

**AN EXPLORATION OF WHY WOMEN WITH BREAST CANCER SYMPTOMS PRESENT LATE IN  
SEEKING TREATMENT AT KOMFO ANOKYE TEACHING HOSPITAL, GHANA.**

**ANITA ESEENAM AGBEKO**  
**BSc Human Biology, MBChB, MGCS**

**A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of  
Philosophy. The candidate has already achieved 180 credits for assessment of taught  
modules within the blended learning PhD programme.**

**May, 2017**

**Faculty of Health and Medicine**  
**Lancaster University**

**DECLARATION**

I declare that this thesis is my own work and has not been submitted for the award of higher degree elsewhere.

## **ACKNOWLEDGEMENT**

I thank God for His grace and provision that has taken me through the past five years of study.

I thank all my lecturers in the Faculty of Health and Medicine, Lancaster University who taught me and prepared me for the thesis phase.

I am very grateful to my supervisors, Sara Morris, PhD, and Anne Grinyer, PhD, for their teaching, guidance and patience with me. God bless you for your invaluable corrections and support to me in conducting my research and writing up the thesis.

I am also grateful to the women who volunteered to participate in this study, to the staff of the breast clinic in Komfo Anokye Teaching Hospital for their help in conducting this study.

Thank you to the 2012 Cohort of the PhD Palliative care programme for being a part of this exciting experience for me. Especially to Sheri Miller, you have been a great sister.

To my family, words cannot express my gratitude to you for your support and sacrifice to enable me complete this programme. I am forever indebted to you. God bless you.

Thank you to all who have contributed in one way or the other, however small, to bring me this far.

**DEDICATION**

I dedicate this thesis to my Mother, Veronica Ivy Dzurek, to my nephews Sedem, Seyram, Selorm, and my niece, Sesinam.

## **ABSTRACT**

**INTRODUCTION:** In line with most developing African countries about 85% of breast cancer patients who attend Komfo Anokye Teaching Hospital (KATH), Ghana, present with stage III/IV disease. This study aimed at understanding what factors influence health seeking behaviour and the decision to seek help in women with breast cancer symptoms.

**METHOD:** Women presenting for the first time with clinical stage III/IV breast cancer symptoms to KATH breast clinic were purposively selected for the study between May 2015 and March 2016. In-depth interviews were conducted to explore the women's symptom appraisal process and the events that prompted health seeking. The Andersen behavioural model for health service use was the conceptual basis for the thematic analysis, with a critical realist perspective. Interpretation of how the identified factors interacted with each other and how they ultimately evolved to influence decision making was done.

**RESULTS:** Fifteen women were interviewed. They were aged between 24 – 79 years. Ten of them had symptoms consistent with clinical stage III and 5 had clinical stage IV breast cancer. Time from symptom identification to attending KATH was 4 - 24 months. The first symptom identified was a breast lump or breast swelling. These were initially appraised as “normal/not serious” because they did not affect the woman's daily functioning. The trigger to seek medical help was worsening of their symptom such that daily function was affected. At this stage, the women were willing to do whatever was required to access healthcare. Misunderstanding of the investigations required and the referral process also contributed to their late presentation to KATH.

**CONCLUSION:** Women appraise their breast symptoms as not needing medical attention until they worsen. Opportunities at first hospital presentation to educate women with breast symptoms on the value of investigations and the need to follow through with referrals could potentially influence health seeking behaviour of women with breast cancer symptoms positively.

## Contents

DECLARATION .....	ii
ACKNOWLEDGEMENT .....	iii
DEDICATION .....	iv
ABSTRACT .....	v
INTRODUCTION .....	1
CHAPTER ONE .....	1
<b>Breast cancer epidemiology</b> .....	1
<b>Organisational structure of the health care system in Ghana</b> .....	2
<b>The study setting: Komfo Anokye Teaching Hospital (KATH)</b> .....	3
<b>Conceptualisation of patient delay in health seeking for breast cancer symptoms</b> .....	4
<b>Purpose of study</b> .....	6
<b>Palliative care and patient delay in seeking breast cancer care</b> .....	7
<b>Research Question</b> .....	10
<b>Research Aim</b> .....	10
<b><i>Specific Objectives</i></b> .....	11
CHAPTER TWO .....	12
LITERATURE REVIEW .....	12
<b>Method of literature review</b> .....	13
<b>Factors influencing delayed health seeking for breast cancer symptoms</b> .....	16
<b><i>Symptom identification and interpretation</i></b> .....	16
<b><i>Socio-demographic factors</i></b> .....	19
<b><i>Psychological factors</i></b> .....	21
<b><i>Health System factors</i></b> .....	23
<b><i>Sociocultural and spiritual factors</i></b> .....	26
<b>The African context</b> .....	29
<b><i>Socio-demographic factors</i></b> .....	29
<b><i>Symptom identification and interpretation</i></b> .....	29
<b><i>Health system factors</i></b> .....	30
<b><i>Psychological factors</i></b> .....	32
<b>The Ghanaian context</b> .....	32

<b>Theoretical perspective of the factors influencing patient delayed health seeking for breast cancer</b> .....	35
<b>Conclusion</b> .....	39
CHAPTER THREE .....	40
<b>CONCEPTUAL FRAMEWORK</b> .....	40
<b>PHILOSOPHICAL APPROACH</b> .....	46
CHAPTER FOUR .....	49
METHODOLOGY .....	49
METHODS.....	51
<b>Access to participants</b> .....	51
<b>Consent and how it was obtained</b> .....	53
<b>Data collection and storage</b> .....	54
<b>Anonymity and how it was maintained</b> .....	55
<b>Method of analysis</b> .....	55
<b>Ethical issues</b> .....	57
<b>Reflexive comments</b> .....	62
CHAPTER FIVE.....	65
RESULTS.....	65
<b>The study participants</b> .....	65
<b>The health seeking process</b> .....	68
1. <i>Symptom identification and appraisal</i> .....	69
2. <i>Deciding to seek medical help (“the tipping point”)</i> .....	74
3. <i>The help seeking journey</i> .....	75
CHAPTER SIX.....	99
DISCUSSION.....	99
<b>The study participants</b> .....	99
<b>Delay time</b> .....	104
<b>Delayed health seeking</b> .....	104
<i>Symptom identification and appraisal</i> .....	104
<i>The health seeking process</i> .....	109
<b>What was not found in this study</b> .....	124
<b>The total experience of health seeking</b> .....	126
<b>Limitations</b> .....	137

<b>Summary</b> .....	139
CHAPTER SEVEN.....	141
CONCLUSION.....	141
<b>Lessons drawn from the study findings and implications for future practice</b> .....	143
<i>The health care system</i> .....	143
<i>Palliative care principles and health seeking behaviour</i> .....	146
<i>Engaging other stakeholders</i> .....	147
REFERENCES.....	149
APPENDICES .....	158
<b>Appendix I: Study selection flow chart</b> .....	158
<b>Appendix II: Summary of data extracted for literature review</b> .....	159
<b>Appendix III: Quality appraisal of researchers papers used for the literature review</b> ...	167
<b>Appendix IV: Participant Information Sheet</b> .....	177
<b>Appendix V: Consent Form</b> .....	182
<b>Appendix VI: Topic led interview guide</b> .....	185
<b>Appendix VIIa: Ethics approval from Committee on Human Research Publication and Ethics</b> .....	187
<b>Appendix VIIb: Ethics approval from Committee on Human Research Publication and Ethics (Amendment)</b> .....	188
<b>Appendix VIII: Ethics approval Faculty of Health and Medicine Research Ethics Committee</b> .....	189



## List of Tables

Table 1 Terms used in the study of delay in seeking care .....	4
Table 2 Inclusion criteria for studies included in the literature review .....	13
Table 3 Fear cascade (Facione 1993) .....	22
Table 4 Reasons for delayed presentation for breast cancer symptoms in Ghana (Clegg-Lamprey et al. 2009) .....	33
Table 5 Socio-demographic information about the study participants.....	67
Table 6 Health care facility journey points for study participants to Komfo Anokye Teaching Hospital breast clinic (KATHbc) .....	77

**List of Figures**

Figure 1 The Andersen Behavioural model for health care utilisation (Ronald Andersen et al., 2013, p. 35) ..... 42

Figure 2 Factors influencing the help seeking behaviour of Int. 7 ..... 130

Figure 3 Factors influencing the help seeking behaviour of all the participants interviewed 131

# INTRODUCTION

## CHAPTER ONE

### Breast cancer epidemiology

Breast cancer is the leading cause of cancer death among women in developed and developing countries (Ferlay et al., 2010) including Ghana (Wiredu & Armah, 2006). In low- and middle-income countries, 30 – 98% of breast cancer cases are diagnosed at stage III or IV (Sloan & Gelband, 2007). Estimates in most developing African countries indicate 70 – 80.6% of breast cancer patients present late (Adesunkanmi, Lawal, Adelusola, & Durosimi, 2006; Ezeome, 2010; Fregene & Newman, 2005). According to the World Health Organisation, of the estimated 1.38 million women diagnosed with breast cancer annually, almost 50% of the cases and 58% of the deaths resulting from it are in less developed countries (Ferlay et al., 2010). Contributing to this high mortality are genetic and biological features such as aggressive tumour type, poor differentiation and triple negative hormone receptor status found among African women (Ohene-Yeboah & Adjei, 2012; Stark et al., 2010). Also, initiating definitive treatment more than three months after patient's discovery of symptom contributes to the high mortality rates (Richards, Westcombe, Love, Littlejohns, & Ramirez, 1999).

In Ghana, reports on breast cancer patients from some of the teaching hospitals show similar trends. The peak age of presentation with breast cancer is 40 – 49 years in both Komfo Anokye Teaching Hospital (KATH) (Ohene-Yeboah & Adjei, 2012) and Korle-bu Teaching Hospital (KbTH) (Clegg-Lamptey & Hodasi, 2007). The tumour type commonly diagnosed is the invasive ductal carcinoma, 82.1% in KATH (Ohene-Yeboah & Adjei,

2012) and 85.8% in KbTH (Clegg-Lampthey & Hodasi, 2007). Eighty five percent of patients in KATH (Ohene-Yeboah & Adjei, 2012) presented with advanced i.e. stage III – IV disease while Clegg-Lampthey and Hodasi (2007) reported a rate of 57.6%. An earlier study from KbTH reported a rate of about 50% of breast cancer patients presenting with advanced disease (Asumanu, Vowotor, & Naaeder, 2000). The average duration of symptoms before presentation among these women was 13.8 months in KATH (Ohene-Yeboah & Adjei, 2012) and 10 months in KbTH (Clegg-Lampthey & Hodasi, 2007).

There is no clarity as yet why so many African women present to the hospital late with advanced breast cancer and what interventions would lead to early access to care (Brinton et al., 2014).

## **Organisational structure of the health care system in Ghana**

In Ghana, three main facilities receive referrals for the treatment of breast cancer from all over the country. They are Komfo Anokye Teaching Hospital (KATH) in Kumasi, Korle-bu Teaching Hospital (KbTH) and the Sweden Ghana Medical Centre (SGMC), a private oncology centre in Accra. These facilities have well established chemotherapy and radiation centres with multidisciplinary teams that provide comprehensive care for breast cancer patients. Ghana is divided into 10 regions. Within each region, there is the regional hospital, district hospitals, health centres and Community-based health planning and services (CHPS) compounds. The CHPS compounds are least resourced. Health centres and CHPS compounds are usually manned by community health nurses who treat common illness like diarrhoeal diseases and uncomplicated malaria, as well as provide maternal and child care related to pregnancy and immunisation. District

hospital staff includes a doctor(s), usually with at least 2 years working experience after medical school. Sometimes in some district hospitals, there may be a surgeon, gynaecologist, and physician specialist as well as physician assistants. The regional hospitals also have doctors with specialist service provision, but usually do not have pathologists or radiologists who are needed in the evaluation of breast biopsies and images respectively. The referral trajectory is usually from a health centre/CHPS compound to a district hospital, then a regional hospital and finally a teaching hospital. Sometimes, the regional hospital is bypassed and referrals go directly to the teaching hospital.

### **The study setting: Komfo Anokye Teaching Hospital (KATH)**

The Komfo Anokye Teaching Hospital (KATH) is 1,200-bed capacity teaching hospital located in Kumasi, the capital of the Ashanti Region of Ghana. Because of its location in the middle belt of the country, and the availability of radiotherapy services, it is a big referral centre for cancer cases. The Hospital's catchment area covers almost 50% of the Ghanaian population. Up to 35% of cancer cases seen in KATH are of breast origin. The management of cases of Breast cancer in KATH is a multidisciplinary effort involving General Surgeons, Oncologists, Pathologists, Radiologists, Nurses and Social Workers. These categories of staff constitute the hospital Tumour Board. The tumour board meets weekly to review cancer cases. The General Surgeons also run a daily out-patient breast clinic as well as offer in-patient surgical services. Breast cancer patients presenting at KATH are first seen at the out-patient breast clinic.

## **Conceptualisation of patient delay in health seeking for breast cancer symptoms**

In cancer literature, “delay” is used to refer to time delays or to suggest advanced stage at diagnosis (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009). This study however focuses on time delays. The study of issues relating to time delays in cancer care was pioneered by Pack and Gallo in 1938 (Pack & Gallo, 1938). They described the term total delay, which is further divided as patient delay and provider delay. Newer terms have evolved since, (Caplan, May, & Richardson, 2000; Gwyn et al., 2004) and their definitions are presented in Table 1.

*Table 1 Terms used in the study of delay in seeking care*

<b>TERM</b>	<b>DEFINITION</b>
Total delay	Period of more than three months between the patient discovering his/her symptoms and the beginning of medical treatment
Patient delay	Period of three or more months between the discovery of symptoms and a visit to the physician
Provider delay	Period of more than one month between the initial medical consultation by the patient and the beginning of definitive treatment
Diagnosis delay	Time between the first patient consultation and the establishment of cancer diagnosis
Treatment delay	Time between establishing a diagnosis and beginning treatment
General practitioner/Referral delay	Time between the first consultation to primary care service and referral to a hospital
Hospital delay	Time from the referral to the beginning of definitive treatment

Although the beginning of patient delay has been the time of self-discovery of symptoms, the endpoint has varied from first attempt to contact a health provider; to first actual provider consultation; to diagnosis; to first initiation of treatment (Facione, 1993; Rauscher et al., 2010).

Pack and Gallo's (1938) time thresholds for cancer delay, though established arbitrarily, have been widely used in cancer delay research over the years. There are however some variability in operational definitions of patient delay (Facione, 1993; Unger-Saldaña & Infante-Castañeda, 2009). It has been defined as "two or more weeks" (Adam, Horner, & Vessey, 1980), more than 4 weeks (O'Mahony, McCarthy, Corcoran, & Hegarty, 2013), and as a continuum ranging from days to years (Facione, 1993). It has also been categorised by some authors as 1 – 3 months (short delay), more than 3 months (long delay) (Arndt et al., 2002; Memon, Shaikh, Rizwan, & Sardar, 2013) and prolonged delay (Burgess, Ramirez, Richards, & Love, 1998; Rauscher et al., 2010).

Other concerns have been raised about how patient delay has been defined. The term "patient delay" is argued to be value laden, suggesting an active decision for inaction (Macleod et al., 2009), culpability or blame to the individual. Such interpretation is potentially stigmatising (Dobson, Russell, & Rubin, 2014; Unger-Saldaña & Infante-Castañeda, 2011). Furthermore, using terms that connote clearly defined time periods after which help seeking is deemed unacceptable, like interval or duration, infers "intent" on the part of the patient (Dobson et al., 2014). Considering how symptoms evolve in relation to social and cultural context, Andersen et al (2009) argue that such measures presuppose symptoms are an objective clinical reality whose time of appearance can be measured. The alternatives offered are a less value laden term like "acceptable/prolonged interval" (Dobson et al., 2014), or a move away from the traditional conceptualisation towards theory construction based on context (Unger-Saldaña & Infante-Castañeda, 2011).

Evidently, there is no consensus over the terms and operational definitions used in the study of patient delay in help seeking (Byrne, 2008; Mairin O'Mahony & Hegarty, 2009b). As a way of standardisation, and achieving maximal benefit in comparing results, Facione (1993) suggests the maintenance of patient delay definition as the time from symptom discovery to first health provider consultation. She also suggests the reportage of this duration as means and standard deviations. For now though, conventionally, most studies on patient delay in breast cancer take the duration of 3 months as the cut-off for delayed versus early presentation (Bish, Ramirez, Burgess, & Hunter, 2005), because this has been found to be of significance in terms of survival in breast cancer (Ramirez et al., 1999).

### **Purpose of study**

Breast cancer causes suffering in all dimensions of the affected woman's life (Arman, Rehnsfeldt, Lindholm, & Hamrin, 2002). Moreover, a delay in presentation of three or more months with breast cancer symptoms can lead to diagnosis with advanced disease (Richards et al., 1999) with attendant poor quality of life and decreased chances of survival. In Ghana, there are on-going campaigns to improve knowledge about breast cancer symptoms and encourage early health seeking. In spite of these, studies show that women with breast cancer symptoms wait between 10 – 13.8 months after self-discovery of symptoms to seek treatment, and as many as 85% present with advanced disease (Clegg-Lampsey & Hodasi, 2007; Ohene-Yeboah & Adjei, 2012). A pilot survey of breast cancer patients in a Teaching Hospital in Ghana by Clegg-Lampsey et al (2009) concluded that the factors influencing delay in seeking care appear more important than screening practices in the efforts to improve disease outcomes. This is because even patients identified through community screening



programmes still present late. There is the need therefore, to understand the women's health seeking behaviour for breast cancer symptoms in the Ghanaian context to help develop ways of reducing undue delay.

### **Palliative care and patient delay in seeking breast cancer care**

Patient delay in seeking care for breast cancer symptoms is viewed in the domain of public health (Lim, 2011). Studies on the subject have been related to screening and education programmes tailored to promote early detection and treatment to improve patient survival. However, less than half of newly diagnosed breast cancers are detected through screening (Rauscher et al., 2010). Health seeking for such individuals will thus be an action taken for self-identified breast symptoms which may not even be interpreted as breast cancer. Indeed, women have delayed seeking care because they have not attributed their symptom to breast cancer or considered it not serious (Ramirez et al., 1999; Sharma, Costas, Shulman, & Meara, 2012).

Social, demographic and economic factors such as older age, low education levels, low income, non-white ethnic status, marital status (married/single/divorced) and rural residence have been found to influence delayed health seeking (Alhurishi, Lim, Potrata, & West, 2011; Ramirez et al., 1999; Sharma et al., 2012; Unger-Saldaña & Infante-Castañeda, 2009). In addition to these factors, some studies have revealed that negative experiences in seeking health care such as being looked down upon (Unger-Saldaña & Infante-Castañeda, 2011), mocked and ridiculed for presenting with advanced disease (Taib, Yip, & Low, 2014), or the fear of being judged as hypochondriacal (Facione & Facione, 2006) have influenced delay in seeking healthcare. In Malaysia, Taib et al (2014) found that the perceptions that conventional

breast cancer treatment offers poor quality of life also contributed to delay in seeking care. Also contradicting information and recommendations from physicians caused confusion and contributed to delay in seeking care for breast cancer symptoms. They also found that the ability to form trusting relationships with alternative therapy providers that fulfils emotional and psychological support needs of some women have drawn them to seek care with them instead. Meeting patient needs for emotional, social, family and work support (O'Mahony, Hegarty, & McCarthy, 2011) and answering questions about their disease (Clegg-Lampsey, Dakubo, & Attobra, 2009) have been suggested to possibly help to prevent delay. Some authors suggest that people's experience with poor outcomes of breast cancer can result into a social norm of doom and futility in pursuing conventional treatment (Taib, Yip, & Low, 2011), beliefs of fatalism (Facione & Facione, 2006; Straughan & Seow, 1998) or hopelessness (Powe & Finnie, 2003). Indeed, in the UK, fear born out of past experiences of cancer in friends and relatives have contributed to delay among some women (Burgess, Hunter, & Ramirez, 2001). Such experiences could contribute to the knowledge, beliefs and attitudes of women and society towards breast cancer, and thus the health seeking behaviour of a woman with breast cancer symptoms. The significance of such psychological and emotional factors, more so, originating from within the health care system have not been discussed extensively regarding delay in seeking care for breast cancer symptoms.

Having become involved in palliative care as a surgeon, I have become continually aware of how management of such negative psychological/emotional experiences with the health care system may potentially modify health seeking behaviour of women with breast cancer symptoms. The biological tumour characteristics of breast

cancers seen in KATH are the aggressive types with poor differentiation and triple negative hormone receptor status (Ohene-Yeboah & Adjei, 2012). These predict poor disease progression with poor long term outcomes. Within the context of my practice, breast cancer management poses a great economic, social and emotional burden on the affected women. Thus, relieving such burden related to breast cancer is not just an issue related to advanced/terminal disease, but one to be considered early in the course of management. And, preventing suffering associated with seeking care for breast cancer symptoms could potentially influence women's health seeking behaviour.

The World Health Organisation defines Palliative care as the approach to care that improves the quality of life of patients and their families facing problems associated with life threatening illness through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). The long held paradigm has been to limit palliative care to patients who are clearly and predictably dying (Kelley & Meier, 2010). The use of palliative care services in standard patient care remains low because physicians still perceive it as an alternative to curative or life prolonging care, rather than simultaneously delivering it as an adjunct to disease focused treatment (Fadul et al., 2009). This paradigm of equating palliative care to end of life care must shift. Palliative care should not be limited by the estimate of life expectancy or preference for curative procedures and medication. It can, and must be initiated alongside standard medical care (Caprio, 2016; Parikh, Kirch, Smith, & Temel, 2013). Parikh et al (2013) suggest that the intensity of supportive care offered should be calibrated over time to the needs of

patients regardless of their cancer outcomes or prognosis. From my clinical perspective, offering supportive care could potentially change the health seeking behaviour of women seeking care for breast cancer symptoms if offered early in clinician patient interaction. These may include for example counselling, facilitated physician-patient communication and social support. Following Parikh et al's (2013) suggestion of delivering calibrated supportive care, it is possible that there are opportunities to initiate some level of supportive care services even before a possible cancer diagnosis. This may offer a preventive approach to suffering as is a defined goal of palliative care.

My study, in exploring the health seeking behaviour of women seeking care for advanced breast cancer symptoms can reveal opportunities for supportive care interventions that can potentially positively influence early health seeking behaviour. The goal of palliative care goes beyond relief of suffering to include the prevention of it. From my clinical perspective, it may be possible that such prevention interventions within the context of breast cancer care can be initiated even before diagnosis of breast cancer.

### **Research Question**

- What factors influence the late health seeking behaviour of women with breast cancer symptoms seeking care at Komfo Anokye Teaching Hospital in Ghana?

### **Research Aim**

To find the factors that influence late health seeking behaviour of women with breast cancer symptoms who are seeking care at Komfo Anokye Teaching Hospital in Ghana.

### ***Specific Objectives***

- To identify how the factors that influence the late health seeking behaviour affect women's decision of when to seek treatment
- To explore how the factors interact with each other to influence health seeking behaviour
- To identify opportunities for interventions that will encourage early health seeking

## CHAPTER TWO

### LITERATURE REVIEW

There have been many studies on factors that influence patient delay (Alhurishi et al., 2011; Facione, 1993; Ramirez et al., 1999; Sharma et al., 2012; Unger-Saldaña & Infante-Castañeda, 2009). Study participants have been women with self-, screening- or physician- detected benign, early or advanced stage breast cancer symptoms (Li et al., 2012; Nosarti et al., 2000; Rastad, Khanjani, & Khandani, 2012). Others have been with patient relatives as proxies (Dye et al., 2012), patient clinical records in cancer registry data (Ali, Mathew, & Rajan, 2008) and asymptomatic women for their likelihood to seek care for breast cancer (Facione, Miaskowski, Dodd, & Paul, 2002; Grunfeld, Hunter, Ramirez, & Richards, 2003). The evidence so far however has some short falls. There are reports of a lack of quality research in this area; the need for theory and contextual understanding of why women delay; the inconsistent operationalisation of variables being studied; and lack of studies that examine the role of social networks and social support in patient delay for breast cancer care (Facione, 1993; Ramirez et al., 1999; Unger-Saldaña & Infante-Castañeda, 2009).

This literature review will discuss the evidence on factors affecting patient delay in seeking care for breast cancer symptoms including how theory has been applied to explain the phenomenon.

## **Method of literature review**

A database enquiry was initiated into PubMed using the Mesh heading : “breast neoplasms”, “Patient acceptance of health care”, “Early detection of cancer”, “Health service accessibility”, “Health seeking behavi\*”, “Presentati\*”, “Diagnosis”, “Appointment”, “Late”, “ Delay”, and “Wait” in titles and abstracts. Titles of the articles were screened for those relevant to the topic. The abstracts of these were then reviewed and full articles of the relevant ones downloaded. The search was modified and expanded into additional databases: CINAHL, PsychInfo, Cochrane Library, Embase and Web of Science. Manual examination of the bibliographies of relevant articles was conducted to identify additional relevant studies. A summary of the search results is presented in Appendix I. The inclusion/exclusion criteria are shown in Table 2.

*Table 2 Inclusion criteria for studies included in the literature review*

<b>CRITERIA</b>	<b>INCLUSION</b>	<b>EXCLUSION</b>
Population	Studies with females with breast cancer symptoms	Males, Studies including patients with other cancer symptoms, Studies relating to breast cancer screening, or on asymptomatic women, or of public knowledge of breast cancer symptoms.
Intervention	Studies on factors influencing delayed patient presentation in seeking help for breast cancer symptoms	
Outcome	Study must define patient delay. Where no explicit definition is given, an explanation must be offered	
Time	Any study conducted after 1990	Any study conducted before 1990
Language	Studies published in English	Studies published in any other language not English

There was no limitation to which region of the world the study was conducted in, what factors influencing patient delay were studied or study design used. Because of limited

data from the Ghanaian context, the study by Agbokey (2014) was admitted into the review although his study population included caregivers, health workers and herbalists. Only literature published after 1990 was considered for this review to focus on evidence with contemporary relevance. The search was conducted in December 2014. The original search was maintained until October 2016 when the final draft of the literature review was prepared. There was no systematic approach to searching the grey literature.

Fifty-six articles, fourteen of which were conducted in the African setting, met the inclusion criteria. Data was extracted to an Excel spreadsheet. A summary of the extracted data is presented in Appendix II.

The quality of all the articles was assessed with the Critical Appraisal and Skills Programme (CASP) qualitative checklist (available at: <http://www.casp-uk.net/casp-tools-checklists>). The qualitative checklist was used for the appraisal as there is no CASP checklist designated for cross sectional studies. The last 8 questions in the CASP qualitative checklist assess the research design, data collection and analysis, ethics, reflexivity and the implication of the research findings. These aspects of research are also applicable in principle to cross sectional studies except for reflexivity. To make the quality assessment more objective, a quantitative assessment for each article was done using a modified CASP qualitative checklist (Duggleby et al., 2010). Duggleby et al's (2010) modification was to score each of the last 8 questions on a three point rating scale as weak (1 point), moderate (2 points) and strong (3 points). Articles with little or no justification/explanation for any aspect scored a weak point. A moderate score was for articles that addressed but did not fully elaborate on an issue and a



strong score for those that that justified and fully explained an issue. The maximum score for qualitative studies was 26 and 23 for quantitative studies because assessment of reflexivity is not relevant in this method of study.

Fourteen of the 56 studies used a qualitative methodology and 2 used mixed methods. The highest and lowest quantitative scores were 20 and 11 out of 23 respectively. The highest and lowest qualitative scores were 23 and 19 out of 26 respectively. All the studies employed a cross sectional design, except for that by Lannin et al (1998), [which](#) was a case control study. The qualitative studies purposively studied breast cancer patients except for three studies where either breast cancer diagnosis was not confirmed (Lam et al., 2008) or participants included women with benign breast disease (Khakbazan, Taghipour, Roudsari, Mohammadi, & Omranipour, 2014a; O'Mahony et al., 2011). All the studies assessed delay retrospectively and thus their results were subject to recall bias. Of the studies, in Africa only Kohler et al's (2017) research in Malawi offered some in depth theoretical analysis. All the quantitative studies from Africa were descriptive. Their survey designs limited the scope of factors that were investigated, with limited statistical analysis of the reported findings. No study was however excluded based on the CASP appraisal outcome. A summary of the quality assessment is presented in Appendix III.

The results of the literature review (Appendix II) are discussed in two parts. The first part discusses factors found to influence patient delay from various studies. The second part focuses on how theory has been applied to help understand it. This is presented under the following heading;

- Factors influencing patient delayed health seeking for breast cancer symptoms

- Theoretical understanding of the factors influencing patient delay in seeking help for breast cancer.

## **Factors influencing delayed health seeking for breast cancer symptoms**

The factors influencing delayed health seeking for breast cancer symptoms are discussed under the following headings; symptom identification and interpretation, socio-demographic factors, psychological factors, health system factors, and sociocultural and spiritual factors. The literature from the African and Ghanaian context are discussed separately.

### ***Symptom identification and interpretation***

Many women discover their breast symptoms themselves (Adam & Soutar, 2003). Rastad et al (2012) found that all 10 Iranian women they interviewed identified their symptoms by chance. Forty-one percent of the women studied by Meechan et al (2003) in New Zealand and 68% of those studied in Hong Kong by Li et al (2012) also discovered their symptoms by chance. Among some Irish women, breast symptoms were discovered during activities such as taking a bath, getting dressed, or breast feeding (O'Mahony et al., 2011). Breast self-examination (BSE) is encouraged among women for early detection of breast cancer symptoms, however, O'Mahoney et al (2011) report from their interviews with 10 women that some women are uncertain about how to do it. Bigger studies in the UK (Burgess et al., 1998), Germany (Arndt et al., 2002), and New Zealand (Meechan, Collins, & Petrie, 2003) have concluded that BSE has no influence on delay in seeking care among breast cancer patients.

Taib et al (2011) concluded from their study of 19 breast cancer patients in Malaysia that symptom interpretation is the first step of the health seeking process. It is at this stage that it is determined whether the discovered symptom is normal or serious and needs medical attention. Studies in Columbia (Piñeros, Sánchez, Cendales, Perry, & Ocampo, 2009), Pakistan (Malik & Gopalan, 2003; Memon et al., 2013), Iran (Rastad et al., 2012), Malaysia (Taib et al., 2011), China (Lam et al., 2008), Germany (Arndt et al., 2002) and the UK (Burgess et al., 2001) report that women have delayed seeking care because they initially interpreted their breast symptoms as not serious. Rather, symptoms have been attributed to hormonal changes (Lam et al., 2008) trauma (Unger-Saldaña & Infante-Castañeda, 2011), breastfeeding (Taib et al., 2011).

Women's expectations of breast cancer symptoms vary across cultures. Where symptoms experienced do not meet these expectations, they can be evaluated as not serious. For example, Burgess et al (2001) found in their study in the UK that some women considered breast cancer to be a painless pea sized lump. On the other hand, Lam et al (2008) found that pain rather than a lump in the breast was considered harmful among some Chinese women. Similarly, women studied in Malaysia (Taib et al., 2011), Mexico (Unger-Saldaña & Infante-Castañeda, 2011) and Iran (Rastad et al., 2012) considered the absence of pain to mean unserious. In a survey of 436 breast cancer patients in Chicago, USA, Rauscher et al (2010) reports that some of the women, especially those of ethnic minority held misconceptions such as a breast lump turning into cancer if it was often pressed or touched; and a lump needed to be checked for cancer if it gets bigger. On the other hand, among 449 women in Ireland with breast cancer symptoms, most of them were aware that a breast lump was significant symptom that needed to be checked (O'Mahony et al., 2013). Interestingly,

more than 50% of them did not know or were unsure of the association between non-lump symptoms like clear drainage from one nipple; a scab or sore on one nipple; persistent itching of the skin; or a hot reddened area on the breast and potential breast cancer. Poor knowledge about symptoms other than a breast lump have been cited as contributing significantly to delayed health seeking (O'Mahony et al., 2013; Unger-Saldaña & Infante-Castañeda, 2009). However, study findings from the UK (Burgess et al., 2006), Malaysia (Taib et al., 2011), and New Zealand (Meechan et al., 2003) have found that women who initially identified breast lumps have also delayed in seeking care.

Burgess et al (2001), Taib et al (2011), and Lam et al (2008) found in their studies that women who delayed seeking help actively monitored their symptoms and sought care when their symptoms were perceived to be serious. O'Mahoney et al (2013) observed similar behaviour in their study in Ireland and found that the women who did so tended to believe their symptom would last for a long time. Findings from some exploratory studies reveal that, eventually, however, there is a trigger that drives women to seek help for their breast cancer symptoms. For example, the onset of pain among Iranian (Khakbazan et al., 2014a), Mexican (Unger-Saldaña & Infante-Castañeda, 2011), Malaysian (Taib et al., 2011) and Chinese (Lam et al., 2008) women has been the trigger to seek medical help. Increasing severity and the persistence of the identified symptom such that it interferes with one's daily activities are also implicated in women's health seeking behaviour (Memon et al., 2013; Unger-Saldaña & Infante-Castañeda, 2011). It seems therefore, that after identifying any breast anomaly, a woman does not seek help until the symptom is interpreted as an illness needing medical help. These findings give credence to Andersen et al's (1995)

assertion that symptom interpretation is the most important step in the health seeking process for cancer diagnosis. In fact they posit that it contributes 60 – 80% of the health seeking process.

### ***Socio-demographic factors***

All the qualitative studies in this literature review (Burgess et al., 2001; Granek & Fergus, 2012; Iskandarsyah et al., 2014; Khakbazan et al., 2014a; Lam et al., 2008; Norsa'adah, Rahmah, Rampal, & Knight, 2012; O'Mahony et al., 2011; Rastad et al., 2012; Taib et al., 2011; Taib et al., 2014; Unger-Saldaña & Infante-Castañeda, 2011) included participants of diverse socio-demographic and economic backgrounds. However, their analysis did not necessarily highlight how these various factors influenced the time to seeking care differently. The quantitative studies however tested the significance of the influence of socio-demographic and economic factors on delayed health seeking behaviour. Two studies in Pakistan (Malik, Pathan, Shaikh, Qureshi, & Talpur, 2010; Talpur, Surahio, Ansari, & Ghumro, 2011) found that women who lived in rural areas delayed seeking care because of a lack of health facilities, the reluctance to see doctors and the tendency to stick to old social customs (Malik et al., 2010). Findings from studies in Sri Lanka (Kumari & Goonewardena, 2011), Columbia (Piñeros et al., 2009), Germany (Arndt et al., 2002), Iran (Harirchi, Ghaemmaghami, Karbakhsh, Moghimi, & Mazaherie, 2005), and Estonia (Innos et al., 2013) suggest that elderly women were more likely to delay in seeking care for breast cancer symptoms. Burgess et al (2006) in the UK, Montazerri et al (2003) in Iran, Lannin et al (1998) and Ruddy et al (2014) in the USA however, found age to have no influence on health

seeking behaviour for breast cancer symptoms. Altogether, the studies that examined the influence of age on delayed help seeking involved 4,022 women. Comparison of their results is however difficult because age results were presented as grouped data, and in 7 out of the 9 studies the range of the categories was different.

Regarding educational status, while Ali et al (2008) in India, Sharma et al (2013) in Haiti and Ruddy et al (2014) in USA found low educational levels to influence delayed care seeking, Arndt et al (2002) in Germany, Facione et al (2006) in USA and Ghazali et al (2013) in Kuala Lumpur found no association. Similarly, with economic status, the findings are contradictory. While some studies found a positive influence of low economic status on delayed health seeking (Harirchi et al., 2005; Kumari & Goonewardena, 2011; Ruddy et al., 2014), others found no influence of it (Facione & Facione, 2006; Ghazali et al., 2013). But in their qualitative study, Angus et al (2007) found that having an adequate income and employment benefits such as extended health insurance and sick leave helped women cater for illness related expenses such as travel/accommodation arrangements, medication and extra help in the home. Meanwhile, low income resulted in having to search and applying for various forms of assistance including finding extra work to get other sources of financial support, which made it difficult to make time for medical appointments. On the other hand, if self-employed, there was loss of income during seeking diagnosis and treatment.

On marital status, being single (Ali et al., 2008; Kumari & Goonewardena, 2011; Lannin et al., 1998; Memon et al., 2013; Montazeri, Ebrahimi, Mehrdad, Ansari, & Sajadian, 2003) has been cited as influencing delayed health seeking. Lannin et al (1998) argue that single women delay because they lack financial and social support. On the other

hand, Harirchi et al (2005) found in their study of Iranian women that being married rather influence delayed health seeking because married women, in fulfilling their traditional roles of dealing with children's needs, household chores and other outdoor activities did not have much time for themselves. Yet still, Sharma et al (2013), Malik and Goplan (2003), Piñeros et al (2009), and Burgess et al (2006) found no significant influence of marital status on delayed health seeking behaviour.

The lack of consensus on the influence of socio-demographic and economic factors on delayed health seeking may suggest that these factors do not influence health seeking behaviour on their own. Rather, their effects are mediated via other contextual factors which may be better explored by qualitative methods. Also, Facione (1993) and Unger-Saldaña and Infante-Castañeda (2009) suggest that poor quality of the studies, the lack of consistency in the operational definitions for terms and variables used in the studies, inconsistency of the scales and tools used to measure variables, and a focus on minority populations as study participants may be the reason for such inconsistencies.

### ***Psychological factors***

Various psychological factors have been described as influencing health seeking behaviour of women with breast cancer symptoms. The manifestation of fear is described in diverse and variable (Table 3; page 22) ways as influencing patient delay. For example, women have delayed seeking conventional medical care and sought to use alternative medicine because of the fear of confirming a cancer diagnosis in Iran (Rastad et al., 2012). The uncertainty about the ability to fight the fatal outcomes of breast cancer with conventional medicine was found to contribute to delayed care

seeking in Malaysia (Taib et al., 2011). Fear has however been noted to cause both prompt and delayed care seeking among breast cancer patients (Burgess et al., 2001; Facione & Facione, 2006; Lauver, Coyle, & Panchmatia, 1995). Fatalism has been found to influence early help seeking among some women (O’Mahony et al., 2011) but led to delay among others because of a perceived sense of the futility of conventional medical treatment (Taib et al., 2011).

*Table 3 Fear cascade (Facione 1993)*

Fear of doctors and hospitals	Fear of abandonment
Fear of ridicule	Fear of loss of control
Fear of embarrassment	Fear of loss of femininity
Fear of chemotherapy	Fear of radiation therapy
Fear of loss of feminine role	Fear of being dehumanised
Fear of illness	Fear of losing a sexual partner
Fear of the unknown of cancer	Fear of pain
Fear of the loss of a breast	Fear of isolation
Fear of disfigurement	Fear of surgeries/anaesthesia
Fear of loss of ability to mother	Fear of entering a submissive role
Fear of unmanageable expense	Fear of cancer spreading after surgery
Fear of death	

In their study of the influence of psychosocial factors on delayed care seeking among 48 African American women, Reifenshtein (2007) assessed denial by questions that included “did you think the breast change will disappear or go away?” and reported a significant association between denial and delay. Unger-Saldaña and Infante-Casteñeda (2011) found that some women in their study reassured themselves of not having any symptoms and described this as denial. Taib et al (2011) also described the unreadiness of the women they studied to accept a cancer diagnosis as denial. However, some studies have found that women continuously monitor their symptoms (Burgess et al., 2001; Lam et al., 2008; Taib et al., 2011), think and reflect on it,



interpret and assess what they have, often with great concern over what it may be, but would still dismiss it or choose not to seek care for it (Granek and Fergus 2012). Burgess et al (2001) argue that such action challenges the assertion that some women are in denial of their symptoms. They assert that 'denial' in the context of breast symptoms is not of the reality of its existence, but a response to reduce the psychological stress that is associated with the threat of cancer. Granek and Fergus (2012) further suggest that socio-political and cultural factors come to play in this process and so make the concept of denial insufficient to explain this apparent ignoring of symptoms. In spite of the inconsistencies, these findings suggest there is a complex psychological response to the identification of the breast symptom.

The mechanism by which these psychological factors mediate such different outcomes in health seeking has not yet been elucidated. In the studies discussed above for instance, there is varied conceptualisation of denial. The variations in instruments and methods used to measure different psychological responses makes comparisons between studies more difficult (Unger-Saldaña & Infante-Castañeda, 2009). A theoretical approach to this may lead to a better understanding of the influence of psychological factors on delayed care seeking.

### ***Health System factors***

Factors related to the health system that influence the health seeking behaviour of women with breast cancer symptoms are related to women's personal previous experience with seeking care and inherent characteristics of the health system.

Some explorative studies have identified women's experiences with care facilities that contribute to their health seeking behaviour. In Mexico (Unger-Saldaña & Infante-

Castañeda, 2011), Malaysia (Taib et al., 2011) and the USA (Facione & Facione, 2006) negative experiences with health services, such as being looked down upon, mocked and ridiculed for presenting with advanced disease, or the fear of being judged as hypochondriacal have been cited as reasons for delay in seeking care. From their study of 19 women with advanced breast cancer, Taib et al (2014) found that some of the women lacked confidence in physicians due to their ineffective ways of communication and the confusion they cause with contradicting information and recommendations. Exploring this issue, Angus et al (2007) found that the Canadian women they interviewed reported needing timely and understandable information and support with decision-making. While some were comfortable to entrust the important details with their health providers, others got more information from books, internet, friends and family with experiences with cancer. But understanding, sorting and deciding what to do with this information required time and effort.

Regarding the health system, Unger-Saldaña and Infante-Casteñeda (2011) found in their study in Mexico that the women they interviewed visited multiple health facilities to get access to a doctor or for investigations to be done. They noted that although some of the women had a medical consultation soon after identifying their breast symptom, the referral system contributed to delayed care. In Iran, Khakbazan et al (2014) found that some women were admitted in public health facilities for long periods before being referred. Comparatively, in the UK (Burgess et al., 1998) and Ireland (O'Mahony et al., 2011) the referral trajectory is shorter. The first point of call is the general practitioner (GP) then onward transfer to receive specialised care. Even then, Burgess et al (1998) report that some women experienced referral delay due to

physician misdiagnosis. Such referral delays were also reported from Mexico (Unger-Saldaña & Infante-Castañeda, 2011) and Malaysia (Taib et al., 2011).

The use of complementary and alternative medicine (CAM) has been cited as contributing to delayed health seeking. Reasons for this include the belief that conventional treatment offers a poor quality of life (Taib et al., 2014), to avoid having surgery, and ignorance of the availability of treatment in a hospital (Norsa'adah et al., 2012). Also, Taib et al (2014) found that some women adopted alternative therapy because of the trusting relationships they have with those providers and how it fulfils their need for emotional and psychological support.

Cost of seeking care also contributes to delay in seeking care among breast cancer patients in developed and developing countries (Iskandarsyah et al., 2014; Lam et al., 2008; Ruddy et al., 2014; Sharma et al., 2012; Unger-Saldaña & Infante-Castañeda, 2011). Indeed, Sharma et al (2012) assert that poverty is a major factor contributing to delayed care seeking for breast cancer symptoms in developing countries. However, Ruddy et al (2014) from their study in USA suggest that it is rather the co-payments and hidden costs that lead to inability to seek care early. Such hidden costs include lost wages and child care expenses that challenge women who are less financially comfortable. Among Indonesian women studied by Iskandarsyah et al (2014), the hidden cost included transportation, accommodation and logistical expenses for themselves and family members who accompanied them to the hospital.

Angus et al (2007) point out from their qualitative study in Canada that time is a central and limited resource in making medical and diagnostic appointments. This is because these activities including negotiating the health system are time consuming.

Longer distance from home to the hospital and travelling to the hospital by public transport have been cited as contributing to delayed health seeking in Sri Lanka (Kumari & Goonewardena, 2011) and Thailand (Poum, Promthet, Duffy, & Parkin, 2014). Interestingly, Poum et al (2014) found the time taken to travel to a hospital (which may correlate with the distance travelled) did not significantly influence delay in health seeking. Sharma et al (2013) also did not find any association between method of accessing the hospital such as using public transport and delay in Haiti. The evidence from these studies is insufficient to draw a conclusion on the influence of means and duration of travel on delayed health seeking. First, there is no description of the type of public transport considered (e.g. train, bus, etc). Secondly, all the studies employed quantitative methods and did not report if other related factors, such as the nature of the road, was considered. Such factors will be significant in interpreting such results as the countries within which these studies were conducted are not of the same economic and infrastructural developmental status.

### ***Sociocultural and spiritual factors***

The social ties that women have influence their health seeking behaviour in diverse ways. Social disclosure has been found to facilitate (Burgess et al., 1998; Lam et al., 2008; Ramirez et al., 1999), delay (Taib et al., 2014) or have no influence (Meechan et al., 2003) on women's health seeking for breast cancer symptoms. On the other hand, Burgess et al (2006), Li et al (2012) and O'Mahoney et al (2011) found in their studies that women who did not disclose their symptoms also delayed in seeking care. Some women did not disclose their symptoms because they did not want to bother others (O'Mahony et al., 2011; Unger-Saldaña & Infante-Castañeda, 2011). Where disclosure led to delay in seeking help, it was because patient's misconceptions about breast

cancer were reinforced (Poum et al., 2014; Unger-Saldaña & Infante-Castañeda, 2011) or from lack of sanctioning (i.e. validation of the seriousness of the symptom) from those they talked to (Taib et al., 2011). Sometimes, misconceptions were held by those to whom the women talked and thus they were misinformed, as Rastad et al (2012) found in Iran. It seems therefore that the influence of disclosure on health seeking behaviour depends on what perceptions about breast cancer exist among those consulted. In Malaysia, Taib et al (2011) found that fatalistic views and the futility of breast cancer treatment were pervasive in the community in their study. They explained that people's experience with poor outcomes of breast cancer, as was the case in their study, could result in a social norm of doom, fatalism or hopelessness for which reason pursuing conventional treatment for breast cancer was considered futile. Burgess et al (2001) found similar sentiments among breast cancer patients who have delayed seeking care in UK due to fear born out of past experiences of cancer in friends and relatives. All these experiences shape the knowledge, beliefs and attitudes of women and society at large towards breast cancer, and thus the health seeking behaviour of a woman with breast cancer symptoms.

Social influence on health seeking behaviour for women with breast cancer symptoms also include their social roles. Many women have deferred seeking care for their breast symptoms because of work and family obligations, social and domestic roles which they had to perform (Angus et al., 2007; Burgess et al., 2001; Burgess et al., 2006; Khakbazan et al., 2014a; Lam et al., 2008; Norsa'adah et al., 2012; O'Mahony et al., 2011). Some women however, have rather relied on social support in seeking help eventually. For example, in Indonesia (Iskandarsyah et al., 2014), women were accompanied by family members to the hospital to seek care for their breast cancer

symptoms. In Malaysia, Unger-Saldaña and Infante-Castañeda (2011) described different kinds of support women received from family and friends in seeking care for their breast cancer symptoms. These are informational support (e.g. advice to seek care and what type of health services to use), instrumental support (e.g. money, help with errands, child care, housing in case of travel), emotional support (e.g. company for medical consultation, ability to talk to someone) and decision making support. Among Canadian women studied by Angus et al (2007), they found that some women needed caregiving themselves because of concomitant chronic health problems they had, and although family and friends may step in to offer a range of help, some women worried about burdening others, and so tried to limit the amount of help they accepted.

The influence of spirituality and religiosity on health seeking behaviour has been equivocal. In their study in USA, Gullatte et al (2010) found that although the women in their study had high levels of spiritual and religious beliefs, this had no influence on the time to seeking medical care. However, women in other studies have expressed how their religious beliefs have been helpful to the final outcome of their breast cancer diagnosis (O'Mahony et al., 2011) as well as how religion and membership of a religious organisation helped them with spiritual, instrumental and physical support (Taib et al., 2014). Others have perceived breast cancer as divine, part of their destiny and a test of their faith (Iskandarsyah et al., 2014).

## **The African context**

Fourteen studies conducted in the African setting were found in this literature review.

The factors affecting patient delay in the African setting are similar, though not the same, to that found in other parts of the world. They are described below, first in the African setting and then the Ghanaian setting.

### ***Socio-demographic factors***

Three studies reported on the influence of socio-demographic factors on delay in health seeking. Their findings were however not congruent. While Ezeome (2010) from Nigeria reported age, education, income, marital status and area of residence had no influence on patient delay, Abdel-Fattah et al (1999) from Egypt found older age and being married to influence patient delay. Ibrahim and Oludara (2012) from Nigeria also found younger age and being single to rather influence patient delay. Abdel-Fattah et al (1999) and Ibrahim and Oludara (2012) both found low level of education positively influenced patient delay.

### ***Symptom identification and interpretation***

Seven studies (Abdel-Fattah et al., 1999; Ezeome, 2010; Ibrahim & Oludara, 2012; Ismail, Abd El Hamid, & Abd El Naby, 2013; Kohler et al., 2017; Otieno, Micheni, Kimende, & Mutai, 2010; Stapleton et al., 2011) found poor knowledge about breast cancer, including breast self-examination to influence patient delay. Only one out of the seven studies (Kohler et al., 2017) used qualitative methodology to explore what such knowledge deficits entailed. Kohler et al (2017) found in their study that women did not know about breast cancer symptoms. Rather, they thought their symptoms were due to aging, trauma, pregnancy, or clogged milk from difficult breastfeeding. Four studies (Ezeome, 2010; Ismail et al., 2013; Otieno et al., 2010; Stapleton et al.,

2011) also reported that women delayed presentation because their symptoms were painless. A change in the symptoms such as onset of pain, ulceration or associated nipple discharge is what triggered women to seek care (Dye et al., 2012; Ezeome, 2010; Kohler et al., 2017). An interesting finding from Kohler et al's (2017) study was that the women believed they came to the hospital quickly after noticing the severity of their symptoms, although they also described waiting for months after noticing their symptoms. Also, in spite of understanding the benefits of early treatment, their intentions did not correspond to their ability to act on their desired behaviour. Among the women interviewed by Dye et al (2012) in Ethiopia, they also found that women sought care after being pressured by their family members or reported their breast symptoms while in hospital for another condition.

### ***Health system factors***

In 3 studies (Abdel-Fattah et al., 1999; Ezeome, 2010; Otieno et al., 2010), the women initially visited a health facility at the onset of their symptoms, however, false reassurance from a physician caused them to subsequently delay in seeking care again. In Malawi, Kohler et al (2017) found that lack of communication from care providers led to misunderstandings. For example, some women believed that a biopsy procedure was treatment and this caused them not to return to the hospital again. In their literature review of factors influencing patient delay in developing countries, Sharma et al (2012) reported poverty to be the underlying factor. Interestingly, only 2 studies, Stapleton et al (2011) from Egypt and Ezeome (2010) from Nigeria reported cost of health seeking as a factor influencing delay.



Studies from Ethiopia (Dye et al., 2010), and Egypt (Mousa, Seifeldin, Hablas, Elbana, & Soliman, 2011) looked at the trajectory women take to access care from hospitals that treat breast cancer. From their studies, Dye et al (2010) and Mousa et al (2011) found that the majority of women reached the cancer centre for care by the 3<sup>rd</sup> point of seeking care. While in Egypt the 1<sup>st</sup> point of care included seeing a general surgeon or a general practitioner, in Ethiopia, it included a non-hospital primary care site, a private hospital, a regional hospital or a traditional healer. In both studies, some patients accessed the cancer centre directly. Interestingly, while those visiting a traditional healer first in Ethiopia had a longer care seeking trajectory, in Egypt, those visiting the general surgeon first had a longer trajectory because these practitioners in Egypt were not equipped to diagnose and treat breast cancer. Only Stapleton et al (2011) report a weak association between long travel times and delay from their study in Egypt.

Five studies, Ibrahim and Oludara (2012) and Ezeome (2010) from Nigeria; Otieno et al (2010) from Kenya, Kohler et al (2017) from Malawi and Dye et al (2010) from Ethiopia reported the use of traditional and complementary medicine as the reason for patient delay. Dye et al's (2010) in depth interviews revealed that the women they studied sought care from traditional healers because they believed traditional medicine to be the most effective choice for their symptoms. The women usually did not know their breast symptom was breast cancer. Where they knew it was breast cancer, they did not consider it treatable in the hospital.

### ***Psychological factors***

Fear was the most reported psychological factor influencing patient delay. This was reported as fear of mastectomy, of disfigurement, of seeking medical advice, of a cancer diagnosis, of death and the socioeconomic consequences of a cancer diagnosis (Abdel-Fattah et al., 1999; Elzawawy, Elbahaie, Dawood, Elbahaie, & Badran, 2008; Ibrahim & Oludara, 2012; Ismail et al., 2013; Otieno et al., 2010). Ismail et al (2013), Ezeome (2010) and Kohler et al (2017) reported denial (i.e. the identified symptom will disappear) as a psychological factor contributing to patient delay.

### **The Ghanaian context**

In Ghana, one survey in Korle-bu Teaching hospital (Clegg-Lampsey et al., 2009) and 2 qualitative studies in the Oncology department of KATH (Agbokey, 2014; Asoogo & Duma, 2015) have been done to understand why women delay in seeking care. All three studies were descriptive of factors influencing health seeking behaviour of the women. Clegg-Lampsey et al's (2009) survey did not test association of socio-demographic factors and delay as has been done in other studies reported in this literature review. The participants were breast cancer patients at different stages of care. Agbokey's (2014) study participants included caregivers, health workers and herbalists. The factors influencing patient delay as found by Clegg-Lampsey et al's (2009) survey is presented in Table 4 (page 33).

From their explorative studies, Asoogo and Duma (2015) and Agbokey (2014) also found poor knowledge about the signs and symptoms of breast cancer, inability to afford the cost of care, inability to afford the cost of travel to the hospital, and competing priorities of child and home care as factors contributing to patient delay. Also, for some of the women, making the decision to seek help involved husbands

(since they paid the hospital bills), as well as children and in-laws. Both studies found that seeking care from traditional healers also caused women to delay. This was done to avoid procedures like mastectomy. Women in both studies described being afraid of surgery, chemotherapy or dying. These fears arose from their past experiences with friends and relatives who had breast cancer. Agbokey's (2014) study also found that women delayed because of the investigations they had to do at the initial hospitals they presented at.

*Table 4 Reasons for delayed presentation for breast cancer symptoms in Ghana (Clegg-Lampsey et al. 2009)*

<b>Reason for delay</b>	<b>No. of women/66</b>	<b>%</b>
Medical consultation	26	39.4
Ignorance	19	28.8
Fear of mastectomy	16	24.2
Herbal treatment	13	19.7
Prayers and prayer camps	13	19.7
Financial incapability	12	18.2
Fear of diagnosis	7	10.6
Other spiritual	6	9.1
Food supplements	6	3
Homeopathy	1	1.5
Chinese acupuncture	1	1.5
Organic foods	1	1.5
Travelled	1	1.5

Neither Clegg-Lampsey et al (2009), Asoogo and Duma (2015), nor Agbokey (2014) discussed explicitly the trajectory the women they interviewed took in accessing healthcare. Also, their reports did not discuss the role of the existing healthcare structure in the health seeking behaviour of the women. Thus, the evidence in Ghana so far, does not offer much understanding of how varied socio-demographic factors

and health infrastructure systems impact on the factors described as influencing women's health seeking behaviour for breast cancer symptoms.

From the discussion so far, it is apparent there are inconsistencies about the influence of various factors on the health seeking behaviour of women with breast cancer symptoms. Other factors apart from the variability in the scales of measuring different factors may account for this. Andersen et al (2009) argue that symptom interpretation to infer illness is a human experience coloured by a socio-cultural context. In the subject of breast cancer, such context further includes the traditional role of females in relation to their family. Also, Sharma et al (2012) point out the fact that potential geographical variation in barriers to care arising from economic, social and cultural contexts cannot be overlooked. As such, although the variability of how these factors affect delay may be considered legitimate, the interpretation of these findings must be with due regard to context.

A theoretical approach to study the subject of delay in seeking care for breast cancer symptoms may offer better understanding of the matter. The next section discusses how some studies have contributed to the understanding of health seeking behaviour of women with breast cancer symptoms from a theoretical approach.

## **Theoretical perspective of the factors influencing patient delayed health seeking for breast cancer**

In this literature review, three studies (Rauscher et al., 2010; Taib et al., 2011; Taib et al., 2014) based their theoretical explanation on Andersen et al's (1995) General Model for Total Patient Delay (GMTPD) (Andersen, Cacioppo, & Roberts, 1995). Rauscher et al's (2010) survey focused on appraisal and illness delay and Taib et al's (2011) exploratory study on appraisal delay. Although of different methodological approach, both studies found factors that relate to knowledge to influence appraisal delay. Rauscher et al (2010) posit that such knowledge arises from a woman's past benign breast problems, her family history of breast cancer and the misconceptions she has about breast lumps. Together, these influence a woman's interpretation of the symptom she identifies. They add that age, ethnicity, marital and socioeconomic status influence a woman's knowledge. Rauscher et al (2010) also found women of older age, low education status and low income to have misconceptions about breast cancer and thus appraisal delay. Taib et al (2011) found that in addition to patient's poor knowledge of breast cancer and its outcome, the information and validation/sanctioning of the seriousness of their symptom from social contacts such as family, friends and the media influenced symptom appraisal. Furthermore, they propose that the appraisal process is influenced by the social, affective (i.e. how a woman copes with the identified symptom after labeling the symptom as threatening) and cultural contexts.

Regarding illness delay, Rauscher et al (2010) suggest that lack of health insurance, undertaking few preventive care hospital visits, and having no regular health provider or one to trust interact together to influence health care access and utilisation and

thus illness delay. Explaining further the GMTPD from their work, Taib et al (2014) also add that after symptom appraisal, disclosure is an independent stage that occurs before illness delay. They suggest that at each stage in the care seeking process, women could rather access complementary and alternative care in a health system. They go on to assert that the decision making process through the stages of the GMTPD is not necessarily based on objectively employed information but on biased information that will lead to a desired outcome. Consequently, after assessing the severity of their situation and the options available to them, women make decisions based on their personal values and the available social support.

Of the African studies, Kohler et al (2017) also based their explanation on Andersen et al's (1995) GMTPD. They modified their stages as noticing and interpreting their symptom; monitoring for changes and inferring illness; deciding to seek help; developing the intention to seek help through traditional remedies, social network or medical care; reaching the health facility; and receiving the appropriate care. They noted that moving along these stages involved cognitive decisions to take action. Also, access to care was influenced by social context and environmental factors. Ultimately, the women either moved along the stages quickly, got stuck along the line, skipped some steps or at some stages looped back to earlier stages. Agbokey (2014) on the other hand suggest that a woman's behavioural intention to seek care or not is what triggers the care seeking process. Such behavioural intention is influenced by her knowledge and attitude to health (affected by her socioeconomic status and past experiences); subjective norms (how they yield to societal pressures from others) and her perceived behaviour controls (i.e. their ability and freedom to perform BSE and decide where and when to seek care).

In their attempt to depict the complexity of the health seeking behaviour of women with breast cancer symptoms, Unger-Saldaña and Infante-Castañeda (2011) rather suggest the factors influencing health seeking exist in four dimensions, i.e. context; symptom interpretation; social networks; and health utilisation. These dimensions interact in an intertwined fashion, with the patient going back and forth within the various levels, seeking help from different healers and lay people at different times and for different reasons during the health seeking process. The contextual characteristics (economic, cultural, social, health system and family related) determine a woman's knowledge and beliefs regarding breast cancer. They also determine her social network's knowledge, beliefs, habits and interrelations; as well as the accessibility, availability and acceptability of different healers and health services available to her. Unger-Saldaña and Infante-Castañeda (2011) found that different factors exert their effect simultaneously in varying degrees, with an uncertainty of their resultant effect or the sequence of events in the health seeking process. For example, the internal dialogue of symptom interpretation and decision making is always ongoing and changes throughout the health seeking process, affected by emotions, knowledge, beliefs and previous experience with cancer. Social networks may be bypassed in the process or accessed for informational (advice to seek care or what specific health service to use), instrumental (money, help with errands or offer housing in the case of travelling) and emotional (cheer them up or accompany to the hospital) support. And at the stage of health service utilisation, encountering medical errors in diagnosis or overcoming a chain of referral processes were issues that could influence delay in spite of overcoming other contextual factors. Rather unusual, they found that time was irrelevant as a woman moved through this health seeking process.

To elaborate the fundamental elements and dynamic relationships that patient, provider and system factors have with one another, Angus et al (2007) interrogated them from the critical realist's philosophical perspective. They studied women of diverse economic backgrounds to understand how their life circumstances and income influenced their experiences, actions and access to diagnosis and treatment of breast cancer. They found that engaging with the health care system and practitioners involved a period of intense new tasks and activities for the women ("health work"). This "health work" involved problem solving, decision making and self-care oriented activities such as: getting a timely/convenient doctor's appointment that did not conflict with everyday responsibilities; negotiating the public health care system to ensure the best possible care or appropriate referral; managing different appointments (e.g. diagnostic labs, outpatient visits) at various locations; and working to maintain a good relationship and communication with different health providers. Angus et al (2007) argue these "health work" activities are entangled with the many everyday tasks normally performed by women, and for many, it is difficult to channel energy and time needed to navigate the health care system. They conclude that to overcome these, women need material and cultural capital in the form of health literacy or the ability to communicate effortlessly with health professionals. When a woman's socio economic status does not provide these resources, then she must put in more effort to create the conditions necessary for seeking care.



## **Conclusion**

The health seeking behaviour of women with breast cancer symptoms is influenced by many factors that appear to interact in a complex manner. These factors cannot be fully understood on the basis of their direct sensory experience alone, as they also exist independent of people's knowledge of them. Some theoretical explanation of the phenomenon have been offered. However, none demonstrates superiority over the other or captures entirely all the factors identified to influence patient delay. Moreover, these theoretical explanations have arisen outside the African context. More research is needed to advance our theoretical understanding of women's help seeking behaviour for breast cancer symptoms, and especially in the African and Ghanaian context.

It is fitting therefore that this is phenomenon be studied further with a holistic approach. The Andersen behavioural model for health care utilisation (Ronald M Andersen, Davidson, & Baumeister, 2013) is employed in my study to understand the health seeking behaviour of women with breast cancer symptoms seeking care at the KATH breast clinic. This conceptual model is applied with the critical realist's philosophical approach.

## **CHAPTER THREE**

### **CONCEPTUAL FRAMEWORK**

The Andersen behavioural model for health care utilisation was used to explore the health seeking behaviour of the women in my study (Ronald Andersen, 1995; Ronald Andersen, 2008; Ronald Andersen et al., 2013). The model suggests that an individual's decision to access health care is a function of her predisposition to use the health service, the factors that enable or impede her use, and her need for the care.

The first version of the model was developed in the 1960s and has undergone modifications over the years due to emerging issues in health policy and health service delivery, new developments in health service research and medical sociology, and critiques of earlier versions (Ronald Andersen, 2008; Ronald Andersen et al., 2013).

The modifications have been additions to the original model with no change in the fundamental components or their relationships. The first model was developed to understand why families use health services as well as define and measure equitable access to health care. The second model included two components; the organisation of health systems in determining population health service use, and consumer satisfaction as an outcome of health service utilisation. Personal health practices and health status as perceived by the population and evaluated by health professionals was included in the third model. The major modification of the fourth phase of the model was the inclusion of feedback loops between the components. The feedback loops show that outcomes can affect subsequent predisposing, enabling and need characteristics of the population and thus health service use. The fifth modification of the model incorporated contextual characteristics measured at organisational, community and national levels. It also included the process of medical care, i.e. the

behaviour of providers interacting with patients in the delivery of care, as a component of health behaviour. Such provider behaviour includes patient counselling and quality of provider-patient communication. The sixth modification added genetic susceptibility as an individual factor and quality of life as an outcome factor. The sixth modification of the model was used in my study (Fig 1) (Ronald Andersen et al., 2013).

According to the model, the determinants of health service use are contextual characteristics; individual characteristics; health behaviour and health outcomes. The contextual and individual determinants are further divided as follows:

- Existing conditions that predispose individuals to use or not to use health services
- Enabling factors that facilitate or impede health service use
- Need, i.e. conditions that individuals or health care providers identify as needing medical care

Individual predisposing characteristics refer to demographic factors (e.g. age and gender), social factors (e.g. ethnicity, cultural norms, education, occupation, and social relationships), health beliefs (attitudes, values, beliefs and knowledge about health) and genetic susceptibility to diseases. Individual enabling resources include personal and family resources (income, wealth) and factors that enhance health service use such as knowledge of the services provided, cost of care, nature, source and quality of care, accessibility (means of transport, time of travel to and back) and the patient's satisfactions and perception of the care provided. The individual need factors include perceived and evaluated need. Perceived need is the subjective evaluation of the individual's health status by herself, including her experience and emotional response

to an illness. The evaluated need is the health provider's assessment based on established medical knowledge and practice.

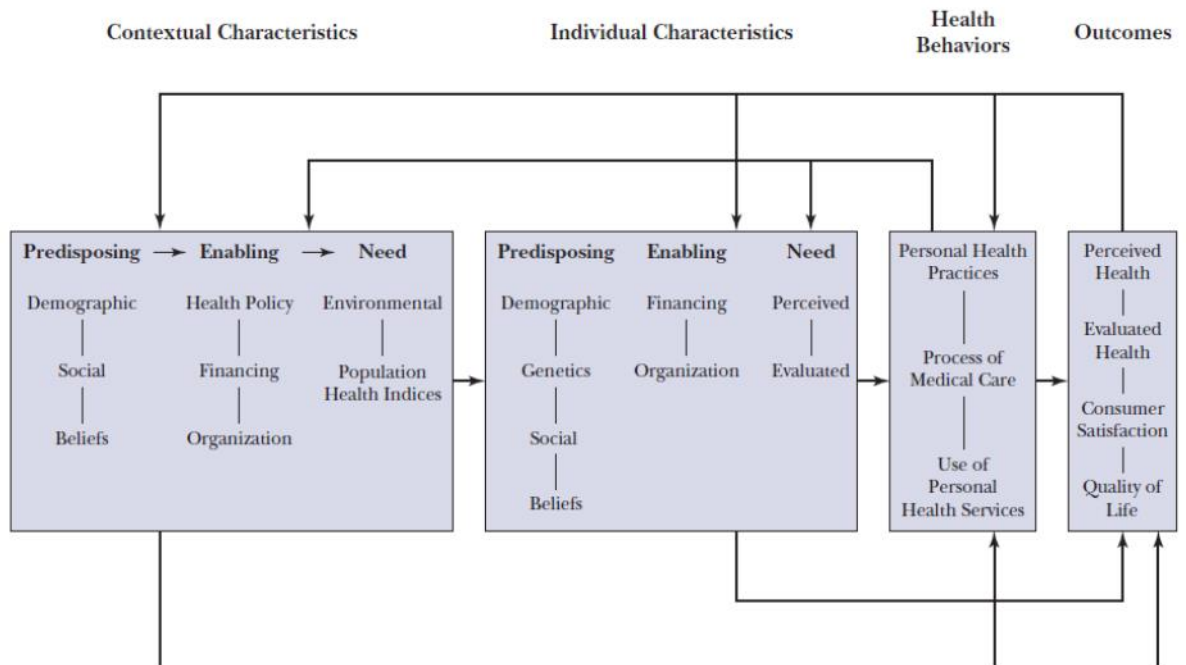


Figure 1 The Andersen Behavioural model for health care utilisation (Ronald Andersen et al., 2013, p. 35)

The contextual characteristics in the model are measured at the aggregate and not individual levels (Ronald Andersen, 2008; Ronald Andersen et al., 2013). The aggregate levels range from units as small as the family, to bigger ones like work groups or local communities, to larger groups like the national health care system. The individual is related to the aggregates through membership of the groups or residence. Contextual predisposing factors include demographic characteristics like age, gender and marital status composition; social characteristics such as educational and employment levels, ethnic and racial composition and crime rates; and beliefs related to organisational values, cultural norms and political perspectives of how health care services should be

organised. The contextual enabling factors include health policies; organisational factors such as the distribution of medical facilities, office hours and personnel; and financing characteristics such as per capita community income, wealth and prices of medical goods and services. The contextual need factors include population health indices such as mortality, morbidity and disability rates and environmental characteristics such as quality of housing quality. The model recognises the importance of the community, structure and process in providing care. This notwithstanding, Andersen et al (2013) maintain that the ultimate focus of the behavioural model remains the health behaviour of individuals regarding their use of health services, and the resulting outcomes related to their health, quality of life and satisfaction with services.

A central feature of the model is feedback (Ronald Andersen et al., 2013). The feedback loops reflects the multiple and mutual influences the components have on health service use and health status (Babitsch, Gohl, & von Lengerke, 2012).

In a review to examine the use of the various models of the Andersen behavioural model in health service research, Babitsch et al (2012) found that the fourth revision of the model was the most used in the sixteen studies examined. They identified a limitation in the number of variables of the model investigated in the various studies. They cited the use of secondary data in most of the studies reviewed as a possible reason for this finding. However, the few studies that employed primary data also investigated limited variables. It is possible that operationalising all the factors in the model and their mutual influences in one survey was not pragmatic. Babitsch et al (2012) also found there was varied classification of some of the factors, suggesting

that certain factors could play dual roles such as being a predisposing and enabling factor at the same time. In their conclusion, Babitsch et al (2012) agree that the complexity of the Andersen model has not yet been adequately operationalised and investigated.

Andersen (2008) admits that implementing the model requires more creative and challenging conceptualisation, longitudinal and experimental studies and innovative types of analysis. This position suggests a leaning towards the use of quantitative methodology for studies using the model. Indeed, the application of the model has been mainly by quantitative methodology as was found in Babitsch et al's (2012) review and in some subsequent studies (Graham, Hasking, Brooker, Clarke, & Meadows, 2017; Porteous, Wyke, Hannaford, & Bond, 2015; Schomerus et al., 2013). One of the 16 studies (Insaf, Jurkowski, & Alomar, 2010) in Babitsch et al's (2012) review however applied the Andersen model using mixed methodology. They used themes identified from focus groups to design survey questions to assess sociocultural factors influencing health seeking behaviour of Latinas in New York. Their report however did not describe how the Andersen model was used in analysing data from the focus group discussions.

In my study, qualitative methodology was used to investigate the health seeking behaviour of women reporting with advanced breast cancer symptoms. Using in depth interviews offered the opportunity to explore all the variables in the model, including how they interact with each other as suggested by the feedback loops. Considering all the factors found to influence health seeking behaviour for breast cancer symptoms in my literature review, the Andersen behavioural model does not capture all. For

example, social factors are described in the model as an individual predisposing factor, i.e. social relationships. But social disclosure and women's social roles contribute to the contextual understanding of help seeking behaviour for breast cancer symptoms (Angus et al., 2007; Burgess et al., 2001; Khakbazan et al., 2014a). The versatility of the Andersen model however (Ronald Andersen, 1995; A. W. Chen, Kazanjian, & Wong, 2008; Gelberg, Andersen, & Leake, 2000) allows for the addition of more factors to it as is fit for the purpose of any particular research without disrupting its structure.

Other models have been used to study delayed health seeking for cancer symptoms such as Andersen et al's (1995) 5-staged "General Model of Total Patient Delay" (GMTPD) and the psychophysiological comparison theory (PCT) where delay in seeking care is divided into appraisal delay, illness delay, behavioural delay, scheduling delay and treatment delay; with the PCT describing the influence of illness prototypes (Andersen et al., 1995). This model has been used to study delay in cancer patients (de Nooijer, Lechner, & de Vries, 2001) including breast cancer patients (Rauscher et al., 2010; Taib et al., 2011; Taib et al., 2014). However, the model suggests some "linearity" and discreteness to the stages of delay. It also suggests independence of patient and physician/health system culpability to care delay. It does not reflect how the stages may overlap, or sometimes, may not occur at all (de Nooijer et al., 2001). Furthermore the GMTPD's representation is inadequate to explain what happens within the stages nor reflect the complexity of the process (Bish et al., 2005), neither the social influence on them (Unger-Saldaña & Infante-Castañeda, 2011).

The Andersen behavioural model for health service use (Ronald Andersen et al., 2013) provides a better framework with an overarching approach to the issues of illness

behaviour by looking at both micro- and macro-sociological factors (Young, 2004). It is predictive of how people use health services, as well as explanatory of health seeking behaviour. It has been used quite widely to study individual and contextual determinants of health service use in communities and among ethnic minorities (Babitsch et al., 2012). On the subject of breast cancer it has been used to study factors influencing mammography utilisation (Lai, Lai, Chen, & Koo, 2012). It appears though that its application has been mainly with quantitative methods and thus limited the investigation of the complex interaction of factors influencing health service use. Applying the model to understand the delayed care seeking of women with breast cancer symptoms by qualitative study methods can offer better theoretical understanding of the phenomenon in the Ghanaian context.

## **PHILOSOPHICAL APPROACH**

Underpinning the conceptual model for my study is the philosophical/epistemological perspective of Critical realism. Critical realism focuses on the interplay between structure and agency, because they are distinct strata of reality that differ in powers and properties (Archer, 2003). As social structural factors do not fully determine an individual's health, but provide the conditions that facilitate or restrict health-related activities, then, the social structures that result in restraints are of as much interest as the strategies devised by the individual to deal with them (Angus, Miller, Pulfer, & McKeever, 2006). These social structures operate at many sites and levels and cannot be fully understood on the basis of their direct sensory experience alone, as they also exist independent of people's knowledge of them (Scambler, 2001). Consequently, critical realists propose that reality exists in the domains of the empirical, the actual and the real (Archer, 2003; Scambler, 2001). The empirical is what is experienced



directly or indirectly, the actual includes events as they exist or actually happen regardless of how or whether they are experienced, and the real is anything naturally or socially existing, including, and going beyond experiences and events that trigger the actual phenomenon (Angus et al., 2006; McEvoy & Richards, 2006). These elements in the realm of the real have been called “generative mechanisms”. Though the generative mechanisms may not be directly apprehended because they are not open to observation, they can be inferred through combining empirical investigation and theory construction (McEvoy & Richards, 2006). This is achieved through retroductive reasoning which involves making inferences about the underlying structures and mechanisms responsible for the phenomenon being studied (Blaikie, 2004), with respect to what could have, must have or may have caused it (McEvoy & Richards, 2006).

The pathway from identification of an initial symptom to seeking care for a woman with breast cancer symptoms can be influenced by underlying generative mechanisms that may be difficult to discern. For instance, Scambler’s (2001) discussion of social class as a generative mechanism regarding access to health care suggests that a woman’s experience of witnessed breast cancer events, the cultural explanatory model of illness she holds, how she is socialised, where she lives, her income, and even conversations she engages in about her ill-health and with whom, affects her health seeking behaviour. He argues that, the woman’s command or management of these issues; especially of those related to economic productivity present her with a form of capital that creates enabling or restraining conditions that contribute to, though not necessarily determining her access to care. These social issues however, revolve around a knowledgeable individual who engages actively with these circumstances

and whose actions or inactions affect them (Angus et al., 2006). Thus, these generative mechanisms, though arising from structures which are culturally contingent, will always work through the individual's actions (Morén & Blom, 2003).

## CHAPTER FOUR

### METHODOLOGY

A qualitative methodological approach was used for this research. This study sought to explore holistically the health seeking behaviour of women who presented late to KATH breast clinic with breast cancer symptoms. The study also aimed at going beyond identifying what factors contributed to delayed care seeking, to understanding how the factors interacted and contributed to delay. The literature reviewed for this study showed some inconsistencies in the influence that various factors exert on the health seeking behaviour of women with breast cancer symptoms. Also, the interpretation of a symptom to infer illness is known to be influenced by social and cultural context (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2009). As such, context could be overlooked in understanding the delayed health seeking behaviour of women for their breast cancer symptoms. The qualitative approach allows for a detailed account of the context within which the women in this research were being studied (Bryman, 2012).

The literature review also revealed little application of theory to understand the delayed health seeking behaviour in the African and Ghanaian context. The critical realist approach to this study offered the opportunity to go beyond identification to understanding how the factors enact their influence on delayed health seeking. Analysing the women's account of their health seeking behaviour to gain this in depth understanding from this theoretical perspective can be achieved through retroductive reasoning. Retrodutive reasoning involves making inferences about the underlying structures and mechanisms responsible for the phenomenon being studied (Blaikie, 2004). The qualitative approach, using in depth face to face interviews offers the rich

data from which such analysis and understanding can be gained from the women's viewpoint, while also giving a scientific understanding of it based on the participants accounts (Blaikie, 2004; Bryman, 2012). Also, the qualitative methodology offers the opportunity to focus on process, a characteristic that makes it the suitable approach to explore the health seeking journey of the women in this study.

The Andersen behavioural model for health service use (Ronald Andersen et al., 2013) was used as the conceptual framework for this study. Qualitative methodology tends to keep structure to a minimum and rather highlight the perspective of the people being studied using general and not specific questions (Bryman, 2012). But Bryman (2012) posits that concepts are useful in qualitative research where they can offer a general guide, not a straightjacket model to study a phenomenon. The Andersen behavioural model (Ronald Andersen et al., 2013) was designed to accommodate modifications to fit a particular study without disrupting its framework (Ronald Andersen, 1995; Gelberg et al., 2000). The qualitative approach is better suited for the application of such a versatile model in this study because qualitative methods offer the prospect of flexibility in research.

The complexity and multidimensional nature of the reasons why women delay in seeking care for breast cancer symptoms makes the qualitative approach better suited to capture a rich description of the diversity of the women's experience (Silverstein, Auerbach, & Levant, 2006). It can also reveal the meanings attached to choices made within a complex culture and social framework, the connections between them, how, and to what extent they influence each other (Willig, 2013) in deciding to seek treatment.

## **METHODS**

### **Access to participants**

Participant selection: Participant sampling was purposive. Women presenting for the first time to the breast clinic of KATH with breast disease clinically suggestive of Stage III or IV breast cancer as defined by the American Joint Committee on Cancer (Singletary et al., 2002) were eligible for selection. Definitive diagnosis of breast cancer is by tissue biopsy showing the characteristic histopathological changes. Thus the women recruited for this study did not have a definitive histopathological diagnosis of breast cancer. However, these women recruited with breast disease highly suggestive of stage III or IV breast cancer would have invariably observed overt changes in their breast during the period before seeking care at KATH breast clinic. Eligibility also included self-identification of the breast symptom, and reporting to KATH breast clinic at least 3 months after identifying the symptom. This sampling approach where participants selected exemplify the phenomenon of interest is called the typical case sampling approach of purposive sampling (Bryman, 2012). There was no age limitation to eligibility for inclusion as no particular age categories have been described for patients presenting late for care (Clegg-Lamptey et al., 2009; Ohene-Yeboah & Adjei, 2012). The aim was to interview between 10 – 20 women. This sample size was considered reasonable and comparable to the sample size of 10 – 20 women interviewed in other qualitative studies conducted on delayed health seeking for breast cancer symptoms (Agbokey, 2014; Asoogo & Duma, 2015; Norsa'adah et al., 2012; O'Mahony et al., 2011; Rastad et al., 2012; Taib et al., 2011; Unger-Saldaña & Infante-Castañeda, 2011).

The clinical breast disease suggestive of Stage III/IV breast cancer was determined by the attending physician. The route of access to the participants was the consulting room nurse in the breast clinic, who was the gatekeeper in accessing these women. As the first health professional the women had contact with on arrival at the clinic, she informed them about the ongoing study. To the eligible women who expressed interest in participation, the nurse gave the research information sheet and the contact details of the researcher. At the close of each clinic, the nurse compiled the list of women who had agreed to consider participation for the researcher.

Recall bias was inevitable in the women's account of their journey to KATH breast clinic and this could be further influenced by the illness experience. Lam et al (2008) argue that a 'post hoc' rationalisation of one's actions especially after having become a patient influences recall. 'Post hoc' rationalisation also influences how the decision to seek care is legitimised and reported (Hay, 2008). In KATH breast clinic, diagnosis disclosure is done after tissue biopsy results have confirmed breast cancer. This takes at least 2-3 weeks after the first visit. As such, in this study, eligible women were interviewed after the first visit and before pathological confirmation and disclosure of the diagnosis. Lam et al (2008) assert that, being unsure of the diagnosis makes the woman blind to it and her account of her health seeking actions remains uncontaminated by any emotional reactions such as rationalisation of prior actions that may arise from knowing it.

The women willing to participate in the study were directed to contact me (the researcher) and personally express their interest/permission for enrolment into the study. The proposed plan was to confirm the women's willingness to participate in the

study one week after first meeting them and have them suggest a time and place for a face to face or telephone interview. However, all the women who agreed to participate contacted me on the same day they first visited KATH breast clinic and agreed to have their interview that same day. All the women opted for a face to face interview in the hospital because they felt better assured of privacy. To avoid the distress of having to return to the hospital at another time purposefully for the interview, they opted to have it done before going home.

Women who were too frail, such as easily tired from the routine clinical consultation and examination were not interviewed. Excluding these women meant the stories of those arriving at KATH breast clinic in such debilitating states would be lost in the data to be analysed. These were potential perspectives that could contribute significantly to understanding the delayed care seeking phenomenon. However, the place obtained in the hospital for the interviews was furnished by only a table and some chairs without any couch. Also, the interviews were expected to last for up to one hour. Having a very ill woman sitting for such duration of time could be very distressing.

### **Consent and how it was obtained**

Participant information (appendix IV) and consent (appendix V) forms were given to the participant during the first contact with her. All participants agreed upon first contact with me to participate. They also opted to have the interview at the time of first contact. The interview was conducted after having confirmed the participant fully understood what the research was about. The participant information and consent forms were read and translated where need be and the participants signed or thumb

printed it. Participants understood they could withdraw from the study before or during the interview and up to 2 weeks after the interview.

### **Data collection and storage**

The face-to-face interviews were conducted and audio recorded. An interview guide (Appendix VI) was used. The interviews lasted between 30 minutes to 1 hour. The questions were used flexibly. The order of questioning was adapted and elaborated to suit each interview context, thus promoting a dialogue that could explore the issues that came up (Bryman, 2012). The open ended nature of the questions allowed the women to give accounts of their health seeking journey in their own language and perspective. The interviews were conducted in the local dialect (Twi). The Twi language is widely understood by all the potential participants and the researcher, thus facilitating easy communication. Translation of the interviews to English was done by the researcher during transcription of the interviews. Transcription was done in English because the researcher has better proficiency in writing the English language than Twi. Collecting the data in Twi language and then interpreting and presenting the findings in English involved translation related decisions that have a direct effect on the trustworthiness of the study (Birbili, 2000). I had the responsibility therefore to translate the interviews into English with meaning as close to the original, i.e. Twi, as possible (Wu, 2006). Birbili (2000) suggests that the translator must have linguistic competence of the original and target language and must know the culture of the people being studied in order to achieve grammatically comparable forms of what the participants say in the target language and make them understandable. I was able to bring these skills to the task because I was born and raised in the culture of the women I studied.



All audio recordings were encrypted and stored on my laptop protected with a password. The electronic word documents of transcribed interviews were encrypted and stored on my computer and protected by a password. The audio recordings and anonymised interview transcripts will be destroyed after the thesis has been approved. Electronic copies of the transcribed interviews will be destroyed years after the research.

### **Anonymity and how it was maintained**

Anonymity was maintained throughout the research process. During transcription of the audio interviews, identifiable data such as names were removed and replaced with codes (Kaiser, 2009). The identifiable data was stored in a separate encrypted file and protected by a password. Because the findings of the research will be presented to the clinicians of the breast and oncology clinic, there is a risk of anonymity breach via deductive disclosure (Tolich, 2004). The participants were thus told clearly how the data would be shared with physicians and the expected benefits to the health seeking behaviour of women with breast cancer symptoms to be derived from their participation (Kaiser, 2009). The participants were however offered the opportunity to elect to have their first name used if they wished, so as to retain ownership of their story (Grinyer, 2004). All the women interviewed left the choice of using either their real or code names to me.

### **Method of analysis**

Interpretation of the data inevitably began at the transcription stage when the interviews were translated from Twi to English. From their review of procedures and techniques used in translation of original language in qualitative research, Chen and Boore (2010) found back-translation to be the most common and highly

recommended procedure for translation. In back-translation, the target language (English) is translated back to the source language (Twi) to evaluate equivalence of meaning (Chen & Boore, 2010). During the transcription, analysis and results writing stages of the thesis, the back-translation process was repeatedly done to ensure that the meaning of participants' accounts was maintained. This involved translating the English quotes into Twi and listening again to relevant sections of the audio transcripts to ensure the meaning had not been lost.

Thematic analysis was the method of data analysis. (Braun & Clarke, 2006; Bryman, 2012; Ryan & Bernard, 2003). It began after the first interview and went on concurrently as further interviews were conducted with the exploration of identified themes in subsequent interviews. The recorded interviews were transcribed after each interview by me, and the transcripts checked against the audio recordings for accuracy (Braun & Clarke, 2006). Transcribing the data myself allowed for re-immersion into it and initiating the process of identifying the themes in it (Ryan & Bernard, 2003). As the transcripts were read and re-read, themes were identified according to a priori that had been developed based on the Andersen Behavioural Model of Health care utilisation (Ronald M Andersen et al., 2013). Note was taken of other recurring motifs (Bryman, 2012), indigenous terms and how they were used, metaphors, linguistic connectors describing relationships between topics and missing data as a guide to identifying themes (Ryan & Bernard, 2003). Responses that fell outside the above characteristics, yet identified to represent something of importance in relation to the research question were also captured as themes (Braun & Clarke, 2006; Bryman, 2012). The latter helped identify new themes and connections that were otherwise not part of the conceptual framework. The themes were checked for patterns,

commonality, consistency and variability. Note was also taken not just of the women's accounts of what influenced their decision making but how the factors were enacted in their health seeking journey. Interpretation was done with reference to existing literature. Theoretical interpretation of the findings was done based on the accounts of the women (Blaikie, 2004; Bryman, 2012). Interpretation of how the factors interacted with each other, their significance along the health seeking journey and how they ultimately evolved to influence decision making was done based on the women's accounts.

### **Ethical issues**

The study participants were a potentially vulnerable group of people because of their breast disease suggestive of Stage III or IV breast cancer. This raised some potential ethical concerns which are discussed below.

The in-depth interviews could provoke distressing situations and emotions. Even in circumstances where this could be predicted, the open-ended nature of the interview makes their avoidance unreliable (Richards & Schwartz, 2002). Richards and Schwartz (2002) suggest questions that will provoke anxiety and distress depend on the participant's experience and biography and these are unpredictable. Being a physician, there is the possibility that participants may ask my medical opinion about their diagnosis, prognosis and treatment options. On the other hand, talking to me could result in them realising how serious their illness was. These instances could evoke anxiety, fear, pain, guilt, anger and regret about their actions prior to arriving at KATH breast clinic. To avoid precipitating such situations, the ethical committee required that all participant communication either in print or verbal used the neutral term

'breast disease' to avoid any suggestive language. However, in the event of evoking any negative emotions, the participant were referred to the primary physician, whose responsibility it is to discuss their disease (Fujimori & Uchitomi, 2009; Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005) and to the KATH palliative care team for support.

There is a potential for exploitation and imbalance of power relationships in research. As a health professional conducting this research, this power imbalance may be exacerbated (Etherington, 2001). This could arise because the participants may feel pressurised to participate since they depend on the health professional's good will, or out of a sense of duty to the health professional for having offered them care (Holloway & Wheeler, 1995). It is possible then, that this reason may have contributed to the participants consenting and participating in the study on the first day they reported to KATH breast clinic. Such situation is more likely if the researcher is a health professional directly involved in the care of the participants (Etherington, 1996). In this research however, I was not directly involved in the care of the participants. Also, the women who agreed to participate chose to have their interviews conducted on the same day they presented to KATH breast centre.

Clarke (2006) suggests that, researchers must consciously create a non-manipulative research relationship through the establishment of rapport to minimise power imbalances. However, the establishment of rapport can create the risk of the study interviews becoming a therapeutic encounter, or may lead participants to divulge information they had not anticipated (Corbin & Morse, 2003; Richards & Schwartz, 2002). Such concerns however do not preclude the establishment of a trusting relationship between the researcher and the participant because the participants may

indeed be far more discerning about the nature of research than they are given credit for (Clarke, 2006). Moreover, the assumption that a trusting relationship may lead them to divulge more than they may feel comfortable with later, removes their agency and control over what they reveal or withhold in the interview (Corbin & Morse, 2003; Nunkoosing, 2005). Invariably, the researcher must ensure that the interview is not used as an interrogation or confession (Nunkoosing, 2005) or as a counselling session (Corbin & Morse, 2003). The above notwithstanding, drawing a neat boundary around rapport and intimacy to avoid counselling can be difficult even among skilled researchers because both activities require similar skills (Coyle & Wright, 1996).

On the other hand, a relationship of trust with the participants can be a source of harm to the researcher. As a health professional conducting this research, there must be a fair balance between a sense of professional detachment as pertains to routine work (Lupton, 1994) and emotional involvement with participants arising from the subjective nature of qualitative research. Failure of this, results in ambiguity of roles between being a researcher, a physician or a counsellor and this can amount to significant stress for the researcher (Dollard, Winefield, & Winefield, 2003; Johnson & Clarke, 2003). The researcher may feel overwhelmed and emotionally exhausted leading eventually to burnout (Dickson-Swift, James, Kippen, & Liamputtong, 2006) and its consequences of anxiety, fatigue and insomnia (Griffiths, 2003). This potential harm is much highlighted in my study because I am a health professional. Among health professionals, the experience of burnout is already well documented (Dickson-Swift et al., 2006). Dickson-Swift et al (2006) suggest emotional distancing as a means to actively manage the boundaries between the researcher and the participant. Emotional distancing was ensured in this study by ensuring the participants

understood that they could only contact me subsequently on issues related to the study. All other health related concerns they had had to be directed to their primary physician at the breast clinic. Also, after the interviews, I made no follow up to what treatment or how far along the management trajectory the participants had gone.

The use of gatekeepers raises ethical concerns about their influence on the research process because their engagement with the researcher and the research process can be complicated (Clark, 2011). This ethical dilemma is further highlighted if the gatekeeper is a health professional (Beauchamp & Childress, 2001; Emanuel, Wendler, & Grady, 2000). The gatekeeper may have to balance their duty to protect patients from harm and the patient's right to choose whether or not to participate in the research (Beauchamp & Childress, 2001; Sutton, Erlen, Glad, & Siminoff, 2003). They also have to work at maintaining their credibility and future relationship (McAreavey & Das, 2013) with colleagues and the researcher who may be in a senior position. Furthermore, their understanding of how knowledge is constructed, what good research is, and the effect of the research on the prospective participants influences the extent and circumstances under which they grant access (McAreavey & Das, 2013; Sutton et al., 2003). Thus, they have the power to facilitate (Eide & Allen, 2005), or deny access (Meadows, Lagendyk, Thurston, & Eisener, 2008; Wanat, 2008) to participation or influence whether participants opt in or out of the research (McAreavey & Das, 2013). Sutton et al (2003) however argue that, the potential participant's opportunity to participate in research must not be influenced by the healthcare provider's beliefs regarding the participant's protection. This violates the principles of autonomy and justice by denying potential participants their right to choose and decide whether or not to participate (Beauchamp & Childress, 2001;

Capozzi & Rhodes, 2000; Emanuel et al., 2000). As a solution, there must be education sessions addressing measures to be implemented to protect participants and staff (Sutton et al., 2003). Such sessions also offer a platform for dialogue to build trust among all persons involved in the research which must be maintained all through the study period (Moody & McMillan, 2002; Oka & Shaw, 2000; Thynne, 2010). The gatekeepers in my study had been involved in previous studies where they received some training on this phenomenon. However, a session was organised at the beginning of my study to address these issues. It was agreed that where one gatekeeper had challenges with a potential participant, another had to be consulted to arrive at a consensus.

Balancing ethical concerns with the need for a reliable and valid research is demanding. Thynne (2010) suggests that this is possible if the researcher is guided by the principles of best practice which include a participant centred approach and value for respect, anonymity and meaningful participation throughout the research process. I adhered to these best practice principles at every stage of the research process.

Ethical approval for the study was obtained from the Kwame Nkrumah University of Science and Technology School of Medical Sciences and Komfo Anokye Teaching Hospital Committee on Human Research, Publication and Ethics (CHRPE) in Ghana (Appendix VII) and the Faculty of Health and Medicine Research Ethics Committee (FHMREC) in Lancaster University (Appendix VIII).

## **Reflexive comments**

Reflexivity refers to sensitivity to the ways in which the researcher and the research process have influenced the data collected, including how prior experiences and assumptions could influence the research process (Mays & Pope, 2000). It involves a continuous awareness of what is influencing the researcher's internal and external responses while simultaneously being aware of the researcher's relationship to the participants and the research topic (Dowling, 2006). Mays and Pope (2000) assert that, to enhance the credibility of the research findings, any intellectual and personal biases such as professional status and the "distance" between the researcher and the participants must be disclosed at the outset of the research report.

My clinical and research background prior to undertaking this study was based on quantitative research methods. However, I chose a qualitative methodology for this thesis because the nature of the question required it to achieve the depth of enquiry of interest.

The use of in-depth interviews to collect my data was a process that required that I step out of my regular role as a doctor into the role of a researcher interested in a phenomenon solely from the perspective of my study participants. I anticipated that shifting between the two roles could be challenging. This is because my role as a researcher required me to listen to the participants' stories from a perspective different from that of a physician. To help me do this, I made sure I was not directly involved in the clinical care that the participants received in KATH. In this way, my interaction with them was purely for the purpose of the study. I had to make a conscious effort to listen to their full story rather than ask only questions of interest,



as is the regular practice as a physician. Where I did interject in the listening process, I encouraged participants to reveal more about their experience than I would have in my medical role. All the participants knew I was a doctor. They also knew I was not directly involved in their care. However, sometimes, some of them appeared to be seeking my personal opinion on actions taken before or yet to be taken about their breast illness. I made a conscious effort to refer them to the clinic nurse or doctor in charge of their care. During the interviews I found some of the experiences they narrated relating to the healthcare system surprising, for example, the number of visits to one care facility before referral to the next. I also found it revealing the cognitive processes involved in deciding to seek healthcare at all cost at a point in time along the health seeking process. At such times, I had to make the conscious effort to avoid any comments that could be potentially perceived as judgemental of the participants or the healthcare system. I anticipated that, considering the state of illness, some of the participants would ask me if they were going to die (this sometimes happens in clinical practice). My plan was to encourage such participants to discuss this with their doctors with the involvement of the hospital palliative care team. This situation however did not arise.

I worked at maintaining my observer/researcher attitude through the interviews and data analysis stage. The consciousness of it made me get better at it as the research process evolved. I made every effort not to allow my expectations or pre-existing conceptions about women's health seeking behaviour to interfere with the interpretation of the participants' stories. Rather, all interpretation was based on the chosen philosophical perspective and conceptual model chosen for the study.

My experience as a student during the research process was also a good learning experience. Being new to qualitative research methods made me somewhat anxious at the beginning. More so because I was working very far from campus and my supervisors. I decided to perform every activity of the research process to enhance my learning experience. I learnt to anticipate some of my challenges and discuss them during supervision so that I was ready to deal with them when encountered. I found myself double checking with literature and with my supervisors to be sure I was applying the right techniques and processes.

I found the experience of “stepping out” of my routine role as a doctor to examine a phenomenon that influences my practice to be revealing and very rewarding.

# CHAPTER FIVE

## RESULTS

The results chapter begins with a description of the study participants. Subsequently, the health seeking process is described under the following headings;

- Symptom identification and appraisal
- Deciding to seek medical help
- The help seeking journey

The chapter ends with a description of the total health seeking experience.

### **The study participants**

Fifteen women were interviewed between May 2015 and March 2016. The socio-demographic details of the women are presented in Table 5 (page 67).

The youngest participant was 24years (Int. 10) and the oldest was 79 years (Int. 6). Ten of the women had breast symptoms suggestive of clinical stage III disease. This was characterised by overt breast swelling or easily palpable breast lump with associated local changes such as ulceration, thickening or indurations of the overlying skin, hardening of part or the entire affected breast with attachment to the chest wall, a swelling in the ipsilateral armpit or associated swelling of the arm on the same side as the affected breast. Five of the women had breast symptoms suggestive of clinical stage IV disease. For them, in addition to the manifestations suggestive of stage III disease, they also had symptoms and signs suggestive of distant spread of disease such as cough, breathlessness (lung spread). Four of the women lived in towns or villages

located in the same region as the Komfo Anokye Teaching Hospital breast clinic (KATHbc), i.e. the Ashanti region. The others lived in towns or villages located outside the Ashanti region. Travel time to KATHbc was about 30 minutes to 1.5 hours for those in the Ashanti region, 2 to 4 hours for those from the Western and Brong Ahafo regions and up to 9 hours for the woman from the Northern region. Travel to KATHbc was by road with a bus or a chartered taxi if the woman felt too ill to travel by public transport.

All of the participants except for one (Int. 2) lived with some family members. These family members were their husband, children, grandchildren, siblings, parents or other extended family. They were in constant touch via telephone with family members who did not live in the same house with them. Int. 2 was a divorcee, she had no children, both her parents had died and she lived alone. She was estranged from her siblings and other family members due to some past family misunderstandings. At the time of the interview, no relative or friend of hers knew she had come to the hospital.

Table 5 Socio-demographic information about the study participants

ID	AGE (yrs)	ADDRESS	EDUCATIONAL STATUS	MARRITAL STATUS	OCCUPATION	MONTHLY INCOME	CLINICAL STAGE OF ILLNESS
Int 1	43	Rural (Ashanti region)	None	Married	Farmer	Irregular	III
Int 2	61	Semi Urban (Eastern region)	Primary	Divorced	Trader	Irregular	III
Int 3	38	Semi Urban (Brong Ahafo region)	Secondary	Married	Trader	Irregular	III
Int 4	50	Rural (Brong Ahafo region)	None	Married	Farmer	Irregular	IV
Int 5	38	Semi Urban (Ashanti region)	Secondary	Divorced	Food Vendor	Regular	III
Int 6	79	Urban (Brong Ahafo region)	None	Widow	Unemployed	None	III
Int 7	67	Urban (Brong Ahafo region)	None	Married	Unemployed	None	III
Int 8	60	Urban (Ashanti region)	Secondary	Married	Trader	Irregular	IV
Int 9	51	Urban (Brong Ahafo region)	Primary	Married	Unemployed	None	IV
Int 10	24	Rural (Brong Ahafo region)	Secondary	Married	Unemployed	None	III
Int 11	53	Urban (Ashanti region)	Secondary	Married	Trader	Irregular	III
Int 12	37	Rural (Northern region)	Secondary	Married	Seamstress	Irregular	III
Int 13	65	Urban (Ashanti region)	Secondary	Divorced	Retired administrator	Regular	IV
Int 14	35	Semi Urban (Brong Ahafo region)	Secondary	Widow	Trader	Irregular	IV
Int 15	48	Semi Urban (Western region)	Primary	Married	Farmer	Irregular	III

None of the women interviewed had economic independence. When their spending needs went beyond what was usual for them, they had to rely on family or friends for support. Five of them were unemployed and had no monthly income except for Int. 13 who was a retired administrative officer and received a regular monthly pension of GhS400 (£70.40). The others received remittances from their children (Int. 6, 7), siblings (Int. 9) and husband (Int. 10) as and when they had needs or as often as the donors could afford to do so. All the others, though employed, did not have a regular and reliable periodic income. This was due to the nature of the work they performed. Among the farmers, their crop harvest was yearly. They made profits of about GhS 600 – 700 (£107 – £125) from these harvests and this was what they saved for their children's school fees and any other expenses for their well-being. The other employed women had no consistent earnings and could not name exactly how much they could save. Whatever they earned was spent on daily living expenses. They all relied on remittances from other family members to supplement what they earned.

The highest level of formal education was secondary (8 women). Three women had no formal education at all.

### **The health seeking process**

The health seeking process for the women was a journey that started from identifying an anomaly in their breast. It involved various physical, emotional and social activities performed at different times and culminating in their arrival at Komfo Anokye Teaching Hospital breast clinic (KATHbc) for care. These activities and their experience of them as described by the women are presented in the subsequent paragraphs

under the headings; symptom identification and appraisal; deciding to seek medical help (“the tipping point”) and the help seeking journey.

### **1. Symptom identification and appraisal**

All the women identified the breast change themselves except for Int. 15 whose lump was noticed by her friend. Some of the women had the habit of touching and feeling their breast periodically because of messages about breast examination they had heard on television or radio. For others their attention was drawn to examine their breast because of the unusual asymmetry they had observed in the breast size or a sense of discomfort/pain they felt in the breast. The first sign identified by most of the women was a lump in the breast, some noticed swelling of their breast, and two of them felt pain in the breast. Their initial impression was that it was nothing serious. This attribution arose from different reasons. For some, what they discovered initially was small in size, was not apparent to others, and their breast still appeared normal. Moreover, signs they expected to be associated with serious illness such as pain and interruption in the ability to go about their normal duties were absent. For many of the women, the change at that time was not perceived to be something that could potentially worsen and have detrimental health effects.

*“It wasn’t big and I thought it won’t worry me, I thought that this will not bring me any problem that’s why I did not go to the hospital” [Int. 5]*

*“I didn’t think it will progress like this” [Int. 15]*

In spite of this initial impression that what they had identified was not serious, the women had now become aware of the change in their breast. This sense of awareness led them to repeatedly re-examine their breast and make efforts at understanding

what it was. They employed various means to achieve this. The women relied on what information they had of breast illnesses and compared what they had identified on themselves to this. Such information included common knowledge of what was culturally/traditionally known regarding breast illness or diseases of lumps and body swellings that were similar to what they had identified in their breast. For example, swellings were commonly regarded as boils and the expectation was that at a point in the swelling process it would discharge pus and subsequently resolve. This disease process was known to be common in the breast especially during breastfeeding. And even during breastfeeding if a lump or swelling did not burst to discharge pus, continuing to breastfeed led to its spontaneous resolution. Although they were not breastfeeding, the women actively monitored their breast symptoms expecting these outcomes. This watchful waiting was also sometimes encouraged by friends and relatives with the same outcome expectations. The expectations were heightened if there was previous personal experience of similar change. For example, Int. 15 had experienced painful breast swelling which burst and discharged pus while breastfeeding her third child. As the pain she experienced now was similar to what she had before, she expected it to resolve spontaneously as the previous one had.

*“What I know is that as a woman when you deliver and your child is breastfeeding it can swell, even that for 3 days.....the way it was hurting I was thinking, as for something that is swollen it will burst and discharge then you are free and that’s all” [Int. 6]*

*“I realised that when the thing wants to burst it does not burst like the way boils do and fluid comes out, rather the surface ulcerates. I was waiting for it to*



*burst but it didn't it was still there. I tried some other herbal medicine but even that it still could not burst" [Int. 13]*

The women also looked to the past experiences of other women who had seemingly similar breast illness to make sense of what they had discovered in their breast. Sometimes they actively sought the opinion of other women on what they had noticed in their breast and the information they got contributed to their interpretation of their symptom. For example, Int. 3, although she was experiencing her breast symptom for the first time and did not know what it was, thought it was not serious. This was reinforced by the assurance she got from the women around that it was nothing serious.

*"I will complain to the elderly people who buy things from me that there is a lump in my breast and they say it is not anything just apply medicine to it"[Int. 3]).*

*"My mother said it was nothing, that my child had coughed into my breast, I should allow him to continue to breastfeed and it will loosen up" [Int. 10]*

The women also based their judgments on what they may have observed in relatives or friends.

*"I had seen women with breast disease some their breast became very huge they used herbal medicine at home and for the majority it resolved" [Int. 10]*

Nine of the women had been exposed to breast cancer messages via media (television, radio, posters) or in their local church/social groups either before or after the identification of their breast symptom. This also served as another source of

information for them to appraise their symptom. Their accounts of the messages they had heard suggested they had learnt general lessons like performing routine examinations of their breasts and reporting to the hospital if they found a lump in their breast. They had also learnt that a breast lump could be cancer and would need to be examined at the hospital for diagnosis. However, this information was not used in their appraisal processes. Int. 3 at one point agreed with her husband who attributed her breast shrinkage associated with the lump to having slept on the breast. Furthermore, because these messages were point in time events, the women could not have access to them at the time of symptom appraisal. For example, Int. 4 had noticed her breast symptom 2 months before she heard about breast cancer in a community education programme and decided to visit the hospital. For Int. 9, noticing a lump towards the armpit but not directly in the breast, the absence of pain and the fact that the symptom identified did not worry her i.e. negatively affect her daily functioning, made her think this was not something that needed to be reported to the hospital.

*“I hear always about breast diseases....as for the breast I did not really see anything in it, it was my armpit that I noticed something” [Int. 9]*

*“Our pastor’s wife is a nurse and taught us periodically to examine our breast. She said breast can develop cancer so you must take the right steps else you can die. I had heard this on radio and TV too. I had heard about breast disease so even though it was not paining me I had to do something about it.....but it was not worrying me and we had entered the Christmas season too so I wanted to work small” [Int. 12]*

The women's account of the campaign messages they had heard did not include information of what other signs or symptoms could be present or absent in addition to a breast lump and yet would be suggestive of breast cancer. It also did not include information on how different or similar breast cancer symptoms could be to what they commonly or traditionally knew breast swellings and lumps to be, and how they evolved. Images of breast cancer that Int. 10 saw were huge swollen breasts, while she had noticed only a small lump in her breast. Int. 13 was exposed to breast cancer messages in the first private hospital she visited when her breast swelling was not resolving in spite of applying herbal preparations. The information focused on death if one refused surgery to cut off the breast and abandonment by family and friends when offensive ulcers developed. She found this threatening and scary and this deterred her from seeking help in that health care facility. In the end, these women's appraisal of the symptom was not different from those who had not been exposed to breast cancer messages (6 women).

Ultimately, all the women lived in a state of awareness of changes in their breast and observed progression of the changes.

*"The lump is still in it and sometimes you feel it has become heavy and later I even saw some fluid coming out of the tip like some oily stuff" [Int. 3]*

*"As time went by the breast started becoming hard" [Int. 9].*

Their inability to appreciate the seriousness of what was going on with them was further expressed in their non-disclosure of the breast changes they had identified to a physician in spite of regular contact for other medical conditions.

*“It has been swollen for over a year, I did not do anything about it....I was seeing the doctor monthly for my hypertension medication” [Int. 6]*

Ultimately, the women were ignorant of the implication of what they were experiencing.

## **2. Deciding to seek medical help (“the tipping point”)**

Eventually, there came a time when the women decided to seek help from the hospital. This decision was triggered for all the women by observed progression of the change they had initially observed. The progression was commonly characterised by an increase in size of the swelling, associated pain, ulceration of the breast or a combination of all.

*“So later I realised I had lost one part of my nipple and my breast was not as it was before. I don’t know what has happened for it to grow so big, it is about to do me some harm, the way things are going this is a matter for the doctor and I realised if I don’t come here it will worry me” [Int. 2].*

Sometimes the progression was such that it had affected their quality of life as well, for example pain of severity that deprived them of sleep and the ability to do anything.

*“I see that the illness keeps getting worse, it is growing bigger and now my neck is also hurting so bad I just sit till morning comes so I decided to go and see the doctor” [Int. 4].*

At this “tipping point” some of the women observed that the breast lump/swelling had not resolved as they had expected, i.e. burst like a boil or melt. Rather, it would have

“burst” and progressed to ulceration without a discharge of pus. Such moments were characterised by a sense of helplessness and loss of confidence in personal efforts made at treatment. Such times were also characterised by worry about what type of breast condition they had (that looked unlike what they knew) and the implications of it, and regret for not having considered their symptom as something needing medical attention earlier.

*“I think if I had gone to the hospital right from the beginning I will not be facing these problems now....if I had not listened to what others said and had come early the lump will not be this big” [Int. 3].*

The activity of appraising the symptom was a process that occurred continually along the path to getting to the Komfo Anokye Teaching Hospital breast clinic (KATHbc).

### **3. The help seeking journey**

Table 6 (page 77) presents the simplified journey points for each of the women interviewed till they arrived at the KATHbc. The shortest course of the journey was one point of call before arriving at KATHbc (Int. 6 and 15) and the longest was 5 points of call before arriving at KATHbc (Int. 2 and 10). At each point of call, there could be several visits before onward referral to the next. Those who sought help initially from a public hospital had a shorter course than those who first resorted to herbal or local preparation for treatment.

The help seeking journey occurred on three levels. These were

- Self-care
- Social help

- Medical help

These activities occurred consecutively or concurrently along the help seeking journey.

Central to all three was the activity of disclosure. The activities of disclosure, self-care, social help and medical help are described below.

Table 6 Health care facility journey points for study participants to Komfo Anokye Teaching Hospital breast clinic (KATHbc)

ID	FIRST SIGN	POINT 1/Time to Point 1	POINT 2/Time to Point 2	POINT 3/Time to Point 3	POINT 4/Time to Point 4	POINT 5/Time to Point 5	POINT 6/Time to Point 6
Int 1	Breast swelling	Herbal preparation: <b>Soon after</b>	Private hospital A: <b>3 months</b>	Community hospital: <b>6 months</b>	<b>KATHbc: 6 months</b>		
Int 2	Lump	LPTC: <b>Not specified</b>	District Hospital: <b>15 months</b>	District Hospital: <b>18 months</b>	Tradionalist/Spiritu alist: <b>not specified</b>	District Hospital: <b>21 months</b>	<b>KATHbc: &gt; 24 months</b>
Int 3	Lump	Nurse: <b>1 month</b>	Private hospital A: <b>3 months</b>	District hospital: <b>4 months</b>	LPTC: <b>not specified</b>	District hospital: <b>9 months</b>	<b>KATHbc: 9 months</b>
Int 4	Lump	LPTC: <b>Soon after</b>	District Hospital: <b>2 months</b>	Private hospital A: <b>3 months</b>	<b>KATHbc: 8 months</b>		
Int 5	Lump	LPTC: <b>Soon after</b>	<b>KATHbc: 4 months</b>	District Hospital: <b>5 months</b>	<b>KATHbc: 9 months</b>		
Int 6	Pain	District Hospital: <b>12 months</b>	<b>KATHbc: 12 months</b>				
Int 7	Lump	District Hospital: <b>2 weeks</b>	Regional Hospital: <b>3 weeks</b>	<b>KATHbc: 23 months</b>			
Int 8	Breast swelling	LPTC: <b>Soon after</b>	Private hospital A: <b>2 weeks</b>	<b>KATHbc: 4 months</b>			
Int 9	Swelling	Regional Hospital: <b>3month</b>	<b>KATHbc: 8 months</b>				
Int 10	Lump	Herbal preparation: <b>Soon after</b>	Community hospital: <b>2 months</b>	Herbal preparation: <b>not specified</b>	Regional hospital: <b>6 months</b>	<b>KATHbc: 6 months</b>	
Int 11	Lump	Private hospital A: <b>1 week</b>	<b>KATHbc: 6 months</b>				
Int 12	Lump	District Hospital: <b>2 months</b>	Regional Hospital: <b>7 months</b>	Herbal preparation: <b>not specified</b>	Regional hospital: <b>11 months</b>	<b>KATHbc: 12 months</b>	
Int 13	Breast swelling	Herbal preparation: <b>Soon after</b>	Private hospital A: <b>2 months</b>	Herbal preparation: <b>not specified</b>	Private hospital B: <b>not specified</b>	<b>KATHbc: 12 months</b>	
Int 14	Lump	District hospital: <b>1 week</b>	Regional hospital: <b>2 weeks</b>	<b>KATHbc: 5 months</b>			
Int 15	Pain	District Hospital: <b>&gt;12 months</b>	<b>KATHbc: &gt;15 months</b>				

### **3a. Disclosure**

The women talked to their husbands, children, parents, siblings, family members, friends, pastors/spiritual leaders, and neighbours about their breast illness. Disclosure was however always for a specific reason or need. Thus, it was to the person perceived to be able to meet the need. As such it occurred at different times along the help seeking process when that need arose. The main times at which it occurred were when there was disease progression and the need for financial help. But sometimes, disclosure was also to help understand their illness, get prayer support, physical help or decide on a local remedy to use. Beyond these, disclosure was sometimes only an act of social courtesy. In such cases it was only to very close relations who may ask about their absence from social engagements or because they were considered as people who needed to know. Besides this, the women did not discuss their illness openly. They would not disclose their illness to anyone who they perceived as potentially having no help or treatment to offer, even if he/she was a close relative or a health care worker

*“I didn’t show it to the other doctor because he attends to the hypertension only” [Int. 6]*

Also, some of the women felt people would gossip about them or pass comments that will alarm them. There was also fear that a person who probably wished them evil will use their vulnerability as an opportunity to attack them spiritually when they talked about their illness to them.

*“Some people wish evil for you so you tell them about your illness and they get you through that” Int. 7]*



There was also concern about being seen as broadcasting one's illness to evoke sympathy and get money.

### **3b. Self-care**

The help seeking journey invariably began with some attempts at self-care. The self-care activities included one, self-medication with locally prepared topical creams (LPTC) or herbal preparations and two, spiritual care. This was an attitude that was already a part of the lives of these women and was driven by the nature of the condition. Conditions considered to be within personal control were treated by self-medication with local drug preparations or orthodox drugs bought over the counter. Hospital treatment was sought only when an inference of illness was made. Illness was inferred when a condition failed to resolve with self-medication or was associated with the inability to perform routine daily tasks or business activities. For example, in spite of recounting previous episodes of febrile illness which were treated with over the counter medications, some of the women maintained that they had never been sick and were very healthy individuals because they were always able to go about their normal business and activities even during those times.

#### **3b(i). Self-care: locally prepared topical creams/herbal preparations**

Self-medication was usually initiated just after identifying the breast symptom. Sometimes there was an initial period of 'doing nothing' about the lump until the time it was seen to have worsened, and then it was initiated. Locally prepared topical creams (LPTC) or herbal preparations that were applied to swellings or lumps as was the practice in their communities were used. The choice of these was based on common knowledge, hearsay or suggestion from someone known in the community to have knowledge of treatment of such conditions, either because they had a

personal experience of it or were selling it themselves. One locally prepared cream (maame dagomba) was what the women commonly applied to their breast. This cream was acclaimed to have the ability to 'melt' lumps

*“Initially it wasn't big and I thought it won't worry me. That time I was applying maame dagomba that maybe it will melt it away” [Int. 5]*

Herbal preparation use was by Int. 10 and Int. 12 who had it offered and recommended by some family and friends respectively; and Int. 13 who lived in the same house with a gentleman who sold them. To be offered such advice and subsequent compliance was considered a normal attitude to medical problems.

*“When I first saw the lump I told a gentleman in my house who has herbal medicine for these kind of things to make them burst or resolve spontaneously and took some from him to apply” [Int. 13]*

The other women did not use herbal preparations although some had had it offered to them by close friends. The reasons given for this included the risk of being deceived into paying money for a preparation that did not offer any cure and how some of the herbal preparation rather than offering some benefit rather resulted in more problems

*“A lot of the herbal preparations are not good, they cause problems” [Int. 8]*

Int. 14 for instance felt that the kind of breast disease she had was not the type to be treated with herbal preparations because it looked different from those she had seen in lactating mothers whose condition had resolved with herbal application.

Int. 12 and Int. 13 interrupted the medical care process and resorted to self-medication instead. Such situations occurred if the medical care at that time was not yielding the anticipated results. Int. 12 also felt self-medication could influence the medical care outcomes in some way

*“I felt if I used the herbal preparation there will be no issue of operation as they had said before and it will go away”[Int. 12]*

Self-medication always lasted for just a particular period during the help seeking journey. The women eventually abandoned it once they were not seeing the expected results. They would have come to the conclusion that what they were using was not the cure because of the ongoing progression of the breast problem

*“As for medicine when you use it and it is good for you, you will see it, but this one that causes me more pain so much that I cannot sleep it will bring me more problems so I cannot use it anymore” [Int. 1]*

### **3b(ii). Self-care: spiritual care**

The self-care actions also included spiritual or religious activities. Spiritual support, mainly in the form of going for prayers, was sought to complement other efforts at seeking help. Unlike the acts of self-medication that occurred at a particular time along the journey, the women who went for prayers did so alongside the rest of the help seeking process. They sought to be prayed for so that every effort made to get well will be successful through the mercies and grace of God. They prayed to overcome any possible influence of evil forces on their illness e.g. death

*“After the pastor came to pray he said they wanted to kill me but now nothing will happen again so I should go to the hospital” [Int. 10]*

Int. 2 went to see a spiritualist to be sure that her illness did not have the evil influence of anyone who hated her.

As religious people, some of the women felt that seeking spiritual support through prayer was a normal thing to do when faced with any adversity. They did not consider their breast condition to be a curse. Rather, they believed that a spiritual influence could be superimposed on or associated with what had already developed in their breast. Such spiritual influence could be the result of people wishing them evil because they did not like them, or arise from the very nature of this world where God existed for good things and Satan for bad things. Such beliefs were reinforced when symptoms worsened in spite of the self-medication practices, if a religious leader had suggested it, or having a previous experience of another illness that was believed to have been due to a spiritual attack.

*“The medicine I applied did not work because there was something behind all this...I went to some place and the pastor mentioned my mother’s name and that of her sibling and said if I crash the bottle of oil he gave me they will say some things and truly the next day they were saying to each other ‘you are the witch who caused her breast to be swollen’” [Int. 10]*

In all instances where a religious leader was consulted, they encouraged the women to seek help from the hospital without delay. For example the traditional healer Int. 2

consulted insisted she report to the hospital immediately because there was nothing spiritual about her breast illness.

*“I went to see her about a lot of things including my breast. She said there was no one behind it, she asked to see my breast and she was very very troubled by it. She asked me to go and see the doctor with it and would not even address the other issues I had gone to see her about”*  
*[Int. 2]*

Also, they offered prayers for the women to get the courage to undergo whatever treatment they received from the hospital

*“Going for prayers did not prevent me from coming to the hospital, rather now I feel as I come whatever God will do whether they will cut my breast or remove all of it I will agree”* [Int. 14]

Int. 12 believed that the prayers with her church pastor had given her the courage to return to the hospital and face any treatment offered, even if it included surgery.

Some of the women did not consult any religious leader. This is because they did not believe there was any spiritual connotation to their condition. Some feared having to pay huge sums of money to pastors to be prayed for and this was money they could rather use to get help from the hospital. The pastors consulted by the other women tended to be in the church they already attended and they paid no money to see them.

### **3c. Social help**

To be able to seek help from the health system, the women had to mobilise financial, social, and sometimes material support to enable them do so. The magnitude of this task required some work to be done by the women within their social network systems.

The income the women earned from their jobs was barely enough to take care of their daily needs and fend for their children. Finding enough money to cover the costs of seeking treatment was a great concern to the women. They anticipated needing to spend a lot of money on things such as diagnostic investigations and drugs in the hospital. They worried about such amounts not being readily available, as well as the challenge of raising what money was needed. Int. 3, Int. 11 and Int. 12 had total financial support from their husbands who were employed as a farmer, an accountant and a teacher respectively. The other women relied on family members for financial support. These were predominantly their children who lived either with them or far away in other cities. They would send the money over when it was needed. Some women also got financial support from a sibling or a parent. The request for money was made in person or through a phone call to the person perceived as having the ability to provide it. Some of the women had to travel to the place where the relative resided, which was sometimes in a different city. Consequently, when they went to the hospital was subject to when the money was made available

*“I was waiting for my son to send me money so I could come here... .....if my children did not get the money I will stop because I can't go to someone else's child for money” [Int. 7]*

This is because the family members from whom help was being sought were often not in stable employment or had their own problems such as illness to deal with.

*“My brother who was giving me money is now very sick and in a prayer camp so it is another brother abroad who we called and he said he will send money [Int. 1]*

Having previously received a lot of financial support from her sister discouraged Int. 9 from asking for money from her again to go to the hospital. She felt that was asking for too much. For some of the women, the one providing the money influenced the health facility from which treatment would be sought. In all cases, the funder was willing to pay for the treatment or investigations requested. Int. 2 who delayed the longest did not have a friend or relative to approach for financial support and relied on her earnings

*“Even if you go cry to someone it’s not as though they will give you something” [Int. 2]*

For some of the women, they did not have enough money due to other issues that arose at/after the time of noticing the breast illness. For example the need to pay their children’s school fees (some of the women had children in secondary or tertiary institutions), or treat a concurrent illness.

*“Recently too I had gone to pay school fees for two of my children so the money on me if I came was not enough” [Int. 15]*

Under such situations, the women ordered their activities based on their priorities. These priorities also affected the timing to seek help. Int. 5 developed a medical

problem on her leg some time after identifying her breast illness and feared the leg problem will worry her more and so pursued the treatment of that first.

*“You see by the time I was discharged about my leg problem, I had no money on me that is why it took me so long” [Int. 5]*

Prioritisation also sometimes arose because there were other family or social obligations to take care of. For example Int. 3 detected her breast symptom at a time she was caring for her second child who was sick (she had already lost her first child at age 1 to a febrile illness) and Int. 12 had to go to the hospital around the Christmas season which was a time her business demand as a seamstress was high and she could make more money.

*“The child’s illness was more serious and so I had to take care of him first before, I didn’t consider mine as that serious [Int. 3]*

Beyond money, the women had to get other help to enable them go to the hospital. These included someone to accompany them to the hospital because they felt ill or they needed someone to attend to them in case they were admitted to the hospital and run errands in the hospital on their behalf. Some of the women also had to move out of their homes to live with a relative closer to the hospital to enable them reach the hospital with less difficulty in their sick state, or to have them take care of their children while they went to the hospital.



### **3d. Medical help**

A summary of the health care facility journey points for the women is presented in Table 6 (page 77). Table 6 also shows the time it took to reach various health facilities after discovery of their breast symptom. The women initially accessed public or private health care facilities before ultimately reporting to KATH breast clinic. Seeking medical help first involved making a choice of where to go. Subsequently, the health system characteristics, together with their expectations and outcomes, invariably affected how the help seeking journey turned out.

#### **3d(i). Choosing where they go**

At the point of deciding which health facility to visit, proximity/easy accessibility to where the women lived influenced where to go. Thus, they visited the community or district hospital in their area. Some women took advantage of being in the hospital for another reason to report their breast symptoms. For example, Int. 15 reported her breast pain to the doctor and Int. 3 to a nurse while taking care of their children on admission in the hospital. Also, being in a place with familiar health personnel was preferred.

*“I had been to district hospital several times and the doctor who saw me there had left so I went to my hometown, there is a hospital close by where we stay and my mother and I know the doctor so if I go there he will help me” [Int. 3]*

None of the women visited KATH breast clinic as the first health facility in their journey. None of them knew that there was a breast care clinic in KATH. Int. 3 for instance believed KATH was not a hospital one could just walk into unless she had a referral.

The women presenting to the public health facilities came to KATH breast clinic as a result of being referred from the district or regional hospital previously visited. The referral to KATH evoked some concerns. There were concerns about the financial implications of being attended to in KATH. At the district or regional hospital from which they were referred, the women spent money on various investigations related to their breast illness. For example, some of the women had to raise as much as GHs 400 (£111.00) to have breast biopsy done. Sometimes, these investigations, e.g. a mammogram had to be done in another town away from where the district or regional hospital was.

*“Like the place they ask us to put our breast down to take images, that is expensive and the labs too some are expensive” [Int. 5]*

The women who had been to the private hospital spent more money on buying medicines at each hospital visit. Thus, there was anxiety about needing to spend more in a bigger hospital, and they felt they did not actually have the money either. This situation was a significant reason for some of the women delaying to come to KATH.

*“Well I wanted to come but the money issues, **the money issues**” [Int. 2]*

*“If there was money my breast will not have become like this” [Int. 5]*

The distance from their homes to KATH was also a source of concern. For some of the women, the long travel times meant they had to travel into town the day before, or on the dawn of the intended day of visiting the KATH breast clinic. This inconvenience was more worrying if they had no relative to host them. Others felt too ill to travel by

public transport and had to bear the cost of travelling in a chartered taxi. They were also anxious about the size and complexity of navigating one's way in a big unknown hospital.

The women who visited the private facility did so based mainly on the recommendation of friends, a health care professional or having heard about them from a breast screening program by the private hospital in the community they lived in. Int. 1 went there because her brother, who was providing the money for her to be taken to the hospital, asked that she be taken there. All the women seen in the private hospital eventually self-referred to KATHbc after having spent at least 3 months there. They did not express concerns about cost of care; some of them had spent up to GHs 400 (£111) per visit to the facility. All of them self-referred because they were worried about the deterioration of their health. Int. 3 stopped going there after her first visit because she became very ill after receiving treatment there and was discouraged from returning to the place

*“Others too were saying that when you go to that hospital you usually face a lot of troubles, some of those who had been there said it” [Int. 3]*

In the end, the concerns about coming to KATH did not prevent any of the women from pursuing treatment there. They all felt the referral was inevitable because KATH was the ultimate health facility to visit if one was unwell.

*“They say however bad a situation is it is to this place that it will come, if you roam in all the hospitals it is still to this place that you will come” [Int. 8]*

At this time, they perceived their condition to be life threatening. There was a sense of desperation and their priority was to get well irrespective of the cost.

*“I am pursuing this because of the children, if I die they will become miserable” [Int. 9]*

*“Well if you want good for yourself you must spend money” [Int. 7]*

*“I was not bothered about coming here because I want my good health back” [Int. 3]*

*“The distance is far but if it will help me then there is no problem” [Int. 12]*

### **3d(ii). The health system: characteristics, expectations and outcomes**

In general, the women had no or very little understanding of their breast illness and what the process of getting diagnosis and treatment during the care seeking process involved. The women’s accounts of the health facility visits suggest a lack of information and understanding of their breast problem, or what was being done for them. Many of them seen in the public hospitals had undergone investigations involving their breast but had no idea what the results meant. The women seen in the private hospital had breast biopsies but did not know the results. Even when they asked questions about what was going on, they were not answered satisfactorily. Communication in the health facilities were usually instructions without explanations.

*“After the scan they did not tell me anything they just said I should take it to regional hospital” [Int. 4]*

The women had to make sense of the processes they were going through in the hospital themselves. This sometimes led to wrong judgments that contributed to their delay. For example, Int. 7 did not understand why she had to do a breast biopsy for a third time and believed the procedure was what was causing the lump in her breast to grow bigger. As a result she left the hospital and didn't return until almost one and a half years later.

*“The way of piercing the breast I had not seen that or heard that before, I did not understand it and I was not happy, I was scared that is why I did not go back” [Int. 7]*

Even at the time of referrals to another hospital, no information was given on the specific reason for referral or any guidance on what to expect. Where some information was given, the content was inadequate or disturbing.

*“You say you don't have medications and yet you tell me if I go and they want to cut it let them cut it” [Int. 2]*

Their expectation from the facilities they initially visited was to be given medications to resolve the breast symptom they had presented with. For those women seen in the private hospital, this expectation was met. However, they noticed worsening of their symptoms in spite of the medications. There was still a lack of information under these circumstances that caused some of the women to feel frustrated and helpless.

*“I keep going there for medications because they are the ones taking care of me though she has not given me the results I just can't stay home*

*I must go and show myself to them, when I go too they don't say anything what can I say" [Int. 8]*

Although it took at least 4 months to get to KATH, 10 of the women were first seen in a health care facility in 3 or less months after discovering their breast symptom (see Table 6; page 77). In spite of reporting early to a health facility, it took at least 4 months to present to KATH. This lapse in time had been spent in the private hospital or navigating the referral process of the public health system, that is district hospital to regional hospital to KATH. Sometimes, the women would have been to the district hospital on multiple occasions before the decision to refer was taken.

*"Each time I went they gave me medicine and on the 4<sup>th</sup> visit they admitted me and when I was discharged I was asked to come here" [Int. 15]*

At some of these repeated visits, an appointment could be missed because of industrial actions at the health facility. Int. 5 who initially reported to KATH did not continue to seek care there at her next visit for this reason.

The delay was further exacerbated where investigations were being done along the referral path. This is because the women sometimes had to mobilise money for the procedure, and after it had been done, wait several weeks for the results for the doctor to see before referral.

*"By the time we got to the regional hospital, all our money was finished so the doctor asked us to go back home and mobilise some money for the tests. We came back with the money after about a week and did the*

*test but then they said the results will be ready in about two weeks” [Int. 14].*

Although most of the women had been registered on the national health insurance which is expected to cover the cost of care of breast related illnesses, the insurance did not pay for the cost of diagnostic investigations they undertook, or the medications prescribed for them.

Many of the women did not know about the existence of a breast clinic in KATH. None of the women knew that they could report directly to this clinic without a referral. Int. 14 for instance was disappointed she was not referred directly to KATH when she first presented at her district hospital. She would have preferred to come directly to KATH breast clinic if she had been informed about the place at her district hospital and not waste time on the multiple visits to the regional hospital where she received no definitive treatment. Ultimately, being seen in a district, regional or private hospital did not appear to facilitate the final arrival at KATH breast clinic for treatment. Besides, they could have reported to KATH breast clinic directly without having to go through this route.

### **The total experience**

The entire health seeking process was characterised by many levels of decision making. The resources available for making these decisions existed in the knowledge base of the woman and others around them (family, neighbours, media), cultural, social, financial and health system factors.

The decision making began with deciding whether the identified breast symptom warranted seeking help; then deciding what kind of help to seek (medical or

traditional); then deciding what material/social help was needed to achieve this and from whom it should be sought. The ability/capacity to manage these resources and use them to make these decisions, and when the decisions were made, within the constraints of their existing circumstances, influenced the health seeking process. Also, their ability to work through their challenges – such as issues around knowledge, social, cultural, financial, health system factors - influenced the timing of their decision making. The women came to a point in the health seeking process where the significance of all the challenges seemed to fade away. At this point, they clearly perceived a threat to their lives, and the need to regain their health was of prime importance. It was important to them that they maintained their functionality at all cost. There was some determination to do whatever it would take to seek help. The women believed they were taking the right steps at the right times that would lead to getting treatment and even cure of their breast disease. If the women could come to this resolution to seek medical help at any cost at a point in the course of their illness, then, there is the possibility of being able to come to this resolve much earlier in the help seeking journey if they had perceived/understood the threat to life earlier. Instead, for some of them, decision making seemed to be relegated, or not within their full control. For example, Int. 8 complied with the decision of her sons even though it was against what she would have otherwise wanted. Moreover, she had the financial means to pursue her choice, but she felt she had to consider her sons' advice out of respect. She felt they were no longer children and could be right. However, if things did not work out well, they would have at least known that she listened to them.



*“I complied with their decision because maybe something happens like money issues come up they will say but we told you and you did not mind us but if I follow their advice and it does not go well they know they said it and it did not go well, like now my son is the one who called and said we should come here. Because left to me alone I would not have gone to the private hospital...I am paying for my own care, I won't keep my money at home and die” [Int. 8]*

This situation seemed to arise from respect for family members who also tended to be males (Sons, brothers, and husbands). Coincidentally, for the other women, the men almost always provided the money to enable them to seek care. Even when a decision had been taken without them, they were informed about it before it was carried out, sometimes as if to obtain some permission.

*“My husband is even the one who let me go to the doctor in our place for a referral to the regional hospital... He said I should come here anytime the children sent me money” [Int. 7]*

This was perceived as culturally appropriate, especially because if anything went wrong later, they were the same family who the women would need to call upon for assistance.

The accounts of the women suggested a resigned attitude to their experiences. Some of the women were of the opinion that they were doing the right thing by going to the hospital at the time they did. Some of the women believed that the time of deciding to seek medical help was right because that was when they perceived a threat to their

life. However, some of them also reflected on how the symptom had progressed and felt that with the benefit of hindsight, they should have sought help earlier. There was a sense of justification for the help seeking actions taken before, as if to suggest 'what I was doing before, under those circumstances, was the right thing to do then'. For example, Int. 1 first reported to the hospital about 3 months after noticing her breast swelling because that was when she had developed unbearable pain. Subsequently, she came to KATH after she had collapsed at home and the doctor in her community clinic referred her. Similarly, Int. 15 expressed no concern about the 12 month lag time between when she started experiencing breast pain and when she first reported to the doctor in her district hospital. In fact, she considered reporting to KATHbc within 2 days of being referred as a right action.

*“Well the time I felt the pain I did not delay I went to the hospital and on the fourth visit they gave me a referral to come here. They gave me the referral on Tuesday, only Wednesday passed and I travelled here on Thursday. I am okay with how things have gone” [Int. 15]*

Although they were aware of what was going on with them physically, as well as with the health system, they appeared ignorant of its implications on their health in the long term and even their survival. The women did not mention making extra effort to get information about what was wrong with them from the health professionals they had encountered. There was a sense of acceptance that that is how things are expected to be. Furthermore, the women appeared not to question authority, that is, the health professionals.

*“Over there they just gave me medicine and said I should come here.....no no no no I did not ask them anything after all everyone works differently, it is what is expected that he has done for me” [Int. 7]*

They believed the health workers knew what was best, and as lay people they could not question the expert. This disposition probably resulted from the cultural tendency to do as was told, respect authority and not question it. Moreover, being of lower educational standing probably made these women feel inadequate to question someone known to be an expert.

## **Summary**

The help seeking process for the breast symptoms involved various physical, emotional and social activities performed at different times and culminating in their arrival at Komfo Anokye Teaching Hospital breast clinic (KATHbc) for care. It began when symptoms were identified as a result of discomfort or pain felt in the breast or through breast self-examination. The symptoms were interpreted as not serious because there were no associated signs like severe pain or incapacitation. The women actively monitored their symptoms, expecting resolution based on common knowledge about breast illness or from past personal or observed experiences about breast illness. Eventually, the observed progression of their breast symptom/s, usually associated with incapacitation or effects on daily functioning triggered medical care seeking.

The health seeking journey occurred at three levels, that is, self-care, social help and medical help. At each level, disclosure of illness was purely on a need to know basis to solicit mainly financial help but also sometimes physical help, prayer support or just as a matter of social courtesy. Self-care initiatives were undertaken because the women

at that time had some sense of control over the illness. It involved self-medication with locally prepared topical creams or herbal medication as well as spiritual or religious activities. Social help mainly involved getting financial support. The availability of money greatly influenced their timing of seeking medical help, especially when other obligations with financial implications like child care, other health matters or work related issues came up. This led to prioritisation of what actions to take, sometimes with the relegation of medical care seeking to a later time. At the time of deciding where to seek help, proximity/easy accessibility influenced the first point of call. Other times, there was opportunistic reporting of breast symptoms while seeking care for other health problems. The women made several visits to one health facility or visited others before ultimately reporting to KATHbc. The health seeking path was characterised by a lack of information, which influenced the women's compliance to undergoing requested investigations and keeping to subsequent appointments.

The entire health seeking process was characterised by many levels of decision making. Ultimately, the capacity of the woman to make these decisions and when she made them influenced the course and timing of the health seeking process. The determination to overcome all perceived barriers to accessing care was heightened especially when the women began to feel their life was potentially threatened by the progression of their symptom. At this point they were prepared to do whatever it will take to access care at KATHbc. However, their prevailing socioeconomic status made their reliance on support (especially financial) from other family and friends an inevitable influence on the timing for seeking care.

## **CHAPTER SIX**

### **DISCUSSION**

This qualitative study was conducted to explore the factors that influence delayed health seeking behaviour of women with breast disease clinically suggestive of breast cancer presenting to the Komfo Anokye Teaching Hospital breast clinic (KATHbc) in Kumasi, Ghana. From the literature review conducted for this study and a recent systematic review published on the subject (Donkor et al., 2016), it seems that this may be the first qualitative study exploring why women delay in seeking help for breast cancer symptoms from both a theoretical and philosophical perspective in Africa. It seems also this is the first time the Andersen Behavioural model for health care utilisation (Ronald Andersen et al., 2013) has been applied using qualitative methods to study delayed health seeking behaviour among women with breast cancer symptoms. The philosophical approach to the study was critical realism. Two qualitative studies carried out previously in the Oncology department of Komfo Anokye Teaching Hospital had been merely descriptive (Asoogo & Duma, 2015) or with some application of the theory of planned behaviour (Agbokey, 2014).

The discussion chapter begins with a comparison of my study results with those found in the literature review and subsequently, discussion based on the theoretical and philosophical background for the study.

#### **The study participants**

The participants for my study were women with clinically suspected stage III or IV breast cancer. They presented to KATH breast clinic 4 or more months after identifying their breast symptom. These women were purposively selected because at this stage

of breast disease, they would have observed overt and progressive changes in their breast and yet would be presenting at KATHbc after a lag time of 3 months, notwithstanding the fact that they may have been to other clinics/hospitals before arriving at KATHbc. Also a delay of 3 or more months before seeking treatment has been associated with advanced stage at diagnosis (Arndt et al., 2002; Burgess et al., 2006) and poor prognosis (Richards et al., 1999) of breast cancer. Their experience could provide further understanding to why women delay in seeking help in spite of their experience or observation of deteriorating health. Similar qualitative studies to understand delay in health seeking for breast cancer among women in Indonesia (Iskandarsyah et al., 2014), Malaysia (Norsa'adah et al., 2012; Taib et al., 2011) and Iran (Rastad et al., 2012) have included women presenting with advanced disease, but none has focused solely on stage III and IV disease. Asoogo and Duma (2015) studied women with stage II and III disease while Agbokey (2014) studied breast cancer patients irrespective of the disease stage, including their caregivers, health workers and herbalists. Neither study considered the time duration from symptom identification until first presentation at KATHbc and subsequently to the KATH oncology department where their study participants were recruited. As such, their findings cannot exclude institutional related factors arising between KATHbc and the KATH oncology department that may have contributed to the advanced stage of presentation to the oncology department. My study however focuses on delayed presentation with regards to time of symptom identification until first presentation at the breast clinic in KATH to look at the factors at play outside KATH.

The demographic features of the women in my study are similar to those of women in other studies who were purposively selected. The youngest participant in my study was 24 years old (Int. 10, Stage III) and the oldest was 79 years (Int. 6, Stage III). This age range is comparable to breast cancer patients previously studied in KATH (25 – 67 years) (Asoogo & Duma, 2015), as well as to that of Iranian (26 – 71 years) (Khakbazan et al., 2014a), Malaysian (26 – 67 years) (Norsa'adah et al., 2012) and Chinese (20 – 81 years) (Lam et al., 2008) breast cancer patients. However, in the studies by Khakbazan et al (2014a) and Lam et al (2008), some of the women had benign breast diseases although they had delayed in seeking healthcare.

Ten of the fifteen participants (66%) in my study were married, 3 were divorced and 2 widowed. Secondary education was the highest educational level of the women (8 of 15) studied in my research. Although there were no women in my study with higher educational backgrounds, other studies have reported delayed care seeking in women of diverse educational backgrounds. Some of the breast cancer patients studied by Asoogo and Duma (2015) and Agbokey (2014) in KATH and Clegg-Lampsey et al (2009) in Accra, Ghana had tertiary level education. Among Iranian women who delayed and presented with advanced breast cancer, 50% of them had at least secondary education or higher (Rastad et al., 2012). Also, in a study in Nigeria where 60% of the breast cancer patients had at least secondary education or higher, including postgraduate qualification, 45.3% of the patients delayed seeking care 3 months or more (Ezeome, 2010). Interestingly, Ruddy et al (2014) assert that educational background does not influence help seeking.

The distribution of the participants in my study in terms of place of residence was similar in proportion. Four of the women lived in a rural area, while 5 and 6 lived in semi-urban and urban areas respectively. A Malaysian study involved 19 women all of whom lived in an urban setting (Taib et al., 2014) while in an Egyptian study of a larger population of 163 women, two-thirds of the women who delayed lived rurally. Here again, this mixed picture does not offer convincing support for the influence of place of residence on delayed health seeking.

Irrespective of their place of residence, none of the women interviewed in my study were economically independent. Those who were employed earned barely enough to cater for their daily needs. All the women relied on other family members for financial support to supplement what they earned. Although Ezeome et al (2010) did not describe their criteria for socioeconomic status stratification in their study in Nigeria, they report 58.8% of their study participants belonged to the lower socioeconomic class and 1.2% in the high socioeconomic class. In a study in Pakistan by Talpur et al (2011), about 70% of the women who delayed had annual household incomes less than \$500 (£382.45) and were considered to be in the lower socioeconomic group. In comparison, the highest yearly income of the women in my study was £107 - £125, placing them in the low socioeconomic group with none in the middle or high socioeconomic group. Poverty has been cited as a major influence in delayed help seeking among breast cancer patients especially in developing countries (Sharma et al., 2012). Poverty reflects on access to public health insurance, inability to afford quality care in private hospitals and inability to cater for basic family needs (Unger-Saldaña & Infante-Castañeda, 2011). In my study some of the women cited the lack of



money as the reason why they delayed. However, others did not consider lack of money as the reason for their delayed health seeking because although as individuals they earned very little, they had ready financial support from family members to seek help. In both situations, when the women had decided they needed and wanted to access medical help, they mobilised the money, however challenging this was, from around them. From their study in KATH, Asoogo and Duma (2015) report some women saved money over time to seek medical help. Indeed, although in lower proportions, women of middle and high socioeconomic status (Talpur et al., 2011; Unger-Saldaña & Infante-Castañeda, 2011) and high family income (Poum et al., 2014) have delayed seeking help for reasons such as un-readiness to confront a cancer diagnosis (Unger-Saldaña & Infante-Castañeda, 2011). It appears then, that, although financial status is very important in health seeking behaviour, it may not be just mere financial capability that ensures accessing health care.

The variability of how these socioeconomic factors influence health seeking behaviour suggests that it may not be the factors themselves, but that they are exerted through other mechanisms. For instance, how an individual utilises these factors creates the ability to seek help. Scambler (2001) suggests that a woman's command or management of factors related to economic productivity present her with a form of capital that creates enabling or restraining conditions that contribute to, though not necessarily determine, her access to care. The findings from my study suggest that the pain and distress women experience as a result of worsening symptoms was a strong force in driving a woman to overcome the challenges of seeking care. The presence,

or absence of this distress resulting from worsening symptoms, is the underlying mechanism that moderates how the women utilise the capital they have to seek help.

### **Delay time**

A previous survey of breast cancer patients in KATH reported symptom duration of 1 – 82 months before presentation (Ohene-Yeboah & Adjei, 2012). In comparison, the women in my study had discovered their symptoms between 4 - >24 months before presenting to KATHbc. Studies conducted in Ethiopia (Dye et al., 2012), Egypt (Mousa et al., 2011) and Kenya (Otieno et al., 2010) reported delay as more than three months, making comparison difficult. Delay time among Nigerian women studied by Ibrahim and Oludara (2012) was longer than in my study, ranging from 1 – 96 months. Delay time of 4 – 36.5 months, similar to findings in my study was reported from qualitative studies in Malaysia (Taib et al., 2014) and Mexico (Unger-Saldaña & Infante-Castañeda, 2011).

### **Delayed health seeking**

The factors that influenced the delayed health seeking are discussed under the following below. The process of symptom identification and appraisal is discussed first, then the health care seeking process.

#### ***Symptom identification and appraisal***

A breast lump was the commonest first symptom discovered among the women in my study (9 out of 15). Four of the women noticed breast swelling, and two, breast pain. Among women studied by Nosarti et al (2000) and Burgess et al (2006) in the UK, Harirchi et al (2005) in Iran, Mousa et al (2011) in Egypt and Otieno et al (2010) in Kenya, a breast lump was the commonest first symptom identified too. Some studies

have suggested that the nature of the first symptom influences delay. Women with initial symptom of breast pain (Meechan, Collins, & Petrie, 2002) or symptoms that did not include a breast lump have been found to delay longer (Burgess et al., 1998). However, women with breast lump have also been found to delay (Taib et al., 2011). In my study, the shortest delay (4 months) was in a woman whose initial symptom was a breast swelling and the longest delay (>24 months) in one whose initial symptom was a breast lump. Rather than the nature of the first symptom, it was the interpretation of the symptom that influenced the care seeking behaviour. The women's initial interpretation of their symptom was that it was not serious. They arrived at this conclusion because of the small size of the lump, it being painless, and it not being associated with any other symptoms that caused their daily activities to be interrupted. Also, in their interpretation, they did not consider cancer per se, but their appraisal was to determine whether their breast illness needed medical attention or not. Interpreting the initial symptom as not serious or harmless is reported among women from diverse backgrounds including Pakistan (Malik & Gopalan, 2003; Memon et al., 2013), Columbia (Piñeros et al., 2009), Germany (Arndt et al., 2002), and Malaysia (Taib et al., 2011). However, the quantitative designs of these studies could not elicit what reasons led to such conclusions. In their exploratory study, Burgess et al (2001) found that women considered a discrete painless pea sized lump as likely to be cancer, so that the presence of pain was rather reassuring and considered not serious. On the contrary, among the Chinese women studied by Lam et al (2008), the presence of pain rather than the lump indicated an anomaly. However, some women rather made causal attributions such as, pain or lump arising from trauma (Unger-Saldaña & Infante-Castañeda, 2011) or from hormonal changes (Lam et al., 2008) to

their breast symptoms to find logical normal explanations for them. It seems then, that, the psychological interpretation of the identified symptom is a significant factor in the symptom appraisal process. It seems also, that symptom interpretation varies across cultures. In my study, a symptom interrupting daily activity was a significant criterion in attributing seriousness. This attitude has also been reported among Mexican (Unger-Saldaña & Infante-Castañeda, 2011) and Pakistani (Memon et al., 2013) women. This may suggest that it is not as much the symptom identified, but its effect on the woman's functionality that qualifies it to be serious or otherwise.

Symptom appraisal to infer illness has been described as a major contributor (60 – 70%) to health seeking behaviour (Andersen, Cacioppo, & Roberts, 1995; de Nooijer et al., 2001). Other studies have given evidence to support this assertion (Burgess et al., 2001; Taib et al., 2011). Similarly in my study, the individual's determination of her breast symptom being one that needed medical attention was key to deciding to seek help. However, inferring illness from an identified anomaly depended on their prior knowledge obtained from personal experience, observation in others or from information already available to them. Clegg-Lampsey et al (2009), from their earlier survey in a tertiary hospital in Ghana found the women in their study had poor knowledge about breast cancer. Ezeome (2010) and Otieno et al (2010) also reported poor knowledge of their study participants in Nigeria and Kenya respectively. However, their survey reports did not describe what knowledge the women had that was described as poor. The accounts of the women in my qualitative study offer more information about what knowledge women who delay have about breast cancer. Although some of the women said that a breast lump could be cancer, none of the

women interviewed in this study could describe any other signs of breast cancer. The accounts of those who had been exposed to breast cancer campaign messages did not suggest knowledge about how the disease evolves over time. Rather, their accounts were related to other body lumps/swellings and breast abscesses. In comparison, Taib et al (2011) report that the Malaysian women studied understood a woman's risk to develop breast cancer was related to her family history of the disease. They also understood how breast cancer evolves over time.

Whatever the source of information that informs the woman's knowledge base, the onus lies on her to label her symptom as serious and therefore seek help. As such, the breast cancer patient remains the index of study in assessing the influence of knowledge on symptom appraisal and health seeking behaviour. However, women access information from others in addition to what they already know to either interpret their symptom as harmless and therefore take no action, or label it as serious and seek help (Khakbazan et al., 2014a; Taib et al., 2011). Some women in my study used information from other individuals (relatives, friends, neighbours) around them to interpret their symptom. Such information was sometimes sought merely for another opinion on what they had identified in their breast, or from individuals they potentially perceived to be more knowledgeable. The information they got from them may have had some role in their symptom appraisal process including endorsing the 'not serious' conclusion. Symptom disclosure has had no influence on health seeking behaviour (Meechan et al., 2003), contributed to delay health seeking (Unger-Saldaña & Infante-Castañeda, 2011) and contributed to early health seeking (O'Mahony et al., 2011; Taib et al., 2011). This may suggest then, that it is how the woman utilises this

kind of feedback in her symptom appraisal process that determines the decision she makes. Burgess et al (1998) report from their study in the UK that women who delayed were more likely to be prompted by others to seek help rather than do so of their own free will. Taib et al (2011) also report a similar phenomenon among Malaysian women where they needed to be sanctioned sick/ill by significant individuals in order to label their symptom serious. This further suggests that trust in who gave the information may influence its value in utilising it for symptom appraisal and decision making. The knowledge of other individuals may therefore be as equally important as the individual's knowledge as they potentially contribute to the individual's cognitive process of symptom appraisal. The extent of this influence was however not assessed in this study.

Some of the women interviewed in my study had been exposed to breast cancer campaign messages on radio, television, posters, or in their church groups. Some of the women who lived in urban areas and had better access to media had not heard about breast cancer messages. Exposure to the campaign messages did not provide the expected knowledge capital in appraising the risk of their identified breast symptom being breast cancer. Because these information sources are available only at a particular point in time, the women could not refer back to them for information during the time of their symptom appraisal. Moreover, depending on how long ago their exposure to them had been (this was not assessed in this study), the information they received may have been forgotten and thus contributed to their poor knowledge at the time of appraisal. Also, their low literacy level may have prevented them from accessing readable material for information. In comparison, the women studied by

O'Mahony et al (2011) in Ireland, most of whom were highly educated and did not delay in seeking help, sought information through reading and accessing websites to interpret their symptoms. This may be where educational background influences health seeking behaviour. Literate women may easily access and utilise reading materials (print, web) during their appraisal process. On the contrary, women who had never been to school, such as some of those in my study who rely on audio/visual messages that are not always available (depending on how frequently they are aired), will not have access to such information at the time of symptom appraisal. The practicability of frequently airing breast cancer campaign messages on audio/visual media will have to be considered to ensure easy and ready access to information. However, it must be noted that having the information does not ensure the care seeking at the expected time. Barg and Grier (2008) attribute this to the different cultural beliefs and experiences that exist about breast cancer. Thus, the intended meaning (i.e. the cognitive and affective response to be evoked) to be conveyed in breast cancer communication may not be the actual meaning created during a woman's interpretation (Barg & Grier, 2008). On the other hand, even where the intended and actual meanings are congruent, Granek and Fergus (2012) assert that women who are not ready to present their breast symptoms to a physician remained deliberately ignorant of it because they have other areas in their life needing attention that are not hindered by the threat of breast cancer.

### ***The health seeking process***

Komaroff (2001) asserts that interpreting a symptom to be an illness does not mean a person will visit a health care professional, because only a minority of illnesses are believed to need medical care. The women interviewed in this study exhibited such

behaviour. However, this initial period of not visiting a health care professional was occupied by other activities. These activities included continuous monitoring of the lump and self-medication until there was a trigger to seek help. Subsequently, there was a trigger to initiate the health seeking process, and then the journey through the health system trajectory until arrival at KATH breast clinic.

### **1. Continuous monitoring and self-medication**

The women in my study remained aware of the change in their breast, continuously monitored it, and looked out for outcomes based on their expectations from common or traditional knowledge. This behaviour of monitoring discovered breast symptoms have been reported among women studied in UK (Burgess et al., 2001), China (Lam et al., 2008) and Malaysia (Taib et al., 2011). Similar to the findings from Taib et al's (2011) qualitative study of 19 women presenting with advanced breast cancer, the women in my study did not consider cancer and its seriousness during this time. As such, ignorance of the consequence of not seeking help early kept the women in this state of continuous monitoring. However, the manner in which these study participants monitored their breast symptoms was different from what has been reported in other studies. While women in other studies monitored for progression or appearance on new symptoms (Burgess et al., 2001; Lam et al., 2008; Taib et al., 2011), some of the women in my study did not merely observe but took actions to direct the evolution of their symptom to their expected outcome. They applied locally prepared topical creams (LPTC) as a way to modulate the progression of their symptom. This was a common cultural practice for lumps to make them resolve.



## **2. Trigger to seek help “the tipping point”**

Failure of the symptom to resolve as expected in the course of monitoring, and after self-medication with the LPTC, led the women to seek medical help. At this stage there was symptom progression characterised by increase in size of the lump, with associated pain, ulceration or a combination of both. The onset of pain has been widely reported as the trigger to seeking help among other breast cancer patients of diverse cultural backgrounds (Ezeome, 2010; Lam et al., 2008; Taib et al., 2011; Unger-Saldaña & Infante-Castañeda, 2011). On the contrary, in Burgess et al’s (2001) study in UK, the appearance of a lump was the commonest trigger to seeking care because the women believed breast cancer was not painful. The critical trigger to seek help for the women interviewed for my study was when their symptoms affected their quality of life and interfered with their daily activities. This was an attitude that informed their general health seeking behaviour. This situation has been found among Pakistani (Memon et al., 2013) and Mexican (Unger-Saldaña & Infante-Castañeda, 2011) breast cancer patients too. For these women, incapacitation, and not a ‘mere’ symptom is what suggests illness needing medical care. Unfortunately, such a time occurs later in the evolution of breast cancer which results in advanced disease at presentation and associated poor prognosis (Memon et al., 2013; Richards et al., 1999). It is evident that there remains some disparity in what health education on breast cancer aims to get women to do and what some women actually do. That is, what some women interpret as serious and needing medical attention is different from what breast health promoters expect. Educational messages must thus be designed to bridge this gap and help women to understand that waiting until there is some degree of incapacitation before inferring an illness needing medical care can be too late where breast cancer is

concerned. Educational content must help such women redefine what is considered as 'illness requiring medical care'.

### **3. The healthcare seeking trajectory**

Table 6 (see page 73) shows the journey trajectory from symptom identification to the time the women reported to KATHbc for care. The first contact with a medical facility for all the women was with a district, community or private hospital. Eight women sought initial help from a medical facility, four used LPTC and 3 women applied herbal preparations before accessing the medical facility. These facilities provide basic medical and surgical care, except for the community hospital that provides no surgical care. Within the medical system, the trajectory was similar for most of the women. From the district or community hospitals they were referred either directly to KATHbc, or to a regional hospital then KATHbc. This referral trajectory is the standard in the medical service delivery structure in Ghana. However, none of the women in my study knew about the existence of KATHbc and that they could report directly to it for care. One woman believed she could come to a teaching hospital like KATH only when referred.

The women in my study described the health care workers (HCW) they first saw in the medical facilities as doctors except for one who identified the HCW as a nurse. District hospitals in Ghana are staffed by medical officers (doctors who have at least 2 years working experience after medical school) and physician assistants. Community health centres may have physician assistants. At their initial point of accessing medical care, the women did not have access to any specialist care. Compared to Nigeria (Ezeome, 2010) which is also in the West African Sub-region, first HCW contact included a

general practitioner, surgeon or an obstetrician/gynaecologist. Five percent of the women in Ezeome's (2010) study first contacted a nurse. Similar to the Nigerian report, first HCW contact in Egypt (Mousa et al., 2011) included a general surgeon, surgical oncologist, medical oncologist, a primary care physician or directly to the cancer centre. In spite of being seen initially on presentation to a medical facility by specialist doctors, the majority of the women in Nigeria (90.1%) were finally seen in the cancer centre 3 or more months later. Furthermore, they would have seen one or more other physicians before arriving at the cancer centre. A similar trajectory is observed among the women in my study. Although their initial contact was not with a specialist, the women would have seen up to 3 other physicians before being seen at KATHbc. It is evident that the referral system contributes to the delay in women reaching the centres for appropriate medical help. As seen in my study, 6 of the women had their first contact with a health facility less than 3 months after identifying their symptom. Some explanations have been offered for such referral delays. Ezeome (2010) and Mousa et al (2011) assert poor physician knowledge and practice in the management of breast symptoms accounts for these referral delays. Other studies have found medical misdiagnosis and false reassurance by health workers as contributing to referral delays (Taib et al., 2011; Unger-Saldaña & Infante-Castañeda, 2011). Some of the women in my study were seen several times in the same health facility before a decision to refer was taken. This may suggest that the doctor was uncertain about the breast condition until some degree of progression had occurred which unfortunately contributes to the disease progression. Ezeome (2010) also cites Hospital industrial actions and lack of needed facilities to make a diagnosis in Nigeria as also accounting for referral delays. In my study, an industrial action resulted in a longer trajectory for

one patient. Also, having to travel to other centres, sometimes outside the town in which their district hospital was located for investigations contributed to spending more time and repeated visits to present investigation results to a particular medical facility before onward referral was done. Occurrences like this were frustrating and sometimes deterred the women from complying with hospital appointments. This has been observed among Mexican women too (Unger-Saldaña & Infante-Castañeda, 2011). Comparatively, the care seeking trajectory reported for women studied in the UK (Burgess et al., 1998) and Ireland (O'Mahony et al., 2011) was shorter. The first point of HCW contact as reported by Burgess et al (1998) and O'Mahoney et al (2011) was with a general practitioner and then onward referral to a specialist. However, Burgess et al (1998) report that there was referral delay for patients who did not initially present with a breast lump. They found that some women were referred only when they had re-presented with the same thing or with a second symptom and such delayed referral could be in excess of 12 weeks, and in a few cases, over a year. It is evident then, that the HCW's appraisal of the breast symptom is very important in facilitating or stalling the care seeking trajectory as most women do not access a specialist as a first point of call for their breast symptoms. It may become imperative that beyond educating clinicians on how to evaluate breast symptoms efficiently for cancer, the practice of immediate referral if in doubt be encouraged.

Misunderstanding what was being done to or for the women in my study led to noncompliance of follow-up hospital appointments or referrals, and thus prolonged the trajectory. The women had little understanding of the screening/diagnostic processes for example, mammography and biopsy. The process of deciphering things

for themselves sometimes led to wrong conclusions, evoked fear and thus decisions such as not attending the next hospital appointment. For example some of the women in my study misinterpreted the breast biopsy procedure as major surgery and this evoked anticipatory fear. Fear of death, of breast cancer treatments and their outcomes arising from women's past experiences with friends or relatives known to have had breast cancer have been reported by Clegg-Lamprey et al (2009), Asoogo and Duma (2015) and Agbokey (2014) from their studies in Ghana. Similar fears have been expressed by women in the UK (Burgess et al., 1998; Nosarti et al., 2000), Malaysia (Taib et al., 2014) Ireland (O'Mahony et al., 2013), and Pakistan (Malik & Gopalan, 2003). In other studies, women reported the fear of being looked down upon, mocked or ridiculed as the reason for presenting late (Taib et al., 2011; Unger-Saldaña & Infante-Castañeda, 2011). In all these instances, an interactive communication experience may have identified and resolved such misunderstanding about breast cancer treatment and outcomes and allayed the women's fears. Communication from HCW to the women in my study was more of instructions and not educative information. The women had no opportunity to have their questions or fears addressed. This may have arisen either because the HCW had poor knowledge of the condition or had poor communication skills. Considering that 6 of the women in my study had been to a medical facility less than 3 months after the discovery of their breast symptoms, the nature of the care they received there could have influenced the care seeking trajectory. Diligent health worker education of women with breast symptoms to bring them to understand the nature and risk of it being breast cancer is a potential avenue to get women to commit to and follow through medical interventions to obtain a definitive diagnosis and appropriate treatment. Such an

initiative will require that all cadres of health workers who encounter women be educated about breast cancer symptoms and its general management approach so that women are not only counselled appropriately but also referred early. This is because like in my study, and in others, (Burgess et al., 1998; Ezeome, 2010; Mousa et al., 2011; Norsa'adah et al., 2012; Taib et al., 2011) wrong or delayed assessment by physicians was one of the causes of delayed referral.

None of my study participants knew about KATHbc. Contrary to what pertains to other health care systems where women need to book an appointment to seek care (Burgess et al., 2001; O'Mahony & Hegarty, 2009a), women can access KATHbc directly without prior appointment or referral. This direct access system, if well publicised, can potentially eliminate or cut short the care seeking trajectory. The women who accessed the private hospital as their first point of call heard about the facility through breast cancer education campaigns delivered by its staff. These women did not report any earlier to the private hospital than those who reported to the government facilities. However, it is interesting to note that they all self-referred to KATHbc after several months of attending the private hospital due to dissatisfaction with the care they received there. This suggests that ongoing educational messages do not adequately inform women where and how they can access care for their breast symptoms accurately and adequately. Although they are informed to go to the hospital immediately they notice an anomaly in their breast, they must be directed to facilities that have the capacity to assess and diagnose efficiently like KATHbc without being subjected to the challenge of navigating the referral system.

### **3(i). Influence of alternative and spiritual care on health seeking behaviour and trajectory**

The earlier survey of 66 breast cancer patients in Ghana by Clegg-Lampsey et al (2009) found 19.7% of the women accessed herbal medicine and another 19.7% went to prayer camps before visiting a medical facility. Asoogo and Duma (2015) and Agbokey (2014) report accessing traditional healers for medicine as contributing to delayed help seeking among women they studied in KATH. Similar trends have been found in surveys from Nigeria, Kenya and Pakistan where although a majority of the breast cancer patients initially visited a medical facility, some of them also visited traditional healers, alternative practitioners and prayer houses before visiting a medical facility (Ezeome, 2010; Ibrahim & Oludara, 2012; Otieno et al., 2010). The exploratory method of my study was able to draw out the reason for such actions among the women interviewed. The women used the LPTC and herbal preparations because this is how they knew lumps to be treated in their culture, with the expectation that it will melt or burst to discharge puss. Such symptoms are considered as ailments that could be managed at home in such a manner without going to the doctor. Some of the women had personal or observed experience of successful use of such treatment. In my study, only one woman applied herbal treatment after visiting the district and regional hospitals and this was to avoid the need for surgery as part of her treatment. Asoogo and Duma (2015) and Norsa'adah et al (2012) report similar reasons for the use of herbal treatment among women studied in Ghana and Malaysia respectively.

Contrary to Clegg-Lampsey et al's (2009) finding that visiting prayer camps was the cause of delay, the accounts of the women in my study suggest accessing prayer support for a different purpose. Prayers were sought to complement their medical

care seeking activities. This was found among some Irish women too (O'Mahony et al., 2011). The women in my study prayed to make all activities in the hospital go on successfully. One woman identified prayer as what gave her the courage to pursue her referral to KATHbc. It is noteworthy that the religious/spiritual leaders consulted by the women encouraged them to seek medical help immediately and the timing of medical care seeking occurred soon after this. Such influence of religious leaders has not been reported in other studies and may be worth exploring in future studies. Women in other studies have expressed how their religious beliefs have been helpful to the final outcome of their breast cancer diagnosis (O'Mahony et al., 2011) as well as how religion and membership of a religious organisation helped them with spiritual, instrumental and physical support (Taib et al., 2014). Breast cancer has been perceived by some Indonesian women as divine, part of their destiny and a test of their faith (Iskandarsyah et al., 2014). In Ghana, women of some ethnic groups believe that breast cancer is a punishment of the gods (Asobayire & Barley, 2014). On the contrary, women in this study did not consider their breast condition to be a curse, but rather, that a negative spiritual influence could be superimposed on what had already occurred naturally. Fear of this spiritual superimposition was also the reason why some of them did not discuss their breast symptoms with other people. The assertion that religious beliefs may operate as an external locus of control over health, with God being seen as having the power to maintain health or inflict disease, and prayer being the mechanism to influence disease and health outcomes (Lillington, Johnson, & Chlebowski, 2000) may be the phenomenon expressed here. Indeed, the women in my study felt that seeking spiritual support through prayer was a normal thing to do in times of adversity.



### **3(ii). The influence of social support on health seeking behaviour and care seeking trajectory**

The women in my study received financial, physical and sometime material support to enable them to seek medical care. Seeking such support was the main reason for disclosure about their breast illness although sometimes it was done as a matter of social courtesy.

In their study of delay in seeking help among breast cancer patients, Unger-Saldaña and Infante-Castañeda (2011) describe kinds of social support women receive in seeking help. These are informational support (e.g. advice to seek care and what type of health services to use), instrumental support (e.g. money, help with errands, child care, housing in case of travel), emotional support (e.g. company for medical consultation, ability to talk to someone) and decision making support. Similar kind of social support, though with some degree of variation was sought by the women in my study as well. The women in my study lived with or were in contact with family members such as siblings, parents, children, grandchildren and other extended family members. These individuals were their source of social support. Although, Otieno et al's (2010) study in Kenya report the number of children the women had, their description does not portray the existing relationships and how they come to play in their health seeking behaviour. Within the West African setting the extended family continues to offer help and care for its members in hard times (Korboe & Tipple, 1993). This is a role that contributed to the health seeking process. Instrumental support in terms of money was the most significant social support sought by the women in my study. Some of the women got support for child care and/or housing during travel related to seeking medical help. Informational support was used differently among

some of the women in my study. The women in my study did not seek advice to seek medical care, this was usually a decision they would have come to on their own. Also, many of them decided where to seek help themselves. They all had family support to seek medical help. One woman however, was 'told' where to seek care by her children and another by her sibling. Compliance with this was as a result of respect for the children and in the case of the sibling, because he was bearing all the cost involved. This is in contrast to Taib et al's (2014) findings where some Malaysian women are prevented from seeking help by their husbands and parents. Information about herbal treatment was offered or recommended to the women rather than sought by them. This was a normal health seeking attitude among the women in their communities although it was not all the women who accepted the offer. Many of the women in my study also travelled with some family to seek help. This was not merely for company as Unger-Saldaña and Infante-Castañeda (2011) describe but usually because they felt too ill to travel alone or needed someone to run errands related to their care in case they were admitted. Ultimately, although the decision to seek medical care was made by the women themselves, they relied greatly on their family, especially for financial support to be able to do so. In many instances, the time the family member in question provided the needed money determined the pace at which the women moved along the health seeking trajectory.

The findings of my study suggest some issues of social importance regarding the health seeking process were solved by family. Many women have deferred seeking help for their breast symptoms because of work, family and social and domestic roles which they had to perform (Angus et al., 2007; Burgess et al., 2001; Burgess et al., 2006;

Khakbazan et al., 2014a; Lam et al., 2008; O'Mahony et al., 2011). In my study, one woman deferred the timing to seek medical help because of the need to take care of a sick child, another because of work, and another to attend to another illness because that was perceived to be more threatening to her work at that time. For some other women, the ability to go about their normal tasks (both domestic and occupational) caused them not to even infer illness in appraising their breast symptom. It appears maintaining the daily routine of work and caring for their home and children was an issue of great priority to the women and they were determined to achieve this.

### **3(iii). Influence of the health care system on health seeking trajectory**

Accessibility to care, assessed by longer distance from home to the hospital, longer travel time from home to the hospital and travelling to the hospital by public transport have been cited as contributing to delayed health seeking in Sri Lanka (Kumari & Goonewardena, 2011) and Thailand (Poum et al., 2014). Stapleton et al (2011) also reports a weak association between long travel times and delay from their study in Egypt. However, Sharma et al (2013) found no association between method of accessing the hospital such as using public transport and delay in their study in Haiti. Similarly, in my study, none of the women expressed concern about accessing the KATHbc by public transport or about the long distance and time to travel to KATHbc. At the time of seeking help from KATHbc, the women were desperate and willing to do whatever it took to get help. This may be why they had no concern about the distance to travel. It seems that at this point, the perceived benefit of travelling to KATHbc outweighed the distress of travelling the distance to KATHbc. However, some of the women did express disappointment at the inability of the hospitals close to them to treat their breast illness without referring them. The task of navigating one's

way in a big teaching hospital evoked anxiety in some of them. Angus et al (2007) from their study among Canadian women found that women have to work to establish and maintain good relationships and open communication with different help providers in their care seeking process. Having to exert such effort in a new care facility may be the reason for the anxiety evoked by going to a new facility. Nevertheless, they had resigned themselves to having to come to KATHbc for the treatment they needed.

The nature and quality of care women receive in health facilities influence their care seeking behaviour. Unger-Saldaña and Infante-Castañeda (2011) describe medical errors in diagnosis that gave women false assurance of benign disease and therefore delay. Furthermore, they describe multiple referral points to access treatment that frustrated some Mexican women and led to delay. In my study, the women did not recount any health care professional specifically telling them their symptom was not serious. However, in a bid to make a diagnosis before referral, the initial facilities they visited requested various diagnostic investigations that kept the women going back to the same hospital. Many of the women had to travel to other towns and find their way to where they had been directed for these investigations. In one instance, the inability of the woman to find the location of the laboratory led her not to carry it out and not report back to the hospital. Visiting many sites such as diagnostic labs and hospitals has been described as the “health work” women have to do which contributes to delay in the care seeking trajectory among Canadian women by Angus et al (2007). Similar “health work” has been described among Mexican women by Unger-Saldaña and Infante-Castañeda (2011). They assert that it is the exhaustion of dealing with such obstacles to accessing care that causes the women to stop pursuing it. Such may be

the reason for failure to follow through all the processes for the women in my study. But also, this back and forth between a hospital and investigation procedures caused some frustration among the women. Furthermore, the lack of communication about why and what was going on aggravated the frustration and led to delay. Failure to get the women to understand the risk involved in what they have and hence get them to be conscientious about the processes of the health care system can contribute to their inability to follow processes through and therefore delay.

Cost of care has been cited as a contributor to delay in seeking care among breast cancer patients in developed and developing countries (Iskandarsyah et al., 2014; Lam et al., 2008; Ruddy et al., 2014; Sharma et al., 2012). Indeed, Sharma et al (2012) assert that poverty is a major factor contributing to delay in seeking care for breast cancer symptoms in developing countries. Ruddy et al (2014) suggest that it is the co-payments and hidden costs like lost wages and child care expenses that challenge women who are less financially comfortable and therefore are unable to seek care early. Money for travel expenses and general upkeep while out of home has also been found to be some of the issues contributing to the financial difficulty in seeking care among some breast cancer patients in Agbokey's (2014) previous study at KATH. None of the women in my study was financially independent. Among these women, the little they earned could cater for their daily needs and other household expenses. As such, any extra cost like health care expenditure brought on some financial difficulty. Contrary to Asoogo and Duma's (2015) finding in their study where the women saved money over time to enable them access care at KATH, many women in my study rather relied on family members for monetary support to seek help. As such, the timing for

seeking care became dependent on when the money became available to them. The accounts of some of them suggested that the monetary cost involved in seeking medical care contributed to their delay in care seeking. The cost involved in getting a mammogram, a biopsy and other ancillary investigations were all borne by the women in this study and these costs are usually above the women's income. Although the National Health Insurance System (NHIS) policy is expected to cover the cost of breast cancer treatment in Ghana, breast cancer patients are required to make out of pocket payments for diagnosis and treatment at the point of service (Opoku, Benwell, & Yarney, 2012) and such moneys are not reimbursed. The NHIS policy on breast cancer must be reviewed with respect to its implementation and appropriate interventions made in health care facilities to allow women access care more easily.

### **What was not found in this study**

Denial (Norsa'adah et al., 2012; O'Mahony et al., 2011; Taib et al., 2014; Unger-Saldaña & Infante-Castañeda, 2011) and preordained fatalism (Taib et al., 2011) are some of the psychological responses women have been reported to experience with the identification of their breast cancer symptoms that influences their delay in seeking medical care. Denial in these studies were described as deliberately ignoring the identified symptom (Unger-Saldaña & Infante-Castañeda, 2011), the un-readiness to accept a cancer diagnosis (Taib et al., 2014), and the belief that the identified symptom will disappear (Reifenstein, 2007). Such psychological responses were not expressed by the women interviewed in my study. Rather, the women in my study remained conscious of the symptom they had identified, continuously monitored it but were

ignorant of the implications of it. Granek and Fergus (2012) from their study of breast cancer patients in Canada, also found that the women who deferred getting medical help consciously monitored their symptoms, thought and reflected on it, interpreted and assessed what they had, often with great concern over what it could be, and yet would dismiss it or choose not to seek care for it. They suggest that socio-political and cultural factors come into play in this process and so make the concept of denial insufficient to explain this apparent ignoring of symptoms. Reflecting on the findings in my study, it appears that these women were focussed on their need to be and feel healthy. This is because their state of health determined their ability to carry out their domestic and economic functions necessary for their livelihood. The absence of any incapacitation associated with their symptoms reinforced their sense of wellness and thus considering their symptom as nothing serious and needing medical attention.

Also in my study, the psychological factor 'fear' was not expressed as has been documented in other studies (Burgess et al., 2001; Facione, 1993; Lauver et al., 1995) including those published from Ghana (Agbokey, 2014; Asoogo & Duma, 2015; Clegg-Lampsey et al., 2009). Only two women in my study mentioned fear as the reason for not complying with scheduled follow-up appointments. Both accounts were related to the breast biopsy procedure; the first after several failed attempts without any acceptable explanation to her of what was going on; and the other before the procedure was scheduled. Compared to the women studied by Clegg-Lampsey et al (2009), Agbokey (2014) and Asoogo and Duma (2015) who were in various stages of breast cancer treatment and so possibly exposed to information about breast cancer, nine of the women interviewed in my study had no exposure to breast cancer

messages. As such, ignorance of what they potentially had is what may have caused them not to be afraid.

### **The total experience of health seeking**

In my study, the women eventually labelled their symptom as serious and needing medical care at a point where there was a perceived threat to life. At this point, the severity of pain or incapacitation was what was interpreted as a threat to their lives. It was not because they had gained any knowledge that their breast symptom was cancer. From then, there was some personal determination – driven by this perceived threat to their lives – to seek help. Also, from this time in the care seeking process, the significance of all the challenges to seeking care at KATHbc seemed to fade away. The perceived threat to life is probably what overshadowed the significance of the initial challenges and caused them to rise above their contextual challenges. The women mobilised different resources to enable them to negotiate the care seeking pathway. Where the resources were not under their personal control, they undertook the work of obtaining them for the goal of seeking medical help. This suggests that if women are well 'motivated', they are able to mobilise the resources they need to access care. For example, in my study, the women actively asked for monetary and other material help to seek medical help. They were even willing to bear the inconvenience of long distance travel to seek medical help. It must be noted again however, that underlying this determination was the perceived threat to their life. Many authors agree that appraising a breast symptom as serious contributes significantly to the health seeking process (Andersen et al., 1995; de Nooijer et al., 2001; Nosarti et al., 2000; Taib et al., 2011).



In the Andersen behavioural model for health care utilisation (Fig 1) (Ronald Andersen et al., 2013), which is the theoretical framework used for my study, all the factors listed, i.e. predisposing factors, enabling resources, needs, personal health practices, use of health services, perceived health status, evaluated health status, consumer satisfaction, the quality of life and contextual characteristics, act to influence health seeking behaviour. The model suggests each factor influences the other and their interaction exists in a loop fashion. The Andersen model is used to describe the factors influencing the health seeking behaviour of one study participant, Int. 7, in figure 2 (page 130), and for all the participants interviewed for the study in Figure 3 (page 131). Int. 7 visited the district hospital regularly for check-ups related to her sickle cell disease (SCD) and was satisfied with the care she received. However, she discontinued her visit to the district and regional hospital about her breast symptom because of the frustration of multiple visits to other facilities for investigations. Also, there was a lack of explanation from the doctors about the need for all the investigations, including repeated biopsies. She feared the repeated biopsies would rather aggravate her breast problem which was not painful or growing bigger. Also, she had to bear the cost of the repeated biopsies and any other investigations. The availability of money for these was subject to when her children provided it. Although all costs related to breast cancer care are supposed to be covered by the National Health Insurance scheme, her accounts did not suggest she knew of this. Her trigger to return to the hospital later was worsening symptoms. Other women in my study admitted utilising the hospital for other personal ailments or to seek care for other relatives during the period after noticing their breast illness. The source of care could be orthodox or traditional, based on recommendation or previous experience. However, the satisfaction of care

received at whichever site was chosen determined further pursuance of care or not from the hospital, or a change from traditional to orthodox, or vice-versa. The urgency with which care was sought increased as the perceived illness became associated with more distressing symptoms.

Examining the interplay of these factors further through the critical realism lens with retroductive reasoning (Blaikie 2004) offers further understanding of the mechanisms by which these factors influence the health seeking behaviour of the women in my study. Firstly, regardless of having heard breast cancer messages asking women to report to the hospital with any breast symptoms, the women at the time of appraising their symptoms considered more how the symptom affected their daily functioning. The ability to go about daily activities of work was very important for the women and this was an important consideration in determining which illness needed medical attention. Secondly, the experience of distressing symptoms, sometimes to the point of incapacitation provoked a sense of urgency to seek care and this is what set the women on the health seeking journey. Once this resolution was made, they mobilised whatever resources they needed to utilise health care. Then, satisfaction with the service at each point led to reassessment of the need to go on, as well as further commitment to mobilise resources to follow the process through. Indeed, the distress experienced by the women may be considered as the 'rate determining' step in this health seeking process because that is what informed how the significance of all other challenges were reassessed. Also, findings from my study show that, this self-determined need is on a case by case basis, because, although some of the women sought care regularly for other illnesses, they did not talk to their doctor about their

breast symptom so long as they saw no need to. Thirdly, as the women went through the health seeking process, their engagement with the health professionals influenced the time it took to arrive at KATH breast clinic. For example, communication to understand issues like where and what investigations needed to be done; the outcome, interpretation and implication of investigation outcomes, and the need to navigate the referral trajectory promptly were poorly done. In some cases they were not done at all. Also, among the women who self-referred from the private hospital, although they were unhappy with the treatment they received there, their accounts did not suggest any attempts at questioning the health care professionals. Rather, they 'endured' the situation until such time they were driven by desperation to self-refer.

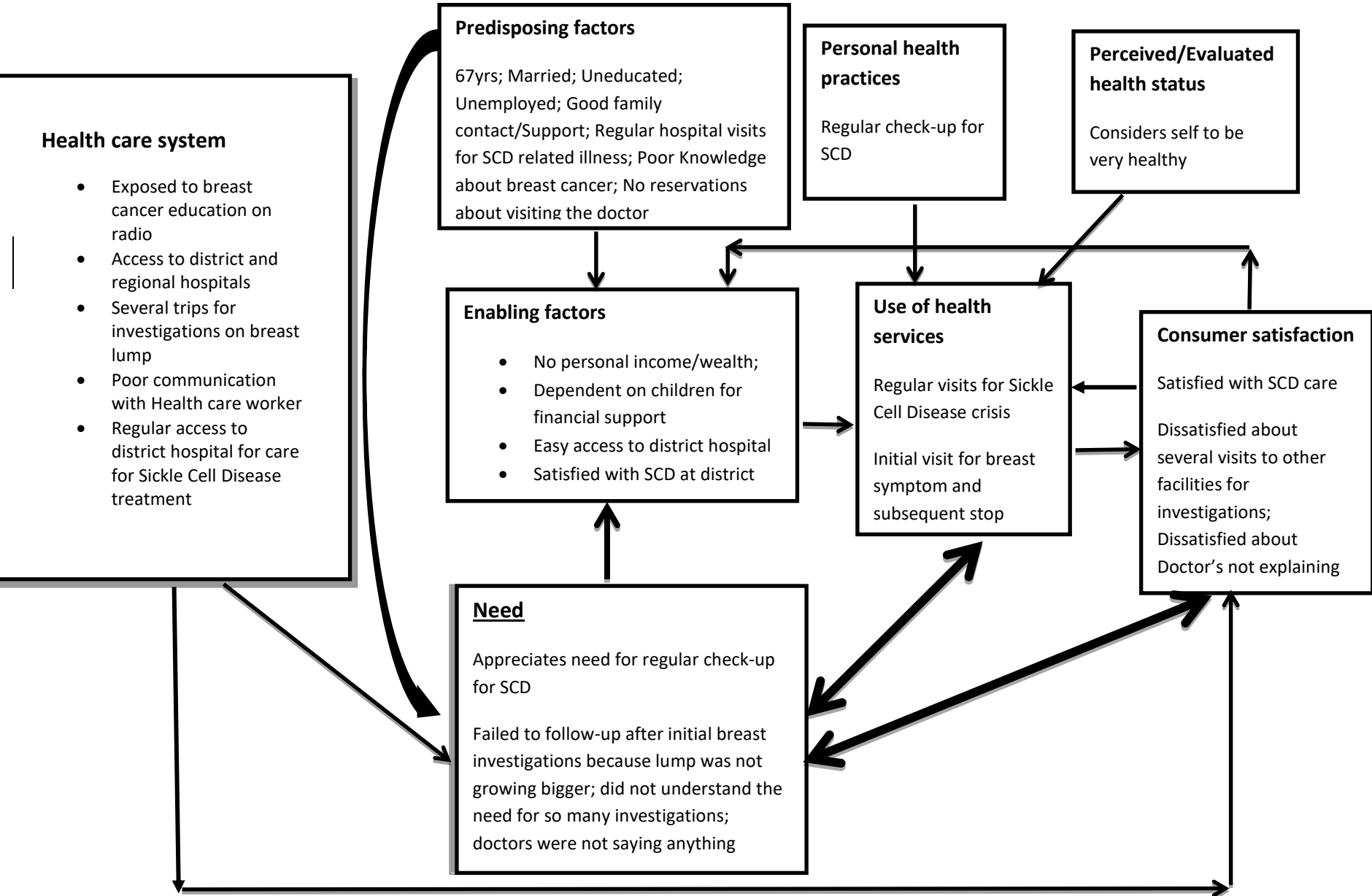


Figure 2 Factors influencing the help seeking behaviour of Int. 7

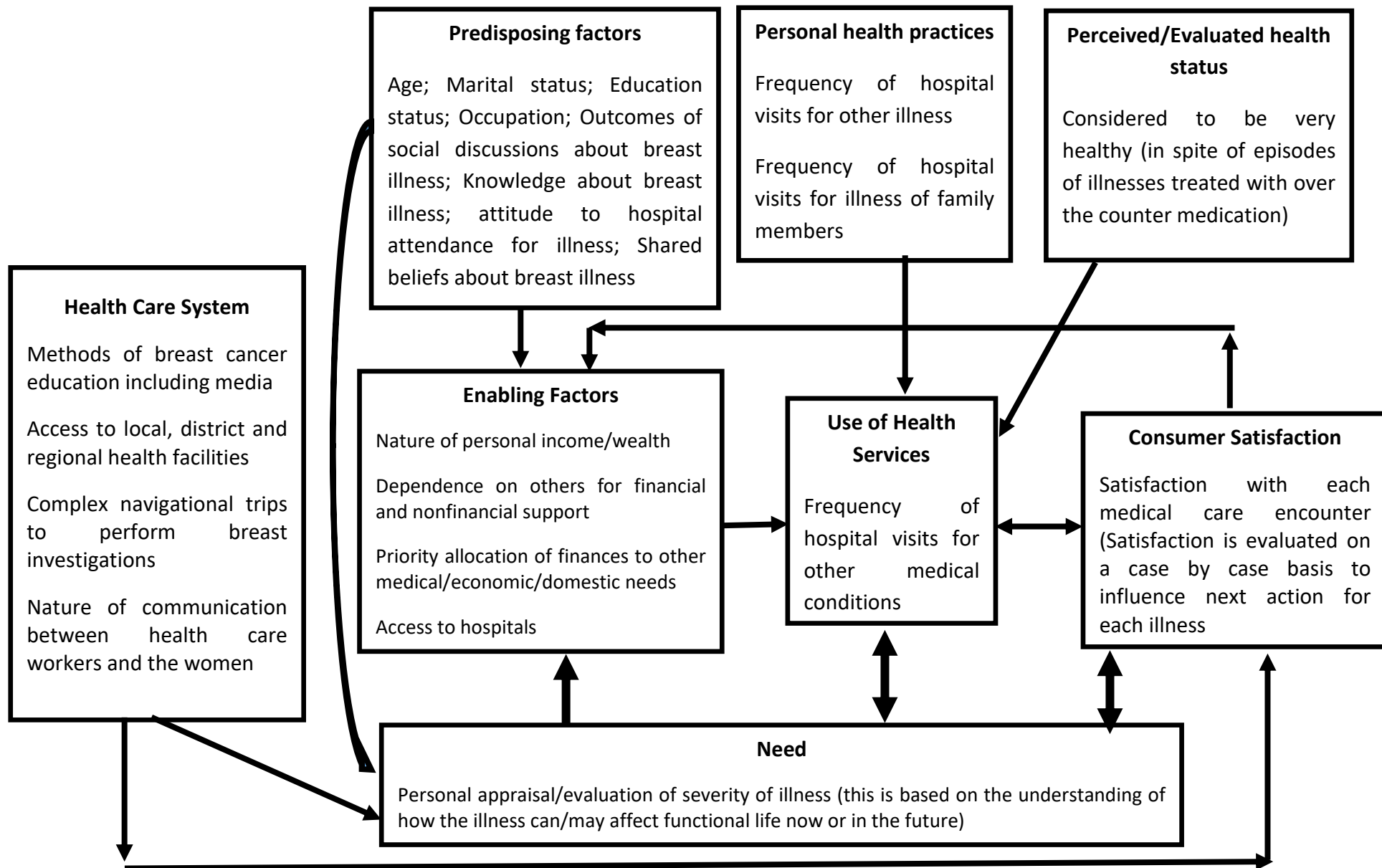


Figure 3 Factors influencing the help seeking behaviour of all the participants interviewed

It appears that the women took responsibility for issues related to the structure of the health care organisation and the health providers, as well as their care seeking process. Where inadequate or no information was provided, they had to find this on their own. Where investigations were not available in the facility visited, it was their responsibility to travel to where they could find it. Their ability to navigate such pitfalls in the health care system influenced the care seeking process. For example one woman (Int. 2) did not undergo an investigation she needed in another town because she was unfamiliar with the town.

Examining health care utilisation from a critical realist's perspective, Scambler (2001) argues that, mere social class status (determined by measures of socioeconomic status) does not determine access to care. Rather, it is an individual's command and management of resources (capital) that determine social class, especially of those related to economic productivity, that act to influence access to health. Scambler (2001) describes these resources (capital) that determine social class as follows. There is psychological capital, such as lay beliefs about controllability and cure of illness; social capital, such as social support and networks; cultural capital, such as ones progress through formal education which influences one's ability to seek out, interpret and act on health information as well as the capacity to interact with health care providers; spatial capital, such as the geographical location; and material capital, such as one's income and any sources of it. These resources enact their influence on care seeking through a woman's command and management of them. Such command and management act as generative mechanisms that can be inferred through investigation.

Drawing on this argument, Angus et al (2006) further suggest that the management of these various resources determining social class provide facilitating or constraining conditions that influence access to breast cancer care. From the 35 women they studied in Canada, they found that the influence of social class on access to breast cancer care was enacted through the new activities and tasks that required some effort to perform (Angus et al., 2007). The tasks included seeking information, communicating with health providers, traveling to and from clinics and finding the means to meet uninsured costs of the care they sought (Angus et al., 2007). The women's resources (capital) determined how much effort was exerted in performing the tasks of care seeking. For example, material capital such as employment with sick leave and health insurance benefits allowed time off to seek care with little effort. Meanwhile, self-employment could mean loss of income while seeking care. Also, low income jobs meant having to put in more effort to find financial assistance to pay for the expenses of seeking care. Angus et al (2007) termed this mechanism by which social class influences access to care as 'health work'.

The women in my study also performed 'health work' in their health seeking process. Their low cultural and material capital caused them to require more effort in navigating the help seeking trajectory. They misunderstood investigative procedures that contributed to decisions not to pursue subsequent appointments. Their low cultural capital made them unable to question the care they received where they were dissatisfied with it. On the other hand, their low cultural capital may be the cause of their ignorance of what to expect from the health system, and thus their acceptance of events as they occurred. Also, their low income levels meant they had to mobilise

money to pay for the cost of care. Their low psychological capital (i.e. understanding of breast illness) resulted in their appraisal of their symptoms as not serious, thus waiting until the symptoms were distressing to seek care. Furthermore, the poor cultural capital made them unable to seek more information even when they had contact with health care providers.

The Andersen behavioural model for health service use (Ronald Andersen et al., 2013) which was used as the conceptual framework for my study describes factors beyond those related to social class to include contextual factors such as those related to the health system that influence health seeking behaviour. Findings from my study suggest that the influence of the health system on health seeking for breast cancer is not enacted/realised through the mere availability and access to the facility but also the nature and quality of the service provided. For example, the women in my study had low psychological and cultural capital that limited their ability to seek information and communicate with the health care providers they interacted with. As such, in spite of initial contact with health care providers, the women still did not perceive the seriousness of their symptom and thus the urgency to pursue seeking care. Rather, ignorance coupled with dissatisfaction and misunderstanding of what transpired in care facilities led to discontinuation of follow-up. The interactions with health providers however, could be opportunities for support, such as information and counselling to explain what investigations needed to be performed, where and when they would be done and answering any questions that may arise. The breast cancer messages some of the women had received before were not utilised or assessable at decision making times for the women. Thus, health provider contact times could be



opportunities to engage the women and give more meaningful information that would guide their decision making.

Also at the contextual level, although the women had access to district hospitals close to where they lived, the organisational structure of care provision contributed to their delay. The inability of the hospitals to provide facilities for needed investigations meant journeys outside the hospital for them. This increased the cost of seeking care.

Granek and Fergus (2012 page 1754) assert that the trajectory from symptom discovery to medical presentation may be “unrealistic, unfeasible or undesirable even if a woman is fully aware of the right steps to take, and even if she knows rationally that early detection might lead to a better outcome”. This suggests then, that in spite of providing all the needed support, a woman must **want** to seek care for her breast symptoms to pursue it. Archer (2003) posits that through internal dialogues, individuals exercise their own personal capabilities and emergent powers to decide a course of action within the limits of their social circumstances and dispositions. But Angus et al (2006) also suggest a woman realises and activates her constraints or enablements not only through her internal conversations but also through discussions with others about her breast conditions. It may be possible then that given the right support at the time of initial contact with a health care facility, the delayed care seeking trajectory can be shortened.

The Andersen behavioural model (Ronald Andersen et al., 2013) also portrays the complex interaction between individual and contextual factors that influence care seeking for breast cancer symptoms. The individual and contextual factors exert their influence concurrently and consecutively, such that the outcome of one influences the

other in a loop fashion (Fig 2). Also, the experiences with the health system are entangled with, and exert an influence on, the process of symptom appraisal and monitoring, as well as activities related to domestic and socioeconomic life that determine enabling and need factors. Furthermore, a positive influence on health seeking for one illness does not lead to same for another illness. For example, although interview 7 had regular hospital visits for sickle cell disease, she did not do the same for her breast symptoms. It appears that her satisfaction with the care she received for sickle cell disease resulted in consistent follow-up. On the contrary, the dissatisfaction with care for the breast symptom led to re-evaluation of her need for further care. Other women in my study also sought care consistently for other ailments and not their breast symptoms. Some of them resorted to alternative care because the outcomes in the hospital did not meet their expectation. This behaviour suggests that women's satisfaction with the care they receive influences their care seeking decisions. Taib et al (2014) also describe how poor physician communication contributed to a delay in seeking help while the ability to form trusting relationships with alternative therapy providers that fulfils the emotional and psychological support needs of some women had drawn them to seek care with them instead in Malaysia. It seems then, that, positive health seeking behaviour for one illness does not necessarily lead to same for another illness, even when they are experienced at the same time.

## **Limitations**

The findings from my study contribute valuable knowledge to the understanding of why women with advanced breast cancer symptoms delay in seeking help at KATH breast clinic, Ghana. Some limitations to this study must however be noted.

Only women with clinically suspected stage III or IV breast cancer at presentation were sampled for my study. The sample did not include women of tertiary level education or with white collar jobs. Women with clinically suspected stage III or IV breast cancer symptoms who did not make it to KATH breast clinic at all were missed. This limits the range of experience of the delay phenomenon explored in my study. However, the account of each woman is still valuable (Silverman, 2013). The rich account from each of the participants offers valuable data that are useful in making judgements about women in a similar socio-demographic, cultural and economic context.

My status as a surgeon conducting the interviews could have influenced my results (Silverman, 2013). The women may have felt intimidated and this would influence their account of what they had done prior to attending KATH breast clinic. Thus there is the likelihood that the women omitted in their accounts some actions they may have taken before reporting to KATHbc. For example, the use of traditional medicine over periods longer than they admitted.

Recall bias was inevitable as the women gave accounts of activities that had occurred prior to arriving at KATH breast clinic. The symptom appraisal process at the time of initial discovery of the breast symptom may be incomplete. This was the first event in the health seeking process, and the women were probably unable to recount the exact thought processes that influenced the appraisal. Also, what they disclosed in the

interview could be a summary of the process based on their interpretation of it in hind sight. The inability to obtain a real time account of all the events limits the completeness of the data collected.

All interviews were conducted in the local Ghanaian language “Twi”. The interviews were translated into English during transcription and reiterative back-translation done to ensure meanings of the original interviews were maintained. The process of reiterative back-translation if not done well could result in findings that are untrue and thus not trustworthy. However, with fluency in both languages, good understanding of the culture of the women being studied and meticulous transcription, this potential error was minimised. The translation was however not validated by any independent person, a process that could have contributed to the trustworthiness of the study (Chen and Boore 2010). On the other hand, being the sole translator maintained consistency of translation and this helped maximise the reliability of my findings (Twinn 1997).

Respondent validation as a process to potentially strengthen the credibility (Bryman, 2012; Silverman, 2013) of my study findings was not done. Also, the use of selected quotations to report my findings makes it subject to anecdotalism and thus influence the validity of my findings (Silverman, 2013). To address this, all parts of the data were examined for similarities and any anomalies sought out to ensure comprehensive data treatment (Silverman, 2013). Moreover, effort was made to ensure every inference was supported from my data.

## Summary

The demographic profile and delay time of my study participants were similar to what has been reported in the literature about women who delayed health seeking for breast cancer symptoms. Findings from my study on the influence of symptom identification and appraisal, the health care system, social support systems, and alternative and spiritual care sources on delayed health seeking behaviour were also similar to findings from other studies cited in the literature review.

Based on the Andersen behavioural model for health service use (Ronald Andersen et al 2013) used as the framework for my analysis, the factors found to influence the women's health seeking behaviour as depicted in Figures 2 and 3 (page 130 - 131) interact in a loop fashion. They include predisposing factors related to sociodemographic factors, knowledge and attitude towards breast cancer, economic and social enabling factors, perceived/evaluated health status, the use of health services, the health care system, women's satisfaction with health delivery services and their perceived need for medical care. One finding to note was how issues related to satisfaction with previous medical care encounters and the enabling factors emerged very influential in the process of determining one's need for medical care.

Also of note is how the interpretation of severe illness needing medical attention influenced greatly the timing of when medical care was pursued diligently. This interpretation also influenced how the needed financial and social resource to seek medical care were mobilised. At this time, the significance of all the challenges earlier experienced or anticipated seemed to fade away.

Although all the factors identified contributed to the women's health seeking behaviour, the time when health seeking was initiated, and the manner in which each woman progressed along the health seeking pathway was shaped greatly by the woman's self-determined need to do so after severe illness was inferred. The women had a focus of maintaining a functional life that would not interfere with their social, economic and domestic function in the present as well as in the future. Illness interpretation was greatly rooted in how the symptom identified and experienced affected their functional goals.

## **CHAPTER SEVEN**

### **CONCLUSION**

Presenting to the KATH breast clinic with symptoms clinically suggestive of advanced breast cancer disease is a problem of great concern to clinicians who work in the breast clinic of KATH. In spite of some efforts at increasing breast cancer awareness through community campaigns to encourage self and clinical breast examination, and thus early reporting of breast symptoms, late presentation persists (Ohene-Yeboah & Adjei, 2012). This study was conducted to find the factors that influence the late health seeking behaviour of women with breast cancer symptoms seeking care at Komfo Anokye Teaching Hospital. The purpose of the study was to go beyond identifying the factors that influence their health seeking behaviour to understand how the factors interacted with each other and affect the decision of when to seek care. Ultimately, this was to help identify and suggest strategies that stakeholders could adopt in making breast cancer treatment accessible to Ghanaian women at an early stage and thus suggest interventions that will encourage early access to care.

Women presenting with clinically suspected advanced breast cancer were selected for this study because they would have had the experience of observing their breast symptoms evolve over the period before presenting to KATH. Thus their accounts could potentially offer a better perspective and understanding of the factors influencing their health seeking behaviour. The in depth interviews of the study participants offered a holistic exploration of the health seeking journey for these women. Also, the Andersen behavioural model for health service utilisation (Ronald

Andersen et al., 2013) was applied in analysing their narratives. It presented a framework that allowed a wide consideration of individual and contextual factors that influenced their health seeking behaviour.

The findings from my study offer some understanding into the health seeking behaviour of breast cancer patients seeking care from KATHbc with clinically suspected advanced breast cancer symptoms. First, all the women in this study identified their breast symptom themselves and spent time appraising them to determine what to do. This appraisal time lag contributed to their delay in seeking care. Although some of them had been exposed to breast cancer campaign messages at certain points in time, the information they received from these messages appeared to be of little, and in some cases, no relevance to their appraising process. There was reliance on common knowledge regarding breast illness known either to themselves or others in appraising their symptoms. Second, the women were focused on having a 'functional self' to undertake all their domestic and economic activities. Thus, it took a perceived threat to their life – the tipping point - to pursue health seeking actively. This perception resulted from progression of their symptoms to stages that interfered with their daily lives or quality of life. Prior to this tipping point, the women remained aware of their breast symptom but prioritised other life activities such as work (pursuing their economic livelihoods), care of family or even other personal illness over seeking care for their breast symptom. At the tipping point however, the significance of these issues seemed to fade away compared to the pursuit of care. Third, the women had encounters with the health care system at different times along their health seeking trajectory. System related issues like inadequate and inappropriate communication



with health professionals, investigations performed at different sites and the referral system increased the time it took them to get to KATH breast clinic.

## **Lessons drawn from the study findings and implications for future practice**

### ***The health care system***

Characteristics of health care access, such as the availability of health services, cost of seeking care and travel access to the health facility, are important factors that influence health seeking behaviour. However, making health care accessible may not necessarily ensure that the appropriate care is accessed or provided, and in time as is expected. The structure of the Ghana Health system provides health services even at the community level. To facilitate breast cancer care, there is a national policy to offer free care under the national health insurance scheme. There are also ongoing campaigns, though not coordinated from the national level, to educate women about breast cancer symptoms. In spite of these enabling structures put in place, they do not effectively translate into expected outcomes.

Although the women may have had access to hospitals close to their areas of residence, none of the facilities had the capability to establish the diagnosis of breast cancer with the resources in their facility. Many of these were district hospitals with fully qualified medical doctors. However, they all had to refer to regional hospitals or to laboratories outside their facility for investigations to be carried out. Even in the absence of diagnostic possibilities, the process and nature of care given was inadequate. A great opportunity to support the women through counselling to understand the potential risk of their breast symptom being cancer, the trajectory of care seeking and the benefits of compliance was also missed.

Effective communication is important because findings from my study suggest that, because of their poor knowledge about breast illness, the women monitored their breast symptoms until the onset of suffering drove them to use a health facility. This knowledge was not just that of the women but of all those around her gained through common knowledge, previous personal or second hand experience and from health education. Unfortunately, the information from health education messages for these women were point in time events that were not utilised effectively at the time when they were needed most. Furthermore, there is very limited material on breast cancer education readily available and the women did not have the capacity to access information from print either because of their low literacy levels.

It is evident then, that the health education methods in Ghana have to be revisited. A study to evaluate the impact of a non-governmental organisations' activities to raise breast cancer awareness in Ghana by Mena et al (2014) found that although women who benefitted from those educational campaigns were more motivated to perform breast self-examination, it did not change their misconceptions. These misconceptions included women with no family history of breast cancer are not at risk; and that breast cancer could be caused by evil spirits (Mena et al., 2014). Among the women in my study, there were misconceptions about breast diseases too, such as the expectation that breast swellings will burst and discharge pus, or melt away with the application of locally prepared topical creams. Mena et al (2014) also report that women who had benefitted from the breast cancer messages demonstrated a positive help seeking behaviour by choosing visiting a doctor as the best approach to care. In my study however, the women had the perception that the type of illness needing medical

attention, is that which 'incapacitates you'. As such, in spite of performing self-breast examination to identify their breast symptoms, this attitude to illness resulted in monitoring their symptoms until the symptoms got distressing before they sought help. Mena et al (2014) recommend that more effort be devoted to changing wrong beliefs about breast cancer as a way to encourage early help seeking. It will be useful therefore to study the cultural beliefs about breast illness in Ghana and thence modify the content of our breast cancer messages to address them. Furthermore, efforts must be made to find ways of making educational interventions more engaging for the women.

There is also need for a national protocol for evaluation, diagnosis and treatment of breast symptoms and breast cancer for all levels of healthcare facilities in the country. Such a protocol will define what each health facility is expected to do when a woman presents with breast symptoms and the appropriate referral trajectory to follow. There was no consistency in the pathway from first contact with the health care system until arrival at KATH breast clinic for the women in my study. Some of the women for instance had visited hospitals of similar capacities consecutively (i.e. from one district hospital to another), or from a district hospital to a regional hospital where treatment could still not be offered. Furthermore, none of the women in my study knew they could access KATH breast clinic without a referral. Accessing the nearest health facility for care of breast cancer symptoms may be an inevitable action for women to undertake. However, there must be clear guidelines for health care providers on what actions to take before onward referral. The implementation of such protocol will include training all relevant health professionals on evaluating breast symptoms and

defining what kind of investigative procedures can be performed at each level of care provision. In addition, counsellors can be trained who can guide the women through the care seeking process. This intervention can be piloted in some districts to test its efficiency before implementation as a national protocol. Guidelines for diagnosis, referral and treatment have been implemented in the care for Tuberculosis and HIV/AIDS in the Ghana health delivery system which has improved access to prompt and effective care and follow up for such patients. This can be replicated for breast cancer care.

### ***Palliative care principles and health seeking behaviour***

The paradigm of limiting palliative care to dying patients is changing to the practice of initiating supportive care at the beginning of cancer diagnosis (Caprio, 2016; Parikh et al., 2013). In this way, palliative care serves its goal of prevention and relief of suffering through early identification (Sepúlveda et al., 2002). But supportive care services could be offered even before the establishment of a cancer diagnosis as a way to actually prevent suffering. The findings from my study show that women have distressing experiences even before the diagnosis of cancer is made. My findings also show that, it is the distressing experiences that prompted health seeking. But this can be prevented by tailoring supportive care services based on patient needs, regardless of illness prognosis alongside standard medical care (Parikh et al., 2013). For the women interviewed in my study, effective communication during the hospital visits could potentially influence their help seeking decisions and behaviour. Efficient communication and counselling is a fundamental principle of supportive care, and is a

significant component of palliative care training (Bond, Lavy, & Wolldridge, 2008). Communication from a palliative care perspective involves helping patients understand their clinical conditions, treatment options and how they can be accessed. Furthermore, it offers opportunity to identify any challenges to the care seeking process and guides patients to informed choices. Such communication opportunities are missing in everyday clinical practice. However, it could be a useful intervention in getting women in settings such as that in which my study was performed (i.e. routine breast cancer screening is not available and diagnosis and treatment of breast cancer is heavily dependent on when women self-report) to complete breast cancer diagnosis and treatment plans. As a follow up to my research, it will be useful to study the influence of offering supportive care such as counselling on the health seeking behaviour of women with breast symptoms. It will also be useful to study the influence of supportive care including counselling provided at the initial point of patient and health care system contact on how women progress through the health care system to receive definitive treatment.

### ***Engaging other stakeholders***

Traditional medicine use is a practice that continues to be an integral part of help seeking behaviour of Ghanaians. In my study, 5 women used traditional medicine and 5 used locally prepared topical creams at some point in their help seeking process. Interestingly, all the spiritual leaders and some of the community traditional healers who were consulted by some of the women in my study immediately advised that the women seek care in the hospital. Currently, the Ghana health system is integrating traditional/herbal medicine into orthodox health care by introducing herbal medicine training at tertiary level of education and setting up traditional treatment centers in

hospitals. These traditional medicine practitioners must be trained to evaluate breast symptoms appropriately. Also, there must be clear guidelines on how women can access other breast cancer treatment not available in the traditional medicine centres without delay. Again, breast cancer campaigns should include messages that offer individuals the opportunity to access care from approved traditional medicine centres.

Finally, the accounts of these women suggest that, probably the 'catalyst' to seeking care for self-identified breast symptoms is distressing experiences resulting from the progression of the symptom that was initially perceived as not serious. At this point, they would mobilise the needed resources to access and pursue care. They would even self-refer to the health facility they believed would offer the care they were seeking. At this point also, it was noted that the significance of factors related to socioeconomic status faded when there was the perceived threat to life. Much as the contribution of the socioeconomic factors to delay cannot be overlooked, it appears from the findings in my study that, given the appropriate 'catalyst', the women made every effort to overcome them to access care. For the women in my study, this 'catalyst' was their distressing experiences that affected their daily activity and quality of life. Further studies are needed to explore the cultural phenomena that define breast illness and thus stimulate women's health seeking behaviour for breast cancer symptoms.

## **REFERENCES**

- Abdel-Fattah, M. M., ANWAR, M. A., MARI, E., EL-SHAZLY, M. K., ZAKI, A. A., BEDWANI, R. N., & NICOLUCCI, A. (1999). Patient-and system-related diagnostic delay in breast cancer. *The European Journal of Public Health, 9*(1), 15-19.
- Adam, D., & Soutar, G. N. (2003). The impact of self-discovered breast changes: some qualitative evidence.
- Adam, S., Horner, J., & Vessey, M. (1980). Delay in treatment for breast cancer. *Journal of public health, 2*(3), 195-201.
- Adesunkanmi, A., Lawal, O., Adelusola, K., & Durosimi, M. (2006). The severity, outcome and challenges of breast cancer in Nigeria. *The Breast, 15*(3), 399-409.
- Agbokey, F. (2014). *Health Seeking Behaviours for Breast Cancer among Breast Cancer Patients at the Komfo Anokye Teaching Hospital, Kumasi, Ghana*. University of Ghana.
- Alhurishi, S., Lim, J., Potrata, B., & West, R. (2011). Factors influencing late presentation for breast cancer in the middle East: a systematic review. *Asian Pac J Cancer Prev, 12*(6), 1597-1600.
- Ali, R., Mathew, A., & Rajan, B. (2008). Effects of socio-economic and demographic factors in delayed reporting and late-stage presentation among patients with breast cancer in a major cancer hospital in South India. *Asian Pac J Cancer Prev, 9*(4), 703-707.
- Andersen, B. L., Cacioppo, J., & Roberts, D. C. (1995). Delay in seeking a cancer diagnosis: delay stages and psychophysiological comparison processes. *British journal of social psychology, 34*, 33-33.
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter? *Journal of health and social behavior, 36*(1), 1-10.
- Andersen, R. M. (2008). National health surveys and the behavioral model of health services use. *Medical care, 46*(7), 647-653.
- Andersen, R. M., Davidson, P. L., & Baumeister, S. E. (2013). Improving access to care *Changing the US health care system: Key issues in health services policy and management* (pp. 33 - 69).
- Andersen, R. S., Vedsted, P., Olesen, F., Bro, F., & Søndergaard, J. (2009). Patient delay in cancer studies: a discussion of methods and measures. *BMC health services research, 9*(1), 189.
- Angus, J., Miller, K.-L., Pulfer, T., & McKeever, P. (2006). *Studying delays in breast cancer diagnosis and treatment: critical realism as a new foundation for inquiry*. Paper presented at the Oncology nursing forum.
- Angus, J., Paszat, L., McKeever, P., Trebilcock, A., Shivji, F., & Edwards, B. (2007). Pathways to breast cancer diagnosis and treatment: exploring the social relations of diagnostic delay. *Texts & Contexts-Enfermagem, 16*(4), 591-598.
- Archer, M. S. (2003). *Structure, agency and the internal conversation*: Cambridge University Press.
- Arman, M., Rehnsfeldt, A., Lindholm, L., & Hamrin, E. (2002). The face of suffering among women with breast cancer—being in a field of forces. *Cancer Nursing, 25*(2), 96-103.
- Arndt, V., Stürmer, T., Stegmaier, C., Ziegler, H., Dhom, G., & Brenner, H. (2002). Patient delay and stage of diagnosis among breast cancer patients in Germany—a population based study. *British journal of cancer, 86*(7), 1034-1040.
- Asobayire, A., & Barley, R. (2014). Women's cultural perceptions and attitudes towards breast cancer: Northern Ghana. *Health promotion international, dat087*.
- Asoogo, C., & Duma, S. E. (2015). Factors contributing to late breast cancer presentation for health care amongst women in Kumasi, Ghana. *curationis, 38*(1), 1-7.

- Asumanu, E., Vowotor, R., & Naaeder, S. (2000). Pattern of breast diseases in Ghana. *Ghana Med J*, 34, 206-209.
- Babitsch, B., Gohl, D., & von Lengerke, T. (2012). Re-revisiting Andersen's Behavioral Model of Health Services Use: a systematic review of studies from 1998–2011. *GMS Psycho-Social-Medicine*, 9.
- Barg, F. K., & Grier, S. A. (2008). Enhancing breast cancer communications: A cultural models approach. *International Journal of Research in Marketing*, 25(4), 335-342.
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*: Oxford university press.
- Birbili, M. (2000). Translating from one language to another. *Social Research Update*, 31(1), 1-7.
- Bish, A., Ramirez, A., Burgess, C., & Hunter, M. (2005). Understanding why women delay in seeking help for breast cancer symptoms. *Journal of psychosomatic research*, 58(4), 321-326.
- Blaikie, N. (2004). *Retrodution* (A. B. M. S. Lewis-Beck, T. F. Liao Ed.): SAGE Publications, Inc. Thousand Oaks CA.
- Bond, C., Lavy, V., & Wolldridge, R. (2008). *Palliative care toolkit: improving care from the roots up in resource-limited settings*: Help the Hospices.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Brinton, L. A., Figueroa, J. D., Awuah, B., Yarney, J., Wiafe, S., Wood, S. N., . . . Clegg-Lampsey, J. N. (2014). Breast cancer in Sub-Saharan Africa: opportunities for prevention. *Breast cancer research and treatment*, 144(3), 467-478.
- Bryman, A. (2012). *Social research methods*: Oxford university press.
- Burgess, C., Hunter, M. S., & Ramirez, A. J. (2001). A qualitative study of delay among women reporting symptoms of breast cancer. *British Journal of General Practice*, 51(473), 967-971.
- Burgess, C., Potts, H., Hamed, H., Bish, A., Hunter, M., Richards, M., & Ramirez, A. (2006). Why do older women delay presentation with breast cancer symptoms? *Psycho-Oncology*, 15(11), 962-968.
- Burgess, C., Ramirez, A., Richards, M., & Love, S. (1998). Who and what influences delayed presentation in breast cancer? *British journal of cancer*, 77(8), 1343.
- Byrne, S. K. (2008). Healthcare avoidance: a critical review. *Holistic Nursing Practice*, 22(5), 280-292.
- Caplan, L. S., May, D. S., & Richardson, L. C. (2000). Time to diagnosis and treatment of breast cancer: results from the National Breast and Cervical Cancer Early Detection Program, 1991-1995. *American journal of public health*, 90(1), 130.
- Capozzi, J. D., & Rhodes, R. (2000). Ethics in Practice Paternalism. *The Journal of Bone & Joint Surgery*, 82(7), 1050-1050.
- Caprio, A. J. (2016). Palliative care: renaming as supportive care and integration into comprehensive cancer care. *Canadian Medical Association Journal*, cmaj. 160206.
- Chen, A. W., Kazanjian, A., & Wong, H. (2008). Determinants of mental health consultations among recent Chinese immigrants in British Columbia, Canada: Implications for mental health risk and access to services. *Journal of immigrant and minority health*, 10(6), 529-540.
- Chen, H. Y., & Boore, J. R. (2010). Translation and back-translation in qualitative nursing research: methodological review. *Journal of clinical nursing*, 19(1-2), 234-239.
- Clark, T. (2011). Gaining and Maintaining Access Exploring the Mechanisms that Support and Challenge the Relationship between Gatekeepers and Researchers. *Qualitative Social Work*, 10(4), 485-502.



- Clarke, A. (2006). Qualitative interviewing: Encountering ethical issues and challenges. *Nurse Researcher, 13*(4), 19-29.
- Clegg-Lamprey, J., Dakubo, J., & Attobra, Y. (2009). During treatment in Ghana? A pilot study. *Ghana medical journal, 43*(3).
- Clegg-Lamprey, J. N. A., & Hodasi, W. M. (2007). A study of breast cancer in Korle Bu Teaching Hospital: Assessing the impact of health education. *Ghana medical journal, 41*(2).
- Corbin, J., & Morse, J. M. (2003). The unstructured interactive interview: Issues of reciprocity and risks when dealing with sensitive topics. *Qualitative inquiry, 9*(3), 335-354.
- Coyle, A., & Wright, C. (1996). Using the counselling interview to collect research data on sensitive topics. *Journal of Health Psychology, 1*(4), 431-440.
- de Nooijer, J., Lechner, L., & de Vries, H. (2001). A qualitative study on detecting cancer symptoms and seeking medical help; an application of Andersen's model of total patient delay. *Patient education and counseling, 42*(2), 145-157.
- Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2006). Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research, 16*(6), 853-871.
- Dobson, C. M., Russell, A. J., & Rubin, G. P. (2014). Patient delay in cancer diagnosis: what do we really mean and can we be more specific? *BMC health services research, 14*(1), 387.
- Dollard, M., Winefield, H. R., & Winefield, A. H. (2003). *Occupational stress in the service professions*: CRC Press.
- Donkor, A., Lathlean, J., Wiafe, S., Vanderpuye, V., Fenlon, D., Yarney, J., . . . Kyei, W. A. K. A. (2016). Factors Contributing to Late Presentation of Breast Cancer in Africa: A Systematic Literature Review. *Archives of Medicine*.
- Dowling, M., (2006). Approaches to reflexivity in qualitative research. *Nurse Researcher, 13*(3).
- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), 148-158.
- Dye, T. D., Bogale, S., Hobden, C., Tilahun, Y., Deressa, T., & Reeler, A. (2012). Experience of initial symptoms of breast cancer and triggers for action in ethiopia. *International journal of breast cancer, 2012*.
- Dye, T. D., Bogale, S., Hobden, C., Tilahun, Y., Hechter, V., Deressa, T., . . . Reeler, A. (2010). Complex care systems in developing countries. *Cancer, 116*(3), 577-585.
- Eide, P., & Allen, C. B. (2005). Recruiting Transcultural Qualitative Research Participants: A Conceptual Model. *International Journal of Qualitative Methods, 4*, 2.
- Elzawawy, A. M., Elbahaie, A. M., Dawood, S. M., Elbahaie, H. M., & Badran, A. (2008). Delay in seeking medical advice and late presentation of female breast cancer patients in most of the world. Could we make changes? The experience of 23 years in Port Said, Egypt. *Breast Care, 3*(1), 37-41.
- Emanuel, E. J., Wendler, D., & Grady, C. (2000). What makes clinical research ethical? *Jama, 283*(20), 2701-2711.
- Etherington, K. (1996). The counsellor as researcher: boundary issues and critical dilemmas. *British Journal of Guidance and Counselling, 24*(3), 339-346.
- Etherington, K. (2001). Research with ex-clients: a celebration and extension of the therapeutic process. *British Journal of Guidance and Counselling, 29*(1), 5-19.
- Ezeome, E. (2010). Delays in presentation and treatment of breast cancer in Enugu, Nigeria. *Nigerian journal of clinical practice, 13*(3).
- Facione, N. C. (1993). Delay versus help seeking for breast cancer symptoms: a critical review of the literature on patient and provider delay. *Social Science & Medicine, 36*(12), 1521-1534.

- Facione, N. C., & Facione, P. A. (2006). The cognitive structuring of patient delay in breast cancer. *Social Science & Medicine*, *63*(12), 3137-3149.
- Facione, N. C., Miaskowski, C., Dodd, M. J., & Paul, S. M. (2002). The self-reported likelihood of patient delay in breast cancer: new thoughts for early detection. *Preventive medicine*, *34*(4), 397-407.
- Fadul, N., Elsayem, A., Palmer, J. L., Del Fabbro, E., Swint, K., Li, Z., . . . Bruera, E. (2009). Supportive versus palliative care: What's in a name? *Cancer*, *115*(9), 2013-2021.
- Ferlay, J., Shin, H. R., Bray, F., Forman, D., Mathers, C., & Parkin, D. M. (2010). Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *International journal of cancer*, *127*(12), 2893-2917.
- Fregene, A., & Newman, L. A. (2005). Breast cancer in sub-Saharan Africa: How does it relate to breast cancer in African-American women? *Cancer*, *103*(8), 1540-1550.
- Fujimori, M., & Uchitomi, Y. (2009). Preferences of cancer patients regarding communication of bad news: a systematic literature review. *Japanese journal of clinical oncology*, *39*(4), 201-216.
- Gelberg, L., Andersen, R. M., & Leake, B. D. (2000). The Behavioral Model for Vulnerable Populations: application to medical care use and outcomes for homeless people. *Health services research*, *34*(6), 1273.
- Ghazali, S. M., Othman, Z., Cheong, K. C., Lim, K. H., Wan, M., Wan, R., . . . Mustafa, A. N. (2013). Non-practice of breast self examination and marital status are associated with delayed presentation with breast cancer. *Asian Pacific Journal of Cancer Prevention*, *14*(2), 1141-1145.
- Graham, A., Hasking, P., Brooker, J., Clarke, D., & Meadows, G. (2017). Mental health service use among those with depression: an exploration using Andersen's Behavioral Model of Health Service Use. *Journal of Affective Disorders*, *208*, 170-176.
- Granek, L., & Fergus, K. (2012). Resistance, agency, and liminality in women's accounts of symptom appraisal and help-seeking upon discovery of a breast irregularity. *Social Science & Medicine*, *75*(10), 1753-1761.
- Griffiths, S. P. (2003). Stress in psychological work. *Occupational stress in the service professions*, 359-388.
- Grinyer, A. (2004). The narrative correspondence method: What a follow-up study can tell us about the longer term effect on participants in emotionally demanding research. *Qualitative Health Research*, *14*(10), 1326-1341.
- Grunfeld, E. A., Hunter, M. S., Ramirez, A. J., & Richards, M. A. (2003). Perceptions of breast cancer across the lifespan. *Journal of psychosomatic research*, *54*(2), 141-146.
- Gwyn, K., Bondy, M. L., Cohen, D. S., Lund, M. J., Liff, J. M., Flagg, E. W., . . . Coates, R. J. (2004). Racial differences in diagnosis, treatment, and clinical delays in a population-based study of patients with newly diagnosed breast carcinoma. *Cancer*, *100*(8), 1595-1604.
- Hagerty, R., Butow, P., Ellis, P., Dimitry, S., & Tattersall, M. (2005). Communicating prognosis in cancer care: a systematic review of the literature. *Annals of Oncology*, *16*(7), 1005-1053.
- Harirchi, I., Ghaemmaghami, F., Karbakhsh, M., Moghimi, R., & Mazaherie, H. (2005). Patient delay in women presenting with advanced breast cancer: an Iranian study. *Public Health*, *119*(10), 885-891.
- Hay, M. C. (2008). Reading Sensations: Understanding the Process of Distinguishing 'Fine' from 'Sick'. *Transcultural psychiatry*, *45*(2), 198-229.
- Holloway, I., & Wheeler, S. (1995). Ethical issues in qualitative nursing research. *Nursing Ethics*, *2*(3), 223-232.
- Ibrahim, N., & Oludara, M. (2012). Socio-demographic factors and reasons associated with delay in breast cancer presentation: a study in Nigerian women. *The Breast*, *21*(3), 416-418.

- Innos, K., Padrik, P., Valvere, V., Eelma, E., Kütner, R., Lehtsaar, J., & Tekkel, M. (2013). Identifying women at risk for delayed presentation of breast cancer: a cross-sectional study in Estonia. *BMC public health*, *13*(1), 947.
- Insaf, T. Z., Jurkowski, J. M., & Alomar, L. (2010). SOCIOCULTURAL FACTORS INFLUENCING DELAY IN SEEKING ROUTINE HEALTH CARE AMONG LATINAS: A Community-BASED PARTICIPATORY RESEARCH STUDY. *Ethnicity & disease*, *20*(2), 148-154.
- Iskandarsyah, A., de Klerk, C., Suardi, D. R., Soemitro, M. P., Sadarjoen, S. S., & Passchier, J. (2014). Psychosocial and cultural reasons for delay in seeking help and nonadherence to treatment in Indonesian women with breast cancer: A qualitative study. *Health Psychology*, *33*(3), 214.
- Ismail, G. M., Abd El Hamid, A., & Abd El Naby, A. (2013). Assessment of factors that hinder early detection of breast cancer among females at Cairo University Hospital. *World Applied Sciences Journal*, *23*(1), 99-108.
- Johnson, B., & Clarke, J. M. (2003). Collecting sensitive data: The impact on researchers. *Qualitative Health Research*, *13*(3), 421-434.
- Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, *19*(11), 1632-1641.
- Kelley, A. S., & Meier, D. E. (2010). Palliative care—a shifting paradigm. *New England Journal of Medicine*, *363*(8), 781-782.
- Khakbazan, Z., Taghipour, A., Roudsari, R. L., Mohammadi, E., & Omranipour, R. (2014a). Delayed Presentation of Self-discovered Breast Cancer Symptoms in Iranian Women: A Qualitative Study. *Asian Pacific journal of cancer prevention: APJCP*, *15*(21), 9427.
- Kohler, R. E., Gopal, S., Miller, A. R., Lee, C. N., Reeve, B. B., Weiner, B. J., & Wheeler, S. B. (2017). A framework for improving early detection of breast cancer in sub-Saharan Africa: A qualitative study of help-seeking behaviors among Malawian women. *Patient education and counseling*, *100*(1), 167-173.
- Korboe, D., & Tipple, G. (1993). The Family House in West Africa: A Forgotten Resource for Policy-Makers? *Third World Planning Review*, *15*(4), 355-372.
- Kumari, P., & Goonewardena, C. (2011). Delay among women reporting symptoms of Breast cancer. *J Coll Community Physicians Sri Lanka*, *16*, 17-22.
- Lai, C.-Y., Lai, C.-M., Chen, C.-Y., & Koo, M. (2012). Factors associated with non-utilization of mammographic screening services in middle-aged and elderly women in Taiwan. *Hu Li Za Zhi*, *59*(2), 61.
- Lam, W., Tsuchiya, M., Chan, M., Chan, S., Or, A., & Fielding, R. (2008). Help-seeking patterns in Chinese women with symptoms of breast disease: a qualitative study. *Journal of public health*.
- Lannin, D. R., Mathews, H. F., Mitchell, J., Swanson, M. S., Swanson, F. H., & Edwards, M. S. (1998). Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. *JAMA : the journal of the American Medical Association*, *279*(22), 1801.
- Lauver, D., Coyle, M., & Panchmatia, B. (1995). Women's reasons for and barriers to seeking care for breast cancer symptoms. *Women's Health Issues*, *5*(1), 27-35.
- Li, W. W., Lam, W. W., Wong, J. H., Chiu, A., Chan, M., Or, A., . . . Fielding, R. (2012). Waiting to see the doctor: understanding appraisal and utilization components of consultation delay for new breast symptoms in Chinese women. *Psycho-Oncology*, *21*(12), 1316-1323.
- Lillington, L., Johnson, I., & Chlebowski, R. (2000). African-American women's perspectives on research participation. *Medicine of the Americas*, *1*(1), 20-20.
- Lim, J. N. (2011). Empirical Comparisons of patient delay and help seeking models for breast cancer: fitness of models for use and generalisation. *Asian Pacific Journal of Cancer Prevention*, *12*(6), 1589-1595.

- Lupton, D. (1994). Medicine as culture. Illness, disease and the body in western societies.
- Macleod, U., Mitchell, E., Burgess, C., Macdonald, S., & Ramirez, A. (2009). Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *British journal of cancer*, *101*, S92-S101.
- Malik, A. M., Pathan, R., Shaikh, N. A., Qureshi, J. N., & Talpur, K. A. H. (2010). Pattern of presentation and management of Ca breast in developing countries. There is a lot to do. *JPMA*, *60*(718).
- Malik, I. A., & Gopalan, S. (2003). Use of CAM results in delay in seeking medical advice for breast cancer. *European journal of epidemiology*, *18*(8), 817-822.
- Mays, N., Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, *320*(7226).
- McAreavey, R., & Das, C. (2013). A Delicate Balancing Act: Negotiating with Gatekeepers for Ethical Research When Researching Minority Communities. *International Journal of Qualitative Methods*, *12*, 113-131.
- McEvoy, P., & Richards, D. (2006). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of Research in Nursing*, *11*(1), 66-78.
- Meadows, L., Lagendyk, L., Thurston, W., & Eisener, A. (2008). Balancing culture, ethics, and methods in qualitative health research with aboriginal peoples. *International Journal of Qualitative Methods*, *2*(4), 1-14.
- Meechan, G., Collins, J., & Petrie, K. (2002). Delay in seeking medical care for self-detected breast symptoms in New Zealand women. *The New Zealand Medical Journal (Online)*, *115*(1166).
- Meechan, G., Collins, J., & Petrie, K. J. (2003). The relationship of symptoms and psychological factors to delay in seeking medical care for breast symptoms. *Preventive medicine*, *36*(3), 374-378.
- Memon, Z. A., Shaikh, A. N., Rizwan, S., & Sardar, M. B. (2013). Reasons for patient's delay in diagnosis of breast carcinoma in Pakistan. *Asian Pac J Cancer Prev*, *14*, 7409-7414.
- Mena, M., Wiafe-Addai, B., Sauvaget, C., Ali, I. A., Wiafe, S. A., Dabis, F., . . . Sasco, A. J. (2014). Evaluation of the impact of a breast cancer awareness program in rural Ghana: A cross-sectional survey. *International journal of cancer*, *134*(4), 913-924. doi:10.1002/ijc.28412
- Montazeri, A., Ebrahimi, M., Mehrdad, N., Ansari, M., & Sajadian, A. (2003). Delayed presentation in breast cancer: a study in Iranian women. *BMC women's health*, *3*(1), 4.
- Moody, L. E., & McMillan, S. (2002). Maintaining data integrity in randomized clinical trials. *Nursing research*, *51*(2), 129-133.
- Morén, S., & Blom, B. (2003). Explaining Human Change. *Journal of Critical Realism*, *2*(1), 37-60.
- Mousa, S. M., Seifeldin, I. A., Hablas, A., Elbana, E. S., & Soliman, A. S. (2011). Patterns of seeking medical care among Egyptian breast cancer patients: relationship to late-stage presentation. *The Breast*, *20*(6), 555-561.
- Norsa'adah, B., Rahmah, M. A., Rampal, K. G., & Knight, A. (2012). Understanding barriers to Malaysian women with breast cancer seeking help. *Asian Pacific Journal of Cancer Prevention*, *13*(8), 3723-3730.
- Nosarti, C., Crayford, T., Roberts, J., Elias, E., McKenzie, K., & David, A. (2000). Delay in presentation of symptomatic referrals to a breast clinic: patient and system factors. *British journal of cancer*, *82*(3), 742.
- Nunokoosing, K. (2005). The problems with interviews. *Qualitative Health Research*, *15*(5), 698-706.

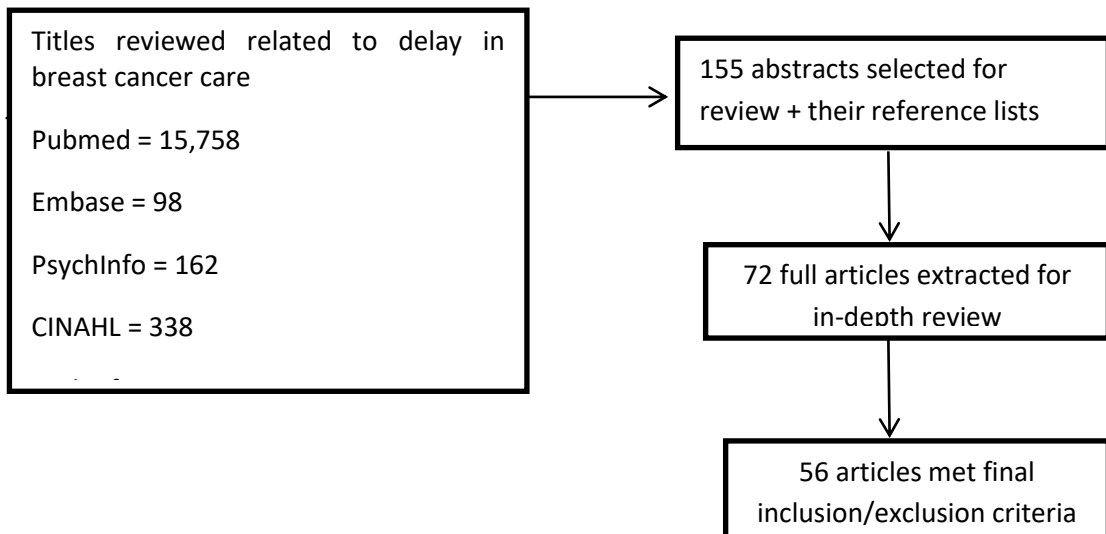
- O'Mahony, M., & Hegarty, J. (2009b). *Help seeking for cancer symptoms: a review of the literature*. Paper presented at the Oncology nursing forum.
- O'Mahony, M., McCarthy, G., Corcoran, P., & Hegarty, J. (2013). Shedding light on women's help seeking behaviour for self discovered breast symptoms. *European Journal of Oncology Nursing, 17*(5), 632-639.
- O'Mahony, M., & Hegarty, J. (2009a). Factors influencing women in seeking help from a health care professional on self discovery of a breast symptom, in an Irish context. *Journal of clinical nursing, 18*(14), 2020-2029.
- O'Mahony, M., Hegarty, J., & McCarthy, G. (2011). Women's help seeking behaviour for self discovered breast cancer symptoms. *European Journal of Oncology Nursing, 15*(5), 410-418.
- Ohene-Yeboah, M., & Adjei, E. (2012). Breast cancer in Kumasi, Ghana. *Ghana medical journal, 46*(1), 8.
- Oka, T., & Shaw, I. (2000). Qualitative research in social work. Retrieved November, 11, 2003.
- Opoku, S. Y., Benwell, M., & Yarney, J. (2012). Knowledge, attitudes, beliefs, behaviour and breast cancer screening practices in Ghana, West Africa. *Pan African Medical Journal, 11*(1).
- Otieno, E., Micheni, J., Kimende, S., & Mutai, K. (2010). Delayed presentation of breast cancer patients. *East African medical journal, 87*(4), 147-150.
- Pack, G. T., & Gallo, J. S. (1938). The culpability for delay in the treatment of cancer. *The American Journal of Cancer, 33*(3), 443-462.
- Parikh, R. B., Kirch, R. A., Smith, T. J., & Temel, J. S. (2013). Early specialty palliative care—translating data in oncology into practice. *New England Journal of Medicine, 369*(24), 2347-2351.
- Piñeros, M., Sánchez, R., Cendales, R., Perry, F., & Ocampo, R. (2009). Patient delay among Colombian women with breast cancer. *salud pública de méxico, 51*(5), 372-380.
- Porteous, T., Wyke, S., Hannaford, P., & Bond, C. (2015). Self-care behaviour for minor symptoms: can Andersen's Behavioral Model of Health Services Use help us to understand it? *International Journal of Pharmacy Practice, 23*(1), 27-35.
- Poum, A., Promthet, S., Duffy, S. W., & Parkin, D. M. (2014). Factors associated with delayed diagnosis of breast cancer in northeast Thailand. *Journal of Epidemiology, 24*(2), 102.
- Powe, B. D., & Finnie, R. (2003). Cancer fatalism: the state of the science. *Cancer Nursing, 26*(6), 454-467.
- Ramirez, A., Westcombe, A., Burgess, C., Sutton, S., Littlejohns, P., & Richards, M. (1999). Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. *The Lancet, 353*(9159), 1127-1131.
- Rastad, H., Khanjani, N., & Khandani, B. K. (2012). Causes of delay in seeking treatment in patients with breast cancer in Iran: a qualitative content analysis study. *Asian Pacific Journal of Cancer Prevention, 13*(9), 4511-4515.
- Rauscher, G. H., Ferrans, C. E., Kaiser, K., Campbell, R. T., Calhoun, E. E., & Warnecke, R. B. (2010). Misconceptions about breast lumps and delayed medical presentation in urban breast cancer patients. *Cancer Epidemiology Biomarkers & Prevention, 19*(3), 640-647.
- Reifenstein, K. (2007). Care-seeking behaviors of African American women with breast cancer symptoms. *Research in nursing & health, 30*(5), 542-557.
- Richards, H. M., & Schwartz, L. J. (2002). Ethics of qualitative research: are there special issues for health services research? *Family Practice, 19*(2), 135-139.
- Richards, M., Westcombe, A., Love, S., Littlejohns, P., & Ramirez, A. (1999). Influence of delay on survival in patients with breast cancer: a systematic review. *The Lancet, 353*(9159), 1119-1126.

- Ruddy, K. J., Gelber, S., Tamimi, R. M., Schapira, L., Come, S. E., Meyer, M. E., . . . Partridge, A. H. (2014). Breast cancer presentation and diagnostic delays in young women. *Cancer, 120*(1), 20-25.
- Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods, 15*(1), 85-109.
- Scambler, G. (2001). Critical realism, sociology and health inequalities: social class as a generative mechanism and its media of enactment. *Alethia, 4*(1), 35-42.
- Schomerus, G., Appel, K., Meffert, P. J., Lupp, M., Andersen, R. M., Grabe, H. J., & Baumeister, S. E. (2013). Personality-related factors as predictors of help-seeking for depression: a population-based study applying the behavioral model of health services use. *Social psychiatry and psychiatric epidemiology, 48*(11), 1809-1817.
- Sepúlveda, C., Marlin, A., Yoshida, T., & Ullrich, A. (2002). Palliative care: the World Health Organization's global perspective. *Journal of pain and symptom management, 24*(2), 91-96.
- Sharma, K., Costas, A., Shulman, L. N., & Meara, J. G. (2012). A systematic review of barriers to breast cancer care in developing countries resulting in delayed patient presentation. *Journal of oncology, 2012*.
- Silverman, D. (2013). *Doing qualitative research: A practical handbook*: SAGE Publications Limited.
- Silverstein, L. B., Auerbach, C. F., & Levant, R. F. (2006). Using qualitative research to strengthen clinical practice. *Professional Psychology: Research and Practice, 37*(4), 351.
- Singletary, S. E., Allred, C., Ashley, P., Bassett, L. W., Berry, D., Bland, K. I., . . . Hayes, D. F. (2002). Revision of the American Joint Committee on Cancer staging system for breast cancer. *Journal of clinical oncology, 20*(17), 3628-3636.
- Sloan, F. A., & Gelband, H. (2007). The Cancer Burden in Low-and Middle-Income Countries and How It Is Measured.
- Stapleton, J. M., Mullan, P. B., Dey, S., Hablas, A., Gaafar, R., Seifeldin, I. A., . . . Soliman, A. S. (2011). Patient-mediated factors predicting early- and late-stage presentation of breast cancer in Egypt. *Psycho-Oncol., 20*(5), 532-537. doi:10.1002/pon.1767
- Stark, A., Kleer, C. G., Martin, I., Awuah, B., Nsiah-Asare, A., Takyi, V., . . . Wicha, M. (2010). African ancestry and higher prevalence of triple-negative breast cancer. *Cancer, 116*(21), 4926-4932.
- Straughan, P. T., & Seow, A. (1998). Fatalism reconceptualized: a concept to predict health screening behavior. *Journal of Gender, Culture and Health, 3*(2), 85-100.
- Sutton, L. B., Erlen, J. A., Glad, J. M., & Siminoff, L. A. (2003). Recruiting vulnerable populations for research: revisiting the ethical issues. *Journal of Professional Nursing, 19*(2), 106-112.
- Taib, N. A., Yip, C.-H., & Low, W.-Y. (2011). Recognising symptoms of breast Cancer as a reason for delayed presentation in Asian women-The Psycho-socio-cultural Model for breast symptom appraisal: opportunities for intervention. *Asian Pac J Cancer Prev, 12*(6), 1601-1608.
- Taib, N. A., Yip, C. H., & Low, W. Y. (2014). A grounded explanation of why women present with advanced breast cancer. *World journal of surgery, 38*(7), 1676-1684.
- Talpur, A. A., Surahio, A. R., Ansari, A., & Ghumro, A. A. (2011). Late presentation of breast cancer: A Dilemma. *JPMA-Journal of the Pakistan Medical Association, 61*(7), 662.
- Thynne, C. (2010). Research with Vulnerable Groups: Collaboration as an Ethical Response. *Journal of Social Work Values and Ethics, 7*(2).
- Tolich, M. (2004). Internal confidentiality: When confidentiality assurances fail relational informants. *Qualitative Sociology, 27*(1), 101-106.

- Unger-Saldaña, K., & Infante-Castañeda, C. (2009). Delay of medical care for symptomatic breast cancer: a literature review. *salud pública de méxico*, 51, s270-s285.
- Unger-Saldaña, K., & Infante-Castañeda, C. B. (2011). Breast cancer delay: a grounded model of help-seeking behaviour. *Social Science & Medicine*, 72(7), 1096-1104.
- Wanat, C. L. (2008). Getting past the gatekeepers: Differences between access and cooperation in public school research. *Field Methods*.
- Willig, C. (2013). *Introducing qualitative research in psychology*: McGraw-Hill International.
- Wiredu, E. K., & Armah, H. B. (2006). Cancer mortality patterns in Ghana: a 10-year review of autopsies and hospital mortality. *BMC public health*, 6(1), 159.
- Wu, S. F. (2006). A two-stage translation and test the validity and reliability of a foreign instrument. *Hu li za zhi The journal of nursing*, 53(1), 65-71.
- Young, J. T. (2004). Illness behaviour: a selective review and synthesis. *Sociology of health & illness*, 26(1), 1-31.

## APPENDICES

### Appendix I: Study selection flow chart





## Appendix II: Summary of data extracted for literature review

AUTHOR/YEAR	REGION	NUMBER OF PARTICIPANTS	STUDY DESIGN	FACTORS INFLUENCING DELAYED CARE SEEKING
Ruddy et al 2014	America	487	Quant	Poor financial status; race; education; employment/marital status; family history
Poum et al 2014	Thailand	180	Quant	high family income, smoking, disclosure to family/friend, previous breast symptoms
Khakbazan et al 2014	Iran	20	QUAL	Attributing symptoms to benign conditions; conditional health behaviour, psychological factors; indecision about where to seek care
Iskandarsyah et al 2014	Indonesia	35	QUAL	Poor Knowledge of disease/treatment; financial problems; poor patient-provider communication
Innos et al 2013	Estonia	703	Quant	Educational status; older age; previous breast disease/mammogram; nature of breast symptom
Sharma et al 2013	Haiti	90	Quant	Low education; older age; unserious symptom; fear of examination/treatment/cost of treatment
Memon et al 2013	Pakistan	100	Quant	Education/Marital status; Nature of symptom; competing priorities; Family history; use of alternative medicine; fear of mastectomy

Ghazali et al 2013	Malaysia	236	Quant	Education/Marital/Income status; Ethnicity; Breast self examination practices
Ibrahim and Oludara 2012	Nigeria	201	Quant	Education/Marital status; Previous history; knowledge about disease; religion; parity; age; fear of mastectomy; belief in herbal treatment
Li et al 2012	Hong kong	425	Quant	Unserious symptoms; financial problems; who/where to seek help; competing priorities
Rastad et al 2012	Iran	10	QUAL	Poor knowledge; competing priorities; fear of cancer diagnosis; personal risk perception
Norsa'adah et al 2012	Malaysia	12	QUAL	Poor knowledge; fear of cancer consequences; use of CAM; sanctioning form others; competing priorities; denial; weak healthcare provider and system
Granek and Fergus 2012	Canada	14	QUAL	Deliberate ignorance; doing the right thing; passive resistance
Dye et al 2012	Ethiopia	69	Mixed	Worsening symptoms
Talpur et al 2011	Pakistan	60	Quant	Economic/education status; delayed referral

Stapleton et al 2011	Egypt	158	Quant	Nature of symptom; BSE; distance to hospital; health facility first attended
Mousa et al 2011	Egypt	163	Quant	Lump 1st symptom; age; education/residential status; family history; healthcare trajectory
Kumari and Goonewardena 2011	Sri Lanka	335	Quant	Elderly age; Marital/income/educational/employment status; distance/cost of travel; non lump first symptom
Yau et al 2010	Hong Kong	158	Quant	Family income; care in public hospitals
Otieno et al 2010	Kenya	166	Quant	Use traditional healers; reassurance by medical personnel; nature of symptom; fear of diagnosis
Malik et al 2010	Pakistan	103	Quant	Rural residence; Family customs; reluctance to expose self to doctors
Ezeome 2010	Nigeria	162	Quant	Poor knowledge; alternative medicine; social/domestic priorities; family/friends discourage; age; socioeconomic/marital/residential status; history of breast disease
Gullate et al 2010	America	129	Quant	Religion; talking to spirituality; cancer fatalism

O'Mahony and Hegarty 2009	Ireland	99	Quant	Poor knowledge; complex life style; GP appointment; symptom type; sociodemographic factors; family history; social support
Ali et al 2008	India	522	Quant	Marital/education status; older age
Pineros et al 2009	Columbia	891	Quant	Education status; older age; housing type; affiliation to health facility; symptom unserious
Elzawawy 2008	Egypt	349	Quant	Fear of socioeconomic consequence of cancer diagnosis/pain/death/disfigurement; fatalism
Burgess et al 2006	UK	69	Mixed	Type of symptom; GP appointment; non disclosure; fear of diagnosis and treatment consequences; competing priorities
Montazeri et al 2003	Iran	190	Quant	Marital/education status; age; nature of first symptom; history of breast disease; household type
Meechan et al 2003	Australia	85	Quant	Age/Marital/Education status; knowledge of others; type of symptom; fear of treatment; BSE
Malik and Goplan 2003	Pakistan	138	Quant	Use of CAM; Fear of surgery/cancer; symptom unserious; competing priorities;

Meechan et al 2002	Australia	85	Quant	Age/Marital/Education status; knowledge of other+E13s; type of symptom; fear of treatment; BSE
Arndt et al 2002	Germany	287	Quant	Older age; history of breast disease; obesity; access to out-patient gynaecologist; participation in general health screening
Burgess et al 2001	UK	46	QUAL	Symptom interpretation; GP attendance; beliefs about treatment; competing priorities
Burgess et al 2000	UK	158	Quant	Life events; depression/anxiety about diagnosis
Nosarti et al 2000	UK	692	Quant	Symptom unserious; psychosocial factors; fear of diagnosis
Burgess et al 1998	UK	185	Quant	Type of symptom; non disclosure; GP consult for other illness; sanctioning; marital/socioeconomic status; BSE; mammography; previous experience with cancer
Lannin et al 1998	America	487	Quant	Cultural/folk/religious beliefs; knowledge; no regular physician; health care utilisation
Facione and Facione 2006	America	28	QUAL	Type of symptom; education status; reasoning patterns during appraisal and decision making

Harirchi et al 2005	Iran	200	Quant	Poor knowledge; poverty; lack of access to physician; older age; marital/income/education status
Taib et al 2011	Malaysia	19	QUAL	Poor knowledge; coping mechanisms and significant others in appraisal
Taib et al 2014	Malaysia	19	QUAL	Use of CAM; Poor patient-provider communication/trusting relationships; language barrier
O'Mahony et al 2011	Ireland	10	QUAL	Denial; fear; competing commitments; poor knowledge; perceived incurability of breast cancer
O'Mahony et al 2013	Ireland	449	Quant	Belief in longer symptom duration; type of symptom; BSE; sociodemographic factors
Unger-Saldana and Infante-Castaneda 2011	Mexico	17	QUAL	Social class and networks; availability/acceptability of health workers; previous experience with health workers; beliefs and knowledge about breast cancer; multiple referrals
Rauscher et al 2010	America	436	Quant	Misconceptions; older age; history of breast disease/cancer; infrequent clinical exam
Lam et al 2008	Hong Kong	37	QUAL	Symptom interpretation; service utilisation; opportunistic help seeking; media prompts; sanctioning by others

Reifenstein 2007	America	48	Quant	Denial; socioeconomic/employment/education/marital status; symptom type; age; history of breast disease
Abdel-Fattah	Egypt	565	Quant	Type of symptom; older age; education/employment/marital status; BSE
Kohler et al 2017	Malawi	20	QUAL	Knowledge/risk perception; nature of symptoms; social norms/networks; distance to facility; cost of travel; nature of care at health facility
Clegg-Lampsey et al 2009	Ghana	66	Quant	Fear of diagnosis/mastectomy; herbal treatment; spiritual beliefs; poor knowledge
Agbokey 2014	Ghana	35	QUAL	Poor Knowledge; BSE/CBE; competing priorities; investigation delays; traditional healers; fear of diagnosis/death
Asoogo and Duma 2015	Ghana	30	QUAL	Poor knowledge; poverty; fear of treatment and its outcomes; traditional/spiritual beliefs; caring for others
Dye et al 2010	Ethiopia	55	Mixed	Healthcare system navigation/referral trajectory; type of facility first visited;
Ukwenya et al 2008	Nigeria	111	Quant	Age; education status;

Ismail et al 2013	Egypt	120	Quant	Poor knowledge; denial; embarrassment; financial problems; lack of time; fear of cancer/divorce; nature of symptom
-------------------	-------	-----	-------	--



**Appendix III: Quality appraisal of researchers papers used for the literature review**

			Little/No explanation (1): Address issue but not full elaborate (2): Strong explanation/justification (3)								
AUTHOR/YEAR	AIMS CLEAR LY STATE D	METH OD	RESEARCH DESIGN APPROPRIATE	RECRUITM ENT STRATEGY APPROPRIA TE	DATA COLLECTION METHOD APPROPRIATE	REL B/N RESEARCH ER AND PARTICIPA NTS CONSIDERE D	ETHICAL ISSUES	DATA ANALYSED SUFFICIEN TLY	CLEAR STATEME NT OF FINDINGS	VAL UE OF THE STU DY	TOTAL SCORE QUANT= 23 QUAL=2 6
Ruddy et al 2014	Yes	Quant	Prospective Cohort 2	Convenienc e 2	Questionnaire 1	N/A	Not stated 1	Yes 2	Yes 3	Yes 2	15
Poum et al 2014	Yes	Quant	Cross-sectional 1	Not stated 1	Questionnaire 1	N/A	Yes 2	Yes 2	Yes 3	Yes 2	14

Khakbazan et al 2014	Yes	QUAL	Cross- Sectional 2	Purposive 2	Interviews 2	No 1	Yes 3	yes 3	Yes 3	yes 2	20
Iskandarsyah et al 2014	Yes	QUAL	Cross- Sectional 3	Purposive 3	Interviews 3	No 1	Yes 1	Yes 2	Yes 3	Yes 2	21
Innos et al 2013	Yes	Quant	Cross-sectional 1	Yes 3	Questionnaire 1	N/A	Yes 1	Yes 1	yes 1	yes 2	12
Sharma et al 2013	Yes	Quant	Cross-sectional 1	yes 1	Questionnaire 3	N/A	Yes 1	Yes 3	yes 3	yes 3	17
Memon et al 2013	Yes	Quant	Cross-sectional 1	Yes 1	Questionnaire 1	N/A	Yes 1	Yes 2	Yes 2	Yes 2	12
Ghazali et al 2013	Yes	Quant	Cross-sectional 1	Yes 3	Questionnaire 2	N/A	Yes 1	Yes 2	Yes 2	Yes 2	15

Ibrahim and Oludara 2012	Yes	Quant	Cross-sectional 1	yes 1	Questionnaire 2	N/A	Not stated 1	Yes 1	yes 1	yes 2	11
Li et al 2012	No	Quant	Cross-sectional 3	Yes 2	Questionnaire 3	N/A	Yes 1	Yes 3	Yes 3	Yes 3	19
Rastad et al 2012	Yes	QUAL	Cross-Sectional 2	Purposive 3	Interviews 3	Yes 2	Not stated 1	Yes 3	yes 3	Yes 3	22
Norsa'adah et al 2012	yes	QUAL	Cross-Sectional 2	Purposive 3	Interviews 3	Yes 1	Yes 3	Yes 3	Yes 3	Yes 3	23
Granek and Fergus 2012	Yes	QUAL	Cross-Sectional 2	Purposive 3	Interviews 3	Yes 1	Yes 2	Yes 3	yes 3	Yes 3	22
Dye et al 2012	Yes	Mixed	Cross-Sectional 1	Not stated 1	interviews 2	Not stated 1	Not stated 1	yes 2	yes 2	yes 2	14

Talpur et al 2011	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 3	N/A	Yes 3	Yes 1	yes 2	yes 2	15
Stapleton et al 2011	Yes	Quant	Cross-Sectional 2	Convenience 1	Questionnaire 2	N/A	Yes 2	Yes 3	Yes 2	Yes 3	17
Mousa et al 2011	Yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 2	N/A	Yes 2	Yes 3	yes 3	yes 3	17
Kumari and Goonewardena 2011	yes	Quant	Cross-Sectional 1	Convenience 2	Questionnaire 1	N/A	Yes 1	yes 2	yes 2	yes 2	13
Yau et al 2010	Yes	Quant	Cross-Sectional 1	Convenience 2	Questionnaire 1	N/A	Yes 1	Yes 2	Yes 2	Yes 2	13
Otieno et al 2010	Yes	Quant	Cross-Sectional 1	Convenience 2	Questionnaire 1	N/A	Yes 1	Yes 1	Yes 2	Yes 2	12

Malik et al 2010	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 1	N/A	not stated 1	yes 2	yes 2	yes 2	12
Ezeome 2010	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 2	N/A	not stated 1	yes 2	yes 2	yes 2	13
Gullate et al 2010	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 3	N/A	Yes 1	yes 2	yes 2	yes 3	15
O'Mahony and Hegarty 2009	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 3	N/A	Yes 2	yes 2	yes 3	yes 3	17
Ali et al 2008	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 3	N/A	Not stated 1	yes 2	yes 2	yes 2	14
Pineros et al 2009	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 2	N/A	not stated 1	yes 2	yes 2	yes 2	13

Elzawawy 2008	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 2	N/A	Not stated 1	yes 1	yes 1	yes 2	11
Burgess et al 2006	yes	Mixed	Cross-Sectional 1	Convenience 2	Questionnaire 1	N/A	Not stated 1	Yes 2	Yes 2	yes 3	14
Facione and Facione 2006	yes	QUAL	Cross-Sectional 1	Purposive 2	Interview 3	Not stated 1	Not stated 1	Yes 3	Yes 3	Yes 3	19
Montazeri et al 2003	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 1	N/A	Not stated 1	yes 2	yes 2	yes 2	12
Meechan et al 2003	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 1	N/A	Not stated 1	Yes 2	yes 2	yes 2	12
Malik and Gopalan 2003	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 2	N/A	Yes 1	yes 2	yes 2	yes 2	13

Meechan et al 2002	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 2	N/A	Yes 1	yes 2	yes 2	yes 2	13
Arndt et al 2002	yes	Quant	Cross-Sectional 2	Convenience 2	Questionnaire 2	N/A	Not stated 1	Yes 3	yes 3	yes 2	17
Burgess et al 2001	yes	QUAL	Cross-Sectional 1	Purposive 3	Interviews 2	yes 1	Yes 1	yes 2	yes 3	yes 3	18
Burgess et al 2000	yes	Quant	Cross-Sectional 1	Convenience 2	Questionnaire 3	N/A	Not stated 1	yes 2	yes 2	yes 2	15
Nosarti et al 2000	yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 3	N/a	not stated 1	Yes 3	Yes 3	Yes 2	16
Burgess et al 1998	yes	Quant	Cross-Sectional 3	Convenience 2	Questionnaire 3	N/A	Not stated 1	yes 2	yes 2	yes 2	17

Lannin et al 1998	yes	Quant	Cross-Sectional/ Case Control 1	Convenience 1	Questionnaire 2	N/A	Not Stated 1	yes 2	yes 3	yes 3	15
Harirchi et al 2005	Yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 2	N/A	Not stated 1	Yes 1	yes 1	Yes 2	11
Taib et al 2011	yes	QUAL	Cross-Sectional 2	Purposive 2	Interviews 2	Yes 1	yes 1	Yes 2	Yes 3	Yes 2	17
Taib et al 2014	yes	QUAL	Cross-Sectional 2	Purposive 3	Interviews 3	Yes 1	yes 1	yes 2	yes 2	yes 2	18
O'Mahony et al 2011	Yes	QUAL	Cross-Sectional 2	Purposive 3	Interviews 2	Yes 1	Yes 1	yes 2	yes 3	yes 2	18
O'Mahony et al 2013	Yes	Quant	Cross-Sectional 2	Convenience 1	Questionnaire 3	N/A	not stated 1	yes 2	yes 3	yes 2	16



Unger-Saldana and Infante-Castaneda 2011	yes	QUAL	Cross-Sectional 2	purposive 2	Interviews 2	Yes 1	Yes 2	yes 2	yes 3	yes 3	19
Rauscher et al 2010	Yes	Quant	Cross-Sectional 2	Convenience 1	Questionnaire 3	N/A	not stated 1	yes 2	yes 2	yes 2	15
Lam et al 2008	Yes	QUAL	Cross-Sectional 1	Purposive 3	Interviews 2	yes 2	Yes 1	yes 2	yes 2	yes 2	17
Reifenstein 2007	Yes	Quant	Cross-Sectional 1	Convenience 1	Questionnaire 3	N/A	Yes 1	Yes 3	yes 2	yes 2	15
Dye et al 2010	Yes	Mixed	Cross-Sectional 1	Random 1	Semi-Structured Q 2	Yes 1	Yes 2	Yes 2	Yes 2	Yes 2	15
Abdel-Fatta et al 1999	yes	Quant	Cross-Sectional 1	Convenience 2	Questionnaire 2	N/A	Not stated 1	Yes 2	yes 3	yes 3	16

Kholer et al 2017	Yes	QUAL	Cross- Sectional 2	purposive 3	Semi- Structured Q 2	Yes 1	Not Stated 1	yes 3	yes 3	yes 3	17
Ismail 2013	yes	Quant	Cross- Sectional 2	Purposive 3	Questionnaire 3	Yes 2	Yes 2	yes 2	yes 2	yes 2	20
Clegg et al 2009	yes	Quant	Cross- Sectional 1	Convenienc e 1	Questionnaire 2	N/A	Not stated 1	yes 1	yes 2	yes 3	13
Agbokey 2014	yes	QUAL	Cross- Sectional 1	Purposive 3	Interviews 3	Not stated 1	Yes 2	yes 2	yes 2	yes 3	19
Asoogo and Duma 2015	yes	QUAL	Cross- Sectional 2	Convenienc e 2	Interviews 3	Not stated 1	Not stated 1	yes 3	yes 3	yes 3	20
Ukwenya et al 2008	yes	Quant	Cross- Sectional 1	Convenienc e 1	Questionnaire 2	N/A	Not stated 1	yes 2	yes 2	yes 2	13

## **Appendix IV: Participant Information Sheet**

***Research title: Why women with breast disease present late in seeking treatment at Komfo Anokye Teaching Hospital, Ghana.***

My name is Anita Eseenam Agbeko, I am a PhD student on the Lancaster University Palliative Medicine program in the United Kingdom (UK) and I am conducting this study at Komfo Anokye Teaching Hospital (KATH), Kumasi, Ghana.

### **What is the study about?**

The purpose of this study is to explore why women with breast disease seek treatment late. It may also help identify strategies that can lead to early presentation.

### **Why have I been approached?**

You have been approached because the study requires information from people who have breast disease and delayed in coming to the hospital

### **Do I have to take part?**

No. It's completely up to you to decide whether or not you take part in the study.

### **What will I be asked to do if I take part?**

If you decide you would like to take part, you would be asked to suggest a date and time that is convenient to you for a face to face or telephone interview with the researcher. With your permission, the interview will be audio recorded. This interview will last no more than one hour. You will be one of 15 women interviewed for this study.

### **Will my data be confidential?**

The information you provide is confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will destroyed and/or deleted after the research
- Paper printed copies of the recorded interviews will be kept in a locked cabinet and destroyed after the research.
- The files of the transcribed interview on the computer will be encrypted (that is no-one other than the researcher will be able to see them) and the computer itself password protected. These will be kept until 5years after the research.
- The typed version of your interview will be made anonymous by removing any information that could identify you including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. I will tell you if I have to do this.

**Voluntariness:**

Taking part in this study should be out of your own free will. You are not under obligation to.

**Alternatives to participation:**

If you choose not to participate, this will not affect your treatment in this hospital/institution in any way.

**Withdrawal from the research:**

You may choose to withdraw from the research during the interview or within 2 weeks of it without having to explain yourself. You may also choose not to answer any question you find uncomfortable or private.

**Consequence of Withdrawal:**

There will be no consequence, loss of benefit or care to you if you choose to withdraw from the study. Please note however, that some of the information that may have been obtained from you without identifiers (name etc.), before you chose to withdraw, may have been modified or used in analysis reports and publications. These cannot be removed anymore. However, I will make every effort to comply with your wishes.

**Costs/Compensation:**

I will compensate you with the cost of your transportation to and from the clinic on the day of the interview to show my appreciation for your participation.

**What will happen to the results?**

The results will be summarised and reported in a dissertation/thesis. It may be submitted for publication in an academic or professional journal, to the non-communicable disease office Of Ghana Health service and to the Tumour Board and Breast clinic of KATH.

**Are there any risks?**

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

### **Are there any benefits to taking part?**

Although you may find participating interesting, there are no direct benefits in taking part.

### **Who has reviewed the project?**

This study has been reviewed by the Faculty of Health and Medicine Research Ethics Committee, and approved by the University Research Ethics Committee at Lancaster University. It has also been reviewed by the Committee on Human Research, Publications and Ethics of the Kwame Nkrumah University of Science and Technology School of Medical Sciences and Komfo Anokye Teaching Hospital.

### **Where can I obtain further information about the study if I need it?**

If you have any questions about the study, please contact: Anita Eseenam Agbeko (the main researcher) on [a.agbeko@lancaster.ac.uk](mailto:a.agbeko@lancaster.ac.uk)

### **Complaints**

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

**Dr Anne Grinyer**

**Division of Health Research, Faculty of Health and Medicine, Lancaster University.**

**E mail: [a.grinyer@lancaster.ac.uk](mailto:a.grinyer@lancaster.ac.uk)**

**Tel: 01524 592677**

OR

Prof Pius Agbenorku

Head of Department of Surgery, Komfo Anokye Teaching Hospital.

Email: [pimagben@yahoo.com](mailto:pimagben@yahoo.com)

Tel: 00233 206300781.

If you wish to speak to someone outside of the department, you may also contact:

Professor Roger Pickup

Tel: (01524) 593718

Associate Dean for Research

Email: r.pickup @lancaster.ac.uk

Faculty of Health and Medicine (Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YD

**Resources in the event of distress**

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance; Komfo Anokye Teaching Hospital Palliative Care Team, Polyclinic, on 00233 508265361.

Thank you for taking the time to read this information sheet.

**Appendix V: Consent Form**

**Study Title: Why women with breast disease present late in seeking treatment at Komfo Anokye Teaching Hospital, Ghana.**

We are asking if you would like to take part in a research project that is aiming to explore the reasons why women with breast disease report to the hospital several weeks after first noticing their breast symptoms.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Anita Eseenam Agbeko

**Statement of person obtaining informed consent:**

I have fully explained this research to \_\_\_\_\_ and have given sufficient information about the study, including that on procedures, risks and benefits, to enable the prospective participant make an informed decision to or not to participate.

DATE: \_\_\_\_\_ NAME: \_\_\_\_\_

1. I confirm that I have read the information sheet/ or have had it translated into a language I understand and fully understand what is expected of me within this study



2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been completed.
5. I understand that my participation is voluntary and that I am free to withdraw up to 2 weeks after the interview without giving any reason, without my medical care or legal rights being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor.

10. I consent to Lancaster University keeping written transcriptions of the interview for 5 years after the study has finished.

11. I consent to take part in the above study.

12. I have received a copy of this information leaflet and consent form to keep for myself.

**Name of Participant** \_\_\_\_\_

**Signature** \_\_\_\_\_

**Date** \_\_\_\_\_

**Name of Researcher** \_\_\_\_\_

**Signature** \_\_\_\_\_

**Date** \_\_\_\_\_

## **Appendix VI: Topic led interview guide**

Greetings, introduce myself establish rapport

Obtain informed consent

### **Demographics**

1. How old are you?
2. Are you married?
3. Do you have children? How many?
4. Where in Ghana do you come from?
5. What is your educational background?
6. What work do you do?
7. About how much do you earn monthly?

### **Current Health**

1. How will you describe your health?
2. What do you usually do when you are unwell/ill?
3. What brought you to the breast clinic?
4. When did you first notice there was something wrong with your breast?
5. What made you decide to come to the hospital?

### **Health seeking**

1. Can you tell me what has happened since you noticed your breast disease?
2. Did you talk to anyone about your breast disease?
3. What will other women you know do if they had breast disease?

## **Delays to seeking health**

1. What experiences shaped your timing to seek treatment?
2. How was it for you getting treatment for your breast disease?
  - Accessibility to a health facility
  - Cost of treatment
  - Social support

## Appendix VIIa: Ethics approval from Committee on Human Research Publication and Ethics



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/386/14

8<sup>th</sup> December, 2014.

Dr. Anita Eseenam Agbeko  
Department of Surgery  
Komfo Anokye Teaching Hospital  
Kumasi.

Dear Madam,

### LETTER OF APPROVAL

*Protocol Title: "Why Women with Breast Cancer Present Late in Seeking Treatment at Komfo Anokye Teaching Hospital, Ghana."*

*Proposed Site: Breast Clinic, Department of Surgery, Komfo Anokye Teaching Hospital.*

*Sponsor: Principal Investigator.*

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

The Committee reviewed the following documents:

- A notification letter of 14<sup>th</sup> November, 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.
- 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.

Thank you Madam, for your application.

Yours faithfully,

Osomfuor Prof. Sir J. W. Acheampong MD, FWACP  
Chairman

**Appendix VIIb: Ethics approval from Committee on Human Research  
Publication and Ethics (Amendment)**



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/033/15

13<sup>th</sup> February, 2015.

Dr. Anita Eseenam Agbeko  
Department of Surgery  
Komfo Anokye Teaching Hospital  
KUMASI.

Dear Madam,

**LETTER OF APPROVAL**

Protocol Amendment: *“Why Women with Breast Cancer Present Late in Seeking Treatment at Komfo Anokye Teaching Hospital, Ghana”*

**AMENDMENTS:** *To modify the Consent Form, Participant Information Leaflet, Interview Guide and sections 2.7 and 2.12 of the CHRPE Application Form.*

Your submission to the Committee on amendment to the above protocol refers.

The Committee has considered the ethical merit of your proposed amendment and approved it.

Please note that any further amendment to this approved protocol should receive prior CHRPE approval before implementation.

Thank you Madam, for your application.

Yours faithfully,

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

Applicant: Anita Eseenam Agbeko  
Supervisor: Anne Grinyer  
Department: DHR

25 March 2015

Dear Anita and Anne

**Re: Why women with breast cancer present late in seeking treatment at Komfo Anokye Teaching Hospital, Ghana**

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the University Research Ethics Committee (UREC), I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact the Research Ethics Officer, Debbie Knight (01542 592605 [ethics@lancaster.ac.uk](mailto:ethics@lancaster.ac.uk)) if you have any queries or require further information.

Yours sincerely,



Sarah Taylor  
Secretary, University Research Ethics Committee

Cc Fiona Aiken, University Secretary, Professor Roger Pickup (Chair, FHMREC); Prof Stephen Decent (Chair, UREC).

Lancaster University  
Services Division  
Lancaster University  
Bowland Main  
Lancaster, LA1 4YT, UK  
T: +44 (0)1524 592 002  
F: +44 (0)1524 593 229  
[www.lancaster.ac.uk](http://www.lancaster.ac.uk)

## Appendix VIII: Ethics approval Faculty of Health and Medicine Research Ethics Committee

Andersen, B. L., Cacioppo, J., & Roberts, D. C. (1995). Delay in seeking a cancer diagnosis: delay stages and psychophysiological comparison processes. *British journal of social psychology, 34*, 33-33.