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Surviving vs. Living: The Importance of Resilience in the Transformative Redefinition of Ghanaian Breast Cancer Survivors

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Abstract

This paper 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 paper 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 paper 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.

Introduction

As I sat in the courtyard of the school, I watched as the final preparations for the funeral were finalised. Photos of Mama Abena, a 55-year-old retired teacher were projected on the side of the building she had been teaching in only a few months prior. Her family and I prepared to say goodbye to a woman known and admired throughout the entire community in which she lived. Mama Abena 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. We 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 hospital, and they did a scan. They found a tumour and removed it. After six months she went for a follow-up scan, and they found that some of the tumour still remained, 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, and she could barely talk. 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.

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). Currently NCDs account for 63 per cent of global deaths. 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' (World Health Organization, 2013, p. 1). However, rarely do NCDs come to mind when people consider the health issues facing low and middle-income countries, particularly those that comprise the 'dark continent of disease' that is Africa. For example, most people upon first thought of the health problems that plague sub-Saharan Africa; do not consider cancers to be significant burdens. They seem, as Livingston (2012, p. 8) suggests, an, 'esoteric distraction from more pressing concerns' such as HIV/AIDS or tuberculosis.

However, cancers have fast become a highly pressing concern across Africa, their incidence rising steadily across the continent. In West Africa, where Ghana is located, 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). Moreover, while the incidence of NCDs increases rapidly, infectious diseases also continue to pose major challenges. This *double* burden of disease has meant that

malaria or tuberculosis for example, can co-exist with breast cancer, and thus, an already strained health care system is now struggling to carry and address the two simultaneously. As a consequence, there are stark differences between incidence mortality ratios in high-income countries such as the United States (0.2) compared to low and middle-income countries like Ghana (0.8) (World Health Organisation, 2004).

However, NCDs continue to remain silent killers. In Ghana, breast cancer is currently the leading cause of cancer deaths amongst women. Survivors of the disease are the exception, not the rule, mainly because it is not until a necrotic, disfiguring growth lies where a breast once did, that women will arrive at clinics and hospitals. Because of this, most of the research to date has focused on the experiences and decision-making processes of Ghanaian women leading up to, and throughout breast cancer treatment. Multiple studies have established that the severity of breast cancer treatment, the social isolation that is experienced due to the prevalence of stigma, the paralysing fear of mastectomy, and economic destitution are but a few of the significant reasons for why up to 75% of Ghanaian women report to hospital in stages III and IV of breast cancer, and then will subsequently abscond from treatment once it has begun (Aziato & Clegg-Lamptey, 2014a; Bonsu, Aziato & Clegg-Lamptey, 2014b; Bonsu et al., 2014; Clegg-Lamptey, Dakubo & Attobra, 2009; Clegg-Lamptey & Hodasi, 2007; Ohene-Yeboah & Adjei, 2012; Obrist, Osei-Bonsu, Awuah, Watanabe-Galloway, Merajver & Soliman, 2014; Reichenbach, 2002).

However, there does exist Ghanaian women that *are* surviving and most importantly *living* after breast cancer, and my research specifically examines the reasons why this is. What I will elucidate and examine throughout this paper, are the socially, culturally, economically and politically structured resilient coping strategies that shape a Ghanaian woman's experience of breast cancer, and breast cancer survivorship. Specifically I will focus on the latter (survivorship), highlighting how fundamental resilience is to obtaining life after breast cancer, while also critiquing some of the reasons for which it is.

Furthermore, I will highlight the ways in which these resilient coping strategies have allowed for the transformative re-definition of the Ghanaian breast cancer survivors

that took part in this research. Their ability to face adversity and hardship while also learning from it, allowed these survivors to function as advocates for breast cancer awareness and prevention through the provision of educational programs.

Methods

Over the course of four months of ethnographic research at a small, private hospital I will refer to as THH,[1] I employed participant observation in tandem with face-to-face interviews to allow for the deep investigation into the social life, and life experiences of breast cancer survivors. Using qualitative interviewing as a way to explore the experiences of the survivors within their social worlds, and how these experiences are informed by broader structural factors, I interviewed thirty breast cancer survivors, while an additional four participated in longer, personal interviews to allow for the exploration of more person-centred themes (Hollan & Levy, 1998, p. 316; Spradley, 1979). 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.

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.

In the context of theoretical underpinnings, this project was shaped by a critical phenomenological theoretical perspective. 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).

[1] Located in the Asante region of Ghana

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).

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 suffers.

The Realities of Breast Cancer: Stigma and Poverty

While the existential experiences of breast cancer are unique to each individual survivor, there are certain 'eidetic characteristics' of this illness that 'transcend the peculiarities and particularities of different disease states' (Toombs, 1987, p. 22). In Ghana, these characteristics are evident firstly, in the social problem of stigma and secondly, in the structural deficiency that is poverty. Both stigma and poverty work together control, limit and determine a Ghanaian woman's ability to seek and adhere to oncological treatment and she must employ copious amounts of resilience to work against, and overcome them. They bolster non-compliance while also simultaneously shaping her experience of breast cancer, breast cancer treatment and breast cancer survivorship.

As human beings we often have an instinctual need to find the cause of the adversity and hardship that we face over the course of our lives. When illness happens to be the reason for adversity or hardship, the need to ascertain direct causality intensifies, not only because of its importance for effective treatment, but also because a known causation can mean prevention in the future. As we know, breast cancer does have a

definitive cause and as a direct result certain cultures have developed ethnotheories of causation so as to analyse and explain the reasoning behind this disease.

In Ghana, breast cancer is often asserted 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 & Erickson, 2011, p. 327). Consequently, stigma and shame are often the most dominant experiences for a Ghanaian woman with breast cancer. Take for example Florence, a mother of three living in a compound house who was diagnosed with cancer at age 42. Knowing that others residing in her compound would 'gossip' if they knew about her disease, 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. She told me:

> They would laugh at me, tell me I'm a witch. Tell me I will surely die. They told my work place and they fired me thinking I would spread the disease to them. So I stopped leaving the house. In the beginning I would not come for treatment. But eventually I had to, so I wouldn't leave the house except on days when I needed to come for my treatment. Even today, while I am fine, people still avoid me. They still think I am witch.

A breast cancer diagnosis results in multiple points of increased vulnerability in Ghanaian women's lives, vulnerability that does not necessarily cease with the completion of formal treatment (Ehlers, 2014, p.114). The social perceptions of cancer and the stigma that they produce have meant that breast cancer survivors continue to face numerous social challenges throughout their lives. While not all beliefs in the spiritual causation of disease are necessarily negative, diseases such as breast cancer that find their roots in social contexts; often mean that the patient will experience severe stigma and blame. Consequently, when women just like Florence are diagnosed with breast cancer, fear is often one of the first emotions they will experience. Not necessarily fear of the disease itself, but rather a fear of what this means for their place in society. More often than not, neighbours will gossip, husbands

will leave, and friends will isolate, and as such breast cancer patients are forced to choose between remaining part of a social world that is so integral to their existence, or seeking treatment that will preserve their physical life, but absolutely destroy their social one.

In addition to stigma, poverty is the most distinct and most determining structural deficiency 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). It is socioeconomically oppressive in that it renders 'individuals and groups vulnerable to extreme human suffering' (P. Farmer, 2003, p. 42).

But what does poverty mean in the context of breast cancer? Throughout my fieldwork, both the survivors and the newly diagnosed emphasised to me that being poor, or 'having no money,' makes breast cancer a sure death sentence. Poverty remains the primary determinant of health and the primary 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, poverty means that utilising healthcare is an expensive and often impossible exercise for women with breast cancer (World Bank, 2013).

For one of my participants, Mama Naammɔ, poverty ensured that breast cancer was a chronic disease, its deleterious effects lasting a lifetime. Poverty meant that her only way to afford treatment was through the selling of her belongings, sleeping on her father's grave, and throwing herself on the mercy of her church. Her husband left her, taking her children with him as he felt that breast cancer was a sure death sentence and the little money he had should not be put toward treatments that would not work. For Mama Naammɔ, poverty ensured that suffering was central to her experience of breast cancer. However she did not suffer in the same way that an Australian woman diagnosed with breast cancer might, who suffers as a direct consequence of her disease. Rather, suffering was central to her experience of breast cancer purely because of her socioeconomic status.

Ultimately 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. The predominantly social and economic barriers evident in the experiences of Florence and Mama Naammɔ provide significant insight into issues of breast cancer treatment compliance for women in Ghana. If a doctor 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 a doctor 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 a patient should have to inform her employer of her diagnosis but suspects she will lose her job, she will again 'refuse' treatment. Surely the ideal is for women with breast cancer should to make decisions based on medical rather than economic and social criteria?

Resilience is Important- but why?

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. Throughout my research I found that the ability to be resilient to poverty and stigma, and resourcefulness because of it, differentiates some Ghanaian women with breast cancer from others. 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). For a Ghanaian woman, learning to be resilient when faced with adversity is often a part of everyday life, she must develop coping mechanisms that make her 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 her own food intake so that her children may be fed first, are but a few of the ways in which a woman must adapt and respond to the difficulties of living in a country such as Ghana.

Women who were able to enlist certain character traits such as faith, hope, optimism, flexibility, adaptability, resourcefulness, strength and humour throughout treatment

have far better psychosocial and economic outcomes in the long term. These traits work together to assist Ghanaian women in facing and overcoming those structural and social barriers that are implicit to 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. The cancer continuum consists of a series of traumatic events, beginning at diagnosis, and continuing well on into the final season of extended survival. 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 often fundamental to being a Ghanaian 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 most Ghanaian diets, was one particular task that women described they were no longer able to carry out. This inability demonstrates the need for women 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 almost always too much to bear, and the catastrophic result is death. What is to be noted 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 of 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 promote suffering in the lives of the poor and the diagnosed—it is clear that the trap of resilience, as Seccombe (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 the odds, so that resilience is an option, not a necessity?

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, memory loss and surgical scarring—or societal—stigma, isolation, abandonment, economic destitution and impoverishment—the scars of survival can mean that life is much worse than death.

Despite these difficulties, the survivors of THH 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. Their ability to utilise and cultivate resilience throughout and beyond their breast cancer experience allowed for a form of transformative learning to occur, that facilitated a reconceptualization of their own purposes for being in the world.

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, two of them relevant to this paper. The first step was the recognition that they are not at fault for having had breast cancer. Although wider Ghanaian society as we have established, attributes a breast cancer diagnosis to spiritual deviation or inappropriate lifestyle choices, 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.

Secondly, after completing formal treatment, women must then adapt to a new stage in their life in which they are deemed a survivor. Survivors had to face the challenge of rethinking what and who was important as they moved forward with living. Being a breast cancer survivor had become a 'new normal' for these women, one that again, required resilience so that they were able to continue thriving through the formation of new ways of thinking about, and dealing with their breast cancer experience and its ongoing impacts on their lives.

Because of these two steps, the breast cancer survivors of THH were able to re-define their experiences of breast cancer into one that was beneficial to others. Their resilience moved them forward despite fear and uncertainty, and allowed for them to embrace a life they had never thought possible when they were diagnosed. Essentially, they reconceptualised and redefined their socially implied role of 'witch,' 'deviant' or as they would say 'dead woman walking,' into one that through advocacy and education had the potential to positively impact the health of their nation and proved the possibility of survival. This social role valued their

experiences and the knowledge they had acquired because these experiences as they pointed to broader structural social and environmental factors.

Conclusion

Throughout this paper I have shown that that the experience of breast cancer in Ghana is shaped by structural factors such as poverty, and social problems such as stigma. Poverty, and stigma work together to embolden non-compliance during treatment, forcing women to make unfavourable choices about accessing health care and altering the experience of breast cancer in such a way that the most negative and harmful components associated with having this disease, often occur outside the clinical setting. 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.

There is a great need for medical communities both internally and externally to Ghana to address the myths and misconceptions surrounding breast cancer and its treatment, while also adequately attending to social determinants of health such as poverty so as to limit health iniquities and to ensure profound improvements for women's health in both the long and short-term. The effects of poverty and stigma on a Ghanaian woman with breast cancer emphasises the need to appreciate a broader, systemic view of resilience, one that facilitates a better understanding of how they are structured by the political, social and economic forces that exist and dominate Ghanaian society. However, if we continue to place emphasis on those infectious diseases that currently dominate the imagery of Africa, NCDs such as breast cancer will continue to 'fly under the radar' of public health initiatives and development programs, and women will continue to fall prey to a disease that in other contexts, is highly treatable and highly survivable.

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