system factors. Patients in this category were convinced that their breast lumps could be dangerous to their health. However, because of their cultural backgrounds, they believed that there might be some spiritual element to the lumps, which modern medicine was unable to address. While self-managing and re-appraising their symptoms, patients did not consider themselves as delaying medical presentation. They assumed they were seeking help from healers who knew more about treating spiritual diseases than modern medical professionals do. As far as they were concerned, these patients

considered themselves as seeking help as they would if they were attending a modern healthcare facility.

The patients' actions in the present study were guided by cognitions and were dependent on plausible explanations of their problem. For example, if evil spirits caused the disease then there was no reason to go to the hospital, because the agents that caused the disease could not be treated at the hospital. In addition to the five domains of illness representations in the self-regulation model (Leventhal et al. 1980), the selection of coping responses to health threats is driven by emotion. Significant to this model is that cognitive and emotional representations of the symptom episode encompass "if-then" rules, meaning certain representations will inform the selection of specific behavioural responses. Therefore, if a person perceives a symptom as something that will recover naturally or with the assistance of traditional medicine, they are unlikely to perceive a reason to discuss the symptom with a healthcare professional and thus will not consider seeking modern medicine help, nor form an intention to do so. Patients who experience fear because of unexplained symptoms, but believe that the benefits of traditional medical consultation outweigh the barriers to seeking modern healthcare, are more likely to consult traditional healers. Cultural beliefs provided the patients with a sense of identity and security; however, when their beliefs were based on erroneous information, inappropriate help-seeking behaviours leading to a prolonged patient interval, were likely to follow (Loehrer et al. 1991).

Social sanctioning by patients' social networks, suggested in the outcome expectancies of SCT (Bandura 1986), describes the effect of social reactions that could influence delayed presentation of symptoms to modern medicine. The patients' motives underlying the use of traditional medicine were reinforced by members of their social networks, irrespective of whether the patients believed the symptoms were serious or not. Indeed, that friends and family were often willing to accompany patients to consult traditional healers, only served to further endorse that mode of treatment. Therefore, the support patients received from members of their social networks has strengthened their self-efficacy. The crucial role of the social network in influencing a patient's decision to seek help from a traditional healer, reflects findings from previous studies in which cancer patients were influenced by their family members to use traditional medicine (Struthers & Eschiti 2004; Muhamad et al. 2012).

The belief that modern medicine cannot cure the disease, if or when surgery was needed (mistrust in the modern healthcare structure), is another negative pull factor towards using traditional medicine (Figure 17). This finding supports the physical outcome expectancies theory of SCT (Figure 18). Outcome expectancies is another central construct in self-efficacy theory, which describes a person's judgement that a given behaviour will lead to certain outcomes that flow from that behaviour (Bandura 1986). Physical outcome expectancies could act as incentives to seek help. In this case, unless patients believe that seeking modern medical help can produce desired effects of removing their symptoms, they will have little incentive to act in that help-seeking way.

Before they first detected the lump, the majority of the patients indicated their belief that there were few cancer treatment alternatives to mastectomy available at hospitals. They also believed that a large proportion of women who underwent mastectomy subsequently died. Some patients suspected that their lump was a sign of cancer and were afraid their breast would be surgically removed if a cancer diagnosis was confirmed. The patients thought they did not have much choice with modern healthcare, other than to seek traditional herbal and spiritual help to avoid hospital treatment. Leong et al. (2009), who indicated that patients in Sabah, Malaysia feared that surgery would disturb the cancer and cause it to grow larger, support this finding. Similarly, in a study conducted in the USA, breast cancer patients refused conventional treatment in favour of alternative therapies, because they knew cancer treatment could be highly toxic and was therefore perceived as likely to cause them more harm than benefit (Citrin et al. 2012).

Unlike previous studies (Clegg-Lamptey et al. 2009a; Leong et al. 2009; Asoogo & Duma 2015), most of the patients in the current study had deep cultural reservations about mastectomy, believing that since evil spirits caused breast cancer, it could not be treatable with modern medicine. Once detected at the hospital, the breast would be surgically removed and death would be imminent. Reasoning from their prior experience with friends and relatives who died from a mastectomy, the majority of patients expected that their attendance at a modern healthcare facility would be similarly ineffective, and potentially fatal. Therefore, it is the misunderstanding about the disease, coupled with self-perpetuated myths and misconceptions, which pervaded the thinking of most patients and resulted in their tendency to avoid modern medicine.

A common perception amongst Ghanaian women that breast cancer at any stage is necessarily incurable, combined with beliefs about the ineffectiveness of modern medical treatment for such diseases, means patients' apprehension about a mastectomy are very strong. Therefore, a significant finding, which is unique in this study, is the notably high proportion of patients who strongly believed that it is the hospital surgery that kills and not the delayed presentation of disease symptoms; this is one of the main reasons for the delay in the women seeking help from modern medicine. While this finding has not been recorded in earlier studies, it is worth noting that most women in the present study avoided consulting healthcare professionals even in the early stages of the disease, when mastectomy might not be necessary and death would certainly not be imminent.

The finding that patients in this study use spiritual or faith healing reflects beliefs about the spiritual origins of the disease, and supports a previous study by Aziato and Clegg-Lamptey (2015). The authors of that study reported that the high cost of treatment together with an inadequate knowledge about breast cancer contributed to women seeking alternative treatment at prayer camps. This finding, supports, with other published studies, the assumption that they perceive any 'strange' disease as necessarily having a spiritual origin (Asobayire & Barley 2015; Asoogo & Duma 2015).

In addition to patients' fear of surgery, some patients avoided modern medicine because they were afraid of the potential side effects of chemotherapy (emotional reaction to symptoms) (Figure 17). These patients delayed modern medicine because of their beliefs about the possibility of losing their hair and vomiting as a result of being treated with chemotherapy. Fear of possible side effects of chemotherapy was also influenced by past experiences where loved ones received such treatment. However, while fear of chemotherapy's side effects have been identified in several studies as reasons for delay in help-seeking (Facione & Facione 2006; El-Charnoubi et al. 2012; Norsa'adah et al. 2012), the negative beliefs among patients in the present study could also be that they were unaware of recent advances in treatments, such as the availability of medicines to counteract the side effects of treatment that involved chemotherapy (Carelle et al. 2002; Yarney et al. 2013).

Secrecy and stigma about cancer have also been identified as factors contributing to delay in presenting symptoms (Licqurish et al. 2016). Although the majority of

the patients in the sample first consulted traditional healers, before subsequently consulting hospital clinicians, they seldom admitted this readily in their interview. It was only as the interview progressed that patients revealed they had been using traditional medicine, and generally, they used it until they became convinced it was not working. Patients were possibly embarrassed about this admission because they were recruited at a hospital, where they could imagine that they might be judged by healthcare professionals to have wasted valuable time.

Patients in the current study also asserted that if their husbands knew about their symptoms, the men would abandon them; in fact, some married women in the present study who revealed their symptoms had been abandoned by their spouses. Based on the social outcome expectancies of the SCT, seeking modern medical help could be delayed by fear of disapproval, rejection, or being discredited by family members (i.e. stigma). The social outcome expectancies involve social sanctions and social reactions that action is thought to evoke. Patients feared that the anticipated societal reaction to them, such as their daughters' prospects for getting married, would cause embarrassment, not only for them but also for their entire family as the stigma of the disease remained with the family. Since it is easier for women to maintain secrecy by using traditional rather than modern medicine, patients, together with the support of members of their social networks, kept the symptoms secret as they tried to deal with them through traditional medicine.

Unlike findings from previous studies where fear acted as a stimulus for immediate medical consultation (Facione et al. 1997; Jones et al. 2015), the present study supports findings from studies such as Lam et al. (2009) and Taib et al. (2001), in which fear and stigma discouraged patients from seeking modern medicine. Although the attitude of secrecy in the present study delayed patients from seeking modern medical help, the concern that cancer brings shame on the family is not only confined to Ghana. In a study conducted in the UK, British participants were reported to believe that any illness such as cancer was a sign of weakness, and its presence therefore brought shame and stigma on the family (Scanlon et al. 2006). The situation of hiding the symptoms from others is similar to a previous study conducted in the United Arab Emirates (UAE) where women kept the disease hidden, not only from their community, but also from their distant family members, in order to avoid social rejection and isolation (Elobaid et al. 2016).

Another element in the patients' sociocultural backgrounds that influenced the use of traditional medicine was the strong authoritarian structure of Ghanaian culture, with the traditional obedience of wives to husbands. The social outcome expectancies of SCT could also help explain the impact of social reactions impacted on the timeliness of help-seeking behaviour of patients. Husbands' disapproval to allow patients to seek help at a hospital delayed symptom presentation. As much as patients believed the hospital would have been a better place to seek help, their husbands who considered modern medicine inappropriate, did not support their inclinations. Patients feared that if they disobeyed their spouse's advice, it could affect their relationships. Therefore, patients often had no other option than to follow their husbands' decisions to use traditional medicine.

A significant number of patients in the present study indicated that their decision to continue seeking modern healthcare depended on their ability to access such care. In accordance with SCT (Bandura 1986), which suggests that socio-structural barriers may prevent patients from seeking help from healthcare professionals, the findings of the present study also identified several healthcare system related factors that influenced delay. Considering the distances patients had to travel, the cumbersome referral system, and cost of the assessment process, patients living in more remote areas far away from the breast clinics used traditional medicine, partly because traditional healers can be found locally everywhere within their neighbourhoods (NPC 2011).

The limited accessibility to modern medical facilities found in this study, was also identified in previous studies, and represents a barrier to seeking medical help to deal with the disease (Anderson et al. 2006; Stapleton et al. 2011). Stapleton et al. (2011) discovered that the majority of Egyptian women delayed because they had to travel a long distance to access a healthcare facility. In other Western studies, help-seeking intentions have been significantly related to perceptions of good access, such as in the USA (Facione 1999), in Canada (Bairati et al. 2007), and in Singapore (Lim et al. 2015), where the lower incidence of advanced cancer was attributed to good access to care and services. However, the situation in Ghana is different from Western countries in the sense that there are additional factors besides accessibility that push patients away from modern medicine towards traditional methods of treatment (Figure 17).

Previous studies in LMICs found that financial problems were the main barrier to achieving effective early diagnosis and adequate breast cancer treatment (Sandelin et al. 2002; Agarwal et al. 2009), and this was also an important positive pull factor for traditional healing in the current study (Figure 17). Linking this finding to SCT, financial barriers may appear to be insurmountable problems to overcome. Patients sometimes did not have the financial means to engage in modern medical help-seeking behaviour and they were not motivated to act in that way, but rather selected the cheaper option of traditional medicine. The current finding regarding limited finances also supports a previous study in Ghana by Sato (2012), which noted that traditional medicine is well liked and levels of satisfaction with the different types are high, because costs are low and accessibility is convenient. Similarly, other studies have indicated that lack of financial resources led many cancer patients to look for inexpensive alternative medicines (Pal 2002; Taib et al. 2007). Nevertheless, a study on stroke patients in Tanzania showed that causation beliefs, such as supernatural causes for illness, outweighed other factors such as cost and geographic distance for medical care seekers (Mshana et al. 2008).

Unfriendly attitudes and lack of empathy amongst healthcare professionals (mistrust in the modern healthcare structure), as reported by some patients in this current study (Figure 17), are another socio-structural barrier suggested in SCT that could also deter patients from utilising modern healthcare. Bandura (1986) maintained that an individual's previous behaviour, their prior experiences with HCPs, and their social context would impact upon present and future confidence to seek help. Healthcare professionals had sometimes been unwilling or unable to comfort and explain issues to patients about their condition. Some of these unpleasant encounters with the medical staff that occurred early on in the cancer journeys of patients did not enhance their self-efficacy to seek modern healthcare, and these women sought traditional healers as a result. Then, later, when the condition of the symptoms became worse, they returned to modern medicine for treatment. Additionally, since their social outcome expectations within SCT, such as a HCP reducing their anxiety, were not previously met within the modern healthcare system, patients looked instead for help from traditional medicine. This movement back and forth between different treatment modalities contributed greatly to patient delay. Other studies have also identified that previous bad experiences with a healthcare professional create barriers between

them and their patients, such as a lack of trust and communication, which results in treatment delays (Bailey et al. 2000; De Nooijer et al. 2001).

Another finding from this study, which seemed to push patients away from the modern healthcare system, is the influence of media advertising on choice of healthcare (influence of social network) (Figure 17). Using the media, especially radio and television, proponents of traditional healers are able to divert patients with breast cancer symptoms away from modern healthcare. This help-seeking behaviour can be explained by the social outcome expectancies concept within SCT, which suggests that modern medical help-seeking was delayed because of received multimedia (lay) advice. Traditional healers promote themselves as healers who offer patients hope, suggesting their cancer can be cured through spiritual means, and thereby eliminating the need for the surgical option at the hospital. Patients believed that by visiting traditional healers and prayer camps, they were taking practical steps to eliminate the symptom. The impact of media messages on help-seeking was identified in previous studies among Chinese-American women who were at risk of breast cancer (Facione et al. 2000b), Chinese women awaiting their first consultation (Lam et al. 2009), and Ghanaian women who had undergone mastectomy (Aziato & Clegg-Lamptey 2015). In all these studies, the media had been successful in motivating patients to act in some way.

Traditional medicine emerged as not only the patients' primary treatment preference for cancer, but also a major reason for them presenting late for medical diagnosis. This finding is supported by studies such as Clegg-Lamptey et al. (2009a) and Asoogo and Duma (2015), which have suggested that using alternative sources of treatment by women contributed to late presentation of breast cancer. Traditional medical practices are not limited to LMICs. In Western countries, the use of unconventional therapies such as traditional herbal medicine and homeopathy, which vary between 6% and 45% of patients diagnosed with cancer seeking treatment, is influenced by cultural values, religious beliefs, language of patients, and social trends (Malik et al. 2000).

In the USA, over 28% of patients with early breast cancer diagnosis are known to rely on various forms of alternative medicine while also being in receipt of modern medical treatment (Morris et al. 2000). However, Ghanaian women view traditional medicine very differently from the way complementary and alternative

medicine (CAM) is perceived by Western women. Complementary and alternative methods of treatment for breast cancer such as massage, herbal medicine, diet therapy, acupuncture, and others have been used with varying effect in many countries (Baum et al. 2006; Fox et al. 2013). Patients in Ghana use either traditional medicine or modern medicine, but rarely use them together, whereas in the 'West', women will access complementary medical approaches simultaneously with modern medicine. Ghanaian patients tend to be directed towards an almost default position, that is using traditional medicine until such time as individuals recognised it to be ineffective, rather than using it merely to complement modern medicine. This is another way in which the findings of this current study differ from those of previous studies conducted in Western countries. Ghanaian women believe in a combination of religious and cultural understandings of illness, and they routinely seek treatment from traditional practitioners and faith healers (Sackey 2002). Sackey (2002) explained that with the poor economic status of Ghanaian women, cultural beliefs, and the uncertainties of continuous medical services resulting from frequent strikes by hospital personnel, as well as the role churches play in health delivery, contributed to women seeking spiritual healing at prayer camps.

5.5.2   Final re-appraisal and decision to change help-seeking

After using traditional medicine for a long time with little or no improvement, the majority of patients suspected their breast symptoms might be more serious than they had initially believed. There was a gradual realisation amongst patients that rather than improving, their symptoms were getting progressively worse. The lumps were becoming more visible over time, pain was becoming increasingly intolerable, and symptoms were not resolving with traditional medicine. Consequently, patients became increasingly desperate, and this desperation overcame their previous fears of social stigma and treatment side effects. These developments led patients to re-appraise their symptoms by comparing their present conditions with memories of prior symptom episodes, and adopting a different help-seeking behaviour (Figure 13).

A 'desperation point' occurred for most of the patients in the current study in their pathway to modern medicine, including those who initially interpreted their symptom as harmless and took no action (Figure 13). This is another significant finding from the present study. Even at this stage when the symptoms became

increasingly intolerable and patients were compelled to seek modern medical care, help-seeking attempts were hampered by the fact that patients lived far away from the nearest treatment centre, they still feared stigmatisation and abandonment, and were suspicious of modern medicine. The desperation point where patients changed their help-seeking behaviour was influenced by specific contributing factors including a change in the nature of their symptoms, in particular, increase in breast size, nipple discharge, and unbearable pain, which altered their perceptions of the symptoms. The progression of symptoms no longer matched the conceptualisations of the breast condition patients had. Consequently, the majority of the patients questioned the accuracy of their existing symptom interpretations, prompting a re-appraisal.

Besides symptoms getting worse and becoming intolerable, other patients pointed out their traditional healers had advised them they were no longer able to treat them and that they should now seek modern medical help instead. The confirmation by the traditional healers, that they were unable to treat the disease, signifies that those healers 'gave up' on their patients. The perceived severity of a health problem, including associated disability, pain, and possible social consequences, influences both health behaviours and responses to health threats, and is a key construct in social cognition models (Safer et al. 1979; Leventhal et al. 1980). As in the case of the current study, the severity of the symptoms and the confirmation from traditional healers after unsuccessful treatment, prompted patients to re-appraise symptoms and alter their help-seeking behaviour. At the desperation point, the strategy of all patients using traditional medicine was finally to shift to seeking help from modern medicine (Figure 13). The finding in the present study, that increasing pain acted as a trigger for medical help-seeking, is supported by several studies (Meechan et al. 2002; O'Mahony & Hegarty 2009; Unger-Saldana & Infante-Castaneda 2011). Such information highlighted alternative explanations and, in turn, led patients to reconsider their beliefs about symptoms. The outcome of this re-appraisal process pushed patients away from the traditional medicine and pulled them toward modern medicine (Figure 17).

The triggers for re-interpretation, which indicate that re-appraisal is not a linear process is in line with Leventhal's proposition that if the output of a self-regulation system does not meet expectations (e.g. if treatment had no effect on symptoms), then there is an increased attention to that system (Leventhal et al.

1982). In this case, for some patients, until they arrived at the desperation point, they would continue to use traditional healing and avoid modern medicine. To trigger re-interpretation or re-appraisal, patients needed to recognise their current traditional approach to treatment was not effective. Therefore, despite most patients initially being pulled towards using traditional medicine after the discovery of their symptoms, an eventual re-appraisal of those progressively worsening symptoms, once it was clear traditional approaches were ineffective, finally prompted them to turn towards modern medicine. Even though the self-regulation theory provides important explanatory models to studying help-seeking behaviour, it does not adequately address the sociocultural impact on the switching coping behaviour in which patients change help-seeking from traditional to modern medicine or vice versa.

5.6   A conceptual framework of sociocultural determinants of delay in help-seeking for breast cancer symptoms

Whilst several theoretical models have been used in this chapter to facilitate an understanding of some of the patients' symptom appraisal and help-seeking behaviour, there are few contemporary theories that seek to explain help-seeking behaviour within a pluralistic healthcare structure and that recognise the influence of sociocultural factors on the use of traditional medicine. For example, in the model of pathways to treatment (Scott et al. 2013), use of traditional medicine is understood as a form of 'self-management', and is included as one of the 'contributing factors' in the appraisal process. However, in Ghana, traditional medicine is a component of the pluralistic healthcare system, reflecting the strong cultural belief that it is an appropriate treatment mode for breast problems.

Furthermore, while a model of help-seeking behaviour developed by Unger-Saldana and Infante-Castaneda (2011) offered insights into the factors influencing help-seeking for breast cancer symptoms, from the perspective of uninsured women in Mexico City, the model represents a different sociocultural and healthcare context from that of Ghana. This indicates that no universal explanatory model of help-seeking behaviour currently exists, which can be applied to Ghanaian women with symptoms indicative of breast cancer. Therefore, to better enhance the understanding of how Ghanaian patients responded to the occurrence of breast cancer symptoms, a conceptual framework

that helps to explain the sociocultural determinants of delay in seeking modern medical help is presented in Figure 19.
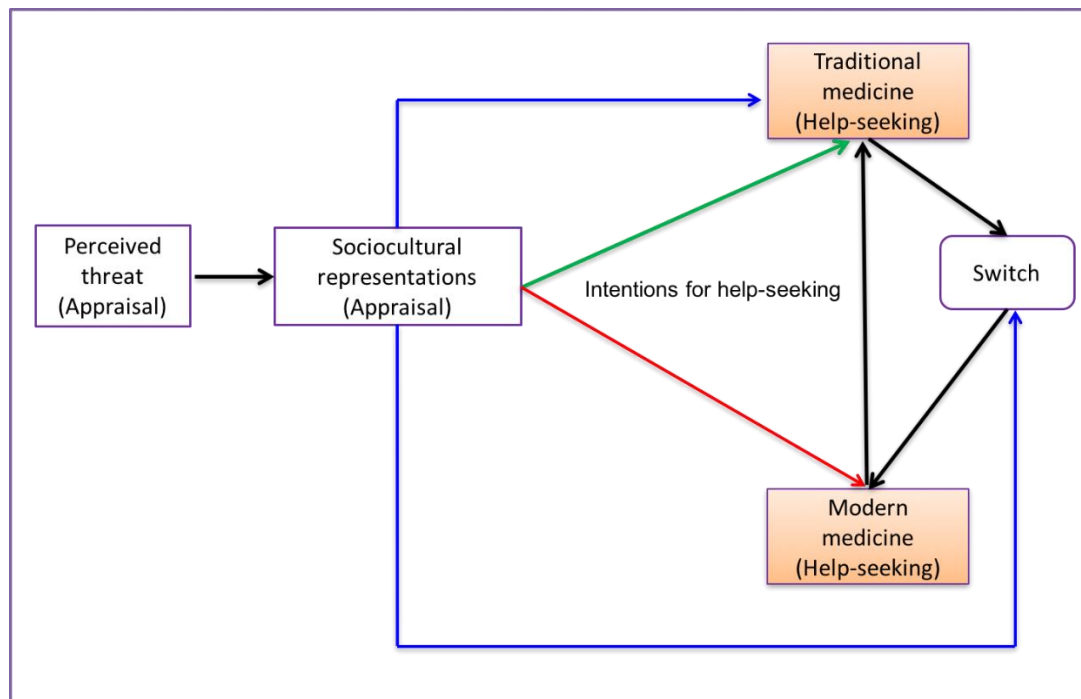
Figure 19 Sociocultural determinants of delay

The framework of sociocultural determinants of delay (Figure 19) was informed by the findings from the current study, the discussion in this chapter, and the theoretical models used. These models include the Model of Pathways to Treatment (MPT), the Social Cognitive Theory (SCT), the self-regulation theory (SRT), and the model of patient's pathways to modern medicine. Whilst the MPT was used as a framework for discussing findings within the two intervals of appraisal and help-seeking, the SRT and SCT were applied to analyse findings within the appraisal and help-seeking intervals respectively. In the process of using it, the MPT was adapted to include the pluralistic healthcare system of Ghana, to create the model of patients' pathways to modern medicine (Figure 13). This adapted model then informed the conceptual framework of sociocultural determinants of delay (Figure 19).

Although the psychological theories within these two intervals (appraisal and help-seeking) have provided important explanatory models to aid an explanation of self-regulation of illness and help-seeking behaviour of patients, they do not adequately address the potential sociocultural issues of the population studied. Given the underlying evidence of emotional reactions to symptoms particularly

the psychological impact on women with breast cancer symptoms and their subsequent behavioural expression, influences of cultural and religious beliefs of causation and interpretation of symptoms, and manifestation of symptoms in terms of severity and duration; this conceptual framework (Figure 19) adopts an explanatory model approach (Kleinman 1980; Kleinman 1988). An explanatory model is seen as dynamic, and can change based on individual experiences with health, health information, or with the illness in question (Scrimshaw 2011).

Figure 19 uses colours to distinguish different components: black directional arrows represent the inter-relationships between perceived threat, sociocultural representations of symptoms (appraisal-detection and interpretation), and help-seeking practices (Traditional medicine and Modern medicine) operating at different decisional points in the framework. Symptom interpretation of harmless swelling is depicted as blue lines. The blue lines pointing to traditional medicine signify a common ailment (e.g. a boil) or the perceived outcome of breastfeeding; the blue one towards the 'Switch' is considered just a normal swelling (lump). The switch describes the point in patients' help-seeking pathways when they change help-seeking from traditional medicine to modern medicine or vice versa. The red line pointing towards 'Modern medicine' represents a breast change that has been interpreted as a potential symptom of cancer (not spiritually related). Similarly, the green line pointing towards 'Traditional medicine' means breast change that has been interpreted as potentially resulting from spiritual causality of cancer.

5.6.1   Concepts and definitions

Individuals with strong supernatural beliefs would interpret changes in the breast as a spiritual disease and subsequently seek traditional medical help. This generates an assumption that any perceived threat, upon identification of a breast change (lump), represents cultural beliefs, socially accepted behaviours, and expectancies that influence psychological processes of motivation and emotions. All these factors compel Ghanaian patients to react in a certain way, from detection of symptoms to their 'first' modern medical consultation where they initially seek traditional medicine, rather than modern medical treatment or vice versa. Four main concepts identified in the framework that represent the sociocultural determinants of delay are: i) perceived threat, ii) sociocultural

representations of breast symptoms, iii) intentions for help-seeking, and iv) switching coping behaviour (Figure 19).

5.6.2   Perceived threat

Perceived threat is defined as a personal belief that a threatening health problem is serious and has potential negative consequences for life if not addressed. The findings of the present study indicated that patients' perceived threat of breast cancer symptoms depend on the potential seriousness of its consequences, particularly social stigma, pain, abandonment, and death. Since a lump without pain was the most common symptom identified (Table 8), actions taken by patients were largely dependent on the degree to which they believed the recommended behaviour (by social networks) can avert the threat (response efficacy), and whether they felt able to perform the behaviour recommended by the message source (self-efficacy). For example, the majority of patients were fearful of a cancer diagnosis and believed that cancer is a 'death sentence'. Therefore, perceived fear of cancer led patients to choose traditional medicine and delayed modern medicine help-seeking. Additionally, social stigma contributed to people avoiding medical help-seeking and ignoring their symptoms or hiding symptoms from their family and avoiding help-seeking, for fear of bringing shame on the family, limiting chances of daughter's marriage, and being ostracised from their community.

The conceptual framework (Figure 19) assumes that due to strong socio-cultural beliefs on the significance of the breast, detected changes to it are perceived as a threat to women. Being the most common breast change identified, a palpable painless lump represents cognitive constructs of identity and cause in self-regulation of illness, which are then used to guide coping and to appraise the outcomes of actions. In general, the identification of the painless lump and other signs presented in Table 7 did not indicate an illness with absolute certainty to the patients in this study, as they believe "serious illness" is associated with pain. This indicates the perceived threat of the breast cancer symptom activated the patients' self-regulatory process. Insufficient knowledge and awareness and a cultural understanding of breast cancer among the population studied shaped patients' interpretation of cancer symptoms.

Although all patients in the study first noticed breast lumps, most did not perceive them as abnormal until additional symptoms, especially pain, enlarged size, and offensive discharges were present. In addition to knowledge deficit, threat perceptions associated with patients' cultural and religious beliefs, particularly the spiritual causality of breast cancer, pulled them towards traditional medicine (Figure 17) and resulted in delays in seeking modern medical treatment. In accordance with the self-regulation of illness theory (Leventhal et al. 1997), these illness representations from the findings are individualised because of one's personal experiences and culturally available knowledge to manage, or regulate, the perceived threat. Subsequently, patients make judgements regarding the origin of and explanation for their threat.

5.6.3   Sociocultural representations of breast symptoms

As indicated in section 5.4.2, and explained within the five cognitive constructs representing illness in the self-regulation model (Leventhal et al. 1980), symptom interpretation in this study (5.4.2) is influenced by patients' strong cultural and religious beliefs of illness, the views of members of their social networks, symptom manifestation of pain and size, and patients' emotional reaction to symptoms (e.g. fear). While the self-regulation model used cognitions to represent the threat of the illness regarding its identity, duration, perceived consequences, cause and controllability, these are identified in the study findings to guide coping strategies to control threats in the framework (Figure 19).

As pointed out in 1.2.5, concepts of health and illness vary according to place and social context. By comparison, Westerners view illness as a physical phenomenon and advocate for modern medical treatment; Ghanaians believe that illness is the result of some mystical force that is beyond scientific understanding that requires spiritual interventions to address the problem. Consequently, cultural and religious beliefs of illness are considered in the framework (Figure 19). This is because the study has found that the cause of strange symptoms of diseases of unknown origin culturally shapes appraisal and results in explanations that such diseases are caused by supernatural means; in particular, this refers to 'bewitching', which may involve some blame for the person being cursed, and having offended the gods. These interpretations create both social and emotional implications of fear, denial, stigma, and isolation because supernaturally linked diseases are perceived by Ghanaians to cause pain,

suffering, and death, just as non-supernaturally linked diseases do. Thus, patients' perceptions of breast cancer being linked to evil-spirits, persuasively pulls them towards traditional medicine as illustrated in Figures 13, 17, and 19.

Another symptom interpretation is based on patients' own experiences, their cultural interpretation of painless lumps as "harmless" could signify no serious sickness until other symptoms, such as bleeding, enlargement, and intense pain, appear before seeking medical treatment. It was also indicated in the study that patients mistook harmless swellings for boils developed from the remnants of breast milk; such boils in Ghana are traditionally treated with herbs. In their attempts to self-regulate symptoms through traditional means, patients subsequently prolong seeking modern medical treatment. As shown in the findings of the study, other instances also have the potential for influencing longer appraisal delays due to patients' inability to receive proper medical attention. These include cases where lumps suspected of being cancer not caused by evil spirits (Figure 13), and patients' emotional reactions such as fear of cancer treatment and prognosis and patients' attempt to diminish cancer risk by denying its existence in the family (Figure 14).

The significance of social context in the self-regulation theory describing the importance of other people in influencing illness representation (Leventhal et al. 2003), was evident in the findings of the current study. Whilst SRT is centred on the effect on the individual, a symptom is experienced within social networks and what they offer in the present study. Unlike other studies (Taib et al. 2011; Oshiro & Kamizato 2017), which reported that social network interactions triggered early help-seeking, the current study found that members of the patients' social networks supported patients by sanctioning their seeking help for using traditional medicine (Figure 17). Members of the patients' social network regarded this as a way of fulfilling their cultural and family responsibilities, reinforcing appraisal decisions, and reassuring patients that their symptom experiences were within cultural norms. This manner of support makes individuals believe that their symptoms are not worth worrying about, thereby, delaying medical presentation. As individuals tend to be motivated to fit in with their group and maintain social harmony, patients tend to focus on their responsibilities and obligations while trying to avoid behaviours that might cause social disruption or disappoint significant others (Kitayama & Uchida 2005).

5.6.4   Intentions for help-seeking

Intentions for help-seeking for a potential breast cancer refer to the likelihood of a patient visiting their healthcare professional for a range of breast symptoms. The present study shows that decision-making for help-seeking within a pluralistic healthcare system is an interplay of individual difference factors (motivational orientation), socio-cultural factors (cultural background), and situational factors (symptom manifestation, healthcare system factors, social support), presented as factors contributing to appraisal and help-seeking intervals (Figure 14). These factors are likely to interact and influence the choice between traditional medicine and modern medical treatment. As previously discussed in section 5.5.2, although both traditional medicine and modern medicine are help-seeking options identified in the patients' pathways to modern medicine (Figure 13), there are many more positive reasons, or 'pull' factors that influence patients in the sample to select traditional medicine, rather than modern medicine (Figure 17).

Due to Ghanaian patients' sociocultural backgrounds and limited knowledge, traditional medicine is preferred because it is perceived to have the ability to cure diseases physically, spiritually, and emotionally, whereas modern medicine is assumed incapable of treating spiritual diseases. The finding that patients who consider the possibility their symptom was spiritual in origin would seek help from a spiritual or faith healer, is compatible with Bandura's (1986) social cognitive theory. This theory posits that individuals engage in behaviour because of the outcomes they hope to achieve, and these action expectations reflect the motivational function of reinforcement (Bandura 1991). Therefore, patients believe that by selecting traditional medicine over modern medicine, they would avoid the apparent consequences of the disease (e.g. death by surgery, previous unpleasant experience with HCPs, social stigma, and high treatment costs) associated with that kind of treatment. Other positive factors identified in the findings that patients perceive as reasons for using traditional medicines include official government sanction within the pluralistic healthcare system, its availability, and affordability (Figure 17). Under this premise, different combinations of help-seeking behavioural schemas are possible through the conceptual framework (Figure 19).

5.6.5   Switching coping behaviour

The inclusion of switching coping behaviour concept in the framework (Figure 19) indicates perceptions of personal control that alters forms of coping with breast symptoms. Within the pluralistic healthcare system of Ghana, patients have the option of choosing between traditional medicine and modern medicine. Influenced mainly by symptom manifestation, 'switching' is activated when symptoms persist beyond the endurance limit set by the individual and/or when traditional healers confirm that traditional medicine is not working as expected, a decision is made to change the help-seeking behaviour from traditional medicine to modern healthcare. Reasons for this change in coping behaviour may vary from patient to patient (e.g. excruciating pain, increasing breast size, and offensive discharges from breast lesions). These alterations cause desperation, and induce a re-appraisal of the symptoms' interpretation and treatment options in response to the symptoms' progression. Based on the study findings, confirmation that traditional medicine has failed to bring relief to a patient, though late, is the most important negative "push" factor towards modern medicine (Figure 17). Evidence from the study suggests that even at this stage of the help-seeking process, members of the patients' social network play a crucial role in the switching process. For example, at the worsening of the symptoms, social interactions allow caregiving, encouragement, and financial support to make the switch possible.

Desperation also modifies cognitive and emotional representations by motivating individuals to overcome their previous fears of social stigma and treatment side effects, while pushing patients away from the traditional medicine and pulling them toward modern medicine, as the last lifesaving option for the patients. Thus, combined levels of susceptibility, symptom severity, influence of members of patient's social networks, and perception of modern healthcare benefits would provide the motivation to make the 'Switch'. The 'switching' concept resulting from desperation can partially be explained by the self-regulation theory, which supports evaluation of whether or not implemented strategies are successful in achieving goals. Thus, the reasons for the switching would confirm appraisal that coping strategy (traditional medicine), which has failed to improve the symptoms, can lead to a change in help-seeking behaviour (modern medicine). Guided by cognitions and dependant on explanations, if-then questions could generate a self-regulation system that refers to self-knowledge and social factors. Actions are re-evaluated and representations changed until they return to a former or a new

status quo. The switch can also be analysed with the suggested in the outcome expectancies of SCT, in which patients learn through their own symptom experiences, and the results of those actions.

Social cognitive theory could exert a unidirectional 'forward & backward movement' influence on patients' help-seeking as illustrated by Scott et al. (2013), which suggests that after initially consulting a healthcare professional, patients may need to monitor symptoms and reconsider seeking help if symptoms persist or change. The unidirectional process reported in Western studies cannot explain the multidirectional movement of Ghanaian patients who initially suspected that their symptoms could be cancer and therefore sought help within the modern medical system, and abandoned that type of treatment and consulted traditional healers. This situation was evident in the findings that some patients might have already had a first consultation with a HCP for their symptoms, and then have switched to traditional medicine before switching back to modern medicine. As demonstrated in Figure 13, patients can vacillate back and forth between different treatment modalities. Nevertheless, the conceptual framework of sociocultural determinants of delay (Figure 19) can now accommodate this process of vacillating help-seeking behaviour.

Considering the purpose for developing the conceptual framework (Figure 19), it is prudent to consider how it integrates with the other theoretical models used in the study. Designed to aid understanding of contributing factors that results in patients delays in presenting symptoms to modern medicine, the conceptual framework was produced using multiple psychosocial and health behaviour theories in the appraisal and help-seeking intervals. Therefore, specific portions of the conceptual framework could relate to the models considered, particularly, the model of the pathways to treatment, self-regulation theory, and social cognitive theory.

The conceptual framework is structurally divided into symptom appraisal and help-seeking intervals based on MPT; hence, it overlaps with that portion of the model. Although SRT was used to address the self-regulatory processes within the appraisal interval, and SCT focused on the help-seeking interval, both models have concepts that are common with those two models regarding cognitive ways of explaining factors influencing health behaviour. Since appraisal and help-seeking intervals have also used some of the constructs such as illness

representation, self-efficacy, coping procedures, self-regulation, and behaviour explained by the SRT and SCT within the MPT, part of the theories within the conceptual framework can be accommodated within that model.

5.7   Chapter summary

This chapter has discussed key findings of the current study in the context of their sociocultural significance and overall relationship with the current body of literature. While the study findings support conclusions of other studies, it has also presented new insights that are different from those published in Western studies. Key factors associated with delay have highlighted the culturally based beliefs underlying delayed presentation of breast cancer symptoms for modern medicine for evaluation and possible treatment.

The model of pathways to treatment was used as a framework for structuring the chapter according to the concepts of appraisal and help-seeking intervals. In addition, specific psychological concepts from both self-regulation and social cognitive theories were used to reinforce findings within the appraisal and help-seeking intervals. Finally, a conceptual framework of sociocultural determinants of delay in help-seeking for breast cancer symptoms, has been suggested and described. Following the perceived threat to health from self-identification of breast cancer symptoms, these models have expanded the understanding of contributing factors that result in delays in presenting to modern medicine.

Chapter 6:   Conclusions and recommendations

This chapter concludes the thesis by providing a succinct overview of the study, followed by a consideration of its original contribution to the body of knowledge regarding factors impacting on prolonged patient interval for breast cancer symptoms. In addition, the chapter critiques the strengths and limitations of the study within the context of its stated aims, and gives suggestions for future research. Finally, the chapter finishes with reflections on my experiences of undertaking the study.

6.1   Overview of the study

This study has focused on one of the most important women's health problems in Ghana, that of breast cancer, for which women in that country tend to seek treatment from modern medicine at a late stage. This is a concern especially as the incidence and mortality rates have been increasing exponentially over the last fifty years (Wiredu & Armah 2006). It is widely known that early detection and treatment of breast cancer enhances survival, yet the majority of new breast cancer patients in Ghana are diagnosed at advanced stages, as a result of the prolonged delay in seeking help from modern medicine. This study was undertaken to increase understanding as to why this is so, when the mortality rate is decreasing in many Western countries (Jemal et al. 2010), and women are not presenting at such late stages.

An early review of the literature gave some indications as to why this might be so. It appeared likely that there were complex socio-cultural influences on Ghanaian women's appraisal of breast cancer symptoms, the meaning they ascribed to those symptoms, the significance of this experience on their timing and choice of healthcare utilisation. These factors were examined by selecting a purposeful sample of patients at two cancer treatment hospitals in Kumasi, Ghana and conducting face-to-face semi-structured interviews with the women, members of their social networks, and healthcare professionals.

Focus was on the processes patients went through as they interacted with their social networks and local healthcare system. Subsequently, both psychosocial and help-seeking theories were used to shed light on how patients understand the origin of their symptoms, their emotional reactions to their discovery, and

utilisation of available treatment options. The model of pathways to treatment was used as a framework to discuss the findings within appraisal and help-seeking intervals. Leventhal's (1980) self-regulation theory was employed to analyse findings within the appraisal interval, and Bandura's (1986) social cognitive theory was adopted to examine findings within the help-seeking interval.

6.2   The study's unique contribution to knowledge

The findings of the study extend beyond what has been reported in previous studies by reinforcing the influence of culture as an important aspect of understanding disease causality and help-seeking behaviour. Equally important is the understanding of how patients' choice of healthcare was also shaped by their sociocultural backgrounds. By providing additional insights into the impact of sociocultural factors on prolonged patient interval, this study advances existing knowledge of delayed presentation and medical help-seeking for breast cancer symptoms in several ways.

The study has revealed that delay in consulting modern medicine was impacted by a set of sociocultural factors that influenced both symptom appraisal and help-seeking behaviour. Four main contributing factors that influenced the timing and type of healthcare system patients' sought included the sociocultural backgrounds of patients, the specific manifestation of signs of breast cancer, patients' emotional responses towards those signs and symptoms, and the existing healthcare system. These contributing factors were instrumental in the illustration of patients' journeys from detection of breast changes to their first encounter with modern medicine. Scott et al.'s (2013) model of pathways to treatment was adapted to include the pluralistic healthcare system, to create the model of pathways to modern medicine. Therefore, the pathways to modern medicine acknowledges how the Ghanaian socio-cultural context within which women must make decisions once they discover a potential symptom is different from that of Western countries.

Patients' decisions to use either the modern medical system or the traditional medical system was dependent on the sociocultural understanding of the cause of the disease, and how the type of treatment sought, would affect them physically, economically, socially, and emotionally. Three diverse symptom

interpretations of breast changes were identified amongst participants: that a lump was a harmless swelling such as a boil, that the changes were a manifestation of a spiritual disease, or that changes were potential symptoms of cancer. These interpretations underscore the difficulty of embracing Western style medicine that arise when sociocultural beliefs on traditional medicine conflict with modern medical treatment to influence help-seeking behaviour.

The study found that appraisal and help-seeking intervals are not linear with the contributing factors interlinking both intervals. As a result, patients' preference for traditional healing may in many cases have acted to extend the appraisal and help-seeking intervals, and delaying the presentation of symptoms to a healthcare professional. Patients' perceptions of delay indicate that they did not believe they were delaying because they put their faith in traditional medicine. Within the pathways to modern medicine, processes within the help-seeking interval revealed that both the negative push factors and positive pull factors, direct patients towards an almost default position of using traditional medicine, particularly herbs and prayers. Once individuals recognised traditional methods to be ineffective, they became increasingly desperate and then switched to modern medical treatment. The 'desperation point', which motivated patients to re-appraise their symptom interpretations, happened to almost all the patients including those who initially interpreted their symptom as harmless and took no action.

Another reason for the delay in seeking help from modern medicine is the patients' perception that as a spiritually linked disease, breast cancer cannot be treated completely at the hospital. Patients experience with someone very close to them who suffered and died at the hospital following mastectomy reinforced their assumption. Patients strongly believe that it is the hospital surgery that kills and not the delayed presentation of cancer symptoms. As patients view mastectomy with death, one of the reasons they avoided modern treatment for months and years, and why they finally decide to go to the hospital at a time when there would be no other treatment option could be explained. The fact that the desperation is so great at this stage, women realise that they will die anyway without treatment. Therefore, the study has reported that it is the misunderstanding of the disease, coupled with self-perpetuated myths and misconceptions of breast cancer that pervaded the thinking of most patients, and

resulted in their tendency to avoid modern medicine and use traditional medicine instead.

As an original contribution to the breast cancer field, a conceptual framework for understanding sociocultural determinants of delay in help-seeking for breast cancer symptoms has been proposed and described. This conceptual framework has identified the facilitating factors that can shape psychological constructs such as illness cognitions, attitudes, and intentions, which may influence delay in help-seeking, among a sample of Ghanaian female patients, for their breast cancer symptoms. The framework can be used as a model to guide future help-seeking behaviour research in other populations with similar sociocultural contexts.

6.3   Strengths of the study

The main strengths of this study relate to methodological issues. The choice of a qualitative research approach allowed the exploration of complex decision-making processes in detail and the study has therefore provided an in-depth understanding of patients' experiences and factors influencing action taken on healthcare choice for their breast cancer symptoms. The face-to-face and audio-recorded interviews were an advantage because they used mainly open-ended questions. These methods of data collection helped to obtain rich descriptions that would have generally not been available otherwise.

The study also derived strength from its originality and the use of more than one group of participants to understand the complex phenomenon of symptom appraisal and help-seeking behaviour of patients with self-discovered breast cancer symptoms. Thus, the research accessed not only the voices of patients, but also members of their social networks such as family and friends, and healthcare professionals to explore and better understand their experiences. The incorporation of multiple sources of informants facilitated a broader understanding of the different aspects leading to prolonged patient intervals. To enrich the information collected, the use of a purposive sampling technique for recruitment enabled the targeting of participants that were likely to make a meaningful contribution to the study. The three data sources and thematic analysis technique promoted rigour and trustworthiness of the findings and a comprehensive understanding of the phenomena.

This research addressed several gaps in the current literature on delay and help-seeking behaviour in breast cancer. For example, the number of qualitative studies dedicated to the impact of culture on breast cancer, symptom appraisal, and help-seeking behaviour in sub-Saharan Africa has been comparatively small in both the psychosocial and health behaviour disciplines. The conceptual framework for understanding the sociocultural determinants of delay in help-seeking for breast cancer symptoms amongst Ghanaian women (Figure 19), should guide the designing of more effective health education messages that are culturally appropriate. It can also help to shed light on why there are prolonged patient intervals amongst women with breast cancer symptoms in other sub-Saharan African populations with similar sociocultural backgrounds.

6.4   Limitations of the study

In considering the factors that may have affected the quality and value of this study, the relatively small patient sample size could be considered a limitation. However, it is argued that the emergent data were rich enough to cover a wide range of views and the recurrence of a number of themes indicated data saturation.

Since purposive sampling was used to identify patients from two tertiary hospitals, the study was limited only to those who were able to reach the hospitals where they were recruited for the study. The accounts of the patients who suffered the greatest access barriers, and were unable to attend a teaching hospital, could not be included in the study. Additionally, patients who went for treatment abroad were excluded. Therefore, the findings of this study would require confirmation, or otherwise, among patients with breast cancer symptoms in general.

Another limitation of this study is centred on how time was estimated by the patients. Since patient interval was obtained retrospectively through patients' self-reporting, this strategy may have caused recall bias as patients were asked to give narrations of their past experience. In order to minimise potential bias, patients were recruited during their first clinic attendance while they waited to see the healthcare professional. Furthermore, by focusing on the stories of the women, which provided very graphic accounts of their journeys and views, this helped to mediate against any such problems about the veracity of their recall.

In line with qualitative inquiry, whilst the sample size was deemed appropriate for this study, the findings cannot be generalised and applied to all Ghanaian women since selection was not random but purposive. Nevertheless, the understandings generated and the tentative theoretical explanations may be transferable to similar settings, depending on the degree of resonance between the actual setting and the study population (Pelusi 1997).

6.5   Suggestions for future research

In view of the findings of the study revealing sociocultural reasons for why a group of patients in Ghana took longer than three months to seek modern medical care, the factors identified opportunities for future specific intervention research, focusing on reducing the avoidable prolonged presentation of breast cancer symptoms to healthcare professionals. Based on this suggestion, four recommendations have been offered, in order to encourage early presentation of symptoms.

First, considering the strongly internalised fear of breast cancer consequences and its perceived incurability among the patients who participated in the study, research into developing programmes aimed at focusing on improving women's knowledge of breast cancer and modifying their sociocultural beliefs regarding the disease is recommended. For example, psychometrically appropriate instruments can be used to measure cultural factors relevant to fear and anxiety related to identification of breast cancer symptoms and help-seeking behaviour.

Second, the current study focused on capturing and presenting sociocultural factors impacting on delay, and it has identified that patients took longer to present their symptoms for medical evaluation because they spent their time seeking help from traditional healers. This occurred until a point when, for various reasons, patients switched to the modern medical system. Within the help-seeking interval discussed, further research is needed to understand additional factors that may influence the overall patient interval reported, which could not be determined from the current study.

Third, the study found that patients' sociocultural factors play an important role in the process of how symptoms are identified and interpreted, when help is sought, and where it is received. However, the relationship between the sociocultural factors identified in this study merit further research to understand

how Ghanaian women participate and respond to cancer prevention and control messages as provided by the Ministry of Health and other cancer advocacy groups.

Finally, a conceptual framework has been developed regarding the sociocultural determinants of delay, and this has provided insights into the psychosocial and health behaviour attributes of this population. Nevertheless, there is a need for further research to validate the importance of such a framework within different patient and healthcare system groups.

6.6   Recommendations for action

In view of the findings from the present study, which indicate that delayed presentation of breast cancer symptoms continues to occur amongst Ghanaian women, the following recommendations are presented for action. These insights would assist healthcare professionals to implement interventions capable of encouraging early diagnosis and treatment of patients who self-discover breast cancer symptoms in Ghana.

The finding that symptom appraisal is dependent on a patient's culture and knowledge could be addressed by developing a more comprehensive outreach programme in more diverse communities than currently exist. Possible locations where women could be targeted include churches/mosques, market places, senior secondary schools, and women organizations. This proposed breast cancer programme would integrate health education on risk factors, BSE and CBE, treatment options, benefits of early diagnosis and treatment, and a patient navigation system. The outcome of such a programme would not only increase women's knowledge and confidence in detecting breast changes, it will also address myths and misconceptions, minimise fear of diagnosis and treatment, and inspire prompt help-seeking behaviour. To ensure sustainability and continuous reiteration of messages endorsing early presentation and treatment, the government should establish a cancer prevention and control network to coordinate and fund breast cancer awareness/education, screening, training of healthcare professionals, access to care, and expedite referrals across the country.

As it has been reported in this study that patients' interaction with members of their social networks sometimes contributed to the delay, a social accountability strategy can be enforced through information campaigns by civil society organizations, community radio and TV, and social media to reduce delayed presentation. This approach would emphasize mutual responsibility and accountability by community members, healthcare workers, and health officials in promoting early presentation of breast cancer.

Patriarchy, and the deference associated with it, was another sociocultural factor identified as an obstacle to Ghanaian women's help-seeking behaviour. Being a patriarchal society, husbands continue to exercise authority over their wives' healthcare decisions. Culturally, wives also feel obliged to respect their husbands' views; divorce is viewed as viewed as a sign of failure and disgrace not only to the woman involved, but also to her entire extended family, could be upon them. For this reason, if husbands have a better understanding of the consequences of late stage disease, they are more likely to willingly permit their wife to report to modern health facilities early when they identify a lump in their breasts, as well as provide the needed funds for transportation and other non-medical expenses.

As indicated in the findings of the study, effective modern medicine treatment of breast cancer was often hindered by patients' initially seeking care from traditional medical sources. However, since traditional medical practice constitutes an integral part of Ghanaian culture, it cannot be ignored nor removed from the mainstream healthcare system. Therefore, to accommodate sociocultural preferences and beliefs of Ghanaians and achieve an efficient integrative healthcare system that is acceptable for breast cancer patients, traditional medical practitioners should be trained regarding breast cancer, particularly, risk factors, signs and symptoms, diagnosis, and innovative treatment modalities prior to integrating them into the mainstream healthcare system. Additionally, to minimise the fierce competition between the modern and traditional medical systems, which is confusing to patients, a revised healthcare policy, which integrates ideas from government, healthcare personnel, and traditional healers should be developed, with the public involved at each stage of the process of policy formulation. This will give each sector a sense of ownership and empowerment towards strengthening the existing healthcare system in the country, while allowing breast cancer patients the freedom to make healthcare decisions without intimidation. Such collaboration would also allow a team of care

providers to work together to present treatment options in a consistent manner that will benefit the patient.

Another finding of the study indicated the need for improving dissemination of appropriate breast cancer information to promote the benefits of earlier breast cancer symptom presentation and treatment, such as lessening stigma, reducing pain, and increasing chances of survival. Currently, the media, particularly television and radio, have relentlessly been used to promote traditional healing practices without any credible censorship. Using the same mode of communication (radio and TV), the ministry of health and the Ghana health service should work with local communities to create culturally appropriate messages about breast cancer and disseminate these in English and in the major languages. Other modern information technology tools to consider in propagating messages to adolescents and younger women include the use of social media (Facebook, Twitter, and Instagram), text messages, call-in radio programmes, and a breast cancer specific website that women can access for information and support.

6.7   Personal reflections

This journey is one I will never forget. The study has been a learning, enriching, and challenging experience for me as I reflected on not only my reactions during fieldwork, but also my feelings during data collection and analysis. I maintained a reflective journal to document the research activities undertaken including data collection, handling of transcription issues and translational challenges, analysis and synthesis of data, preliminary codes, merging themes, as well as my emotional responses to the interviews. Keeping a reflective journal was a way to assist the identification of my personal values, judgments, background, assumptions, and aided transparency regarding these factors to minimise their impact on the phenomenon under investigation.

I was aware of my personal and professional experiences, cultural background, social position, and public health principles that could influence the questions I asked throughout the interview process. As a native of Ghana, I could relate to some of the issues addressed by the participants. I was particularly conscious about a potential situation whereby, being a male investigator, interviewing women on such a sensitive topic might be difficult for some women to disclose to

anyone other than their immediate family or medical practitioner. To deal with this situation, two female nurses, who were not involved in patient care management, and who were willing to volunteer for this study at no cost, were trained as interviewers. This put a contingency plan in place to address the sensitivity of this situation.

Whilst the main intention was to understand the complex factors at play in women presenting at a late stage with symptoms of breast cancer, it has become evident that this understanding has potentially generated a stimulus for policy changes regarding education, behavioural, and healthcare reform, to improve the performance of the existing healthcare system to shorten delays. Such a combination of public policy and personal intervention measures is important in promoting and supporting the efforts of individuals to make good cancer control decisions to encourage early detection, presentation, and treatment of illness, and therefore improve survival.

Since the findings revealed factors influencing prolonged help-seeking behaviour, development of policy and practice need to focus upon ensuring that appropriate assistance is available for health professionals to alleviate stalling. Additionally, to minimize delay in seeking treatment, patients' expectations and understanding of early presentation of breast cancer symptoms for modern medicine should be addressed in culturally appropriate health-education programs. Therefore, to facilitate the planning and developing of broad-based policy that may be applicable to other communities, findings from the study would be available through publications and presentation at conferences.

Appendices

Appendix A Summary of 21 final articles included in the study

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
[1]	(Bottorff et al. 2007)/ Canada	To examine experiences related to self-discovered breast cancer symptoms from the perspective of Punjabi immigrant women residing in Canada	25 women with breast cancer symptoms Ethnic diverse South Asian Punjabi community in Vancouver	Qualitative interviews/ ethnographic approach/ Narrative analysis		Women drew on the support of their extended families, their religious beliefs, and their need to care for their families
[2]	(Burgess et al. 2001)/UK	To explore the factors that influence GP consultation by women with breast cancer symptoms	46 women newly diagnosed with breast cancer at oncology outpatients department	Qualitative study/Purposive selection/Semi-structured interview/Framework method analysis		Women who presented promptly recognised symptom seriousness

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
[3]	(De Nooijer et al. 2001)/ Netherlands	To investigate factors influencing the process of detecting cancer symptoms and seeking medical help	Total of patients=23 Patients' homes	Qualitative study/Andersen's model of patient delay/Semi-structured, in-depth interview/ Framework analysis	Model of total patient delay	Several factors were found to play different roles for different patients groups
[4]	(Facione & Dodd 1995) /USA	To examine narratives of women with self-discovered breast cancer symptoms to gather qualitative data	39 women with self-discovered breast cancer symptoms	Qualitative narrative/ Interviews/Narrative analysis		Influencing factors causing delay were attributed to false assurance from providers

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
		regarding their diagnostic experience and to chart the frequency of key events contributing to the timing of their diagnosis.	Eight oncology clinics, office practices, and Community hospitals			
[5]	(Gates et al. 2001)/USA	To describe caring behaviours and demands and to identify possible relationships between caring demands and delay for African American women	13 African American women with a primary diagnosis of breast cancer (ages 30–66) Two oncology clinics in the mid-South	Focused ethnographic design/Audiotaped ethnographic interviews, snapshots, participant observation/Purposefully selected/Leininger's phases of ethnographic analysis	Leininger's theory of culture-care diversity and universality	Caring both for and from others was supportive in seeking and continuing diagnosis and treatment

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
[6]	(Gould et al. 2010) /Canada	To qualitatively explore the cognitive emotional, and contextual experience of women with locally advanced breast cancer in the time between symptom discovery and seeking healthcare	In person (n = 8) or on the telephone (n = 6) Unique multidisciplinary LABC clinic	In-depth qualitative interviews and a cross-case, content analysis		Participants delayed help-seeking because they did not perceive themselves to be at risk for developing breast cancer
[7]	(Granek & Fergus 2012) /Canada	To understand the interplay between experiential and discursive processes by which women make decisions to seek help	14 women and the male partners of 7 of these women Cancer centre Toronto	Qualitative method/ A Semi-structured interview/ Grounded theory/Critical discursive approach		Women who were unaware of their symptoms delayed help-seeking

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
[8]	(Khakbazan et al. 2014) /Iran	To explore the perceptions and experiences of Iranian women with self-detected possible breast cancer symptoms	27 Iranian women with self-discovered breast cancer symptoms Women who attended Cancer Institute	Qualitative method/ involving in-depth semi-structured interviews/Purposive sampling/content analysis		Entangled cognitive, emotional and socio-cultural responses affecting understanding of symptom seriousness require further investigation
[9]	(Lackey et al. 2001) /USA	To describe the experiences of African American women living with breast cancer following the primary diagnosis	13 African American women/between 30 and 70 years of age, within three to six months of diagnosis, and initial treatment	Phenomenology/Purposefully selected/Colaizzis analysis plan		Experience Trajectory, Femininity, and Spirituality were the three major themes

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
			Two oncology clinics			
[10]	(Lam et al. 2009) /Hong Kong	To describe help-seeking patterns in Chinese women with self-detected breast symptoms	37 women with self-detected breast symptoms who are aged 21 years and above Three regional public hospitals	A grounded theory-based qualitative study/Semi-structured interview at first consultation before diagnosis/Theoretical sampling/Grounded theory approach		Atypical and painless presentation was more common among women delaying presentation
[11]	(Lu et al. 2010) /Taiwan	To explore the experiences of older Taiwanese women when they first faced a new diagnosis of breast cancer	14 women, aged 65 to 91 years with a new diagnosis of breast cancer. Cancer hospital	Qualitative research design/ Purposive sampling/In-depth interview/Content analysis		Participants faced physical discomfort, shock, denial, fear, worry, and hopelessness

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
[12]	(Mathews et al. 1994) /USA	To explore the factors that contribute with presentation for treatment with disease at an advanced stage	26 black women who presented with late-stage, advanced breast tumours (defined as TNM stage 3 or greater) Breast clinic and patient's home	Qualitative study/In-depth interviews/Narrative analysis		Fatalism and other attitudinal variables may be part of the complex of behaviours leading to presentation with an advanced stage disease
[13]	(Norsa'adah et al. 2012) /Malaysia	To explore reasons for delay in seeking help among patients with breast cancer from the East Coast of peninsular Malaysia	12 breast cancer patients who had been histo-pathologically confirmed and were symptomatic on presentation Any	A qualitative study /Face-to-face in-depth interviews were carried out		Help-seeking behaviour was influenced by a complex interaction of cognitive, environmental, beliefs, culture and psycho-social factor

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
			of the three government hospitals in the East Coast of peninsular Malaysia			
[14]	(O'Mahony & Hegarty 2009) /Ireland	To identify the extent of delay and the factors influencing women in seeking help from a healthcare professional on self-discovery of a breast symptom	100 women with self-discovery of a breast symptom Breast care clinic	Quantitative/ Descriptive, cross-sectional, correlational design Questionnaire/		Delay time was significantly related to women's knowledge and beliefs and social issues

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
[15]	(O'Mahony et al. 2011) /Ireland	To explore women's health seeking behaviours for a self-discovered breast symptom	10 women with self-discovered breast symptoms Women's homes, Researcher's workplace, Telephone interviews	Qualitative descriptive approach/''Help-seeking behaviour and influencing Factors'' framework/Semi-structured interviews/Content analysis		Delay still persists despite continued emphasis on early help-seeking
[16]	(O'Mahony et al. 2013) /Ireland	To describe women's help-seeking behaviour (HSB) and the associated influencing factors on self-discovery of a breast symptom	449 symptomatic women attending breast clinics Breast clinics	Quantitative/ Descriptive, correlational survey design/ survey data/SPSS/ Logistic regression/Chi square/		HSB is influenced by multiple factors which can impact on patient outcomes

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
[17]	(Rastad et al. 2012) /Iran	To gain insight into the causes of delay in seeking treatment in patients with breast cancer	10 breast cancer patients in the stages of II b, III or IIV, with at least 3 months patient delay in seeking treatment A major oncology clinic	Qualitative study/Semi-structured interviews/content analysis		Major themes were lack of knowledge, fear of being diagnosed with cancer, not seeing oneself at risk, mental preoccupation and wrong diagnosis by physicians
[18]	(Reifenstein 2007) /USA	To assess for delay in care-seeking for breast cancer symptoms	48 African American Women with self-identified breast cancer symptoms	Quantitative/Participants completed mailed questionnaires/Pearson correlation and separate regression analyses	Theory of care-seeking behaviour	Denial was associated with increased delay. Coping, social support, and problem-solving strategies had no relationship with delay

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
			Participants completed and then mailed questionnaires			
[19]	(Taib et al. 2011) /Malaysia	To explore the experience of Malaysian women presenting with advanced breast cancer with regards to their interpretation of breast symptoms	19 breast cancer patients presenting with delayed treatment and/or advanced cancer	Grounded theory/Purposive sampling/In-depth interviews/Thematic analysis		Outpatient clinics and in-patient admissions at the University Malaya Medical Centre Women delayed seeking diagnosis despite their awareness of the symptoms
[20]	(Unger-Saldana & Infante-Castaneda 2011)	To develop an understanding of the dimensions involved in delayed medical care of	17 women with breast symptoms (highly suspicious breast	Qualitative study/Grounded theory / Purposely selected/in depth interview/	Theory of illness behaviour	Delay is a result of the interplay between patient's socio-cultural context, and aspects of local health services

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
	/Mexico	breast cancer patients from their own perspective	cancer diagnosis) and 11 of their relatives, before the patients' first consultations with the breast specialist The Mexican National Cancer Institute			
[21]	(Yusoff et al. 2011) /Malaysia	To assess why women delay in getting treatment for breast cancer, as well as to explore what type of	16 husbands (men) 10 women at Oncology Clinic,	Basic interpretative of qualitative methodology Purposive sampling /In-depth interviews/ Thematic analysis	Health Belief Model Theory of Reasoned Action	Six themes were identified: new conception of breast cancer treatment, psychological defences, health support system, symptom experience, and barriers

Paper number	Author(s)/Study location	Aim/Objective	Sample/setting	Methodology used	Theoretical framework	Key findings
		issues are involved in such delay cases	Hospital, Malaysia		Theory of Planned Behaviour	

Appendix B Participant Information Sheet for patients

UNIVERSITY OF Southampton

Study Title: Impact of sociocultural factors on help-seeking behaviour among Ghanaian women with breast cancer symptoms

Researcher: Seth A Wiafe   **Ethics number**:

Please read this information carefully before deciding to take part in this research. If you are happy to participate, you will be asked to sign a consent form.

Introduction

I am a public health professional with over 10 years of experience in disease prevention. I am currently studying for a Doctor of Philosophy degree (PhD) at the University of Southampton in the United Kingdom (UK) and as part of this; I am conducting this research, which seeks to explore the impact of sociocultural factors on help-seeking behaviour among Ghanaian women with breast disease symptoms.

It is important for you to understand why this research is being carried out and what it will involve before you decide to join. Please take time to read the following information carefully and discuss it with your family and friends if you wish. If something is not clear or you would like further information, please do not hesitate to contact me at the address below or telephone number given at the end of this information sheet. Thank you for your time and consideration.

What is the research about?

The aim of this research is to understand the help-seeking behaviour of Ghanaian women with breast disease symptoms. The purpose is to explore personal experiences of Ghanaian women with unusual breast symptoms from the time they detected the symptoms to the day they appeared before a healthcare professional for evaluation. I hope to learn more about how your personal experiences of the symptom discovery may have affected all aspects of your life especially how this experience influenced your decision to seek help from a trained medical professional. I hope to gain a better

understanding of your perceptions and the meaning related to your experiences with breast disease symptoms.

Why is this research important?

Early detection of unusual breast disease symptoms significantly improves a woman's chances of successful treatment and survival. Because tumour size is primarily a time dependent factor, significant delay in diagnosis and treatment by the patient and various parts of the healthcare system commonly result in a larger tumour size at diagnosis. This leads to an advanced stage of the disease, which is associated with decreased survival. Therefore, it is important to understand the factors influencing longer delay in Ghanaian women so that appropriate intervention programs can be designed to minimize delay and reduce mortality from breast abnormalities.

Why have I been chosen?

You are being invited to join this research because you meet the following inclusion criteria.
  a) You are a woman above 18 years of age
  b) You self-detected an unusual breast disease symptom such as lump, inverted nipple, dimpling, nipple discharge, and others
  c) You attended the hospital for the first time for medical professional consultation of the symptoms
  d) You speak English or Twi language fluently

Do I have to take part?

You do not have to agree to take part in the study. If you decide not to take part or you decide later to withdraw, you do not have to give a reason. This will not affect your current or future healthcare.

What is the research method used for this study?

A qualitative narrative research design will be used as a research strategy in this study. A face-to-face loosely structured interview will be the method of collecting the data. Purposive sampling will be used to select the participants. Study participants will include; symptomatic women who self-discovered breast disease symptoms and attending breast clinic for the first time, relatives, friends, or colleagues women would suggest, and healthcare professionals. The women and the healthcare professionals will be recruited from Komfo Anokye Teaching Hospital Breast Care Centre (KATH-BCC), and Peace and Love Hospital (PLH) in Kumasi. The total period for data collection for this research will be six months.

What will happen to me if I take part?

If you decide to take part in this research, you will be asked to sign the informed consent form. The researcher will make an appointment with you to interview you at a location that is convenient and private for you. The length of the interview will be 45- 60 minutes at which time you will be asked open-ended questions. You will be audio recorded during the interview process. The researcher may take notes during the interview process. Your real name will not be revealed in the study. A second interview may be required for clarification purposes. In addition, if you agree to join the study, the researcher may look at your medical record for information about your definite diagnosis if necessary. Anything you say can be used in the study. Once the study is complete, the audio recorded files will be discarded.

Are there any benefits in my taking part?

The benefit of your participating in this study for you personally is minimal. You will not be paid to join the study and you may not directly benefit from participation. This study will benefit women by contributing to the understanding of factors influencing delay of breast symptom presentation. Understanding these factors will help public health professionals to develop appropriate strategies to reduce delay in breast disease presentation in Ghana.

Are there any risks involved?

One risk associated with this study is that you will be asked to share personal information regarding your experience. You do not have to answer any question that you do not wish to answer. Due to the length of the interview (45- 60 minutes), you may become tired or fatigued. Should that happen, you may take a break or choose to discontinue this interview. Due to the sensitive nature of this topic, a professional counsellor affiliated to the hospital will be available to provide service at no cost to you if needed.

Will my participation be confidential?

The identifiers of your settings and you will not be revealed. All data collected from you will be treated as highly confidential. You will be interviewed in a private setting and the information you give will be kept private and secure. To protect the privacy of your information, your real names will not be used; instead, only false names will be used to identify you. Raw data in the form of objects will be kept in a locked room, while raw and coded data in the form of electronic /computer files will be kept in a researcher's laptop computer with security password and in an electronic hardware at the University of Southampton. Only the researcher, his supervisors, and the typist of the transcripts can

access these data by using a security password. Data will be stored at the University of Southampton for 10 years.

What happens if I change my mind?

Joining the study is your decision and it is entirely your choice to decide whether you wish to take part in the study. You will also have the freedom to withdraw from the study at any time without having to give a reason for your decision. If you do not want to join the study, it will not affect your access to regular healthcare.

Who is organizing the research study?

The research is organised through the University of Southampton in the United Kingdom (UK).

What will happen to the results of the study?

The results of this study will be used for my PhD thesis, research publication, and conference presentations. However, your name and identity will not be revealed. You will be assigned a pseudonym, which will be used in any reporting of your comments. The researcher will only know your name and any transcriptions of this interview will be kept in a locked file cabinet accessible only to the researcher. On completion of the research study, the data collected will be securely stored at the University of Southampton for 10 years according to the University policy.

Who has reviewed the study?

To ensure that the study complies with institutional policies regarding research, the ethics committee in the research governance office of the University of Southampton, KATH, and PLH have reviewed the research proposal and granted approval before the commencement of this study.

What if there is a problem or I have a complaint?

If you have a concern or a complaint about this study you should contact Martina Prude, Head of the Governance Office, at the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk .   If you remain unhappy and wish to complain formally, Martina can provide you with details of the University of Southampton Complaints Procedure.

Where can I get more information?

If you would like any further information, please contact:

1) Seth A. Wiafe, PhD Student (Tel: +233 (0)243820491, Email: saw2m11@soton.ac.uk)

2) Professor Judith Lathlean, Professor of Health Research and Professorial Lead for PGR (Tel: +44 (0)23 8059 8234, Email: J.Lathlean@soton.ac.uk)

3) Dr Richard Wagland, Faculty of Health Sciences (Email: R.Wagland@soton.ac.uk)

Thank you for your consideration to take part in this study. You will be given a copy of the information sheet and a signed consent form to keep for your records.

What should you do to join the research?

I am at the clinic right now so just fill the Consent to Participate Form below and return it to the researcher or one of the nurses. The researcher will contact you later and schedule an appointment for the interview.

Consent to Participate Form

Please write your initials next to each item below if you agree:

_ _ _ _   **Interview:** I agree for the researcher to contact me at the number below to schedule an appointment for an interview about my personal experience with breast disease symptom discovery.

------- **Contact Information**: I have someone in mind who is a relative/friend/colleague to suggest for interview

By signing this Consent to Participate Form, you acknowledge having read this document and understand the conditions of participation in the research study.

Your Name   --- Telephone ------------------------------------

Signature -- Date ---------------------

Appendix C Informed Consent Form

UNIVERSITY OF Southampton

Informed Consent Form

Study title: Impact of sociocultural factors on help seeking behaviour among Ghanaian women with breast symptoms

Researcher name: Seth A Wiafe

Ethics reference: 9247;|CHRPE/AP/245/14

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

I have read and understood the participant information sheet
and have had the opportunity to ask questions about the study.

I agree to be interviewed as part of this research and agree for
my 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 agree to the researcher audio-recording the interview

I agree for the researcher reviewing my medical records

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 (print name)...

Signature of participant..Date.....................

Name of Witness (print name):..

Signature of Witness: .... Date.....................

Name of Researcher (print name)..

Signature of Researcher..Date.......................

[March 10, 2014] [Version 02]

Appendix DInterview guide for patients

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Interview guide for patients

1. Tell me your story about how you became aware of changes to your breast
    a. What symptoms did you detect?
    b. What was your reaction to the symptoms detected?
    c. What were your explanations of the symptoms?

2. Describe the length of time and the steps you took before seeking medical evaluation at the breast clinic

    a. How did you assess and interpret the symptoms?
    b. How did you consult others about your symptoms?
    c. What were your feelings about the symptom discovery at that time?

3. What made you decide to bring this particular breast problem to the attention of a health care professional

    d. What did you think would happen if you brought it to the attention of a health care professional?
4. What was your experience with the health care system when you decided to bring your breast problem to the attention of a health care professional?
5. Describe the symptom assessment process you went through with the health care professional at the hospital prior to receiving a definite diagnosis
6. What could the health care system have done differently that would have made it easier for you to seek care?
7. How did the discovery of the symptoms affect you both physically and emotionally around this experience?
8. What meaning did you gain from this experience of breast symptom discovery and seeking help?
9. What aspects of your symptom experience that you think might have impacted your help seeking efforts?
10. Do you have anything else you want to share?

Appendix E Demographic questionnaire for patients and their social networks

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Background demographic information for patients and social network

Recruitment Site: 01 Komfo Anokye Teaching Hospital (KATH)

02 Peace and Love Hospital (PLH)

03 Other (Specify) _____

1) What is your current age in years? --

2) What is your affiliation with the symptomatic woman?
Self	01
Relative/Friend/Colleague	02

3) What is your gender?
Male	01
Female	02

4) Which of the following best describes your current marital status? (Choose only one)
Married	01
Living with a partner	02
Widowed	03
Divorced	04
Separated	05
Single/never married	06

5) What is the highest level of education you have completed? (Choose only one)
No formal education/some primary school	01
Primary school	02
Junior secondary school (JSS)	03
Senior secondary school (SSS or SHS)	04
Sixth form	05
Vocational/technical/polytechnic/some college	06
Completed degree at college/university	07
Masters degree	08
PhD, MD, JD or other terminal professional degree	09

1

6) What is your current employment status?

Employed (full time)	01
Employed (part-time)	02
Employed but on medical leave/disability	03
Self-employed	04
Other (specify) _____	05

7) What is your estimated monthly income in Ghana Cedis?

<100	01
101-200	02
201-400	03
401-600	04
601-800	05
801-1000	06
1001-1200	07
1201-1400	08
1401-1600	09
>1601	10

8) Do you currently have a valid National Health Insurance Scheme (NHIS) Card?

Yes	01
No	02

9) What religion do you currently practice? (Choose one)

Christianity	01
Muslim/Islam	02
Traditionalist	03
No Religion	04
Other (specify) _____	05

10) Which town/city do you currently live in? _____

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11) Which of the following districts does your current town/city of residence belong? (select only one)

Kumasi Metropolitan	01
Bosomtwi	02
Atwima Kwanwoma	03
Ejisu Juaben	04
Atwima Nwabiagya	05
Kwabre	06
Afigya-Sekyere	07

12) To which ethnic group do you belong? (select only one based on inheritance)

Asante	01
Akwapim	02
Fante	03
Ga/Adangbe	04
Ewe	05
Guan	06
Mole-Dagbani	07
Grussi	08
Gruma	09
Hausa	10
Akyim	11
Kasem	12
Mosi	13

Other ethnic group (Specify) _____

3

Appendix F Ethics approval from University of Southampton

Saturday, April 5, 2014 at 11:08:23 PM Greenwich Mean Time

Subject: Your Ethics Submission (Ethics ID:9247) has been reviewed and approved
Date: Tuesday, March 25, 2014 at 2:39:18 PM Greenwich Mean Time
From: ERGO
To: Wiafe S.A.

Submission Number: 9247
Submission Name: Impact of sociocultural factors on help seeking behaviour among Ghanaian women with breast cancer symptoms
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 making these amendments. We are pleased to approve this resubmission. We wish you all the best with this study.

Click here to view your submission

ERGO : Ethics and Research Governance Online
http://www.ergo.soton.ac.uk

DO NOT REPLY TO THIS EMAIL

Page 1 of 1

Appendix G Ethics approval from KNUST-CHRPE

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

Our Ref: CHRPE/AP/245/14   14th July, 2014,

Mr. Seth Agyei Wiafe
Faculty of Health Sciences
Building 45, Room 001
Highfield SO17 1BJ
University of Southampton
SOUTHAMPTON.

Dear Sir,

LETTER OF APPROVAL

Protocol Title   *"Impact of Sociocultural Factors on Help Seeking Behaviour among Ghanaian Women with Breast Cancer Symptoms".*

Proposed Site: *Breast Care Clinic, Komfo Anokye Teaching Hospital, Kumasi.*

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 9th April, 2014 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 Proposal.
- Oral Script for Recruiting Participants.
- Recruitment Guidance Sheet.
- Interview Guide.
- Questionnaire.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, renewable annually thereafter. The Committee may however, suspend or withdraw ethical approval at anytime 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 the 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 study, annually or at the close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

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

Thank you Sir, for your application.

Yours faithfully,

Rev. Prof. John Appiah-Poku.
Honorary Secretary
For: **CHAIRMAN**

Appendix H Ethics approval from Peace and Love Hospital

PEACE AND LOVE HOSPITAL

Tel: +233-244-145-064
Email: peaceandlove2002@gmail.com
URL: www.breastcareghana.com

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

Our Ref: EA005/PLH   Your Ref: ....   Date: April 4, 2014

Mr. Seth Wiafe
Faculty of Health Sciences
University of Southampton
Building 45, Highfield
Southampton SO17 1BJ, United Kingdom

Dear Mr. Wiafe

Letter of Approval

Study Title: Impact of sociocultural factors on help seeking behaviour among Ghanaian women with breast cancer symptoms

Proposed Study Site: Peace and Love Hospital, Oduom-Kumasi

Sponsoring Institution: University of Southampton

Your submission to the Peace and Love Hospital (PLH) and Breast Care International (BCI) Ethical and Protocol Review Committee (EPRC) on the above named study based on the following documentation:
- Research study protocol
- Participant information sheets
- Informed consent form
- Researcher application letter

The committee considered the ethical value of your submission and approved the protocol, therefore; you can start your study as planned. This approval is for a specific period of time between April 7, 2014 and November 30, 2014. However, the committee has the right to suspend or revoke this ethical approval at anytime if it is found that your study contravenes the approved protocol.

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

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

We wish you all the best in your study.

Sincerely Yours,

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

* Community Participation *

Appendix I Coding strategy for patients' data

DETECTION OF BODILY CHANGES

Any awareness of a change in or around the breast. These include bodily sensations (nausea, pain, fatigue), visible alterations (rash, change in size, colour, discharge, dimple), and symptoms (lump, thickened tissue in or around the breast, dimpling, discharge from nipple, swelling, change in size or shape, auxiliary lumps)

SYMPTOM INTERPRETATION

Ways women explain symptoms – normal, serious, it will go away.

HELP SEEKING

Any awareness that women could get breast cancer. Finding initial change in their breast and seeking medical help from their healthcare professional (whether this was done promptly or if they delayed). The symptoms they had and any influencing factors that prompted help seeking.

EMOTIONS

Any discussion where emotions were described. Including anger, fear, concern, anxiety, need for assistance, shock, and why me?

DISCLOSURE

Who participant's told and their reactions. When they told them (immediately, delayed) and discussions on nondisclosure and reasons for this.

EXPERIENCES OF HEALTHCARE SYSTEM

Positive and negative experiences. Interactions with medical and nursing and allied health staff.

INFORMATION SOURCE

Any source of information given such as from leaflets, radio, television, and newspapers.

FINANCIAL IMPLICATIONS

Any financial implications around breast cancer symptom evaluation and diagnosis.

FEMININITY

Narrative where things that appear to have significance to femininity. Includes sexuality/intimacy, issues of self-esteem, and remarks about women and their position.

CULTURAL ISSUES

Any personal, cultural, and environmental issues that could influence help seeking behaviour.

Appendix J List of factors impacting help-seeking

Social factors	Cultural factors	Treatment choices	Names signs
• Strong family bonding • Authoritative system • Stigmatisation • Information sharing • Spousal abandonment • Social support • Media • One's health is the responsibility of others	• Evil spirits • Maintaining traditional healing • Fatalism • Self-management of diseases • Expectation of gender roles • Traditional beliefs • Gender dominance • Allowing disease to heal itself • Curse in the family	• Prayer camp • Herbal technology • Hospital • Medical clinic • Traditional healing • Home treatment • Spiritualist • Local drug store	• Growth in breast • Painless lump • Lump with pain • Pricking lump • Seed • Raised spot • Heavy • Stone in breast • Knot in breast • Boil • Something pulling from inside • Death sentence • Cancer • Disease of old people • Clotted breast milk • Thickened tissue

Appendix K Sample letter to nurse in-charge of clinic

UNIVERSITY OF Southampton

Date

Dear Nurse in-charge,

Assistance to identify eligible patients

I am Seth Wiafe, a post graduate student at the University of Southampton in the United Kingdom (UK). I would like to request your assistance to identify potential candidates for a research being conducted as part of a PhD degree in Health Sciences at the University of Southampton entitled; Impact of sociocultural factors on help-seeking behaviour among Ghanaian women with breast cancer symptoms. The study has received ethical approval from the University of Southampton, Komfo Anokye Teaching Hospital (KATH), and Peace and Love Hospital (PLH).

While patients wait for their turn for physician consultation, I would ask you to help identify potential participants attending the clinic for the first time with complaints of suspected breast cancer symptoms and refer them to my attention. Please find attached the recruitment guidance sheet to help identify potential recruits. I will be available to describe the project to them, provide them with information sheet, determine eligibility, and possibly enrol them into the study.

Please read the attached Information Sheet, which tells you more about the study. If you would like additional information, contact me at 024382049 and I will be happy to answer any questions you may have. My contact information can also be found on the information sheet.

Thank you for your time,

Yours sincerely,

Seth A Wiafe

PhD Researcher

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Author: Kim Brandes, Barbara Mullan

Publication: Health Psychology Review

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Glossary of terms

Breast Self-Exam (BSE): an exam by a woman of her breasts to check for lumps and other changes.

Breast Cancer: cancer that forms in tissues of the breast, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk). It occurs in both men and women, but male breast cancer is rare

Clinical Breast Exam (CBE): a physical exam of the breast performed by a healthcare provider to check for lumps and other changes

Metastasis: the spread of cancer from one site in the body to another

Mastectomy: surgical removal of the breast

Mammography: the use of film or a computer to create a picture of the breast

Prevention: the planning for and taking action to forestall the onset of a disease or other health problem before the occurrence of undesirable health events

Primary Prevention: preventive measures that forestall the onset of illness or injury during the pre-pathogenesis period

Reflexivity: A process of self-awareness that clarifies how one's beliefs have been socially constructed and how these values impact interaction and interpretation in research settings.

Secondary Prevention: preventive measures that lead to early diagnosis and prompt treatment of a disease or injury to limit disability and prevent more severe pathogenesis.

Help-seeking behaviour: A response to health changes and part of the broader process of health seeking behaviour as the time (in weekly intervals) from symptom discovery to the presentation of the symptom to a HCP.

Self-discovered breast symptom: Denotes that a woman herself or her husband/partner has discovered the breast symptom, as opposed to by a nurse/doctor/ health practitioner or through screening mammography.

Appraisal interval: Time taken to interpret bodily changes/symptoms.

Glossary of Terms

Help-seeking interval: Time taken to act upon those interpretations and seek medical help.

Patient interval: Time interval in a patient's pathway to treatment from first symptom detection to first presentation to a healthcare professional.

Health care professionals: Refers to all members of the multidisciplinary team who have contact with women before, during, and after their symptom discovery experience.

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