

Resilient and Redefined: Understanding the Experiences of Breast Cancer Survivorship for Ghanaian Women

Naomi Thompson

BA

A thesis submitted in fulfillment of the requirements for the degree of a Master of Research (MRES)

**Department of Anthropology
Macquarie University
Sydney, Australia**

October 2015

Table of Contents

Table of Contents	ii
Abstract	1
Declaration of Originality	2
Acknowledgements	3
Glossary of Acronyms	4
Preface	5
Chapter 1: You're Late!	6
1.1 An Anthropology of Cancer	7
1.1.1 Survivorship.....	9
1.2 Methods	10
1.2.1 Critical Phenomenology	12
1.3 The Asante	13
Chapter 2: A Risen Epidemic—Africa, Ghana and a Pale Blue Building	16
2.1 Breast Cancer in Africa: a Fully Fledged Epidemic	16
2.2 Breast Cancer in Ghana	19
2.3 The Culture of Biomedicine	22
2.4 Two Hills Hospital.....	24
Chapter 3: Experiencing Cancer—The Importance of Care	29
3.1 Auntie Vera.....	30
3.2 Improvising Medicine.....	33
3.3 The Realities and Commonalities of Breast Cancer	35
Chapter 4: Being Resilient—The Structural Barriers of Poverty	40
4.1 Mama Naammɔ.....	40
4.2 Shifting Resilience.....	43
4.3 Blame	45
Chapter 5: Changing Lives—Enacting Transformation	48
5.1 Surviving vs. Living.....	50
5.2 The Importance of Counsellors.....	51
5.3 Transformative Steps	54
5.4 From One Social Role to Another	58
References	60
Appendix 1: Ethics Approval	69

Abstract

This research explores the treatment and post-treatment experiences of breast cancer survivors in Ghana. While rates of breast cancer continue to rise steadily across the African continent, the disease often remains misunderstood, extremely underfunded and responsible for an inestimable number of needless fatalities. Many factors influence the experiences and the quality of life of breast cancer survivors, yet there is minimal research in Ghana and throughout West Africa on post-treatment and survivorship issues. This research offers a perspective into the experiences of Ghanaian, breast cancer survivors, arguing that these Ghanaian women, often with a range of post-cancer treatment issues, are not passive, powerless victims. With the help of a survivor community, women with breast cancer are able to move from stigmatized and ostracized social roles to one that transforms and exalts their cancer experience. This research emphasises the importance of recognizing not only the structural forces that shape cancer experiences, but also the narratives of transformation, resilience and strength and the role these play in enabling survivors to exercise agency over their disease.

Declaration of Originality

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a higher degree or to any other university or institution; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: Naomi Thompson On: 14/03/2016

Acknowledgements

First and foremost, I want to thank the breast cancer patients and survivors of THH for their incredible kindness and generosity. In particular I want to thank Aunty Vera, Mama Naammɔ, Aunty Flora and Hagar. Thank you for taking the time to sit with me each day and share your experiences.

I would also like to thank Dr M and all of the other staff at THH who guided me throughout my fieldwork. Dr M, your passion, drive and love for Ghana's women is simply amazing. Each day you change lives.

Thank you also to all the taxi drivers, restaurant staff, shop assistants etc. for willingly engaging me in conversations about breast cancer while you were working.

Thank you to my supervisor Dr Aaron Denham for your patience, advice and support.

Thank you also to the Anthropology Department at Macquarie University for all you have taught me over the past 5 years.

Thank you to the rest of my MRes cohort for your encouragement throughout this process.

Thank you to my Ghanaian family: Isaac, Cynthia, Comfort, Prince, Stephen and Thelma for ensuring my wellbeing over the four months.

Finally, thank you to my husband Daniel, and my mother Lee and for your love, support and constant encouragement throughout this process.

This thesis was edited by Elite Editing and editorial intervention was restricted to Standards D and E of the Australian Standards for Editing.

Glossary of Acronyms

CHW- Community health worker

NCDs- Non-communicable diseases

NHIS- National Health Insurance Scheme

THH- Two Hills Hospital

WHO- World Health Organization

Preface

In July 2011, a 55-year-old retired female teacher was buried in the courtyard of her school in Accra, Ghana. Her family and I said goodbye to a woman known and admired throughout the entire small town in which she lived. She died of metastatic breast cancer, six years after her initial diagnosis. Joe, her son, turned to me before the start of the service and reflected on the lead up to this moment:

She was feeling the pains, feeling the pains in her left breast. The local chiefs took her to the *dunsinyi* [traditional healer] and they gave her the local medicine, the one where they grind it into a paste and you apply it. She applied the paste for six months, but the pain remained, so she went to Korle Bu Teaching Hospital, and they did a scan. They found a tumour, but they removed only the tumour. After six months she went for a follow-up scan, and they found some of the tumour still inside, so they removed the whole breast. After that she spent four years in the house, she suffered a lot. The doctors told me that her survival rate was 50–50. When you cut one off, your survival rate is just luck. She kept getting sicker, and the doctors told her that her blood was also spoiled. So she couldn't eat, she couldn't drink, all her blood was spoiled. You can't even use a drip on her. It is better to go early you see. It's better than to sit down and allow people to concoct stories. Maybe if she had gone earlier the medicine from the hospital would have worked.

This paper is dedicated to Mama Abena.

Nyi krataa re atuasiho ko Mama Abena.

Chapter 1: You're Late!

Dr M sits at her desk frantically writing notes in preparation for her next patient. The piles of paper that cover her desk continue to rise and fall as the air conditioning blows rapidly. It is always freezing in her consulting rooms. Having left Ghana to study medicine in Russia, Dr M is fond of cool, chilling air. She is one of only a handful of oncologists in Ghana to return and practice medicine, and the only one to have built her own hospital to accommodate for the increasing incidence of breast cancer within the country.

She shuffles her chair back and reaches for the white switch on the wall. I hear the bell sound and a patient slowly opens the door. She walks in laughing, prompting Dr M to look up from her notes and say, 'Ah! You! You last came here when?' She searches quickly through the patient's folder: '18 months! You have run away for 18 months! I tell you you're sick and you come back here after 18 months! You're too late!' The patient drops to her knees and her laughter turns abruptly to tears. She places one hand out in front of her, palm facing the ceiling and begins to hit it with the back of her other hand. She is begging.

By 2030, global deaths from non-communicable diseases (NCDs) such as breast cancer are 'expected to eclipse the combined toll from infectious disease, malnutrition and death during childbirth' (Geddes, 2013, p.8). Yet across Africa, cancers remain gravely misunderstood, extremely underfunded and responsible for an inestimable number of needless fatalities. For most women in Africa, breast cancer is both a death sentence and a chronic illness. Survival is not often likely, but if achieved, the burden of having had cancer often leaves those affected in a much worse condition than before their illness was diagnosed. Current 'research indicates that there is a complex interplay between the biological, psychological and social factors that influence the experiences and quality of women diagnosed with survive breast cancer' (Coggin & Shaw-Perry, 2006, p. 108). In particular, cancer affects a range of body parts and functions that not only reveal aspects of embodiment, but also point to broader structural and environmental factors.

The experiences and decision-making processes of Ghanaian women throughout breast cancer treatment have been studied (Aziato & Clegg-Lamptey, 2014a; Bonsu, Aziato & Clegg-Lamptey, 2014b; Clegg-Lamptey, Dakubo & Attobra, 2009; Ohene-Yeboah & Adjei,

2012; Obrist, Osei-Bonsu, Awuah, Watanabe-Galloway, Merajver & Soliman, 2014). However, there is limited research on post-treatment and survivorship issues despite the fact that survivors of breast cancer are confronted with a range of post-cancer treatment-related issues. Readjustment to life, changes in bodily perceptions and the reality of having a life-threatening illness are just a few of these issues. Therefore, there is a great need to better understand how to support the adjustment processes following diagnosis and treatment (Brennan, Butow, Spillane & Boyle, 2008; Burke, Sabiston & Vallerand, 2012; Stan, Loprinzi, & Ruddy 2013). Moreover, as we continue to see a rise in women surviving breast cancer, disparities in post-treatment outcomes are becoming more evident, and these also need to be addressed (Fagundes, Lindgren, Shapiro, & Kiecolt-Glaser, 2012).

Further research is needed to improve our understanding of survivor needs so as to enhance the quality and also the appropriateness of care, and long-term outcomes. As we will see, breast cancer has profound effects on the body, effects that can be challenging to manage. According to Gerber, Stout, Schmitz & Stricker (2012, p. 2201), ‘the myriad of medical and functional impairments faced by patients during and after treatment can be challenging to manage and require vigilance and resourcefulness on the part of the patient.’ Though it is generally recognised that sociocultural beliefs affect and inform health-seeking behaviours, the diverse and unique needs of women from non-Western backgrounds are rarely addressed in breast cancer survivorship programmes. This lack of attention to culture can result in ineffective programmes that assume a standardised, Western set of issues and coping strategies for example, that are unique to a Western vision of a breast cancer survivor.

This research project was developed with the aim of studying the treatment and post-treatment experiences of breast cancer survivors and the social and cultural context of breast cancer survivorship in Ghana. It is important because it specifically examines the needs, resilient coping strategies, sociocultural context and the political and economic structures that shape women’s experiences of breast cancer survivorship.

1.1 An Anthropology of Cancer

Anthropological research over the past two decades has played a significant role in understanding cancer, particularly with respect to its aetiology, epidemiology and prevention.

Prominent works such as *Improvising Medicine* (Livingston, 2012) have been key to informing anthropological research on cancer, particularly in this study, which made similar observations. Livingston's thoughtful and detailed ethnography offers a troubling portrait of the cancer epidemic in Botswana, drawing critical attention to the unavoidably improvisational nature of oncological care in Africa, as well as the social experience of cancer treatment. By attending to these dynamics, Livingston emphasizes the challenges that African healthcare systems must confront across the continent. 'Cancer in Africa', she insists, 'is an epidemic that will profoundly shape the future of global health' (Livingston, 2012, p. 7).

Despite significant advances in the oncological field, the biomedical means to prevent and cure all cancers have not yet been attained. Moreover, the likelihood that such technologies when developed would be both readily and equally available to the poor is low. Consequently, early diagnosis is currently the most effective way to minimise the costs of cancer at the individual, community and national levels. As culture is *the* key influence in people's understandings and perceptions of cancers, anthropology has been, and continues to remain, pivotal to elucidating those sociocultural factors that are key to achieving 'more effective policy implementation, better welfare and sustainable development' (Lora-Wainwright, 2010, p. 85).

Most anthropological research on cancer to date has been related to diagnosis, treatment and screening. For example, Boonmongkon's (1997) research into gynaecological cancers in Northeast Thailand found that women will present for pap smears because of the widespread belief that they will also be screened, diagnosed and treated for all gynaecological problems they may possess. Odigie et al., (2010) in their research into breast cancer in North-western Nigeria revealed that diagnosed women know little about the disease, and thus prefer to utilise traditional or spiritual treatments. In other research among Aboriginal communities in Western Australia, Shahid, Finn, Bessarab & Thompson (2009) found that blame is central to a cancer diagnosis, and consequently people hide their symptoms from others and delay or deny treatment. Ultimately it is pivotal for the success of not only early prevention campaigns, but also for ensuring the utilisation of treatment, to understand the cultural perceptions of cancers (Manderson, 1999).

An anthropology of cancer has ultimately 'sought to integrate the biological and physiological with the cultural' to understand how cancer is perceived by particular

communities (Hubert, 1990; Manderson, 1999, p. 317). Central to this research are explanatory cultural models of illness that have been developed in the works of Kleinman (1988) and Good (1994). These models offer a method and a mode of representing people's understandings and perceptions of cancer, its causation and prevention. Eliciting explanatory models of cancer experiences can advance our understanding of the 'meanings and impacts of cancer' that are so central to our ability to prevent and control it (Manderson, 1999, p. 319). Ultimately, if one is unable to ascertain for example, what factors drive women to present in the advanced stages of breast cancer—one can misconstrue community held knowledge as ignorant, and subsequently 'blame them for their own suffering,' or offer recommendations not suitable to the local setting (Lora-Wainwright, 2010, p. 85).

1.1.1 Survivorship

Over the past 50 years, definitions of survivorship have evolved substantially. Mullan (1985) initially unpacked the concept by breaking it down into three distinct seasons: acute survival, meaning diagnosis and treatment; extended survival, meaning the phase after treatment; and finally permanent survival, meaning the phase when the patient is considered cured or in complete remission. Carter (1989) and Leigh (1994) later defined the concept as an ongoing process that encompasses the experience of living through and beyond cancer. Building on these concepts, the National Cancer Institute (2014) incorporated family, friends, and caregivers into the definition of survivorship, asserting that they too, are affected by the cancer experience.

For the purposes of this paper, survivorship encompasses all of these definitions. Survivorship begins at diagnosis, and extends for the remainder of the survivor's life. It is both an individualised and also a collective experience. A survivor for the purposes of this research is a 'person who *lives* despite adversity, one who continues to live after, or one who comes through, lasts, persists, pulls through, weathers, outlasts, and outwears' (B. Farmer 2002, p. 779). Survivors continue to face numerous challenges throughout their lives, even after they are medically considered cured.

Carers factor significantly in the lives of cancer survivors. Having conducted research with a self-help breast group in North Carolina, Mathews (2000, p. 394) found that the 'psychosocial needs of patients' and their carers can be adequately addressed though the

use of support groups. In particular, Mathews (2000) found that therapeutic support groups ‘typically function to try and reduce patients emotional distress and sense of isolation by providing information about the disease and its treatment ... and by giving patients a chance to share their personal experiences with cancer in a supportive and safe environment’ (Mathews, 2000, p. 394).

Lopez-Class, Gomez-Duarte, Graves & Ashing-Giwa (2012) examined the quality of life among Latina breast cancer survivors. Through exploring the ‘social determinants of health,’ Lopez-Class et al. (2012, p.115) frame the ‘key domains of survivors’ quality of life within an ecological–contextual model.’ Their research demonstrated that living in ‘low-resourced neighbourhoods... with inadequate health care plans’ impedes the ability of the patient to manage their illness (Lopez-Class et al., 2012, p. 121). As such, neighbourhood characteristics and the accessibility and availability of clinical resources needed to be better addressed and understood so as to understand the impacts that structural factors have on Latina breast cancer survivors.

Breast cancer diagnosis and treatment results in a rapid transformational process. While survivors are often forced to recognise that cancer, even after treatment, will remain a part of life forever, diagnosis and treatment are much better understood than the journey after. Since breast cancer survivorship is a dynamic process, there is a distinct need to understand this phenomenon in women’s health through an approach that integrates sociocultural, political and economic factors.

1.2 Methods

From December 2014 until April 2015 I undertook fieldwork at a small private hospital in Ghana (Two Hills Hospital (THH))¹ to examine the perspectives and experiences of Ghanaian breast cancer survivors. This research was informed by the work of van der Geest and Finkler (2004) on hospital-based ethnography. They state that ‘biomedicine, and the hospital as its foremost institution, is a domain where the core values and beliefs of a culture come into view’ (van der Geest & Finkler 2004, p. 1996). Therefore, my own research looks at how the

¹ Pseudonym

values and beliefs that surround breast cancer occur in, and interact with, a particular biomedical setting.

I interviewed thirty breast cancer survivors, and an additional four participated in longer, personal interviews to allow for the exploration of more person-centred themes. These themes were ascertained through the use of Hollan and Levy's (1998) technique of person-centred interviewing and observation. Person-centred interviews allow for the engagement with the interviewee as a knowledgeable person who can share and contextualise information about a particular culture. Further, they allowed me to position the interviewee as an object of 'systematic study and observation' in order to observe behaviour, reactions and responses to 'various probes, questions and topics' (Hollan & Levy, 1998, p. 316). I also interviewed staff at the hospital as well as the general public so as to gather context and insight from those working within and outside the oncological field, and clinical setting. Additionally, participant observation was carried out in both the hospital environment and the participant's domestic spaces, to allow for an exploration of the patient experience within and also outside of the clinical world of the hospital.

Spending time in both the hospital and also the private homes of my participants, allowed me to investigate and understand the complex mix of challenges and determinants that shape their lived experiences. These experiences are not only unique to each individual survivor, but they are also inherently informed and influenced by the larger sociocultural, political and economic structures that surround her. Consequently, qualitative interviewing was used as a way to explore the experiences of the survivors within their social worlds, and how these experiences are informed by broader structural factors (Spradley, 1979).

Both Macquarie University's Human Research Ethics Committee and THH's Ethical and Protocol Review Committee granted ethics approval for this research.² Most interviews were conducted in English, but a translator was present when I interviewed those who preferred to speak Asante Twi, who would relay information back to me in English. Each interview session lasted up to two hours and was subsequently transcribed by myself for the purposes of analysis. Interviews were audio recorded after attaining written consent, and interactions from participant observation were recorded in my field notes. To ensure the

² Macquarie Ethics Committee Approval Number 5201400967; Two Hills Hospital Approval Number NT001.

privacy of my participants, I changed their names and altered certain details. Findings were compared with the wider academic literature on breast cancer, survivorship, illness, suffering and the context and culture of modern Ghana.

After completing treatment at THH, breast cancer patients have the opportunity to join a survivor's association that has two distinct functions. First, it provides support and employment for the survivors themselves by creating opportunities for counselling and advocacy; second, it ensures that newly diagnosed breast cancer patients complete their treatment through their pairing with a survivor. I wanted to understand what the transition from patient to survivor entailed in Ghana. What is a survivor's experience of breast cancer? How did it change her life? How did it affect her relationships with those around her? What psychosocial issues did she, and does she still continue to face?

1.2.1 Critical Phenomenology

A critical phenomenological theoretical perspective has shaped this project. On its own, phenomenology allows us to consider the relationship between the 'biological body and the living body' (Henry, 2012, p. 6). It allows us to understand the ways in which this relationship is both experienced and informed by surrounding environments (Ram & Houston, 2015). Breast cancer as a disruption within the body and also everyday life is a way of *living* for phenomenology, rather than a simple deviation from normal biological function (Carel, 2013; Henry, 2012).

According to Merleau-Ponty (1962, p. 85), in illness we find that 'bodily events become events of the day.' In other words, when we find ourselves ill, our body and what it can and cannot do, becomes foregrounded in our everyday consciousness. Phenomenology is thus useful as it is a step back from common biomedical metaphors of the body as a machine; and focuses instead on how this foregrounding shapes the everyday experience of illness (Merleau-Ponty, 1962). Although it does not deny the validity of biomedical interventions, it prefers to focus on first-person experience.

By examining what it 'means to be human, to have a body, to suffer, to heal and to live among others,' *critical* phenomenology in addition to the above, contrasts the political, social, cultural and economic forces that influence and shape lived experience (Desjarlais &

Throop, 2011, p. 88). While looking closely at the individual experiences of illness, a critical phenomenological perspective prefers to rather elucidate how widening disparities in health shape these experiences. For theorists such as P. Farmer (1996, p. 259), this allows one to be ‘critical of facile claims of causality that scant the pathogenic roles of social inequalities’ and direct blame towards sufferers.

1.3 The Asante

A woman is a flower in a garden, and her husband is the fence around it
— Ghanaian proverb

Ghana is a colonial creation. It is country that was pieced together from numerous indigenous societies according to European (mainly British) interests.³ The Akan people are the most numerous of these indigenous societies, comprising over 40 per cent of the total population (Yankah, 2012). This ethnic group is made up of different tribes of which the Asante are one, and they dominate (particularly in terms of population size and economic acuity) most of modern Ghana, particularly the central and southern regions. Kumasi is the capital city of the Ashanti region, and the majority of the Asante population reside there.⁴

While Ghana’s national language is English, Asante Twi is most commonly spoken in day-to-day life, especially within the home. The Asante are matrilineal: the line of descent is traced through the mother. Family is the most important aspect of Asante culture and obligations to the family always come first. Consequently, it is important for the Asante to maintain dignity and honour in all that they do. A bad reputation is reflective of the entire family, and thus a positive outward image must be presented at all times.

Asante families are commonly pronatalist and the value of children is inestimable; they are the ‘*raison d’être* of life... a sign of a woman’s normality and femininity’ (Francoeur, et al., 2004, p. 468). As such, reproductive organs such as breasts are representative of not only beauty and womanhood in Ghana, but they also symbolically

³ Portugal, the Netherlands and Denmark also had colonial influence.

⁴ The proper spelling in Asante Twi is ‘Asante.’ However English constructs of the word spell it ‘Ashanti.’ The latter is used when referring to geographical boundaries determined during colonisation.

signify a woman's ability to produce and raise children to ensure the continuation of the family line.

Among the Asante, women assume the basic domestic roles whereas men are the household head. Although declines in the economy have meant that women are now increasingly taking part in the formal economy,⁵ a woman's main responsibility is to look after her husband, their children, and their extended family. She must complete all household chores, sometimes work outside the home for money, and also take care of the family. Unlike her husband, who Mensah (2005) asserts is defined by his engagement with public institutions, a woman is defined by her family and her marriage.

The Asante people, just like the rest of wider Ghanaian society, are patriarchal in nature. Asante men dominate all decision making, especially in terms of finances, education and employment. Consequently, women are often unable to practice autonomy because of their inability to make decisions. For example, although divorce is frowned upon, it is not uncommon that an Asante man may leave his wife or take another. Asante women do not often have this same freedom.⁶

Traditionally, the Asante perceive all problems to be of spiritual origin. While rural to urban migration has meant that Asante's are beginning to seek biomedical care more often, they do still continue to seek those forms of traditional medicine that were central to their society before colonisation. As will become evident throughout this paper, an Asante, when sick, would likely consult a fetish priest or a *dunsinyi*. While the growing popularity of Christianity has had a substantial impact on the utilisation of traditional medicine, the beliefs that underpin these local aetiologies continue to remain strong in the Asante mindset.

Men also dominate decisions regarding access to traditional vs. biomedical medicine. Asante women will consult dominant males within their family (typically their husband or oldest brother) to seek advice regarding the appropriate avenue of healthcare. These decisions are pertinent to women with diseases such as breast cancer who without the permission of these dominant males, are unable to commence proper biomedical treatment.

⁵ Trading in the markets is the most common way women take part in the formal economy.

⁶ Although this is changing, it is still uncommon for women to leave their husband of their own accord.

As my research was carried out in Kumasi, the majority of my participants were Asante. Going forward, I will use the terms Ghanaian and Asante interchangeably, unless the participant was not Asante. ‘Asante’ will be used when discussion is specific to Asante culture and society, whereas ‘Ghanaian’ will be used when discussion is not specific to any ethnic group but rather the general Ghanaian population.

Chapter 2: A Risen Epidemic—Africa, Ghana and a Pale Blue Building

Globally, low- and middle-income countries are undergoing rapid changes. A distinct epidemiological shift is occurring, arising from changing patterns of population age distributions, increased life expectancy and modernisation (Meyrowitsch, 2007). As a consequence, non-communicable diseases (NCDs) such as cancer are fast becoming more burdensome than communicable diseases, accounting for 63 per cent of global deaths every year (World Health Organization, 2013). Low and middle-income countries make-up 86 per cent of these deaths, which, over the next 15 years, will result in ‘cumulative economic losses of US\$7 trillion... and millions of people trapped in poverty’ (World Health Organization, 2013, p. 1).

Ghana is no exception. According to Chireh (2011, p. ii), ‘the burden of non-communicable diseases is increasing rapidly whilst infectious diseases continue to pose major challenges.’ This *double* burden of disease has meant that malaria or tuberculosis for example; co-exist with breast cancer or diabetes. NCDs most often ‘affect adults in their most productive age, affect poor communities disproportionately [and] push individuals and households further into poverty’ (de-Graft Aikins, Boynton & Atanga, 2010, p.1). In the context of breast cancer, there are stark differences between the incidence mortality ratios in high-income countries such as the United States (0.2) and low and middle-income countries such as Ghana (0.68) (World Health Organization, 2004). Statistics such as these emphasise not only that opportunities for survival are far from universal, but also that breast cancer in Ghana equates to a particularly poor prognosis for women.

2.1 Breast Cancer in Africa: a Fully Fledged Epidemic

Rarely does cancer come to mind when people consider the health issues facing African people. Most people, upon first thought of sub-Saharan Africa and its health problems, do not consider cancer a significant burden. It seems, as Livingston (2012, p. 8) suggests, cancer is an ‘esoteric distraction from more pressing concerns’ such as HIV/AIDS or tuberculosis. However, over the last decade, cancers have become common in Africa, their incidence rising steadily across the continent (Parkin et al., 2008). In West Africa, for example, breast cancer

is currently the ‘leading cause of death among women,’ with an estimated 30,000 new cases diagnosed every year (Abdulrahman & Rahman, 2012, p. 1).

Epidemiological shifts in Ghana are becoming increasingly more evident. Every month, Dr M’s days get longer, more patients wait to see her, and there is less ward space to accommodate them. She describes this at length:

The work is more and more. Before, there were maybe 10 patients waiting to see me when I arrive in the morning. Now sometimes I come and there is over 100! 100! We don’t have space for them to sleep, let alone wait. So they have to sit outside in the heat, sweating. They bring cloth to sleep and rest on. I don’t close some days until 11 pm. But what can I do? Go home? Leave them? No! Some have travelled for days, others hours. I have to see them all because most of the other hospitals just ignore them or turn them away. In the big public hospitals and even the small ones, the doctor could arrive in the morning and decide that he will only see 10 patients that day. So once he has seen 10, he closes! It could take a week of waiting before they even see a doctor! So I wait and I see them all. I make sure I see them all.

There has been substantial progress in reducing deaths from breast cancer in high-income countries; however, evidence of decreased mortality is yet to be seen in countries that are low and middle-income. According to Niens, Nyarko, Zelle, Jehu-Appiah & Rutten (2014, p. 100), ‘studies have revealed differences in global breast cancer burdens by race, urbanisation, insurance status and socioeconomic status,’ with each burden contributing to limited access to care, increased inability to afford treatment and significantly poorer outcomes. Research into the effects of these burdens has been limited because of a lack of population-based breast cancer registration in low-income countries such as Ghana (Niens et al., 2014). However from the research that does exist, it is clear that for low and middle-income countries and individuals, these burdens result in a prevalence of advanced breast cancer diagnoses that result in the removal of the breast (mastectomy), being the most common surgical method to treat this disease.

Research into the epidemiology of breast cancer in Africa has shown that the mean age of diagnosis across the continent is lower than those recorded in the Americas and Europe (Abdulrahman & Rahman, 2012). According to Brinton, Figueroa, Awuah, Yarney, Wiafe, Wood & Clegg-Lampsey (2014, p. 468) ‘the average age of diagnosis of breast cancers among

African women tends to be young, with estimates that a majority of cancers develop among women 50 years or younger.’ When breast cancer incidence is consistently located in age groups involved in employment, the negative social and economic consequences intensify.

Take, for example, Maame. Maame was 43 years old when she was diagnosed with breast cancer. Two years prior to her diagnosis she lost her husband to complications from diabetes, leaving her alone with four children. Before her diagnosis, Maame traded in one of the largest markets in Ghana. Her work required her to travel long distances in *tro tros* (small buses used for public transport) to rural areas of the country to purchase merchandise and bring it back to the capital city, Accra, to sell. As Maame does not own a car, she would need to pack and unpack her trading stand into a large black suitcase at the beginning and end of each day and place it on top of her head to move to and from her home. Following the death of her husband, her work was the only source of income in her household. It fed her children, sent them to school and allowed her to continue to pay the rent on the small white compound house she had rented with her husband for over 10 years. When Maame was first diagnosed with cancer, she was adamant that she needed to continue trading so as to continue to support her family. She noted:

I was working; in fact I was very busy before I went through all this. After I had the operation the remainder of my breast became very hard so Dr M told me to go for chemotherapy. This chemotherapy cost me a lot, I was very sick, I became very sick! I was vomiting, I could not eat, I was very weak. So I had to leave my work in the hands of others so that I could spend six months resting. It affected my business. I had to use my savings to pay for the treatment; there was no insurance. At long last when I was ok and I could go back to work my business had collapsed. I tried to start again but I could not carry the suitcase on my head anymore. My children’s school sent me a letter saying that they would send my children home because I couldn’t pay their fees so I had to remove them. I cannot afford the rent so now we have to stay with my sister. I also cannot afford the tests or the drugs I need to make sure I am still fine. Cancer affected me so much. Up to this day, I am not ok and neither are my children.

When analysing the experiences and consequences of breast cancer for African women such as Maame, broader structural issues become apparent. Although public primary education is free in Ghana, Maame had wanted to keep her children in a private school

because of the stark differences in educational standards between the two. Though having insurance would have been useful, the National Health Insurance Scheme (NHIS) had not yet been introduced, so Maame was required to pay for all of her medical bills up front before commencing treatment. Finally, Maame was unable to keep her home because the majority of rental properties in Ghana require the tenant to pay two years rent in advance, and with all of her finances going towards treatment, this was not possible. The devastating effect of medical costs for women diagnosed with breast cancer affects much more than just a woman and her being. When breast cancer prevalence is consistently located in the younger factions of society, particularly in age ranges that necessitate employment, the social and economic consequences intensify (negatively), and it is no longer only the fate of the diagnosed woman that is transformed.

There is a strong relationship between socioeconomic status and health inequality. In the case of Maame, these inequalities are evident in Ghana's inadequate health systems. Poor infrastructure, poverty and unemployment on continents such as Africa have ultimately resulted in NCDs such as breast cancer having a much more devastating impact and outcome. Poverty in particular, which remains the primary determinant of health across the majority of the African continent, is *the* significant contributory factor to high mortality rates from breast cancer. For countries such as Ghana, the fact that healthcare is not free and an estimated 24.2 per cent of the population live below the poverty line, means that utilising healthcare is an expensive and sometimes impossible exercise (World Bank, 2013).

2.2 Breast Cancer in Ghana

In Ghana, necrotic, disfiguring growths are what drive women into clinics and hospitals each day. It is no surprise then that breast cancer is currently the 'leading cause of cancer deaths among women' (Ohene-Yeboah & Adjei, 2012, p.8). The multidisciplinary nature of breast cancer treatment and its consequences in Ghana have adverse affects on the psychosocial experiences of Ghanaian women throughout, but particularly after, having breast cancer. However, data that elucidates the experiences of Ghanaian women after breast cancer treatment has ceased remains limited.

Ghana was reclassified as a lower middle-income country in 2010. Although it agreed to the Millennium Development Goals in 2000, Ghana has not achieved several of them, particularly those that are health related (United Nations Children's Fund [UNICEF], 2013). The Ghanaian government has recognised the need to increase its expenditure for healthcare by implementing the NHIS in 2003; however, this commitment remains exceptionally inadequate. Breast cancer patients and survivors alike will tell you that although the NHIS reduces costs for some medications, the majority of those medications they are prescribed are not covered. Additionally, healthcare institutions with oncological capabilities are limited and mostly located within private facilities in urban areas, so the vast majority of women cannot access them.

Research has established that most Ghanaian patients (47–75 per cent) report in stages III and IV of breast cancer, 'approximately eight months or more after first noticing a change in their breasts' (Bonsu et al., 2014; Clegg-Lampsey & Hodasi, 2007, p. 72). This means that Ghanaian women present in the advanced stages of the disease, leaving mastectomy as the only viable treatment. There are many reasons for the prevalence of late presentation including the paralysing fear of a cancer-caused death, participation in decision-making processes and financial incapability. However, the fear of mastectomy is responsible for the highest percentage of delayed presentation in Ghana—approximately 34.8 per cent in a study conducted by Clegg-Lampsey, Dakubo and Attobra (2009). Similarly, I found that women tend to flee at the mere mention of mastectomy, ceasing treatment from that point onwards. This is due to the symbolic importance of the breast and a public consensus that if one presents to hospital with breast cancer, the hospital will, in the words of one woman, 'cut you, scar you and kill you'.

Absconding, that is to discontinue treatment against medical advice, is another significant barrier to breast cancer management in Ghana. The reasons for absconding are similar to those for delayed presentation, mastectomy again being the most common. Clegg-Lampsey et al. (2009) also found that married women are more likely to abscond from treatment because of the need to seek approval from dominant males within their family, who do not often see the relevance of biomedical treatment. I found that the majority of women who started chemotherapy at THH would experience a downsizing of their tumours and subsequently abscond, due to the perception of 'no lump, no problem.' Furthermore, while

many women happily adhere to those non-invasive oncological treatments such as chemotherapy and radiation, once advised of the need for invasive surgery, they also abscond.

As breast cancer does not have a definitive cause, the Asante often assert it to be a direct result of failing to ‘adhere to moral, spiritual or behavioural prescriptions,’ to social pathos such as witchcraft, or to inappropriate lifestyle choices (Manderson as cited in Singer & Erikson, 2011, p. 327). Consequently, women are often forced into the hands of the fetish priest, or *dunsinyi*’s such as herbalists, if not at the determination of the household, then by the shaming eye of society. This results in local remedial treatment comprising the initial step in help-seeking behaviour. I asked Evelyn how she came to discover that she had breast cancer. She told me:

It was about six years ago. I noticed that my left breast was getting very hard, and the skin was going in [dimpling]. I showed my breast to my husband and he took me to the herbalist. The herbalist examined me for some time and then asked me if I keep money in my brassiere, because he has seen other women with the same problem who keep money in their brassiere. I told him of course! I am a trader; it is safest to keep the money in my bra! So he told me I am not allowed to keep the money in my bra anymore and then he gave me the medicine, the herbal paste to apply twice a day to my breast for one month. Actually it seemed as if the paste was working because the breast was looking better, it wasn’t going in as much. I remember I was happy that the problem was getting better. So I went back after one month, and he made me some more medicine, this time once a day for two months. It was after maybe six weeks that I noticed the problem had returned, actually it was much worse. My breast began to feel much, much harder and I was in a lot of pain. I had told my husband and he said I should go back to the herbalist and when I did, he referred me here, to THH.

Traditional medical practitioners (TMPs), or *dunsinyi*’s in Asante Twi, are socially sanctioned healers who are commonly consulted in Ghana. According to O’Brien et al. (2012, p.2, 7) they ‘play important psychosocial and perhaps medical roles in conducting treatments not provided by allopathic medicine’ as they ‘prescribe medications, keep records, follow up with patients and refer patients to other medical practitioners.’ The Asante belief in the spiritual causation of disease means that diseases such as breast cancer find their roots in

social contexts. The resulting stigma and blame is severe. It will most often also affect the larger extended family of the sick, which, as discussed previously, is highly problematic.

In the context of cancer management, previous studies in Ghana and across the African continent reveal that patients commonly seek herbal, spiritual and traditional treatments for cancer, due to their efficacy and also their accessibility (Clegg-Lamprey et al., 2009a,b; World Health Organization, 2002). In fact, ‘several previous studies found that TMPs often cite cancer as one of the diseases they commonly see and treat among their patient populations’ (Abubakar, Musa, Ahmed & Hussaini, 2007; Birhan, Giday & Teklehaymanot, 2011; de-Graft Aikins, Boynton & Atanga, 2010; O’Brien et al., 2012, p.2).

Understanding and recognising the role that TMPs currently play in treating and perceiving breast cancer is central to understanding the reasons Asante women often delay seeking biomedical treatment. Though it is not my intention to analyse the specificities of this role within this paper, I, like O’Brien et al. (2012, p. 7) suggest that TMPs have the potential to become an ‘important service delivery resource in the [Ghanaian] healthcare system, and certain tasks of early detection could be shifted to them, in an effort to maximize the utilisation of health care practitioners of all types in the war against cancer in Ghana and sub-Saharan Africa.’ The recognition and utilisation of the role that TMPs play in health and illness needs to be better recognised by the medical community in Ghana. Continued attempts to construct alternative forms of medicine as ‘senseless’ and ineffective do nothing for improving the plight of breast cancer patients. Rather they can confuse patients when attempting to make decisions about their health-seeking behaviours and subsequently result in delayed or inadequate treatment as well.

2.3 The Culture of Biomedicine

‘Under common biomedical understandings, a disease’s aetiology, signs, symptoms, natural history, treatment and prognosis are considered similar across all individuals, ethnic groups or cultures’ (Yew & Noor, 2014, p. 119). As such, the biomedical model of disease assumes that breast cancer in a Ghanaian woman will mirror breast cancer in an Australian woman for example. This Western, epidemiological approach treats disease as a biomedical category that

should remain consistent across the human race no matter the ethnicity or culture (Fabrega & Silver, 1973).

Central to the biomedical model is the theory of specific aetiology (Mishler, 1981). It essentially assumes that individuals should be able to identify when their bodies are not functioning normally, as ‘each disease is caused by a specific, potentially identifiable agent’ (Mishler, 1981, p. 16). As Bunton and Petersen (2005, p. 202) state, people are called upon to be ‘attuned to the dangers lurking within them and knowledgeable about how they as individuals, might help to prevent disease.’

Additionally, biomedicine, according to Mishler (1981, p.40), adopts a reductionist approach that prefers to focus on advancing technological medical care and a science-based, ‘cure-oriented, hospital-centred’ view of health and illness, rather than the causal influences that stem from society and culture. There are two reasons why this reductionist approach continues to fail in the majority of contexts outside of the West. First, if sociocultural barriers such as stigma prevent a patient from accessing this care, it no longer matters how technological it may be. Second, the reductionist approach assumes that given the choice, people will always choose biomedicine as the most viable and rational treatment avenue. This is overwhelmingly not the case; ‘most alternative traditions have survived in one form or another’ (Mishler, 1981, p. 41). Ultimately, biomedicine can, and often does, completely neglect other causal influences such as the social, cultural, economic, political and environmental factors that are key to shaping health outcomes. This neglect forms the basis for contemporary criticisms of biomedicine.

In the context of Africa, biomedicine has historically ‘represented both a valuable tool of Western science to combat disease, and an ideological set of sociocultural beliefs and practices suitable to civilise and Westernise the Africans’ (Baranov, 2008, p. 91). Little has changed: beyond Africa, biomedicine continues to be a highly globalised phenomenon that dominates medicine. Its scientific basis is thought to make it globally applicable as it is not affected by the particularities of any ethnic group, culture or society.

However in many cases, when biomedicine is adopted by post-colonial cultures, it can take on neo-colonial characteristics that project solely Western morals, values and principles that define the biological body as autonomously bounded, and promote individualist

conceptions of personhood. Definitions such as these most often do not align with the morals, values and principles of the cultures attempting to adopt them. Moreover, they fail to take into account that all bodies are not 'equal in terms of health, their access to healthcare, or their access to basic conditions for health' (Bennett, 2006, p. 268).

This paper will show that biomedicine can be practised in more humanistic ways that attend to both the structural circumstances and the cultural life worlds of female Ghanaian breast cancer survivors. In doing so, this practice of humanistic biomedicine maintains something of a 'check' on the reductionist tendencies inherent to biomedical culture, and acknowledges the role that Asante culture and society plays in conceptualising the body, and the illnesses that plague it.

2.4 Two Hills Hospital

Beyond the dirt roads, constant traffic and bustling market place of Kumasi exists a small pale blue hospital at the top of a hill. Largely, THH is known and regarded as a breast cancer treatment centre, the only one in the country home to what patients will tell you, is the kindest and most caring breast cancer specialist you will ever meet.

A petite woman, Dr M is always armed with a smile. Her charisma can be felt from the moment her car pulls into the hospital parking lot. She is a wife, mother and a teacher, but one could argue that it is her work for which she is most highly impassioned. Her manner is refined, gentle and very courteous, as are the majority of Ghanaians you will come to meet. However, Dr M does not take no for an answer: if she sees the need for something, she will ensure that she gets it. When it comes to her work, she makes no compromises.

For over 22 years Dr M has specialised in breast cancer management. Building THH from the ground up, Dr M has ensured it has become a resource centre for diagnosis, treatment, rehabilitation, research and counselling for women with breast cancer. Women line the hallways of THH every day to see Dr M, many having to wait all day. Some must travel from their villages for hours to reach THH, while others come from Kumasi, or the capital Accra in Ghana's south. Everyday of the week she will examine up to thirty women, see patients on the wards, aspirate lungs and operate. On weekends, mostly Sundays, after an

exhaustive week, Dr M and her team of nurses, laboratory technicians, breast cancer survivors and other hospital staff embark on outreaches (screening and advocacy programs) in which they visit women's groups, churches, schools and universities; most often at the expense of her own financial and logistical resources.

THH has four floors, the ground and the first floor being the most important. As you enter through the brown trimmed glass doors that comprise the main entry, women sit on dark blue chairs either waiting for chemotherapy or resting after it. Those that have had their course administered sit with black plastics bags spitting up excess saliva, a common consequence of the chemotherapy known as oral mucositis (American Cancer Society, 2015; Eilers, 2004; Epstein & Murphy, 2010; Rodriguez-Caballero et al., 2012; The University of Chicago Medicine, 2014). To the left of the main foyer are the doors for the operating theatres—the only place more feared than the chemotherapy room.

Upstairs on level one is Dr M's consulting room and reception. Her consulting room is bright, with large windows at the back and the front. The windows that connect her consulting room with the outside corridor are cloaked in thick purple patterned curtain to ensure the privacy of those inside. Her desk sits directly opposite the door; to the left of it stands a basin and to the right, an examining table with a patient privacy screen wrapped around its lower end. It is within the walls of this room that Dr M carries out some of her most challenging, important and life-changing work.

Although hospital bureaucracy and the authority of biomedical clinical culture can often intimidate patients, clinicians, nurses and fellow patients have the power to humanise the illness experience. Obrist, et al (2014, p. 826) assert that the physician in Ghana 'serves as an authoritative figure in the medical system.' As such, the majority of patients at THH will agree to follow Dr M's prescribed treatment regime without discussion, particularly because they are unable to understand and comprehend oncological regimens (Obrist et al., 2014).

Ghanaian culture, with the import and appropriation of biomedical clinical culture, has created a specific type of patient-hood with what Harvey (2008, p. 580) asserts to be a certain set of 'clinical expectations, sociolinguistic patterns and comportment (bodily) practices.' Specifically, this type of patient-hood determines what the patient will say, how much time

they have to say it, and the appropriate amounts of emotion they are expected to display (Harvey, 2008). I was often told that outside of THH, the specifications of this role equated to the doctor doing the majority of talking, while the patient waits reverently for instruction. Emotional displays were not welcome because there was not enough time to accommodate them, and questions on the part of the patient were limited because the confidence to ask them is superseded by a lack of comprehension surrounding the illness.

In the case of Dr M and THH, the expected patient role described above has been somewhat manipulated to allow for more humanistic forms of expression. Specifically, Dr M has removed those aspects of biomedicine that Kleinman (1988, p. 54) considers commoditise 'the healer-sick person relationship.' Instead at THH, this relationship is grounded in care, commitment and love so that her patients feel they can ask any question they need to, share any information they deem necessary, and display copious amounts of emotion should they feel the need.

It is because of the openness of THH's clinical spaces that Dr M is able to engage her patient's in honest, and sometimes frank conversations about their health-seeking behaviours, particularly those that occur outside of the hospital. The following observation from my field notes conveys some of this:

The bell rings and a woman, Akua, is brought into Dr M's consulting room in a wheelchair. As she is wheeled past me, the scent of what can only be a deeply stinking tumour interrupts my train of thought. Dr M greets her with a smile and asks how she is feeling. No matter how offensive the smell, Dr M will never cringe or recoil. She slowly peels back the makeshift dressing, aware that the smell will strengthen significantly once Akua's chest is bare. The wound is awful. The middle of what used to be her breast appears to have eroded to the point that all that remains is a hollow shell of necrotic tissue that looks as though it may soon collapse. Dr M sits back in down in her chair. 'Why have you taken so long to see a doctor?' she asks Akua. 'I was seeing the herbalist, he was treating me. I was applying his medicine two times a day and it was working. Even when the breast started to smell, the medicine was covering the stench. But then it was too painful to keep applying the medicine. And then the smell, it was too strong. If I leave the house people stare and talk about me. They say I smell. They won't come near me. So then I was shy, I was embarrassed. So I stayed inside the house. Then my older brother returned from

overseas, he had travelled for work. He came to visit me and saw that I am not ok. And he brought me here.’ Dr M’s expression has changed somewhat, I can see the frustration that is hidden behind her eyes, yet she is careful not to place it on Akua. ‘Being shy is not a good excuse. You see how sick you are now? Once you saw that the herbal medicine wasn’t working, that is when you should have come here. I’m happy you are here now, we will help you. But what you have, it is serious, and the time you have taken to get here has not helped you,’ she says softly.

As is evident here, patients just like Akua often utilise alternative treatments such as herbal remedies alongside, or prior to, their biomedical treatment (Obrist et al., 2014). Unlike the Western biomedical perceptions of the patient that prefigures her as individualistic and autonomous, the Ghanaian patient role that Dr M has allowed for prefigures the patient in relation to the society that surrounds her and her own place within it (Harvey, 2008). Consequently the seeking of alternative forms of treatment is constructed as almost rational, given their relevance in Asante culture. Most of the consultations I was able to be a part of were open dialogues between Dr M and the patient. Although she was always disapproving of health-seeking behaviours that had delayed a patient’s arrival to THH, she was often understanding of the reasoning behind them.

Dr M first directs patients to the survivors/counsellors as their first point of contact after diagnosis. I combine survivor and counsellor here because the roles are interdependent. You must first be a breast cancer survivor before you are able to counsel.⁷ Rather than funnelling the newly diagnosed into the agency-depriving and individualising practices of biomedical culture, Dr M understands that having a larger social context in which to process and discuss diagnosis and treatment with those that are familiar but also embody the journey they are about to take, is essential. The president of this association, Aunty Vera, and another member of the executive, Mama Naammɔ, work full time at THH as primary counsellors for the newly diagnosed. They spend their days on the other side of the corridor, opposite Dr M’s consulting room in reception. There, they wait for Dr M to send patients to them, one after the other, so that they can initiate the counselling process.

⁷ From this point forwards, survivors and counsellors will be mentioned separately. A survivor should be taken as someone who has survived breast cancer, whereas a counsellor should be taken as someone who has survived cancer and counsels about the experience.

Dr M created the survivors association for the primary purpose of ensuring all those engaged in the breast cancer experience feel supported and informed. On the part of the patient, being counselled by a breast cancer survivor who has undergone the same course of treatment upon which they are about to embark is invaluable to their breast cancer experience. In the initial stages of counselling, patients are able to ask any questions about their diagnosis, treatment and prognosis that Dr M may not have had the time to explain, or that the patient may not have felt comfortable to ask.

Most patients at THH have open fungating wounds that sit where a breast once did. A small fraction of them have family and friends that will follow up on their wellbeing. However, for the majority of women on the THH breast cancer ward, home is a long way away and so is family. Social isolation and abandonment become the most common experiences. Of course distance is a factor, but really it is the response of family and friends that contributes most significantly to this isolation and abandonment. The social world of the patient is transformed in such a way that they are unable to participate in common social activities and interactions (Ram & Houston, 2015). Breast cancer becomes the ‘elephant’ in their relationships. Consequently, the support that women receive at THH not only from the doctors and nurses, but also particularly from the counsellors who guide them through their journey, is invaluable. They become a connection to a new social world that can act as a family who, unlike their own, understands their experiences and does not shame them.

According to Knaul et al., (2012, p. 85) ‘cancer, particularly when it affects women and reproductive health, epitomises the complexities and the inequities of the epidemiological challenges faced by low and middle-income countries.’ In Ghana it highlights those glaring disparities in the way cancer affects the rich and the poor. However, as we will continue to see in the following chapters, the story of THH is ultimately one of resilience, support, care and life-changing transformation.

Chapter 3: Experiencing Cancer—The Importance of Care

A typical day at THH begins at 6am. All staff present in the hospital at that time (nurses, cleaners, doctors) start their day in the front courtyard of the compound. It is there that Auntie Ama, the matron, leads morning devotion; songs and prayers to God. Patients admitted to THH at the time and able to mobilise from their beds congregate at the windows of the wards facing the courtyard to join the devotion from afar. Those who had already begun their extensive wait to see Dr M would also rise from their chairs. Devotion always finishes in prayer, giving thanks to God and asking for continuous blessings over the hospital, the patients and particularly Dr M.

The importance of this moment each morning cannot be overemphasised. Ghana is an overwhelmingly Christian country, with just over 70 per cent of its population identifying as such (Central Intelligence Agency, 2014). I would often walk past someone preaching passionately to the masses as I embarked on my daily commute to work. In Botswana, Livingston (2012) found that moments shared with God in the clinical context clarified the purpose of medicine. They remind the staff that it is God's work they are carrying out, and most importantly, they reinforce to very sick patients that God is there for them and so are the staff. For a Ghanaian woman with breast cancer, whose morality awareness is more acute than ever, the reminder that she is part of God's plan is absolutely crucial to her overall wellbeing.

Believing in God helps to make traumatic events manageable. Researchers have for a long time regarded the religious and spiritual domains as potential resources for individuals experiencing hardship. Spilka, Spangler and Nelson (1983, p.104), for example, found that patients 'speak of the profound significance their religious faith has for them.' In particular, religion functions as an important support mechanism for breast cancer patients, especially since they often become more spiritual and reliant on God after diagnosis (Cavanaugh, 1994; Heim, Augustiny, Shaffner & Valach, 1993; Johnson & Spilka, 1991).

For both the patients and the survivors at THH, God was central to their ability to cope with the reality of having breast cancer. The religious beliefs of Christianity, such as having faith in God's plan, provided a framework for understanding their experiences, especially when they seemed unexplainable (Acklin, Brown & Mauger, 1983; Pargament et al., 1990).

Moreover, moments such as devotion shared between members of this clinical community demonstrated the importance of unity in both illness and also religion. As we will continue to see throughout this paper, the patients, but more importantly the survivors at THH, employ their own religious interpretations of their illness to help reframe their experience as having positive, life-changing consequences.

3.1 Aunty Vera

It is 10.20 am on an ordinary January day and I arrive at THH feeling somewhat under the weather as my body deals with the pitfalls of recovering from malaria. As I climb the two flights of stairs up to reception, I find myself needing to pause continuously (malaria substantially weakens your body). When I finally reach reception I noticed that Aunty Vera is not inside; rather, she is sitting on one of the plastic chairs that line the hallway outside Dr M's consulting room. 'Today it's my turn to see doctor', she tells me while laughing. Aunty Vera is a small, petite woman who moves slowly on her feet. Even though her right arm is perpetually swollen (a consequence of her own breast cancer treatment), Aunty Vera takes great pride in her appearance, ensuring that she is always dressed beautifully in traditional Ghanaian cloth. It is important, she will tell you, to 'dress very nicely so that the patients will see that you can still look nice even after having breast cancer.'

I met Aunty Vera on my first day at THH when she walked me around the hospital, talking me through her role as a survivor and a counsellor, and explaining the purpose of each room and clinic. After the tour concluded, she sat me down in the hospital cafeteria and began to chronicle the journey that led up to her breast cancer diagnosis. She was 46 when she was diagnosed with advanced stage breast cancer, and her story of delayed diagnosis is an all-too-familiar one:

I was reducing in weight, feeling dizzy and very uncomfortable. I thought it was just ordinary malaria until one day I was bathing and I saw that there was a small lump in my right breast. At that time, I didn't know anything about breast cancer so I left it until I noticed that it was swelling. I told my family members, and they told me it's a curse. They informed me that two of my female cousins and an aunt had also been diagnosed with breast cancer and they had died. So it must be a problem in the family. So they took me to the prayer camp north of where I was living at that time.

The pastor there, he also told me that I have done something wrong, so I need to stay in the prayer camp for six months before the lump goes and the curse is no more. So I stayed in the prayer camp for six months, only to see that my breast was not improving. In fact the breast became very big and it opened. I didn't think that the prayer camp was working for me, so I decided to leave and go to the nearest hospital, Komfo Anokye Teaching Hospital. After waiting in the hospital for maybe three days, I saw a doctor. He sent me for a scan, and later told me he will need to operate on my breast. Eventually I had the operation and was sent home, but after only a few weeks, the lump came back again, so I returned to Komfo Anokye. They did the operation a second time and this time they told me they will test to lump to see what it is. As I was waiting and waiting for the results I began to see that I was still growing lean, losing more weight. Nobody could recognise me. One month went by and still they did not call me with the results. So again I went back to the hospital, but I was told that my results were still not ready. So I had no choice but to go home and wait. After another month the hospital finally called me to come for the results. When I went there the doctor told me that it was cancer, so he needs to remove a large part of my breast. I began to cry. I thought I will surely die. But the doctor was getting angry, he said he had many patients to see so I should go away. As I was leaving, I was still crying and a nurse saw me. She took me to the side and she comforted me, she said that if I am having the cancer I should come here to THH rather than get treated at Komfo Anokye. She said at THH there is a woman who is very good, a breast cancer specialist. So I went back home and I told my family. They were not happy that I had left the prayer camp and when I said it was cancer, they stopped talking to me. Other people were also talking to me, saying what is wrong with your family, how can four people in one family have the same problem! But I came to THH anyway. When I saw Dr M she looked at all my paperwork, especially the pictures from my scans. She turned to me and also told me I am having cancer. She said that even though I went for the two operations, the other doctor had not removed everything so I would also need chemotherapy. After having chemotherapy, she told me I would also need to go for another operation, just as the other doctor said, otherwise I cannot survive. I cried and cried again. I am thinking I am definitely going to die. But you see Dr M she just let me cry. She let me cry for maybe 30 minutes in her office.

According to Livingston (2012) and Kleinman (2012, p. 1150), care-giving is a moral endeavour; 'it is one of the foundational moral meanings and practices in human experience everywhere.' However, its ability to be carried out *morally* is profoundly shaped by social, political and economic factors. In Aunty Vera's case, it is not that her doctor at Komfo Anokye did not care for her predicament or her feelings about it, rather his own reaction was shaped by a system of universal biomedical care that privileges numerical targets, demands resource frugality and is often bogged down by a lack of medical staff and an overwhelming patient load. His reaction in this case was shaped by more than sixty patients sitting outside his consulting room, the broken mammography machine that remains broken no matter how many calls he makes, and finally the knowledge that he will not see the majority of his patients again, no matter how long he spends with them at the time of diagnosis, until they are near death.

These frustrations are not unique to that doctor or that hospital; rather they are a regularity in the lives of most physicians in Ghana, including Dr M. She must make decisions about the distribution of scarce resources, asking which lives are 'worth' spending more resources on. In conversation with Dr M, she confirmed the challenges of resource allocation when reflecting on those patients who have absolutely no means to begin treatment:

I have to make a decision. I have to look at the woman and decide if I can personally help. I used to tell my patients just make part payments, but it ended up that a lot of people owed the hospital a lot of money. But even now I still try and help where I can. If the patient tells me she cannot pay, I will call her husband, parents, siblings, children—anyone who can help her! If there is no one, I will pay for her treatment, but I have to be careful or I'll go bankrupt!

In spite of these challenges, Dr M has made it clear that care-giving is the most important part of cancer treatment, and what Livingston (2012) asserts to be a deeply personal endeavour. Her own experiences from working at various public hospitals around Ghana provided her with insight into the failing bureaucratic regimes of government hospitals that often leave patients such as Aunty Vera waiting days for initial consults and when finally attended to, feeling intimidated and irrelevant by doctors attempting to adhere to the 'professional and efficient' standards of medical practice that have been placed upon them.

For Dr M, good care-giving defines and shapes her patient's experience of breast cancer, which is crucial to their wellbeing and their survival. Experience, just like care-giving, is also moral. According to Kleinman (1998, p. 362), it is a 'medium of engagement in everyday life in which things are at stake and in which ordinary people are deeply engaged stakeholders, who have important things to loose, gain, and to preserve.' In the context of this research, the stakeholders are the patients, and what they have to loose is more than important.

Once diagnosed, THH becomes a significant part of a patient's everyday life. It is where she will spend the majority of her time learning about her disease, waiting for hours to have it treated, and meeting others who can share in her experience. She becomes accustomed to the security and routine of its environment. As such, THH and its entire staff form what I deem a community of sufferers. Everyone suffers empathically with and for the patients to ensure that cancer, in all of its terribleness, is humanised through understanding. Communal suffering is incredibly important in contexts such as these. For Kleinman (1998), this is because experiences of diseases and dying are intersubjective. He states, 'contrary to our pronounced Western ideological tendency' to individualise the suffering of an individual, suffering in this context exists in the 'intersubjective space' between the patient and those that surround her at THH (Kleinman, 1998, p. 390).

3.2 Improvising Medicine

For THH to operate as a healthcare provider that embodies a true commitment to the plight of its patients, improvisation is often at the core of care-giving. Take Dr M for example: the time and resource constraints that she faces on a daily, if not hourly basis, ensure that she must practice a form of very highly improvised oncology. I recall:

After finishing consulting with the patient, Dr M turns to me and explains her prognosis: 'She is in stage III, I want to begin chemotherapy immediately, but her HB [haemoglobin] is low, I need her to have at least three pints of blood before we give her the first course. But she is telling me that she doesn't have any money'. Dr M turns to the patient and asks for her husband's phone number. She proceeds to call him and explain the situation. She advises him how much the treatment will cost, and advises him strongly that he must help his wife in any way possible if he

wishes her to survive. After ending the call, Dr M turns to the patient again and asks for the phone number of her eldest child. She also calls him and explains the situation and the need for his help to ensure his mother receives the best treatment she can. Dr M repeats the process with all three of her children.

According to Livingston (2012, p. 6), it is this kind of improvisation that has become a defining feature of oncological care and biomedicine in Africa, as ‘doctors, patients, nurses, and relatives tailor biomedical knowledge and practices to suit their specific situations.’ In Ghana, clinical improvisation is accentuated because of the social, economic and health inequities that shape the everyday. In the example above, improvisation was evident in Dr M’s ability to act not only as a social worker, but also an extortionist (in the lighter sense of the word). She must convince those males that surround the patient to pay for her care.

Care must also be improvised in this context because of the realities of Ghanaian medicine. Most patients arrive in the advanced stages of breast cancer, while also being infected with comorbidities such as diarrhoea and malaria. These patients require specialised treatment to account for their multiple conditions. However, the significant economic constraints of patients often means they are unable to afford what is required to treat them, especially when treatment is required for more than one condition. Therefore, Dr M and her patients must improvise *together* to determine what forms of treatment are appropriate and affordable—appropriate, because most often Dr M must decide which medications to prescribe while undergoing the long wait for biopsy and histology results; and affordable, because there is no point developing a treatment regime that patients are unable to adhere to.

Finally, the social vulnerabilities inherent to Ghanaian culture have also contributed to the improvisational nature of breast cancer treatment at THH. The ethnotheories of causation and the dominance of patriarchy explored in Chapter 2 mean that a patient’s treatment is always heavily intertwined with the opinions and abilities of others. The flow of care is never direct and purely binary—between doctor and patient. Rather, hospital staff must convince family members of the necessity to improvise so that treatment can be properly adhered to. Whether it be a nurse convincing a father to perhaps sell his car so that his daughter can afford a radical re-section, or a counsellor accompanying a husband to his local church to collect donations to pay for his wife’s radiotherapy, families play a vast role in all facets of

breast cancer management, particularly in terms of decision-making processes, adherence to treatment and successful recovery.

3.3 The Realities and Commonalities of Breast Cancer

Breast cancer engulfs not only the patients, but also their families. Those that surround the patient are often unwilling or unable to provide the support required of them. Hence, patients must negotiate the individualised experience of breast cancer and the already-established social world that they find themselves forced into (Mathews, 2000). For example, not only a patient, but also her husband, must trust and live out ‘economic, social, emotional and moral commitments’ to care for his wife ‘in the long-term aftermath’ of whatever decisions they choose to make at the time of diagnosis (Livingston, 2012, p. 86). These commitments occur in a ‘complex social world where lives are deeply intertwined with households and families’ (Livingston, 2012, p. 87). For example, from my field notes:

Jane, Dr M’s receptionist, enters her office in a hurry, ‘the patient from last week, she has come back with the husband again to see you’. Jane is referring to a woman Dr M examined a few weeks ago. She is in the advanced stages of breast cancer. The entirety of her right breast is necrotic. It is a smell that I will never forget. She needs a mastectomy, but her husband will not allow her to go through with the operation. Dr M has talked to him once before but to no avail. ‘Bring them in in a few minutes’, she says. Jane leaves and Dr M sighs and looks at me. ‘Her husband said he will not allow the wife to have the operation, he said he will divorce her! I just don’t understand! If not for the operation she will surely die! How can he just say no? It’s like he is one with the breast!’ Jane walks back into Dr M’s consulting room with the patient and her husband. They take a seat next to me and opposite Dr M. She begins by explaining the patient’s prognosis once again, and the necessity of the mastectomy. She aims most of her explanations towards the man as he sits rigidly in his chair. After she finishes, the man asks why chemotherapy will not be enough for his wife. I see that Dr M is agitated by that question, given she had just spent five minutes explaining that point. ‘If all she needed was chemotherapy then all I would give her would be chemotherapy. But she is sick! She needs the operation or she cannot survive!’ The man shakes his head, ‘I don’t agree, she cannot have the operation’. Dr M asks him to reconsider, but she is frustrated and the man can tell.

He begins to anger as well, and I can see that this conversation is not going anywhere. Dr M excuses herself and leaves. She returns with a beaming Naammɔ who asks the couple to come with her. I follow inquisitively and we move into the empty consulting room next door. Naammɔ asks the couple to sit opposite her behind the desk, I take my seat on the examination table. ‘Your wife needs a mastectomy. I know it’s hard to understand why. When I first came here, my breast even looked ok, but Dr M told me that I also needed a mastectomy. I was very upset, I didn’t understand why my whole breast should be removed. But you see that operation saved my life. Now I am surviving cancer for 10 years! That would not have been possible without having the operation. If you allow her, I know she can survive.’ I look over at the patient, realising that I haven’t actually heard her say one word the entire time I have been with her. I can’t help but wonder what she would say if given the opportunity to speak on her own behalf. But this is not the way decisions are often made in Ghana. Naammɔ reaches into her *kava* [blouse] and removes the silicone breast insert from her bra. ‘This is what we will give her after the operation, so that no one will know she is having just one breast.’ The man sits back and looks at his wife. She doesn’t look back at him, she continues to focus her gaze on the floor. ‘If you remove the breast, she will survive and she will be ok? We have children!’ the man says to Naammɔ. ‘Yes she can survive! There are many of us with just one breast, and we are all ok!’ The man says nothing. He simply nods. Naammɔ looks over at me with a big grin on her face.

All forms of cancer treatment are ‘aversive;’ they leave scars whether visible or not (Livingston, 2012, p. 19). However, mastectomy is a facet of cancer medicine that is unique in its own right. For patients and their families, it is an often incomprehensible and overwhelming form of treatment. In the case of this patient and her husband, a mastectomy represented the loss of a part of the body that struck at the very heart of what it means to be an Asante woman.

According to Toombs (1987, p. 229), ‘phenomenological description[s] of illness-as-lived reveals certain... eidetic characteristics of illness.’ Of course, each experience of illness is unique, however Tombs (1987, p. 229) goes on to state that these ‘eidetic characteristics of illness,’ namely feelings of incompleteness, familiarity and control, transcend the peculiarities and particularities of different disease states.’ Take, for example, the

experiences of three women, Agnes, Florence and Grace: though the specifics of their lives are different, they share something similar. They represent the most common experiences of Ghanaian women once diagnosed with breast cancer.

Agnes was 47 and working as a caterer when she was diagnosed with breast cancer. Her breast had started to itch one evening and the sensation would not dissipate. After seeing Dr M, Agnes informed her workplace that she would need time off while undergoing chemotherapy. Convinced that breast cancer was contagious, her workplace promptly fired her and informed other catering companies of her diagnosis: ‘They told all of the other companies that I had this disease that I could spread around, so no one should hire me. I tried talking to many people but no one would listen to me. I was very embarrassed, it made me very shy.’ Agnes was not able to find another catering job and now relies on her children to support her ongoing cancer management.

Florence, a mother of three living in a compound house in central Kumasi, was diagnosed with cancer at age 42. Knowing that others residing in her compound would ‘gossip’ if they knew about her diagnosis, Florence refused to share her diagnosis with anyone but her husband. However, after she had begun her chemotherapy and the visible signs of oncological treatment such as hair loss began to show, those with whom Florence shared her compound began to gossip just as she had predicted: ‘They would laugh at me, tell me I’m a witch. Tell me I will surely die. So I stopped leaving the house except on days when I needed to come for my treatment.’

For Grace, who was 39 when she was first diagnosed with breast cancer, it was not stigma that dominated her breast cancer experience, but the economic consequences. Grace actually presented to THH in the early stages of the disease, but after learning that it was cancer, she absconded from treatment for eight months. It was not until necrotic tissue began to form around her left nipple that Grace—who could no longer stand the smell, let alone the twice daily do-it-yourself dressings required because of the excessive weeping of the wound—decided to return to THH and show her breast to Dr M once again. By that time, Grace’s husband had left her (sure that her death was imminent) and her cancer had moved to the more advanced stages. She told me that Dr M, angry with her for running away, advised her sternly that she would now need aggressive chemotherapy (20 rounds), a mastectomy and most likely several pints of

blood (equivalent of AU\$25 each): ‘I remember making my way down the stairs to the pharmacy to pay for the blood and the first round of chemotherapy. When they told me the amount I was shocked! Oh! I started to cry. The amount was plenty! I knew this thing, cancer, would take all of my money. And it did. The medicine took all of my money. When I first finished treatment I remember thinking, ‘I have a life, but I don’t have anything to help me live it.’

Although the exact details are different, the examples of Agnes, Florence and Grace (in fact all of the women discussed in this chapter) are remarkably similar, representing the most common experiences for women diagnosed with breast cancer in Ghana. In all instances, breast cancer strips women of a part of themselves or at least their lives that affects them markedly. Their initial visit to THH marks the beginning of a journey that hurls them into uncharted territory.

Consultations with Dr M are usually quite short. She would say, ‘the lump you feel is *kokoram* (cancer), but the medicine will make it smaller.’ Dr M would often not reference any further surgical interventions. She would write ‘mastectomy’ or ‘lumpectomy’ on a pink post-it note and hand it to a counsellor so that she could explain the situation to the patient in their counselling sessions. These conversations were much more intimate, carried out mostly by either Auntie Vera or Mama Naammɔ. They would say:

The medicine will make you throw up and you will lose your hair. But this won’t last. Your hair will also return. But you must come for all of the rounds of chemotherapy Dr M has prescribed for you. You have to complete all of them. Then maybe you will need surgery. Dr M will decide if you need just the lump removed, or whether she will need to take the whole breast. But whatever she tells you, you must do it. Then you can be like me, a survivor!

Before Dr M decided to employ and train survivors to counsel the newly diagnosed, there were no professional counsellors at THH. Dr M did not have the time, though she did often try. The nurses also attempted to bridge the gap but their own patient demands almost always prohibited them. As a consequence, most patients would acknowledge but not really understand and digest the information and instructions they were given. Thus, they would often abscond from treatment or pair alternative, often damaging behaviour (such as herbal

remedies causing liver failure) with the clinical management of their breast cancer. Patients with a strong desire to better understand what is happening to them are rare, so counsellors are pivotal to ensuring all questions can be asked and are answered, and the treatment process is given a chance to be well understood.

According to Livingston (2012, p. 6) ‘understanding breast cancer as something that happens between people is critical to grasping its gravity.’ The experiences in and of cancer are inherently shaped by those that surround women diagnosed with it—from the neighbour who snickers as she walks past, to the husband who leaves when she shares her diagnosis, to the employer who fires her when she asks for sick leave. It is these experiences that isolate, denigrate and disturb a breast cancer patient, often leading her away from appropriate treatment, rather than toward it.

Chapter 4: Being Resilient—The Structural Barriers of Poverty

4.1 Mama Naammɔ

Mama Naammɔ's smile is one of the best things about her; it has a certain ability to comfort, calm and convince any patient or family member, regardless of their circumstances, or their opinions on breast cancer. Having been diagnosed with stage III breast cancer at age 42, Mama Naammɔ's experience of the disease is an extremely troubling, yet again, not so unusual:

I'm a woman who usually screens her breasts when bathing. One day while I was doing that I detected a lump in my breast. I told my elder sister, and she introduced me to a friend who took me to a herbal clinic. I went to the clinic for about three years. They gave me some medicine capsules and every three months scanned my breasts. I wasn't in any pain and they told me the lump in my breast is nothing, so I thought that I was fine. At that time I owned a store next to a church. I heard that there was a breast cancer outreach programme organised at the church. At that time I didn't know anything about breast cancer, so I decided to go to the outreach to learn. The main speaker was Dr M. After she spoke the nurses screened me. They told me that they detected a lump in the same breast that I had treated at the herbal clinic for three years. So they referred me to THH for further investigations. I had a mammogram and a blood test. The results showed that I had cancer. I went home and told my husband, but he didn't say anything. I stayed at home for three days, and then came back to THH to start my treatment. It was quite funny actually; during the treatment I lost my hair, not only my head but my private parts too. But I completed the chemotherapy and then came back to see Dr M. She told me that I needed a mastectomy, but I said that if she is going to remove my whole breast I will not consent to the surgery. Dr M told me to think about it; she sent me to the female cancer ward. I stayed there from morning to evening. I think it was not until 7 pm that I finally agreed to have the surgery. After I did, Dr M told me the final part of my treatment would be to have radiotherapy. But I had no money left. I had already sold everything I own to pay for the chemotherapy and the surgery. All I had left was one dress, one brassiere and one pair of pants. Sometimes I even had to use my bed sheet as a dress when my other dress wasn't clean. I was very sad. I have never

been so sad before. I didn't have a place to live. My husband, he had thrown me out of the house and taken my three children. He told my family that I had breast cancer, and that if they should come near me, they too will also get cancer and also die. So they also left me; they wouldn't speak to me. At one point I was sleeping on my father's grave, asking him to send God to help me to pay for my treatment. I also went to the churches to ask for help. I went to about 10 different churches until I had enough money to pay for the radiotherapy. But after completing the course I started to realise that I wasn't able to understand what anybody was saying unless I look at their mouth while they speak. I also began to realise that I had forgotten the alphabet and how to count to 10! So I told Dr M about what was happening and she introduced me to a psychiatrist and a teacher. I saw them for a few months. I began to slowly be able to put my sentences back together until I was back to normal. Dr M, she gave me a bed on the ward and I lived there for two years! Dr M, she supported me so much. I was very lonely you see. Everyone had abandoned me! I suffered so much! So I took her as my second mother. I could enter her consulting room at any time without knocking when there was something on my mind! Now when I see her at work, I become very happy! Very, very, very happy! I always ask God to give her long life, so she can help other women just as she helped me.

At this point Mama Naammɔ can tell that I want to ask her something. She pauses and looks at me inquisitively. I tell her that her strength and her resilience is amazing, and I ask her how she can reflect on her experience with such positivity, to which she replies:

No matter what happens to you in life, you have to give thanks to the Almighty. You see, I think the Almighty wanted me to change the lives of women, make sure that other women can survive breast cancer just as I did. Because of cancer I have a job! I am a counsellor! So yes, I have to be happy!

For Kleinman, Das, and Lock (1997, p. 1) 'suffering is one of the existential grounds of human experience; it is a defining quality, a limiting experience in the human condition.' For Mama Naammɔ, suffering was central to her experience of breast cancer. However, her reasons for suffering were not a direct consequence of her disease. Rather, as we will see throughout this chapter, they were a direct consequence of the social indicators and social processes, elucidated by her disease. It is through looking at how these indicators and processes effect the experiences of the sick, that one can 'locate the appropriate space for

anthropological and clinical engagement with the social sources of human misery and with the social experiences of adversity' and resilience (Kleinman et al., 1997, p. xxi).

Western literature on resilience in the face of adversity is vast. Early conceptualisations of resilience depict it as a trait inherent to certain individuals who are able to succeed in the midst of adversity (Arbona & Coleman, 2008). Such individuals have a 'dynamic capacity to contextually modify one's level of control in response to situational demands and affordances,' by possessing personality traits such as flexibility, adaptability and the inventive use of resources (Letzring, Block & Funder, 2005, p. 396). Building on these conceptions, Skodol (2010) proposed the notion of the resilient personality that adaptively uses confidence, empathy and sociability as internal resources.

Although definitions such as these prove useful in highlighting the individual traits that contribute to resilience, they do not account for contextual factors. Individuals constantly interact with their sociocultural environments during the process of being resilient (Lamp, 2013). Based on this, more recent research into resilience has proposed a set of protective factors that occur naturally within the environments of individuals (Rutter, 2012). Resilience is thus conceptualised as 'the flexible use of personal, social, cultural and environmental resources' in the process of responding to hardship (Lamp, 2013, p. 5).

Defined in this way, resilience accounts for not only individual traits, but also for the broader sociocultural supports that are tools for adapting to stressors (Lamp, 2013). It is this definition of resilience that explains most appropriately the developmental process of learning to be resilient that the women of THH undergo. Learning to be resilient when faced with adversity is a part of everyday life for a Ghanaian woman. For example, during periods of economic hardship, it is almost certain that it will be the girls of the family who are removed from school and put to work as street vendors to ensure that the boys can continue their education. Often this new revenue stream then becomes indispensable to the family, and opportunities to return to education are suddenly obsolete.

As evidenced in Chapter 2, the exposure to stressors continues throughout the lives of Ghanaian women, as they carry different burdens and expectations to men. I recall a conversation I had with Mama Naammɔ one Sunday afternoon as I helped her with her washing that supported this point. As she scrubbed the clothes she turned to me and said, 'if I

could come back to this earth again after I die, I wish to come back as a man, then I can lie down while my wife washes, cleans, cooks, works and looks after the children.’

Research indicates that gender influences sensitivity to hardship as ‘individuals are often affected by hardship in accordance with their roles and responsibilities’ (MercyCorps, 2014, p. 3). As we have established, the many domestic responsibilities of Asante women in particular, contribute to the development of a psyche that is, in its essence, resilient. Being coupled with abject poverty, this means these women must also learn coping mechanisms that make them adaptable to change and resourceful as a consequence. Mechanisms such as working multiple jobs (informal and formal), borrowing money or food from relatives, and reducing their own food intake so that their children and husbands may be fed first, are but a few of the ways in which women must adapt and respond to the difficulties of living in a country such as Ghana.

4.2 Shifting Resilience

Resilience is highly contextual; it is a feature of the ‘social and physical ecology’ that surrounds an individual (Ungar, 2011, p.1). A breast cancer diagnosis for an Asante woman essentially represents a shift in what they need to be resilient to. The cancer continuum consists of a series of traumatic events, beginning at diagnosis, and continuing well on into the final season of extended survival. Despite this, adversity was not what defined the women of THH. As we have seen in the cases of Mama Naammɔ and also Aunty Vera in Chapter 2, the structural deficiencies and social problems present in Ghana result in women having to draw on a range of personal and social resources to not only be able to survive breast cancer, but to do so in a resilient manner.

Poverty is the most distinct and most determining structural deficiency and social problem in the lives of Ghanaian women. For the most part, it is the primary condition of their lives. Poverty means inadequate access to health care, a deficiency in social security arrangements, financial hardship, and personal distress (P. Farmer, 1996). The effects of poverty emphasise the need to appreciate a broader, systemic view of resilience, one that facilitates a better understanding of how poverty is structured by the political, social and economic forces that exist and dominate Ghanaian society.

Poverty is socioeconomically oppressive in that it renders ‘individuals and groups vulnerable to extreme human suffering’ (P. Farmer, 2003, p. 42). Take, for example, the suffering that Mama Naammɔ experienced. Her form of, and reason for suffering is distinct. She did not suffer in the same way as an Australian woman diagnosed with breast cancer might.

During my time in Ghana, both the survivors and the newly diagnosed emphasised to me that being poor, or ‘having no money,’ makes breast cancer a sure death sentence. I recall one morning overhearing a conversation between Aunty Flora and Aunty Beatrice. Aunty Flora was hunched over, her body seemingly reflective of her mental state at the time. Aunty Beatrice had placed her hand over Aunty Flora’s and was talking to her softly. ‘What did he say?’ asked Aunty Beatrice. ‘He doesn’t say anything and he doesn’t support me. I have to support myself but my business is not going well, with the *dumsor dumsor* [power outages] I am closed most days. Today I don’t have enough money for the drugs. So I have only bought half of what Dr M prescribed for me. I also need to do my CA15 [a test for cancer markers], but I don’t have money for that either!’

Aunty Flora is a seamstress; it is her only source of income. Although her husband may provide financial support for their children and the basic household needs, Aunty Flora must pay for her own oncological treatment, as he feels she will not survive. Before her diagnosis in 2012, Aunty Flora was doing relatively well for herself. Her business as a seamstress was doing well thanks to the promising success of the Ghanaian economy. In 2011, ‘fiscal consolidation and burgeoning oil production’ gave Ghana the fastest growing economy in the world (14 per cent), enabling the ‘transition from a lower middle-income country to a middle-income country’ (Akweley, Okertchiri & Tarlue, 2015).

Unfortunately, this growth was short lived and Ghana’s economy has been steadily declining since. The government continues to overspend, public debt has ballooned and the NHIS can no longer support the ever-growing health demands of its people. The result has been a somewhat broken healthcare system. In addition, Ghana is experiencing an ongoing energy crisis due to a power supply shortage; the ‘*dumsor dumsor*’ referred to by Aunty Flora, which literally translates to ‘off and on’. *Dumsor dumsor* has become an extremely popular Ghanaian term used to describe the constant electric power outages nationwide. For example,

during my time in Ghana, electricity ran on a 12-hours on, 24-hours off cycle. Of course, this disruption was frustrating for me at the best of times, but the true gravity of its consequences were most obvious during my time spent within the hospital walls.

For Aunty Flora though, *dumsor dumsor* meant that her business was closed more days than it was open. Without electricity, her sewing machines were unable to operate, she could not see as the shipping container in which she worked did not have windows, and without a fan, it was often too hot to manage. For those who can afford it, generators are able to offset the power shortages, but for the vast majority, this is not an option. As a result, women such as Aunty Flora are no longer able to rely on basic infrastructure to sustain their livelihoods. When a breast cancer diagnosis is added to their lives, poverty starts to become a very realistic probability and treatment, while necessary, does not seem a more pressing priority over basic necessities such as food and housing.

4.3 Blame

The predominantly social and economic structural barriers evident in the experiences of Mama Naammɔ and Aunty Flora provide significant insight into issues of breast cancer treatment compliance for women in Ghana. For example, if Dr M should instruct a patient to have a blood transfusion before she is able to start chemotherapy, but the patient cannot afford to purchase the blood, the patient will ‘refuse’ the treatment. If Dr M in another instance should instruct a survivor to have a mammogram because her cancer marker is elevated, she also will ‘refuse’ if she cannot afford the test. If she would have to inform her employer of her diagnosis but suspects she will lose her job, she will again ‘refuse’ treatment. Women with breast cancer should be able to make decisions based on medical rather than economic and social criteria.

In Ghana, poverty and stigma work together to embolden non-compliance in breast cancer treatment. They both force women to make unfavourable choices that mean the difference between life and death; yet from what I observed in clinical environment’s outside of THH, they are not considered acceptable excuses for failing to seek appropriate healthcare. Ghanaian women are often blamed for their inability to access treatment and are branded as ignorant for their choices, or lack thereof. However, the blaming and shaming of patients for

their non-compliance is counterproductive, particularly as it is predicated on structural and social factors that are beyond their control.

In the absence of access to basic primary care and preventative services, breast cancer *is* a death sentence for Ghanaian women. Resilience to this fact and resourcefulness because of it, differentiates some women from others. However, before the stage of life after breast cancer, diagnosis and treatment had worked together to ensure that though their life had been preserved; the former (diagnosis) took their family and friends, and the latter (treatment), their breast(s), hair, cognitive function and financial capabilities. The women at THH had to enlist certain character traits they had developed over the course of their lives: faith, hope, optimism, flexibility, adaptability, resourcefulness, strength and humour are but a few of these. With help from those that surrounded them at THH, these traits worked together to assist these women in facing and overcoming those structural and social barriers that are implicit in a breast cancer diagnosis. Faith, hope and optimism provided a means to make sense of their illness; flexibility, adaptability and resourcefulness assisted in the discovery of new ways to afford treatment; and strength and humour served as a powerful and effective coping mechanism that encouraged positivity.

However, the enlisting of these resilient characteristics cannot stop after treatment is completed. Besides the need to form new supportive relationships and to rebuild finances, the fact that the bodies of these women have also been through an enormous assault forces them to form a new understanding of their altered appearance and altered boundaries of ability. ‘Any crisis in the body,’ as Ram and Houston (2015, p. 12) state, ‘makes it surge into awareness, its usual role as support all too painfully made evident in our sudden or slow impairment, our deteriorating ability to comport ourselves in our usual way.’

Fundamentally, breast cancer is a disruption within the body that changes how women exist in the world (Toombs, 1987). For example, the responsibilities that are fundamental to being an Asante woman, such as washing and cooking, require a certain level of strength that breast cancer survivors often no longer possess. The pounding required to prepare *fufu*, a cassava-based dish that is a staple in the Ghanaian diet, was one particular task that women described they were no longer able to carry out. This inability demonstrates the need for survivors to recognise these new-found limits to their abilities; limits that are not always forgiven by those around them.

For those that are not able to cultivate resilience throughout breast cancer treatment and beyond, the trauma is always too much to bear, and the catastrophic result is almost always is death. What is unique about this death though, is that it is characterised by isolation, emotional despair and economic destitution. By cutting straight to the heart of resilience, we can begin to see that removing structural barriers to treatment compliance would dramatically improve the lives of both the newly diagnosed, and those that have survived breast cancer. Yes, the women at THH are highly resilient—they can overcome the direst of circumstances in order to call themselves survivors—but it is the reasons for which they need to be highly resilient that are problematic. If we are able to recalibrate our response to the breast cancer epidemic in Ghana—that is, to recognise that forces such as poverty conspire to ensure suffering in the lives of the poor and the diagnosed—it is clear that the trap of resilience, as Secombe (2002) states, can function as a mere distraction from the actual structural problems that determine and shape the cancer experience of women. So, rather than forcing the women of THH to overcome the odds, to exercise resilience not only throughout treatment but also beyond it, why not change them so that resilience is an option, not a necessity?

Chapter 5: Changing Lives—Enacting Transformation

We all step off the buses into the extreme Ghanaian heat. Today we are at a senior high school. Dr M has begun to direct her outreaches towards Ghana's youth, believing that change will be more effective if concentrated among this demographic. She would often say, 'it's too late for the grown women. Trying to change their beliefs, it's just too hard. But the young girls, they are still learning and they are willing to listen to educational programmes about their health.'

We make our way to the school's church, an ideal location as it can hold large numbers of people. Small balconies and other rooms offer private spaces to screen the women. Already the church hall is full. The nurses make their way upstairs to set up the tables for the screening and blood donation. I follow Mama Naammɔ and Auntie Vera into the pews next to the preaching area. They are both dressed in pink; Mama Naammɔ in a bright pink tutu-like skirt, pink scarf and pink collared t-shirt; Auntie Vera also in a pink collared shirt, pink hat and jeans. Ghana too is subject to the global circulation of pink in recognition of breast cancer support. They begin distributing the large laminated photos of the fungating wounds and swollen, dimpled breasts to the rest of the team. They will walk around displaying the photos as Dr M talks about breast cancer to those attending. The girls typically laugh and turn away from the photos, snickering uncomfortably among themselves.

Outreaches always begin with prayer and song—thanking God for the opportunity to come together to learn and share. Auntie Adjoa, the outreach coordinator, then introduces Dr M and asks each team member to come forward for introduction. This point of the outreach was always highly nerve-racking for me, and extremely entertaining for all those in attendance. Auntie Adjoa would always leave my introduction until last, and then mandate that I welcome the audience in Twi and explain to them my purpose for being in Ghana. Luckily for the attendees, my attempts to speak were effort enough and I was always able to start the programme off on a lighter, rather comical note.

Dr M then begins the educational component of the programme by stating that 'breast cancer is curable, survivable and highly treatable if you seek treatment early.' This is a message that she repeats numerous times throughout her lecture. The importance of 'being early' in her opinion, is invaluable. Drawing on case studies from her patients, Dr M separates

the cases that were successful with treatment from those that were not. After discussing the signs and symptoms of breast cancer, she shows the girls how to examine their breasts on a monthly basis, briefly mentioning the importance of also adding mammograms to their screening routine once they reach 35 years of age.

It is after the conclusion of Dr M's speech that the most magical, most inspiring and, I would argue, the most important part of the outreach takes place. It is at this point in the programme that everybody pays attention. It is at this point when the most vital information is shared and when the true transformational nature of breast cancer is enacted. Aunt Vera and Mama Naammɔ make their way to the front of the church. It is often only these two that speak at outreaches, due to time constraints. Aunt Vera speaks first. She talks about her own experience of breast cancer, from diagnosis to the present day. She reaffirms Dr M's message, that 'early detection is the key to surviving.' She speaks boldly to the girls, drawing particularly on the importance of recognising familial patterns of breast cancer because of the presence of cancer within her own family. For Aunt Vera though, stigma is the biggest challenge facing Ghanaian women with breast cancer and it is this that she addresses for the majority of her speech:

Breast cancer is not a curse. It is not caused by witchcraft. Breast cancer is a disease just like malaria. Anyone can have it. It does not matter if you are rich or poor. I can get it, you can get it and she can get it. Even he can get it! Do not listen to people that try to tell you that if you get breast cancer you will die. Do not listen to people that say that you will spread the disease to others. Do not listen to people who may tell you that you did something wrong. This is not true. Breast cancer cannot be spread. You cannot catch it. Most importantly, if you seek help from a doctor early enough, you can survive. I have been a survivor for nine years because I went to the hospital and I completed all of the treatment. We should accept breast cancer as an ordinary disease. Let us be breast cancer aware, not scared!

Aunt Vera then hands the microphone to Mama Naammɔ. It is always inspiring watching Mama Naammɔ speak with such passion and persistence. She will shout, point, walk around, and most importantly, she will sing. It is a process that involves her entire body. Often Mama Naammɔ recounts the story of her diagnosis and abandonment by her family and friends. She emphasises the importance of seeking the correct treatment,

sharing her own experiences at the herbal clinic and what led her to undergo mastectomy.

It is always the last part of Mama Naammɔ's speech, however, that has the most impact:

(Singing repeatedly) Thanks to be to God, I have survived breast cancer! I have just one breast but today I can stand tall and be proud! I am triumphant! I am happy, I am healthy, I am renewed! I have even re-married to a handsome Asanteman!

Thanks be to God!

Once she has sung a few verses, it is not uncommon for those attending the outreach to join in. Today is no exception. While Mama Naammɔ continues to sing, one of the nurses displays a laminated photo of the large, somewhat risen mastectomy scar that extends from the middle of Mama Naammɔ's sternum to just under her left arm. After each participant has had the chance to see the photo, Mama Naammɔ reaches into her t-shirt and removes the silicone that sits where her left breast once did. Pushing down on her t-shirt to make sure that the girls can see that there is in fact, no longer a breast there, she waves the silicone-moulded breast around with great pride, showing each girl whether or not they are willing to look.

5.1 Surviving vs. Living

Surviving is not the same as living. Women in Ghana are not guaranteed to *live* after surviving breast cancer as life, as it was known before, does not resume. Survivors must adapt to the physical and psychological realities of surviving breast cancer—learning to live with the uncertainty of coming out of remission while also trying to reconceptualise a body with no, one, or just a partial breast. They must also learn to live with the extensive physical and psychological scarring. Whether medical—hair loss from chemotherapy, and surgical scarring—or societal—stigma, isolation, abandonment, economic destitution and impoverishment—the scars of survival as I was often told, can mean that life is much worse than death.

Despite these difficulties, the survivors of THH have made it their mission to *live* after cancer, rather than just *survive*. They have chosen to view breast cancer as a 'blessing' that has transformed the very nature of, and the very reason for, their existence. It is this unique transformation that I found to be the most profound at THH. It is embodied

in four unique but necessary steps, and facilitated by an ethic of care and a support system located at THH.

A breast cancer diagnosis results in multiple points of increased vulnerability in Ghanaian women's lives. Their bodies' 'capacity and incapacity, mortality and morbidity, become the inalienable stuff of the everyday,' and dependency becomes the absolute norm (Ehlers, 2014, p.114). However, those on whom the patient is dependent are frequently unwilling to accept the burden of care-giving that is placed upon them, often due to social perceptions of cancer. Patients and survivors must therefore establish or access new support networks they can depend on.

For many of the survivors who sought treatment at THH, dependency was and continues to remain, a welcomed state of being. From the initial moment a patient walks through the glass doors, a nurse will guide them to reception, Aunty Vera or Mama Naammɔ will show them where to sit, and Dr M will guide them through diagnosis. At every point of the process someone who understands it and assures them of their ability to endure through it, accompanies them. It is a clinical community that recognises the courage it has taken for these women to come to THH to seek treatment, commends them for it, and then works together to ensure that it results in a positive outcome.

5.2 The Importance of Counsellors

The counsellors at THH play what I argue is the most important role in care-giving. They carry out what Kleinman (2012. p. 1551) asserts to be the moral tasks of 'empathic witnessing, listening to the illness narrative and providing moral solidarity through sustained engagement.' Counsellors work reciprocally with the newly diagnosed, exchanging illness experiences for practical and useful information, all the while projecting care, love and understanding.

Because the process of care-giving is affected by social, political and economic realities, the counsellors themselves are in a privileged position, given that they inhabit the same local worlds as the newly diagnosed. They understand the social realities of having breast cancer, the economic hardships of struggling to afford its treatment, and the personal

crisis that can emerge when confronted with mortality. Moreover, they are aware that some of the patients' most trying moments will not occur between 'office hours,' and thus they make themselves available to their patients 24 hours a day, seven days a week.

Counselling begins from the moment a patient is diagnosed. One of the four principal or part-time counsellors (Aunty Vera, Mama Naammɔ, Hagar and Aunty Flora) will sit down with the patient and give her the chance to share her own illness narrative. The sharing of this narrative not only provides context to the counsellors, but also allows the patient to decide what information to present when sharing their experiences (Good, 1994; Kleinman, 1988). The counsellor will then review the patient's notes and treatment regime, explaining the nature of chemotherapy, the surgical procedures they will undergo and the purpose of radiation, while providing opportunities for the patient to ask questions. After this initial meeting, the counsellor and the patient will exchange contact information and schedule their first phone call, and home visit. The counsellor will also ensure that when the patient is scheduled to return next to begin treatment, she will be present to guide her through this overwhelming experience.

I recall one hot Thursday morning when I noticed Mama Naammɔ talking somewhat intensely to another woman in front of the cashier's counter. The woman's face was extremely grimaced as she watched Mama Naammɔ search through her own handbag. I walked over and asked Mama Naammɔ if I could get her anything. She stated, 'this woman, Akosua, she needs a blood transfusion before she can start her chemotherapy, but she cannot afford the pint of blood!' Mama Naammɔ had been assigned as a counsellor to Akosua over one month prior when she had been diagnosed; however, despite her persistent phone calls, house visits and appeals to Akosua's family members, she was unable to convince her to return to THH to commence treatment because of financial constraints.

Finally Mama Naammɔ told Akosua that if she would come to THH, Mama Naammɔ would pay for the pint of blood herself so as to allow Akosua to begin her chemotherapy immediately. I watched in shock but not necessarily surprise as she took 50 Ghana cedi from her wallet and handed it to Akosua. As she did she looked up at me said, 'what is the point of surviving cancer if you can't help others!' I smiled back at her, knowing that for Mama Naammɔ this money was so precious. She had three children in

school and a substantial debt to repay to THH as she was one of the patients who had been allowed to make part payments for her treatment. Nevertheless, I knew that in her eyes, a patient's ability to survive cancer just as she did, depended on her support. She knew she could always find a way to earn back the money, whereas Akosua did not have the same 'luxury.'

An action such as this is commonplace at THH. On more days than not I would observe one or more of the counsellors take it upon themselves to financially support a newly diagnosed patient unable to commence or continue treatment. As many patients are unable to find the money to pay for their treatment, the counsellors—just like Dr M—find creative ways to financially enable them to begin treatment. Aunty Vera may pay for their transport to and from the hospital; Hagar may provide them lunch before chemotherapy is administered and Aunty Flora may pay for some of the medicine Dr M has prescribed. It is this support that not only ensures more and more of Ghana's newly diagnosed patient's survive cancer, but also gives the counsellors an entire new purpose and intent for living that extends well beyond the societally expected domestic sphere.

Returning to the outreach, Mama Naammɔ has finished singing and those in attendance (students and teachers) begin to line up to have their breasts screened. I sit next to her as we watch the chaos begin to unfold as the women attempt to queue. A lady, perhaps 55 years of age, makes her way towards us and takes a seat in a chair opposite mine. She looks at Mama Naammɔ and says:

Because of you today I have brought my sister to be screened. I listened to you talk at an outreach a long time ago and because of what you said, showing you are surviving with just one breast I stayed and had my breasts screened. They found a lump but it was nothing. So today I have also brought my sister to have her own breasts screened and it's all because of you! You made me feel as if even I'm having the cancer in my breast, it's ok. I can be ok.

Moments such as these demonstrate the pivotal and multi-faceted nature of the breast cancer survivor/counsellor role. Weekend outreaches would always bring many patients to THH the following week, mostly as a consequence of Aunty Vera and Mama Naammɔ's spectacular displays of perseverance, pride and most importantly life. The importance of women who survive breast cancer becoming advocates who can

communicate the importance of early detection is paramount not only in Ghana, but also globally; especially since their existence is evidence enough of ‘favourable breast cancer outcomes’ (Anderson, Cazap, Saghir, Yip, Khaled & Harford, 2011, p. 387; Kobetz et al., 2011). Nothing is more influential to a woman learning about a disease than watching another who is not only surviving but, more importantly *living*, after having overcome it.

5.3 Transformative Steps

Transformative learning refers to the ways in which the experience of cancer can result in the learning and development of cancer survivors. This theory, according to Hoggan (2014, p. 201), ‘is based on the constructivist premise that making meaning of one’s experiences is a continual,’ contextual process for which some form of epistemology lies at the centre. Each individual will have their own set of epistemologies readily available for when they are making meaning within any given context.

For the breast cancer survivors of THH, transformative learning occurred in three distinct steps, the first being the recognition that they are not at fault for having had breast cancer. Although wider Ghanaian society attributes a breast cancer diagnosis to bad behaviour, the survivors now know very well that this is not the case. Recognising that breast cancer is in fact ‘for everyone’ meant that internal struggles with shame became obsolete, and survivors could take comfort in the fact that they were no different from other Ghanaian women.

After having adapted to diagnosis and treatment, the women must then adapt to a new stage in their life in which they are deemed a survivor—the second step in the transformative process. Aunty Vera, being the president, will formally invite each individual woman to join the THH survivors’ association. Not all survivors wish to join the association: some live too far to commit whereas others, as Bell and Ristovski-Slijepcevic (2013) found, see the term as a reference to an identity they choose not to relate to. However, many survivors welcomed the opportunity, hoping to gain some insight into this new stage of life they were about to enter. Survivors now had to face the challenge of rethinking what and who was important as they moved forward with living.

Learning from shared experience and receiving positive support are the two central functions of the THH survivors' association. I have the privilege of attending a meeting on a rainy January morning. Over twenty breast cancer survivors cloaked in pink make their way into the small conference hall at the top of the building. They embrace, shriek and clap as they meet those that they have not seen in a while. The communal bonds formed out of this community of sufferers and their importance are incredibly evident.

The meeting, led by Aunty Vera, of course begins with prayer. The pure fact of survival had ensured a much greater connection to God that needed to be acknowledged and constantly appreciated. After prayer we sing briefly and end the meeting with informal conversation. Topics of conversation are the struggles of ongoing aftercare, the associated financial costs and the particular ways one can adjust a silicone implant if it is not the exact size of the other remaining breast.⁸ Being a breast cancer survivor had become a 'new normal' for these women. One that required the exchanging of information and support to ensure they are able to continue thriving through forming new ways of thinking about, and dealing with the experience and its ongoing impacts on life.

As we have seen, the survivors' association also affords women the opportunity to support and assist others. In late 2013, Dr M organised a three-day peer navigation training session to equip any survivor with the skills to guide newly diagnosed patients to what she describes as 'quality health outcomes.' At the time it was Aunty Vera, Mama Naammɔ, Hagar and Aunty Flora who volunteered and were later employed as full, and part-time counsellors.

During my time in Kumasi, these women counselled more than fifty patients between them. I would often accompany Mama Naammɔ on her house visits. Frequently patients would not open the door for us, the fear of stigmatisation being enough to make the newly diagnosed prefer avoiding treatment rather than seeking it. However, Mama Naammɔ would always continue trying, sometimes knocking so loudly that the patient was forced to give in. The significant void in the Ghanaian public's accurate knowledge of breast cancer, and most importantly its severity, has meant that the role of discipline has

⁸ Silicone implants were available for purchase from the dressings clinic at THH. They cost approximately 60 GHS (AU\$22).

become a substantial part of Ghanaian biomedical culture. Healthcare workers are often met with resistance when trying to speak on the importance of treatment and adherence to it, and as such employ what some may call brute force to ensure the preservation of life.

For Mama Naammɔ, this brute force was needed in her role as the informal⁹ non-relenting community health worker (CHW). CHWs have been proven to be useful in communities throughout the world, particularly in low- and middle-income countries (Wadler, Judge, Prout, Allen & Geller (2011, p.4). Research conducted by Wadler et al., (2011, p. 4) on cancer control in South Africa found that CHWs, because of their ‘grounding in the community, are uniquely prepared to understand and acknowledge’ local aetiologies, while providing accurate information about the causes of breast cancer to destigmatise it. Similarly, approaches across Ghana would assist in improving the health-seeking behaviours of women as CHWs can respond to ‘local societal and cultural norms and customs to ensure community acceptance and ownership’ of the information they are sharing (Wadler et al., 2011, p. 3).

For Mama Naammɔ, working as a CHW not only made her happy, but was effective. If she had the chance to sit down and talk to a patient, Mama Naammɔ’s persuasive banter would *always* convince her to commence treatment. She would often tell me:

When I counsel, I don’t even know what I am saying. I just talk, talk, talk, talk, talk. If they don’t want mastectomy before, I make sure that they do after! You see, all it takes is support. When I talk to them, they think they are the only ones having cancer. I become their friends so they are not lonely. Loneliness can kill you! Sometimes I think maybe the Almighty wanted me to have cancer so that I can change the lives of other woman who are having it. So I can also make them a survivor and then they too can do the same for someone else.

This account provides insight into the ways Asante women respond to a breast cancer diagnosis. Most pertinently they feel alone, and without hope. However, seeing is believing when it comes to medicine in Ghana, and conversations such as these initiate a shared connection that is invaluable to the newly diagnosed. Mama Naammɔ’s personal

⁹ The term ‘informal’ is used here because Mama Naammɔ was employed as a counsellor, not a community health worker.

experiences of breast cancer survival validated the information she shared with the newly diagnosed, purely because she stood before them alive and well.

Working to help the newly diagnosed has two very important functions for the counsellors. The first is that it provides financial stability and independence through the provision of empowering employment. Recall from Chapter 4 that the social role previously occupied by women was one that was defined by the patriarchal nature of Asante culture. If permission was granted to possess a job that existed outside of the domestic sphere, these finances were controlled by their husbands. Counselling changed this. Not only did it lead to the realisation that their own experiences of breast cancer gave them the capital they needed to transform these experiences into employable skills, it also produced an inner cyclical fulfilment in the knowledge that empowering others to survive breast cancer was in turn empowering to themselves.

Second, counselling functioned as a reminder to the survivors that perhaps the role was God's way of using them to help others. Patients frequently attempt to cope and make sense of their diagnosis by becoming more spiritual, and many scholars assert the benefits of these forms of coping (Feher & Maly, 2000; Holland et al., 1999; McLaughlin et al., 2013). Being able to find purpose in a breast cancer diagnosis is transformational for these women. It becomes a defence mechanism when facing their sceptics, an affirmation when self-doubt and uncertainty begin to unsettle, and a new purpose for being in the world that directly affects the lives of others.

The final step in the transformational process brings us back to Aunty Vera and Mama Naammɔ advocating for breast cancer awareness and survival at the THH outreach. Throughout this paper I have highlighted the great strength and resilience it takes to survive cancer. More though, is the strength and courage it takes to stand in front of a large group of complete strangers and share the very intimate details of this process in the hope of building community awareness. Ultimately, survivors are key communicators when it comes to emphasising the importance of early detection, since their very existence is proof of survival.

5.4 From One Social Role to Another

Breast cancer for the survivors participating in this study had the unique ability to make clear the ontology of what it is to be an Asante woman, revealing aspects of life and thought that are ordinarily implicit and go unnoticed. The sharing of their stories publicly challenged the very meaning of society's prefigured Asante woman, highlighting what Kasper (1995, p. 216) perceives, 'a disjuncture between socially imposed expectations for women and women's own experience of recovery, well-being and womanhood.' Instead, this group of women demonstrated that with remarkable resilience and adaptive strength, they are capable of being so much more than wives and mothers. They redefined and reconceptualised their female bodies, recognising that it was no longer the outward symbols of femininity, namely their breasts and what they symbolically represent, that make them women.

Furthermore, breast cancer gave the survivor's agency. They now possessed meaningful employment purely because of who they were, and what they had been through. It had shaped a purpose for them that improved their socioeconomic circumstances and self-worth, while also validating another purpose for being in the world. Additionally, breast cancer had strengthened their connection with God, a fundamental part of being Ghanaian in the present day.

The general Ghanaian population is beginning to better understand breast cancer, its causes and treatments. However, there is still much work to be done on the continued presence of stigma and shame surrounding breast cancer in Ghana. The stigmatisation of breast cancer has altered the experience of it in such a way that the most negative and harmful components associated with having this disease, often occur outside the clinical setting. More hospitals in Ghana would do well to follow the approach of THH and not only organise educational programmes that address the myths and misconceptions surrounding breast cancer and its treatment, while also mirroring its ethic of care and utilising their own survivors so as to demonstrate that one can *live* after breast cancer. Furthermore, given that early detection is currently the most effective way to screen for breast cancer in Ghana, advocating for the importance of self-examination is also pertinent to reducing unfavourable outcomes. Educational programs that promote both awareness and advocacy have the potential to ensure profound improvements for women's health in

both the long and short-term, particularly in terms of reduced fatalities and better life outcomes.

However, if we continue to place emphasis on those infectious diseases that currently dominate the imagery of Africa, non-communicable diseases such as breast cancer will continue to ‘fly under the radar’ of public health initiatives and development programs. Throughout this paper we have learned that the experience of breast cancer in Ghana is shaped by structural factors such as poverty, and social problems such as stigma and patriarchy. Poverty, stigma and patriarchy work together to embolden non-compliance during treatment, forcing women to make unfavourable choices about accessing health care. Consequently, women must cultivate new forms of resilience from the moment of diagnosis, right into the final season of survivorship in order to ensure better psychosocial outcomes and functioning in their new circumstances. However, being resilient in the face of adversity is dependent on adequate practical and emotional social supports. Not all Asante women have this support, and consequently THH attempts to bridge this gap with the provision of good care.

For the newly diagnosed, THH is a clinical space they feel comfortable to share their experiences, and also supported throughout their journey. For the survivors it is more than a clinical space, it had been a home throughout treatment and was now a place in which they are valued for their knowledge, and can take great pride in their ability to create a new normal of empowerment, advocacy and opportunity. For both groups of women, THH attempts to facilitate an experience of breast cancer that yields positive benefits and transformative learning.

Ultimately, THH and its survivor community allow Ghanaian women to move forward despite fear and uncertainty, and embrace a life they never thought possible- a life in which breast cancer forms the basis of their ability to transform the distinct social role they occupied pre-diagnosis into one that gave them new purpose. A social role that actually impacts the health of their nation, a role in which their opinions, thoughts and feelings are valued, a role that insists on the exaltation and pronouncement of their breast cancer experience. It is the social role of survivor, counsellor and advocate.

References

- Abdulrahman, G. O., Jr. & Rahman, G. A. (2012). Epidemiology of breast cancer in Europe and Africa. *Journal of Cancer Epidemiology*, 2012(2012), 1-5. doi: 10.1155/2012/915610
- Abubakar, M., Musa, A. M., Ahmed, A., & Hussaini, T. M. (2007). The perception and practice of traditional medicine in the treatment of cancers and inflammation by the Hausa and Fulani tribes of Northern Nigeria. *Journal of Ethnopharmacology*, 111(3), 625–629. doi: 10.1016/j.jep.2007.01.011
- Acklin, M., Brown, E., & Mauger, P. (1983). The role of religious values in coping with cancer. *Journal of Health and Religion*, 22(4), 322–333. doi: 10.1007/BF02279928
- Akweley Okertchiri, J. & Tarlue, M. (2015, February 21). Declining state of our economy. *Daily Guide Ghana*. Retrieved from <http://www.dailyguideghana.com/declining-state-of-our-economy/>
- American Cancer Society. (2015). Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families. Retrieved 25 September, 2015, from <http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nutritionforpeoplewithcancer/nutritionforthepersonwithcancer/nutrition-during-treatment-dry-mouth-thick-saliva>
- Anderson, B. O., Cazap, E., Saghir, N. E., Yip, C-H., Khaled, H. M., Otero, I. V., Adebamowo, C. A., Badwe, R. A. & Harford, J. B. (2011). Optimisation of breast cancer management in low-resource and middle-resource countries: executive summary of the Breast Health Global Initiative consensus, 2010. *Lancet Oncology*, 12, 387-398.
- Arbona, C., & Coleman, N. (2008). Risk and resilience. In S.D. Brown & R.W. Lent (Eds.) *Handbook of counseling psychology* (4th ed., pp. 483-499). Hoboken, NJ: Wiley.
- Aziato, L., & Clegg-Lamptey, J. N. (2014). Breast cancer diagnosis and factors influencing treatment decisions in Ghana. *Health Care Women International*, 36(5), 1–15. doi: 10.1080/07399332.2014.911299
- Baranov, D. (2008). *The African transformation of Western medicine and the dynamics of global cultural exchange*. Philadelphia: Temple University Press.
- Bell, K., & Ristovski-Slijepcevic, S. (2013). Cancer survivorship: Why labels matter. *Journal of Clinical Oncology*, 31(4), 409–411. doi: 10.1200/JCO.2012.43.5891

- Bennett, B. (2006). Globalising the body: Globalisation and reproductive rights. *UNSW Law Journal*, 29(2), 266–271.
- Birhan, W., Giday, M., & Teklehaymanot, T. (2011). The contribution of traditional healers' clinics to public health care system in Addis Ababa, Ethiopia: A cross sectional study. *Journal of Ethnobiology and Ethnomedicine*, 7(1), 39. doi: 10.1186/1746-4269-7-39
- Bonsu, A. B., Aziato, L., & Clegg-Lampsey, J. N. A. (2014). Living with advanced breast cancer among Ghanaian women: Emotional and psychosocial experiences. *International Journal of Palliative Care*, 2014, 1–9. doi: 10.1155/2014/403473
- Boonmongkon, P. (1997). Living through infertility: From loss to resolution over the life course of Thai women. In V. Somsawasai & S. Theobald (Eds.), *Women, Gender Relations and Development In Thai Society*, (pp. 499–516). Chaing Mai: Chaing Mai University.
- Bosu, W. K. (2012). A comprehensive review of the policy and programmatic response to chronic non-communicable disease in Ghana. *Ghana Medical Journal*, 46(2), 69–78.
- Brennan, M., Butow, P., Spillane, A., & Boyle, F. (2008). Survivorship care after breast cancer. *Australian Family Physician*, 37(10), 826–830.
- 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. doi: 10.1007/s10549-014-2868-z
- Bunton, R., & Petersen, A. (Eds) (2005). *Genetic governance, health, risk and ethics in the biotech era*. New York: Taylor & Francis Group.
- Burke, S. M., Sabiston, C. M., & Vallerand, R. J. (2012). Passion in breast cancer survivors: examining links to emotional well-being. *J Health Psychol*, 17(8), 1161–1175. doi: 10.1177/1359105311429202
- Carel, H. (2013). *Illness: The cry of flesh*. Durham: Acumen.
- Carter, B. (1989). Cancer survivorship: A topic for nursing research. *Oncology Nursing Forum*, 16, 435-437.
- Cavanaugh, M. (1994). Ministering to cancer patients. *Journal of Religion and Health*, 33(3), 231–241. doi: 10.1007/BF02354914
- Chireh, J. Y. (2011) Forword. In Ministry of Health, *National Strategy for Cancer Control in Ghana 2012-2016* (pp. ii-iv). Retrieved from <http://www.iccp-portal.org/sites/default/files/plans/Cancer%20Plan%20Ghana%202012-2016.pdf>

- Clegg-Lampitey, J., Dakubo, J., & Attobra, Y. N. (2009a). Psychosocial aspects of breast cancer treatment in Accra, Ghana. *East African Medical Journal*, 86(7), 348–353.
- Clegg-Lampitey, J., Dakubo, J., & Attobra, Y. N. (2009b). Why do breast cancer patients report late or abscond during treatment in Ghana? *Ghana Medical Journal*, 43(3), 127–131.
- Clegg-Lampitey, J. N., & 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), 72–77.
- Coggin, C., & Shaw-Perry, M. (2006). Breast cancer survivorship: Expressed needs of black women. *Journal of Psychosocial Oncology*, 24(4), 107–122. doi: 10.1300/J077v24n04_06
- de-Graft Aikins, A., Boynton, P., & Atanga, L. (2010). Developing effective chronic disease interventions in Africa: Insights from Ghana and Cameroon. *Globalisation and Health*, 6, (6), 1-15. doi:10.1186/1744-8603-6-6
- Desjarlais, R. & Jason Throop, C. (2011). Phenomenological approaches in anthropology. *Annual Review of Anthropology*, 40(1), 87–102. doi: 10.1146/annurev-anthro-092010-153345
- Ehlers, N. (2014). The dialectics of vulnerability: Breast cancer and the body in prognosis. *Configurations*, 22(1), 113–135. doi: 10.1353/con.2014.0003
- Eilers, J. (2004). Nursing Interventions and Supportive Care for the Prevention and Treatment of Oral Mucositis Associated With Cancer Treatment. *Oncology Nursing Forum*, 31(4), 13- 23. doi: 10.1188/04.ONF.S4.13-23
- Fabrega, H., & Silver, D. (1973). *Illness and shamanistic curing in Zinacantan: An ethnomedical analysis*. California: Stanford University Press.
- Fagundes, C. P., Lindgren, M. E., Shapiro, C. L. & Klecolt-Glaser, J. K. 2012). Child maltreatment and breast cancer survivors: Social support makes a difference for quality of life, fatigue and cancer stress. *European Journal of Cancer*, 48(5), 728–736. doi: 10.1016/j.ejca.2011.06.022
- Farmer, BJ., & Smith, ED. (2002). Breast cancer survivorship: Are African American women considered? A concept analysis. *Oncology Nursing Forum*, 29(5), 779-787. doi: 10.1188/02
- Farmer, P. (1996). Social inequalities and emerging infectious diseases. *Emerging Infectious Diseases*, 2(4), 259–269. doi: 10.3201/eid0204.960402

- Farmer, P. (2003). *Pathologies of power, health, human rights, and the new war on the poor*. London: University of California Press.
- Feher, S., & Maly, R. (2000). Coping with breast cancer in later life: The role of religious faith. *Pyscho-Oncology*, 8, 408–416. doi: 10.1002/(SICI)1099-1611(199909/10)8:5<408::AID-PON409>3.0.CO;2-5
- Francoeur, R., Noonan, R. J., Opiyo-Omolo, B., Pastoetter, J., Raibin, L., Perper, T. & Cornog, M. (Eds). (2004). *The continuum complete international encyclopedia of sexuality: Updated, with more countries* (Vol. 2). New York: The Continuum International Publishing Group.
- Geddes, L. (2013). How to halt Africa's next epidemic. *New Scientist*, 220(2942), 8–9.
- Good, B. (1994). *Medicine, rationality and experience: An anthropological perspective*. Cambridge: Cambridge University Press.
- Harvey, T. (2008). Where there is no patient: An anthropological treatment of a biomedical category. *Culture, Medicine, Psychiatry*, 32, 577–606. doi: 10.1007/s11013-008-9107-1
- Heim, E., Augustin, K. F., Shaffner, L., & Valach, L. 1993). Coping with breast cancer over time and situation. *Journal of Psychosomatic Research*, 37(5), 523–542. doi: 10.1016/0022-3999(93)90008-4
- Henry, M. (1975) *Philosophy and Phenomenology of the Body*. (G. Etzkom, Trans.) The Hague: Nijhoff. (1922).
- Hoggan, C. (2014). Insights from breast cancer survivors—the interplay between context, epistemology, and change *Adult Education Quarterly*, 64(3), 191–205. doi: 10.1177/0741713614523666
- Hollan, D. & Levy, R. I. (1998). Person-centered interviewing and observation in anthropology. In H. R. Bernard & W. Creek (Eds), *Handbook of methods in cultural anthropology* (pp. 333–364). CA: Altamira Press.
- Holland, J., Passik, S., Kash, K. M., Russak, S. M., Gronert, M. K., Sison, A. ... Baider, L. 1999). The role of religious and spiritual beliefs in coping with malignant melanoma. *Pyscho-Oncology*, 8, 14–26. doi: 10.1002/(SICI)1099 1611(199901/02)8:1<14::AID-PON321>3.0.CO;2-E
- Hubert, A. (1990). Applying anthropology to the epidemiology of cancer. *Anthropology Today*, 6(5), 16–18. doi: 10.2307/3033096
- Johnson, S., & Spilka, B. (1991). Coping with breast cancer: The role of clergy and faith. *Journal of Religion and Health*, 30(1), 21–33. doi: 10.1007/BF00986676

- Kasper, A. S. (1995). The social construction of breast loss and reconstruction. *Women's Health: Research on Gender, Behaviour and Policy*, 1(3), 197-219.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. United States of America: Basic Books.
- Kleinman, A. (1998). *Experience and its moral modes: Culture, human conditions, and disorder*. Paper presented at the The Tanner Lectures on Human Values, Stanford University.
- Kleinman, A. (2005). *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. California: University of California Press
- Kleinman, A. (2012). The art of medicine. Caregiving as moral experience. *Lancet*, 380, 1550-1551.
- Kleinman, A., Das, V., & Lock, M. (Eds.) (1997). *Social suffering*. University of California Press.
- Knaul, F., Bhadelia, A., Gralow, J., Arreola-Ornelas, H., Langer, A., & Frenk, J. (2012). Meeting the emerging challenge of breast and cervical cancer in low- and middle-income countries. *International Journal of Gynaecology & Obstetrics*, 119(1), 85-88. doi: 10.1016/j.ijgo.2012.03.024
- Kobetz, E., Menard, J., Dietz, N., Hazan, G., Soler-Villa, H., Lechner, S. ... Auguste, P. (2011). Contextualizing the survivorship experiences of Haitian immigrant women with breast cancer: Opportunities for health promotion. *Oncology Nursing Forum*, 38(5), 555-560. doi: 10.1188/11.ONF.555-560
- Lamp, K. E. (2013). *Personal and contextual resilience factors and their relations to psychological adjustment outcomes across the lifespan: a meta-analysis* (PhD thesis). Loyola University Chicago, Chicago.
- Leigh, S. (1994) Cancer Survivorship: A consumer movement. *Seminars in Oncology*, 21, 783-786.
- Letzring, T., Block, J., & Funder, D. (2005). Ego control and ego resiliency: Generalization of self-report scales based on personality descriptions from acquaintances, clinicians, and the self. *Journal of Research in Personality*, 39(4), 395-422. doi: 10.1016/j.jrp.2004.06.003
- Livingston, J. (2012). *Improvising medicine: An African oncology ward in an emerging cancer epidemic*. Durham & London: Duke University Press.

- Lopez-Class, M., Gomez-Duarte, J., Graves, K., & Ashing-Giwa, K. (2012). A contextual approach to understanding breast cancer survivorship among Latinas. *Psycho-Oncology*, 21(2), 115–124. doi: 10.1002/pon.1998
- Lora-Wainwright, A. (2010). An anthropology of ‘cancer villages’: Villagers' perspectives and the politics of responsibility. *Journal of Contemporary China*, 19(63), 79–99. doi: 10.1080/10670560903335785
- Manderson, L. (1999). Cultural aspects of cancer and palliative care. *Anthropology and Medicine*, 6, 3.
- Manderson, L. (2011) Anthropologies of cancer and risk, uncertainty and disruption. In Singer, M. and Erickson, P. (eds) *A Companion to Medical Anthropology*. London: Wiley Blackwell, 323-338.
- Mathews, H. (2000). Negotiating cultural consensus in a breast cancer self-help group. *Medical Anthropology Quarterly*, 14(3), 394– 413. doi: 10.1525/maq.2000.14.3.394
- McLaughlin, B., Yoo, W., D-Angelo, J., Tsang, S., Shaw, B., Shah, D. ... Gustafson, D. (2013). It is out of my hands: How deferring control to God can decrease quality of life for breast cancer patients. *Psycho-Oncology*, 22, 2747–2754. doi: 10.1002/pon.3356
- Mensah, B. (2005). *Women in politics and public life in Ghana*. Accra: Friedrich Ebert Foundation.
- MercyCorps (2015). Rethinking resilience: Prioritizing gender integration to enhance household and community resilience to food insecurity. (Report) Oregon: Portland.
- Merleau-Ponty, M. (1962). *Phenomenology of perception*. Paris: Routledge & Kegan Paul.
- Meyrowitsch, D. W. (2007). Global burden of disease—a race against time. *Danish Medical Bulletin*, 54(1), 32–34.
- Mishler, E. (1981). *Social contexts of health, illness, and patient care*. New York: CUP Archive.
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, 313(4), 270–273.
- National Cancer Institute of Cancer Survivorship. (2014). *Facing Forward: Life After Cancer Treatment*. Retrieved April 11, 2015, from <http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=445089>. NIH Publication.

- Niens, L. M., Nyarko, K. M., Zelle, S. G., Jehu-Appiah, C., & Rutten, F. F. (2014). Equity in Ghanaian breast cancer treatment outcomes—a modeling study in Komfo Anokye Teaching Hospital. *Breast Journal*, 20(1), 100–102. doi: 10.1111/tbj.12217
- Obrist, M., Osei-Bonsu, E., Awuah, B., Watanabe-Galloway, S., Merajver, S. D., Schmid, K., & Soliman, A. S. (2014). Factors related to incomplete treatment of breast cancer in Kumasi, Ghana. *The Breast*, 23(6), 821–828. doi: 10.1016/j.breast.2014.08.014
- O’Brien, K., Soliman, A. S., Annan, K., Lartey, R., Awuah, B., & Merajver, S. D. (2012). Traditional herbalists and cancer management in Kumasi, Ghana. *Journal of Cancer Education*, 27(3), 573–579. doi: 10.1007/s13187-012-0370-z
- Odigie, V. I., Tanaka, R., Yusufu, L. M. D., Gomna, A., Odigie, E. C., Dawotola, D. A., & Margaritonhi, M. (2010). Psychosocial effects of mastectomy on married African women in Northwestern Nigeria. *Psycho-Oncology*, 19, 893–897. doi: 10.1002/pon.1675
- Ohene-Yeboah, M., & Adjei, E. (2012). Breast cancer in Kumasi, Ghana. *Ghana Medical Journal*, 46(1), 8–13.
- Pargament, L., Ensing, D. S., Falgout, K., Olsen, B., Reilly, B., Haitsma, K. V., & Warren, R. (1990). God help me (I): Religious coping efforts as predictors of the outcomes of significant negative life events. *American Journal of Community Psychology*, 18(6), 793–824. doi: 10.1007/BF00938065
- Parkin, D. M., Sitas, F., Chirenje, M., Stein, L., Abratt, & Wabinga, H. (2008). Part I: Cancer in Indigenous Africans—burden, distribution, and trends. *Lancet Oncology*, 9(7), 683–692. doi: 10.1016/s1470-2045(08)70175-x
- Prince, R. J., & Marsland, R. (Eds). (2013). *Making and unmaking public health in Africa: Ethnographic and historical perspectives*. Cambridge Centre of African Studies Series. Athens, OH: Ohio University Press.
- Ram, K., & Houston, C. (Eds). (2015). *Phenomenology in anthropology: A sense of perspective*. Bloomington: Indiana University Press.
- Rodriguez-Caballero, A., Torres-Lageres, D., Robies-Garcia, M., Pachon-Ibanez, J., Gonzalez-Pailla, D., & Gutierrez-Perez, J L. (2012). Cancer treatment-induced oral mucositis: a critical review. *International Journal of Oral & Maxillofacial Surgery*, 41(2), 225–238. doi: 10.1016/j.ijom.2011.10.011
- Rutter, M. (2012). Resilience as a dynamic concept. *Development and Psychopathology*, 24(2), 335–344. doi: 10.1017/S0954579412000028

- Seccombe, K. (2002). 'Beating the odds' versus 'changing the odds'—poverty, resilience, and family policy. *Journal of Marriage and Family*, 64(2), 384–394. doi: 10.1111/j.1741-3737.2002.00384.x
- Shahid, S., Finn, L., Bessarab, D., & Thompson, S. C. (2009). Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Services Research*, 9(132), 1-9. doi: 10.1186/1472-6963-9-132
- Singer, M., & Erickson, P. I. (2011). *A Companion to Medical Anthropology*. West Sussex: Blackwell Publishing.
- Skodol, A. (2010). The resilient personality. In J. Reich, A. Zautra & J. Hall (Eds), *Handbook of adult resilience* (pp. 112–125). New York: The Guilford Press.
- Spilka, B., Spangler, J. & Nelson, C. (1983). Spiritual support in life threatening illness. *Religion Health*, 22(2), 98–104. doi: 10.1007/BF02296390
- Spradley, J. (1979). *The Ethnographic Interview*. New York: Holt, Rinehart & Winston.
- Stan, D., Loprinzi, C. L. & Ruddy, K. J. (2013). Breast cancer survivorship issues. *Hematology/Oncology Clinics of North America*, 27(4), 805–827, ix. doi: 10.1016/j.hoc.2013.05.005
- The University of Chicago Medicine. (2014, 24 April 2015). Oral Complications of Chemotherapy and Head/Neck Radiation. Retrieved 25 September, 2015, from <http://www.uchospitals.edu/online-library/content=CDR62871>
- Toombs, S. K. (1987). The meaning of illness: A phenomenological approach to the patient–physician relationship. *Journal of Medicine & Philosophy*, 12(2), 19–40.
- Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *American Journal of Orthopsychiatry*, 81(1), 1–17. doi: 10.1111/j.1939-0025.2010.01067.x
- UNICEF (2013). At a glance: Ghana. Retrieved 25 August 2014 from http://www.unicef.org/infobycountry/ghana_statistics.html
- van der Geest, S. & Finkler, K. (2004) Hospital Ethnography: introduction. *Social Science & Medicine*, 59, 1995-2001. doi: 10.1016/j.socscimed.2004.03.004
- Wadler, B., Judge, C. M, Prout, M., Allen, J. D., & Geller, A. C. (2011). Improving breast cancer control via the use of community healthworkers in South Africa: A critical review. *Journal of Oncology*, 2011, 1-8. doi: 10.1155/2011/150423
- World Bank (2013). Ghana: World development indicators. Retrieved 4 October 2015 from <http://data.worldbank.org/country/ghana>

- World Health Organization (2002). Traditional medicine growing needs and potential. In *WHO policy perspectives on medicines*, 2, 1-6.
- World Health Organization (2004). *WHO Global Burden of Disease Report*. Geneva
- World Health Organization (2013). *Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020*. Retrieved from http://apps.who.int/iris/bitstream/10665/94384/1/9789241506236_eng.pdf?ua=1
- Yankah, K. (2012). *The proverb in the context of Akan rhetoric* (2nd ed.). New York: Diasporic Africa Press.
- Yew, V. W. C. & Noor, N. A. M. (2014). Anthropological inquiry of disease, illness and sickness. *Journal of Social Sciences and Humanities*, 9(2), 116–124.

Appendix 1: Ethics Approval

MACQUARIE
UNIVERSITY



Office of the Deputy Vice-Chancellor (Research)

Research Office
C5C Research HUB East, Level 3, Room 324
MACQUARIE UNIVERSITY NSW 2109 AUSTRALIA

Phone +61 (0)2 9850 7850
Fax +61 (0)2 9850 4465
Email ethics.secretariat@mq.edu.au

21 November 2014

Dr Aaron Denham
Department of Anthropology
Faculty of Arts
Macquarie University
NSW 2109

Dear Dr Denham

Reference No: 5201400967

Title: The Experiences of Survivorship among Ghanaian Women with Breast Cancer

Thank you for submitting the above application for ethical and scientific review.

Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)) at its meeting on 24 October 2014 at which further information was requested to be reviewed by the HREC (Human Sciences and Humanities) Executive.

The requested information was received with correspondence on 10 November 2014.

The HREC (Human Sciences and Humanities) Executive considered your responses at its meeting held on 19 November 2014.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*).

Details of this approval are as follows:

Approval Date: 19 November 2014

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	2.3	July 2013
Correspondence from Ms Naomi Thompson responding to the issues raised by the HREC (Human Sciences and Humanities)		Received 10/11/2014
Appendix B: Research to be Undertaken Outside of Australia		March 2010

MQ Participant Information and Consent Form (PICF)	1	Oct 2014
Interview Schedule	1	Oct 2014
Poster	1	Oct 2014

This letter constitutes ethical and scientific approval only.

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement*, which is available at the following website:

<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely



Dr Karolyn White

Director, Research Ethics & Integrity,
Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.