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RESEARCH ARTICLE

Breast Cancer: The Death Sentence: The Socio-economic and Socio-cultural paradox of the underprivileged in Ghanaian Society

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ABSTRACT

For most rural dwellers, breast cancer is a death sentence. While the concern and discourses of health practitioners and professionals, researchers and analysts may focus on medical attention and the creation of awareness, defined as a deliverance from 'ignorance', the personal experience of victims of breast cancer and the members of the community in which they are embedded have a different take. Their focus is more on the origins of the illness and its management in waiting for the ultimate inevitable fate. The paper uses the approach of personal experience and Guttenplan's categories of consciousness/experiencing, attitude/attitudinizing, and act/action/activity to undertake a somewhat longitudinal examination to investigate the anatomy of the decision-making processes involved in such incidents - socio-cultural and socio-economic -involving personal and family perspectives, facts/experiencing, beliefs, critical decision-making processes and conclusions attendant with the course of management of the disease through a case study. It concludes that the outlook as currently enacted on what creates and causes delayed medical attention may need to be more critically reviewed. It recommends that the acceptance of seeking medical attention for perceived 'death sentence' diseases such as breast cancer should first tackle the certainty of 'cure' and the solidarity with victims to 'fight' and 'defeat' the disease rather than on awareness creation based on unexamined and unsupported assumptions of 'ignorance' of victims and their communities that make the efforts to tackle the breast cancer menace in Africa not as effective as they could be.

Introduction:

As far as most rural experiences of breast cancer were concerned before recent times, breast cancer was a definite death sentence. No cure was ordinarily known in rural communities, and no medical facilities held promise. And no one had the means and power to convince others of any way out of death when breast cancer struck. The few victims who hoped for respite through consent to have their breasts taken off at medical facilities did not survive long enough to give confidence about the prowess of modern medicine – they died anyway. And in the thoughts of people who valued womanhood and femininity, of what use was it to lose a breast or both, to look like or 'become like a man' and still lose your life anyway? The dread of breast cancer was understandable, and its origins pre-occupied people more than its cure – for it was invariably and inevitably a death sentence no matter what anyone did. This research focuses on this settlement on the search for the origins and readiness for the inevitable.

The observations and experiences of rural folks which formed the assumptions upon which they based their decisions can be described as 'knowledge'. From the perspective of the Sociologist of Knowledge such as Bloor, "The Sociologist is concerned with knowledge, including scientific knowledge, purely as a natural phenomenon. … knowledge for the Sociologist is whatever people take to be knowledge. It consists of those beliefs which people confidently hold to and live by. In particular the Sociologist will be concerned with beliefs which are taken for granted or institutionalized or invested with authority by groups of people. Of course, knowledge must be distinguished from mere belief. This can be done by reserving the word 'knowledge' for what is collectively endorsed, leaving the individual and idiosyncratic to count as mere belief."[1].

Taken from the perspective of Bloor, the observations and experiences of rural folks about the phenomenon of breast cancer as a 'death sentence' and the implicit derivations and decisions that issue from them cannot be simply dismissed as 'ignorance'. This justifies the investigation of the knowledge of rural folks with respect to the phenomenon of breast cancer and its management processes.

Brookfield[2], in seeking to understand how the valuing of experience and reflection construct the basis of knowledge adopted Horton's[3] insight into the value of experience. Citing Horton, he noted: "I knew that it was necessary…to draw out of people their experience, and help them value group experiences and learn from them. It was essential that people learned to make decisions on the basis of analyzing and trusting their own experience, and learning from what was good and bad….I believed then and still believe that you learn from your experience of doing something and from your analysis of that experience" [2,3]

In rural communities, as in others, people come to realize the value of their own experiences, trust them, take a critical perspective on these, and learn how to use these reflections to help them deal with whatever problems they face.

In evaluating the risks involved in the valuation of experience and the decisions derived from personal experience reflections, Brookfield[2] articulated a number of concerns: "Of course, experience can sometimes be a terrible teacher. Simply having experiences does not imply that they are reflected on, understood, or analyzed critically. Individual experiences can be distorted, self-fulfilling, unexamined, and constraining. In fact, it is a mistake to think that we have experiences in the sense that our own being stands alone while the river of experience flows around us. Events happen to us, but experiences are constructed by us as we make sense of these events. Neither is experience inherently enriching. Experience can teach us habits of bigotry, stereotyping, and disregard for significant but inconvenient information. It can also be narrowing and constraining, causing us to evolve and transmit ideologies that skew irrevocably how we interpret the world. A group's pooling of individual experiences can be a myopic exchange of prejudices. Even when cross-disciplinary groups work on the same problem … there can still be a form of groupthink. This is caused by … being drawn from the same class, race, cultural group, and geographical area, and by their having gone through similar educational experiences." [2]

Another risk Brookfield identifies regarding the valuing of personal experience is the possibility of superficial analysis. There is the danger that we can analyze our experience enthusiastically to help us deal with problems, yet the analysis can be a superficial one that ignores the political and cultural constraints we face. Rooted in such superficial analysis, the tendency would be to focus on changing rules of procedure and ignore the fact that it is rather the organizational reward system that a group follows, or the ways in which access and conditions are commodified in the wider society that really need to be examined and changed.[2]

In spite of these apparent risks, Brookfield still maintains an unequivocal confidence in the valuing of experience or use and analysis of personal and group experience as a basis for valid and meaningful judgement and decision making and knowledge for good reason. He summarises it this way: "Despite these caveats concerning the uncritical celebration of personal experience, the pressure on us to disregard our privately crafted truths in favour of expert pronouncements are so strong that sometimes we need to err on the side of taking experience more seriously. If you don't already do so, then you should begin to trust your inner voice a little more and accept the possibility that your instincts, intuitions, and insights might possess as much validity as those of experts in the field." [2]

These perspectives on the analysis and valuation of personal and group experience have significance for providing a meaningful way of examining the experience of breast cancer victims and their communities in respect of the hesitation and delay in resort to modern medical facilities. Is it the case that cancer patients and their socio-cultural support systems are just trusting their inner voice a little more and accepting the possibility that their instincts, intuitions, and insights might possess as much validity as those of experts in the field, creating the phenomenon described as 'delay in seeking medical attention' in the parlance of medical, health workers, and experts in the field?

Consequently, the necessity of exploring the puzzle of the hesitation in reporting breast cancer for treatment is important and requires examination from various and multiple perspectives to create more and more understanding of the factors involved in the decisions towards well-being under the threat of cancer and its terrifying consequences. While socio-cultural factors may play a significant role in the decision-making and management processes of cancer sufferers, what aspects of socio-cultural factors are involved, and how are they involved? In the end, what evokes the socio-cultural perspectives and what role do they play in providing social safety nets for victims of breast cancer? And what are the drivers of the socio-cultural factors? This leads us to the aim and scope of the study.

Aims and Scope: The paradox of socio-cultural and socio-economic dynamics of breast cancer management in rural communities.

The study aims to provide an insight into the paradox of the socio-cultural and socio-economic dynamics of breast cancer management in rural communities by examining the phenomenon of delayed medical attention seeking behavior among breast cancer sufferers in typical Ghanaian rural communities. It aims to engage the decision-making and management processes of disease involved in rural communities, and the knowledge that constitutes its assumptions and subsequent derivative attitudes, postures and actions. It assumes that rural communities have their own ways of decision-making and management of diseases, especially intractable diseases and situations that are nestled in wider societal and economic influences that they cannot transcend unless fundamental changes occur in the mode of access and conditions related to the pool of societal and economic resources available to enable ready alternative recourses. In other words, do they really have a choice? In the end, the study tries to explore what some of the decision-making and management processes are, and what kinds of recourses and resources are available to sufferers and yet what forces and factors create limitations for socio-cultural success and subsequent last-minute assistance-seeking outside the socio-cultural social safety nets.

Rationale/Justification of the Study: Is there a need to shift assumptions?

The perspective of this research and its approach embraces the factors identified by kindred researchers intended to unravel the causes of the factors themselves culminating in delayed reporting of breast cancer to centres of professional medical cure. This perspective, nevertheless, subscribes to the belief that the assessment of factors and their causes could still push further to scrutinize the intertwining socio-economic and socio-cultural factors that shape decision-making and management processes among rural folks leading to alternative recourses and resolutions to an apparently insoluble conundrum.

In the end, most studies seem to end in a conclusion that the delayed action or reporting to medical facilities by cancer patients in African communities is largely the result of socio-cultural factors that produce ignorance. Most campaigns against delayed breast cancer advertise and promote awareness about the disease based on the assumption that they seek to dispel ignorance about the disease and the socio-cultural myths that create delayed reporting of the disease. What such campaigns, although well-meaning, omit is understanding the knowledge base of these delays rooted in personal and group experience in rural communities, and the stranglehold of commodification in society that restricts access to resources outside the socio-cultural safety net.

This study thus seeks to adopt a slightly different outlook and argues that in order to understand the attitude or posture and behaviour of breast cancer patients especially in rural communities and in socio-cultural settings, the mode of experiencing, attitudinizing and actions need to be fully taken into consideration in regard to how they interact with the decision-making and management processes of strange and intractable diseases in their contexts.

Methodology: Study Design:

The study follows the case study as understood and described by Stake[4], Yin[5], Gillham[6], and Bassey[7]. Stake examined the case study as an individual case from which much can be learned by understanding it in all its complexity. As Stake, and also Gillham observe, one of the important features about the case study is that it also has the knack of giving insight into unique traits and seemingly isolated outlying entities and phenomena which might remain unnoticed except through the case study. Stake also identifies three main modes in which a case study research can be carried out: the intrinsic, the instrumental, and the collective modes. The instrumental approach embraces as its aim, the acquisition of insight from the study of an individual case in order to build or refine a theory or theories. It thus directs the study towards community and a degree of generalization before additional case studies establish a collective approach to reinforce the generalizations of the single case study. [4,6]

My research adopted the instrumental approach towards the case study. In this approach, unlike the intrinsic approach where the case itself is of primary interest, in the instrumental approach, the case itself is of secondary interest. The case serves instead as the scaffolding for understanding the issue of delayed breast cancer reporting in rural communities and the insights that can be derived from it for generalization and theorization. Consequently, my approach to the case study can also be summarized as operating like an ethnographic epistemological approach as described by Bourdieu [8], and also by Blommaert [9]. It is therefore grounded in the ethnographic study of a single case to examine it in detail in order to derive patterns of behavior and social organization in such a fashion that reinforces Bourdieu's suggestion that 'single cases, even if they don't speak to the totality of the population or the system, can speak to theory'.

Data Collection Strategy:

My strategies for data collection were influenced by the desire to collect as much useful information as possible in accordance with the methods of 'rich information' gathering described for case study methodologies.[10] The case itself was selected as an opportunistic or convenience case study using a theoretical sampling technique. It was selected according to how much information I thought the particular context of study would yield for analysis about delayed breast cancer reporting in rural and socio-cultural communities. The consent of the participants and the prospect of their cooperation played a crucial role in the end. It was based upon whether the participants in the study were willing to be interviewed for a publication, and whether they would find the research non-threatening to them and the community. Hence, I adopted strategies including face-to-face interviews with surviving relatives and care-givers, family members and community members of the case under study, telephone conversations with community members who now lived elsewhere after thirty years, and some of the documentations made by the breast cancer sufferer herself.

I selected a thirty year case because of its resonance with Bruwaa , 55 years, in the research work carried out by Karikari and Boateng as recently as 2018, which also points to the importance breast cancer victims place on their children, and their children's influence on their decision-making and management regarding socio-economic, socio-cultural, affectiveness, directedness and meaning-making attitudes and behaviour. Bruwaa said: ".... Now I am in hospital, what can I do? He is my son and I do not want to appear as a stubborn mother." [11]

Another reason for selecting the case is the opportunity it offers to examine the impact a breast cancer occurrence has had or has on rural communities, care-givers and families.

Apart from these, beyond more information about breast cancer, conditions and situations have not changed much from thirty years ago to alter the situation of breast cancer sufferers in rural areas significantly and their impact on communities, care-givers and their families.

Meta Analysis: Personal Experience: Consciousness, Attitude and Actions:

The aims and objectives of the investigation of the subject warrant an engagement of readers affectively in the content of the research. This is to enable a means of exposing them to multiple perspectives on breast cancer experience, its effects and its management in rural communities. The approach is supposed to engage readers in such a way that they can be involved in participatory forms of experiencing and consequently develop a somewhat close-up experience of democratic conversation on breast cancer experience and management in rural communities and related socio-cultural settings. It will, therefore, avoid as much as possible, instrumental scientific parlance and resort mainly to ordinary language use in expressing its investigative efforts.

In order to align with its avowed aims, the study adopts a case study in a rural setting in Ghana who suffered from the disease from 1986 and died of the disease in 1993. Research concerning breast cancer in Sub-Saharan Africa seem to be concerned mainly about and dominated by measurable and statistical data analysis. Although these approaches provide a general picture of breast cancer patterns, the minute close-up details of the cases, factors, and processes giving access to the socio-cultural variables and other pertinent factors that affect decision-making and the management processes of the course of the ailment such as the socio-economic variables almost disappear under statistical concerns. Yet our personal experiences as members of family, communities, care-givers and care-receivers, sympathizers and empathizers, or even as mere distant observers represent some of the most important sources of insight yet into disease-management and decision-making to which we have access.

Brookfield[12] significantly illustrates the impact of the fact of personal experience on participants as follows: “It is true, of course, that at one level, all experience is inherently idiosyncratic. For example, no one experiences the death of a parent in exactly the same way as anyone else, with the same mix of memories, regrets, affirmations, and pain. Yet at the same time, bereavement as a process of recognizing and accepting loss contains a number of patterns and rhythms that could be described as generic. The fact that people recognize aspects of their own individual experiences in the stories others tell is one reason for the success of peer support groups for those in crisis or transition. As I hear you talk about going through a divorce, struggling with illness or addiction, or dealing with the death of partners, friends, or parents, I am likely to hear echoes of, and direct parallels to, my own experience of such events. The same dynamic holds true in teacher reflection groups. As we talk to each other about critical events in our practice, we start to realize that individual crises are collectively experienced dilemmas. The details and characters may differ, but the tensions are essentially the same.”[12]

The argument of these examples is that our experiences as care-givers, care-receivers, sympathizers, empathizers, observers and learners are felt at a visceral, emotional level that is much deeper than that of reason. We draw insights and meanings from these experiences that are likely to have profound and long-lasting influence enough to shape our posture and attitudes and eventual action. And one thing that is certain is that they affect us more powerfully than methods or injunctions that we learn from textbooks or hear from superiors. And, “In the face of crises or ambiguities, we fall back instinctively on memories from our times … to guide us in our responses.[12]

Indicating and tracing how we try to recover our personal experiences because of how they had been beautiful and gave us pleasure or avoid them for that matter because of their painful and unpleasant nature and the memories, echoes, parallels and tensions they evoke, Brookfield notes that whether we admit it or not, the roots of why we do the things we do and the way in which we do them ‘are found in the complex web of formative memories and experiences’ of care-giving, care-receiving, sympathizing, empathizing, observing and feeling. For instance, placing it in the domain of teachers, “We remember teachers we loved and hated, imitating those we admired and striving to avoid working in ways that resemble those we hated. We may espouse philosophies of teaching we’ve learned from professional development workshops, but the most significant and most deeply embedded influences are the images, models, and conceptions of teaching derived from our own experiences as learners.” [12]

Although as we become distant from the formative memories that stayed with us and their exact freshness and outlines fade so that we cannot recall the exact visceral dimensions of our initial experiences and our knowledge and comfort or discomfort about what we do grow in our practice and discipline, we begin to find it difficult to understand how others can't ‘get’ something that’s so clear to us. “We forget the butterflies of nervousness or the sheer panic we feel as we take a test or approach a new and difficult learning task.” [12]

Consequently, one of the harder things for researchers and health practitioners and facilitators to do is to imagine the fear that victims of breast cancers feel as they try to cope with the menace that strikes them. If we've been practitioners of health for a long time we most likely forget what it feels like to wake up to the realization of being attacked by a disease that carries the mark of a 'death sentence'. As health practitioners who are good at what they do and love, therefore, it becomes almost impossible to understand, much less empathize with patients who find the subject of medication and medical environment boring, intimidating, meaningless and perhaps at the same time hopeless.

Brookfield's examples give modes by which health workers and researchers can put themselves into the mode of teachers and understand their own relations of thinking in respect of the subjects of research and patients suffering from breast cancer.

They introduce us to the mode of recovery of the visceral dimensions which is capable of taking us straight back to the emotional understanding deeper than reason can re-image an experience concerning something that is unpleasant or painful in adulthood in respect of breast cancer experience. Learning to undertake such an exercise in adulthood is bound to provide a rich vein of experience that can be mined for insights into the power dynamics of medical and health-seeking matters. Learning something new and difficult as an adult and then reflecting on what this experience means for health restoration and management is a visceral rather than intellectual route into critical reflection. It develops our emotional intelligence and reminds us of the affective components of living.[12]

Brookfield's views on personal experience accord with Guttenplan's [13] reflections upon how personal experience enables the construction of three category sets of articulating personal experience through consciousness/experiencing, attitude/ attitudinizing/posture, and acting/ actions/ activity, relevant for analyzing the personal experience of the case under study. The information, reflections, stories, facts and all data was analyzed on the basis of the assumption that cancer patients and their families' choices, behavior and actions are heavily influenced by the emotions created from consciousness/experiencing. These emotions in turn create attitudinizing modes that result in specific attitudes and postures related to their perceptions; these attitudes are consequently moulded into behaviours or actions aimed at affecting what they are experiencing at the level of consciousness. [12.13]

Adjoe [14] elaborates Guttenplan's [13]scheme as follows:

"In exploring the landscape of the mind, Guttenplan (2000), identified three important aspects of mental activity: experiencing or consciousness, attitudinizing, and acting. He argued that while experiencing refers to and relates to the manner in which the mind appropriates consciousness, or how mind organizes the objects and events in which it is participating, or in which it is affecting it by bringing it to attention, attitudinizing refers to the modes in which and by which consciousness relates its appropriation and organization of mental activity to the emotions leading to the creation of attitudes. The process continues into acting. Acting points to the relating of the mental activity of attitudinizing or the modes along which consciousness affects the emotions, and the translation of the attitudes created through the process of attitudinizing into behavior and activity or actions. Thus, mind is central in this environment; it is the agent responsible for organizing and relating the objects, events, and the participation of the individual in all of these in a particular way to consciousness as experiencing. The mind, in a similar way, relates what it has organized into modes of affecting the emotions of the individual. The modes which consciousness shapes for the emotions lead into actions and are manifested in the behaviours of the individual."[14,13]

Consequently, the following questions are being examined through the processes enacted by the personal experience methodology and modes.

Research questions:

- How can personal experience offer a mode of understanding the delay in breast cancer reporting?
- How do victims of breast cancer in rural areas come to realize and evaluate their own experiences, take a critical perspective on these, and learn how to use this reflection to help them deal with the problem they face?
- How do the mental activities of consciousness, attitudinizing, and action frame the choices and behavior of breast cancer victims and the decision-making and management of their situations in rural contexts?
- How does the ways of commodification in the wider society impact upon victims of breast cancer in rural areas?

- How does the organizational reward systems that victims of breast cancer in rural areas follow create a safety net to cushion them to cope with their condition?

Significance of the Study: Empathy and personal experience in breast cancer research and advocacy

The study projects the value of empathy and personal experience in breast cancer research and advocacy. It argues that in rural and socio-cultural communities, people come to realize the value of their own experiences, take a critical perspective on these, and they learn how to use this reflection to help themselves deal with whatever problems they face, especially in dealing with intractable diseases. The role that socio-cultural factors play are not as negative as some perspectives seem to suggest with the implications of 'ignorance'.

It will add to the multiple perspectives for health practitioners, health researchers, experts and campaigners on health issues, especially for breast cancer matters, encouraging them to alter their discourses such that they no longer view reflection on the personal experience of breast cancer victims as in itself worthless because the opposite may be truer, so that the starting point for dealing with breast cancer patients' problems should be breast cancer patients' own experiences.

It hopes to suggest the development of such emotional intelligence in health practitioners and researchers that reflects the recovery of the visceral dimensions in them capable of taking them straight back to the emotional understanding deeper than reason can re-image an experience concerning the unpleasant or painful in adulthood in respect of breast cancer experience.

It also hopes to highlight the basic structuring of the life-course and management of life based upon the effects of socio-economic factors and commodification in their interaction with intractable diseases in the lives of rural folks and the underprivileged.

It ultimately will raise awareness about the impact a breast cancer occurrence imposes on rural communities, care-givers and families.

Literature Review: The phenomenon of delayed medical attention by breast cancer victims

In their article titled "Socio-cultural interpretations of breast cancer among female patients at the Cape Coast Teaching Hospital, Ghana", in the *Ghana Social Science Journal*, Nana Afia Karikari and Willian Boateng [11] cited various researchers who made pertinent statements about breast cancer reflecting the aggressive and destructive nature of breast cancer among women, the kinds of population it affects, and the apparent hesitation of women in Ghanaian communities to seek early enough medical attention for support and possible cure at the appropriate medical facilities, causing avoidable late diagnosis and avoidable mortalities.

Such studies note as Sarfo et al.[15], state that "Breast cancer is one of the most aggressive and highly destructive cancers among women. It is a disease that has its affected population from urban and rural, wealthy and poor, old and young. That is, the disease is not restricted to one's culture, ethnic affiliation, race, social status or creed." [15]

Karikari and Boateng further cited Banning, Hafeez, Hassan, Faisal and Zafar (2009) who concluded from their research that "more than two-thirds of all breast cancer mortalities occur in Africa". [11]

The high mortality rate in Africa is explained by Segni, Tadesse, Amdemichael and Demissie, (2016) as originating from two main causes: "This high degree of mortality rate is due to late diagnosis, and lack of modern cancer equipment."[11]

However, the emphasis is put on the late reporting of the disease: "Late presentation of the disease for diagnosis is the most common cause of poor survival rate in Africa especially in sub-Saharan region. For instance, Ohene- Yeboah, Adofo and Akpaloo (2013) note that in sub-Saharan Africa, 90 percent of breast cancer patients delay in seeking medical help and as a result the disease easily advances to its optimal state, that is, either stage III or IV. This situation demands the most resource intensive treatment, where even optimal western therapy may offer minimal survival benefits for patients."[11]

In offering reasons for the late presentation of the disease for diagnosis and treatment among breast cancer sufferers in Ghana, Karikari and Boateng state that "The tendency of women to seek early medical treatment or not, is mostly influenced by their socio-cultural beliefs. Socio-cultural beliefs provide the medium through which people frame their attitudes toward health and illness. Helman (2000) asserted that women's understanding and explanations of cancer are socio-culturally patterned and have the tendencies to inform their interpretations of what the disease is. As such, the interpretations women give to the illness have been identified as significantly playing a role in their decisions regarding breast cancer diagnosis and treatment." [11]

In the end, they conclude that: "Although, breast cancer is commonly occurring in Ghana, there is however, poor knowledge and understanding of the phenomenon." [11] Consequently, breast cancer awareness campaigns obviously focus solely on the dissolution of the 'poor knowledge and understanding of the phenomenon', which are the perceived causes of the hesitancy of breast cancer sufferers to seek early medical attention.

Case Study: The Case of Akua in rural Ghana:

When breast cancer struck through the manifestation of a boil beside the nipple of her breast in February 1986, Akua was 48 years old. It is often said that life begins at 40; yet for Akua, it was the opposite – life was ending at 40+. She would succumb to death seven years later in 1993 at the threshold of her 55th birthday.

Akua was from a small village in one of the Districts of the Volta Region. Earlier in 1969, she was installed a Paramount Queen-mother or Women's Asafoatse (The chief Women's Organizer) for a traditional area. Before, she was married to a teacher and they lived peacefully together far away from their own traditional area – she, as a housewife, engaged in backyard gardening.

When she was made a queen-mother, it was not a decision she was part of or ever anticipated. She was invited back home abruptly by her family on account of some urgent family matters. Three days after she responded to the invitation home, she was sent on an errand to a market to shop for the family because it was market day at the nearest market town. She returned home and set her shopping items down. Immediately, a group of men emerged from nowhere and poured powder and white clay over her according to the traditional rituals of the area, proclaiming her a queen-mother for the traditional area. It commenced her confinement and the seven-day ritual towards installation as a chief.

The invitation to her taking her away from her husband, the few days stay at home, and the errands she undertook also to the market all served the purpose of further observations by the kingmakers to confirm her physical appearance, features and bearing, and her character as compatible with those desired of a chief or queen-mother. Thus, when breast cancer struck, her status as a chief would play a role in decision-making about the mutilation of her body, because as a chief, you could not give any cause for the mutilation of your body that would leave your body to be described as 'not whole'. It also signals that her status and identity had changed; her body did not belong entirely to her as an isolated individual anymore – and her relationship to her body and its management had to take into consideration her office and the community's being.

Hevi[16] describes the qualifications for traditional office among the Ewe people thus:

"Tradition has it that, originally 'fia' (Chief) was chosen according to his physical, intellectual, and moral qualifications rather than simple heredity. As Madeleine Manoukian observes: 'The Ewe themselves recognize that the actual power wielded by a chief depends to a great extent on his personality, and those who select him try to choose a man of tractable disposition who will follow the advice of his elders'. The most important qualities looked for by chiefmakers are initiative and drive, valour, humility and wisdom." [16]

It is noteworthy, however, that the qualities required for a male are the same for a woman.

The closest relatives who lived with or interviewed the deceased indicate that when the disease manifested, it did not appear menacing for a long time. The first thing that drew her attention to the breast was a small boil that attacked the side of her nipple. However, boils were a regular disease that disturbed rural folks. There were local ways of dealing with boils which were quite effective and posed no problems. Moreover, as a mother of nine children, she had known that there were various types of ailment that attacked the breast, which were conveniently treated with local medication until they disappeared. And so, this time too, when a boil appeared, local boil medication took care of it and it posed no concerns. It healed, but after a few months, another did appear. She had no idea of how breast cancer attached itself to the breast nor how it developed beyond the rare cases she saw or heard of which ended in death.

Akua's case was different from her second cousin, Esi's, which occurred in 2007. Esi noticed a hard lump in her breast in 2005 after hearing about symptoms of breast cancer through radio and other awareness programmes. Nervous about what it might be, she took it to hospital for examination and it was certified as a developing case of breast cancer. She noticed it at the age of 43. After a tortuous decision making in which she was persuaded by doctors and counselling, she finally made a decision based upon the optimistic advice of her siblings who encouraged her to take the risk of surgery and removal of the breast for a possible survival and prolongation of life. They gave her examples of persons whom they had heard had their breasts removed and continue to live for ten years or more. She conceded and took herself through the surgery to remove her breast and subscribe to chemotherapy. After surgery and chemotherapy, she returned hale and hearty; but a year on, she began to deteriorate rapidly. It was later explained that the cancer had spread through her entire body before she subscribed to the surgery. Within two years of noticing the lump in her breast, she was dead, although she did not delay about medical attention.

At the time these incidences of boils on the breast began, Akua had eight surviving children. She had lost her husband in 1976, ten years before the manifestation of the disease through boils on the breast. Her main concern was first and foremost, her children and their survival. Her eldest child was eighteen years old when her husband died. She turned seriously to petty farming to feed her children and to buying avocado pear, oranges, and charcoal from the surrounding villages when the farming season was over and transported them to the capital for sale where her elder sister lived with her own family.

To protect herself from robbery and pickpocketing, she hid money in her brassiere after sales in the city. Later on, when she began to suffer from her breast, it was the opinion of some surviving eyewitnesses, that the infection to her breast should be partly attributed to this practice. By this, relatives began to seek explanations for the disease and its origins.

The disease was usually referred to in the community as ‘the evil disease’, and Akua referred to it with this term whenever she spoke about it. And she often said that she did not know where ‘this evil disease’ originated from. For her, the disease prevented her from employing all her energies in doing her farming and petty trading, limiting and preventing her from what she must do in order to look after her children and give them a life and a future in the absence of their father. And so, when Akua referred to the disease as ‘this evil disease’, she had several things in mind.

The first boil, which was on the left breast was about 2 centimeters and situated on the breast above the nipple and at the left side of the left breast. With the application of local herbs which are usually used for such ailments, the boil burst after some days. In rural communities, scarcely would modern medical solutions be the first thought in such cases.

However, while the spot where the boil burst healed, the nipple later became reddened and began to soften and slowly peeled off as the cells died and fell off leaving a permanent wound at the tip of the breast. After some time the nipple of the left breast that was attacked began to disappear, creating a dent at the place of the nipple. The wound was painless such that she could still wear a brassiere and work, but as the nipple disappeared, it felt more and more uncomfortable.

Realizing that no known local medications for boils and wounds were working in healing the wound at the nipple and that the wound failed to heal for several months, she began to think that something strange was happening. She gathered the courage to seek medical attention at the nearest hospital in 1988. Doctors at the hospital suspected it was parget’s disease of the nipples and therefore referred her to the Pathology Department of one of the Teaching Hospitals for a test to determine the extent to which the disease had spread in the breast. Immediately, she suspected that it was the beginning of the end of her life, and all that she cared to focus on was her eight surviving children and who would care for them after her passing.

She stalled the referral to the Teaching Hospital because she did not think she could bear the cost. Referral to the biggest hospital in the country meant that the disease was a rare and serious one, and the costs would be enormous. None of her children had started working yet. A peasant farmer and petty trader with eight surviving children could not afford such a cost. She continued her peasant farming to feed the children, and to keep them in school, and continued her petty trading when the farming season was over.

She continued to live in her husband’s home and village a few kilometres from her own village and family home. However, from 1989 when she began to feel less energetic and felt the illness was advancing, she moved to her own village and family home with all her children, and she continued peasant farming and petty trading as before. In 1990, it became apparent that she could do less than before. But by then, one of her sons had gained employment to work in a civil service job. The son noticed her mother’s weakening condition and the growing wound on the breast that her mother had been nursing and suggested they pursued the referral to the Teaching hospital. With the assistance of her sister living in Accra, they arranged the visit to the hospital for further examination of the breast. She did not resist it.

She reported at the Teaching Hospital in April 1991 where a minor surgery was performed to remove tissues from the nipple to mammary glands up to the point where the breast was attached to the body. The test results confirmed the pargets disease of the nipple.

But as she lay on the hospital bed after the surgery, her cubicle mate, in conversation, expressed shock at how long it took her to regain consciousness after her surgery – 24 hours! It shocked Akua too. Immediately, she came to the conclusion about what had happened to her; what she knew would happen had already happened once in the twinkle of an eye - she had actually died and resurrected, and that her wakefulness was only meant for her to prepare for the ultimate by putting herself and her children and their affairs in proper order. It was also the end of any desire to go further with any medical recommendations. She believed that a major surgery to remove the whole breast would only end in certain death.

And so when Akua was scheduled for a surgery on the 17th of February 1992 to have her breast removed at the then Regional Hospital, currently a District Hospital, she had two reasons to delay the surgery: firstly, she was a traditional leader who was still occupying the stool, and she could no longer hold herself out as a traditional leader with such a surgery that would render her incomplete. Secondly, she believed she had already died and therefore needed no surgery, and she would not want to die and be buried without ever seeing her firstborn son whom she had not seen for about three years. Her firstborn son had gained a scholarship to study in the United Kingdom.

It took the intervention of a Catholic Bishop to persuade her to agree to undergo the surgery with the promise that her firstborn son would be informed of her condition and persuaded to return home to visit her mother. However, travelling across countries was not a ready item in the early 1990sas in contemporary times. The day of the surgery, however, also coincided with the day her second-born son who had supported her going for the minor surgery and the one sponsoring the removal of the breast was supposed to compulsorily report for duty at his station post very far away (750 km) from home in the northern part of the country. It meant that he could not be present when she would be undergoing the surgery; yet it was imperative for the son to depart or face the consequences of loss of job. Fearing that she might not wake up from the surgery in the absence of her sons, she did not proceed to the hospital for the surgery. She dismissed any further persuasion and continued her life as if nothing was happening to her – her farming, her chiefly and social duties, and her religious life.

However, from October 1992, there was a marked shift in her condition as it started to deteriorate rapidly. She knew she was reaching the end of her life, and her greatest wish was to see her first-born son for the last time before her departure. When the son arrived, he found Akua in the family house lying on the mat, serenely holding her first infant grandchild to her non-affected breast. Looking at her breast, the son, in shock asked why Akua did not go for the surgery as recommended. She said nothing, but son and mother looked at each other in silence with a knowing sense of the approaching end: She had stopped explaining to anyone the reason she would not go for surgery. For her, her last wish had been fulfilled, and she was ready to die. Her first-born son had arrived and visited her, but had to return to his teaching post at a Secondary school where he was also scheduled to begin teaching. Two weeks after, Akua, travelled to visit her son at the school he was teaching at. She was well-dressed and showed no signs of illness. She travelled on very rough roads because the village in which her son was teaching was in a remote region. This was not in the days of ready handsets and mobile phones yet, and the son had no prior information of Akua's coming. She was well received in spite of the shock. She spent the whole day with the son, asking many questions about his travel and current condition settling back in Ghana. She asked many questions both about the United Kingdom and about how he was settling in. They held many conversations about family and responsibilities, but she did not focus on herself. When the son asked how she managed to travel in spite of the big wound on her breast and whether she was not feeling any pains, and whether she would not find problems after such a travel, she dismissed it with a simple, 'I am alright, don't worry.' After her passing, a short letter was discovered on top of her well-arranged clothes in a wooden box which she wrote shortly after visiting her first-born son. It was addressed to her first-born son, detailing her wishes for all the children – details she could not disclose in her last conversation and sojourn with her son that could give away her feelings of impending death. She was well-prepared for the end. Her firstborn son was to act as the father of the family and the firstborn daughter was to take her place as the mother of her siblings.

After arrival back home, she could not do the things she used to do anymore. She had made her last journey to say goodbye to her son. As she deteriorated and the pain became unbearable day and night as no local palliatives worked, the family head decided to take her to a traditional healer or herbalist far away from the village.

Akua had refused to be taken to a prayer camp or to a traditional place of healing or herbalist as would be expected in the absence of any further hope. However, in her powerlessness, she had no choice as she was bundled to a traditional healer or herbalist for local medication and palliatives. When the first-born son heard what had transpired, he went to retrieve Akua from the place of traditional healing and sent her directly to the hospital for whatever could be done to lessen her pain. In her pain, all her lamentation remained: 'Oh, my children! Oh, my children!' She said to her son who took her to the hospital: 'Please, don't spend anymore money on me, don't incur any further expenses; spend whatever you have on your brothers and sisters.'

Discussion: What are the significant aspects of Akua's experience?

When asked why the family head decided to take his sister to the traditional healer of herbalist when he knew that she did not wish to go to such a place, he responded that "If you are ill and not recovering, it means only one thing: your next destination is death". The implication is that the illness was identified as terminal and there was no hope of recovery – it was a death sentence. However, the family could not be seen to be doing nothing to help the poor victim. The sense of inevitability of death as a result of the disease influenced many decisions by both the individual, Akua, and the collective decisions represented by the family head. In times of powerlessness due to illness, the family head took over decision-making because he was now responsible for the helpless victim. With the incessant moans of pain and suffering, the family head could not be seen doing nothing to help. It would signal lack of care for his sister and family member. But the choice of a prayer camp or traditional medicine camp or the hospital depends first on the affordability, and secondly, on the belief of the immediate decision-makers.

Socio-cultural solutions are a search for meaning in the midst of evil – inevitable death and the powerlessness against it because of lack of the means to bear the financial costs due to other obligations or responsibilities. In the case of Akua, she surmised that the survival of her eight surviving children would be jeopardized if the little resources available were used on her medication in hospital facilities. She did not reject medical attention because of ignorance, but because of prioritization of the survival of her children. She knew that the treatment of 'the evil disease' as she referred to it, at a modern hospital facility would incur enormous costs, including several sessions of chemotherapy and several types of drugs and hospital sessions which costs and resources could be better used to raise her growing children rather than used up by her alone whose life course was coming to an inevitable end regardless of any type of intervention.

For the Ewe woman, the breast of a woman is a symbol of femininity and 'nurture'; and although it may not be explicitly pronounced in everyday life and at face value, it is at the basis of much decision-making in the community – the nurturing of children and giving them priority. The chief guardian of the traditional area in which Akua was a paramount queen-mother was called 'Diawonor', the mother of the children. Consciously or unconsciously, this cultural vision governs the chieftaincy of the woman in the traditional area. It would not be surprising that Akua's identity and decision-making should be to a great extent influenced by the value of priority towards her children than towards a focus on her individual self and survival at all cost.

Bloor [1] refers to Raymond Williams' book *Culture and Society* (1958) in throwing light upon the influence of culture on both collective and individual decision-making and management of life whether imminent or immanent. He investigates the changing meaning of the word 'culture'. "This used to refer simply to the growing or cultivation of crops, and still has these connotations. The metaphor of organic growth with its agricultural overtones made it appropriate for use by the tradition of thought stemming from Coleridge which lamented the growth of industrialism and individualism. If we introspect on the meaning which the word 'culture' now has for us it is immediately clear that it has connotations of tradition, unity and spirituality or loftiness of some form. The very notion of culture already contains in embryo the ideas which can be filled out into the Romantic image of society."[1]

In the attack by the evil disease of breast cancer, this romantic image of tradition, unity, spirituality and loftiness were being disintegrated in the life of Akua, and she had no illusions about it. Nevertheless, she had to withstand this disintegration with valour, wisdom, and integrity.

The Evil Disease:

"The logic of the concept is a residue of its social role, not vice versa. Conversely, one cannot think of the word 'culture' without tacitly relating it to its antithesis. This will be something which shatters tradition and stands for change and activity. It will be something which undermines unity, suggesting division, conflict, struggle and atomization. The antithesis must be opposed to spirituality and what is higher, suggesting worldliness, practicality, utility and money." [1] For both Akua and the community in which she lived, the death sentence disease which attached itself to her was an 'evil disease'. The understanding of this designation of the disease can be located in its antithetical orientation to everything signifying tradition, unity, spirituality and loftiness. Its antithetical character manifests in its undermining of the vision of the individual and of the community, producing division, conflict, struggle and atomization and suffering for the individual.

The repugnant smell from the rotting flesh of the breast was an indication of evil and the devil compared with the external beauty and goodness associated with Akua. The first task undertaken by the family head upon noticing the marks of the 'evil disease' was to seek divination to certify the righteousness of Akua as a queen-mother and if she had not offended the gods or violated the chiefly stool upon which she had been installed for which reason she was being punished.

Having certified her righteousness in terms of spiritual and moral character in this regard, people wondered how such an evil could make an inroad into her life. For this reason, members of the community could also label the disease 'the evil disease'. She had made her decision that she would not remarry after the death of her husband in order to devote herself to raising her eight surviving children, and her community could vouch for her moral integrity, and so members of the community wondered why and how evil got an inroad into the flesh of such a person.

The pain, the human suffering, the unimaginable, monstrous, beastly, and repelling nature of the disease also made them sometimes refer to it as a beast. These are all ways of trying to make sense of senseless suffering in spite of the innocence of the victim and the paradox, dilemmas, and powerlessness invoked by such a situation.

Conclusion: How can Akua's attitude, posture and behavior be understood?

Akua's decisions and actions were neither a mindless act nor mere stubbornness nor ignorance but the reflection of a personhood, a conscious meaning-making, decision-making and management of life according to a vision articulated from all dimensions of experiencing. She was well-educated and literate according to the standards of the times. She completed her Standard Seven level education creditably but could not proceed to a Secondary school only because her parents could not afford to enable her further and decided to marry her off. She, therefore, read the Bible often, read the daily newspapers when her husband was alive and whenever they were available in later years, and was interested in current affairs. She wrote mainly in the Ewe language although she could also read and write English. Her actions were all well-considered ways of managing herself, her world, and life-course in relation to the life-course of her children and the circumstances that dictated the times.

They were also decisions and actions based upon the discourses that generated meaningfulness for her identity, direction and purpose within the knowledge of an impending end due to a terminal disease – a death sentence. She told her best friend that she knew her end was inevitable, that she had not known any survivors of the disease, that in her lifetime she had seen at least two sufferers of the disease whose breast were taken off through surgery but who did not survive for long, let alone others who had no such interventions. All she cared about from then was how to prepare for the ultimate end, and for that she believed that as long as her firstborn son returned home, her children had a chance of survival.

The Socio-cultural recourse is mainly a safety net and last resort for victims of terminal diseases or evil diseases or death sentence diseases. It enables them to live within the discourses that have nurtured and sustained them, and within which they feel secure that their powerlessness can be contained. It gives a means of continuing to make meaning of their lives and to be an individual with the capacity to make decisions until they can no longer function; and when they can no longer function, they have the certainty that they will continue to be safely taken care of by caring relatives without falling into debt.

Recommendations:

As health researchers and practitioners, when discourses focus on delay and ignorance and cultural beliefs, we tend to forget the fact that individuals have personal histories, identities, lives, and that decision-making about life and death are not clear-cut routes as it may seem, given what an individual has to work through to reach a final preparatory stage in readiness for a satisfactory transition. Understanding and recognizing the decision-making of cancer sufferers has to play a major role in any interaction with the victims as they are bound to articulate and make meaning of their situations and life, and ultimately, what it means to be dying inevitably. It means the personal experience of victims need to be prioritized in the efforts to provide succor for them.

The medicalization of patients before and after surgery, and the commodification of life resulting in unbearable financial costs before and after attempted treatments hurt. Breast screening with mammography screening, although in some cases now is 'free', is on regular basis costly and is a ready and feasible provision only in specialized medical facilities with good infrastructure tending to be farther away from rural dwellers. On account of this, early detection does not guarantee affordability. The aftermath of detection and surgery are themselves costly ventures. Motivation for seeking modern medical attention for 'death sentence diseases will always depend upon facilitating affordability and closure rather than prolonged and serial sessions of chemotherapy and other related medical seeking obligations involving being tied to medical facilities often, to costs, and to limitations in time and freedom to do anything else or to live one's life productively afterwards.

Socio-cultural recourses by victims is a recourse to social safety nets. In being close to family and friends, one is taken care of, not necessarily on the basis of paid services, but on the empathy, compassion, and dedication of family and friends in assisting the victim to receive care with full understanding while helping in the process of trying to make sense of the origins and purposes of the evil disease and its attacks.

The recent efforts at giving hope, health, and empowerment to communities in Ghana through the provision and dissemination of quality breast health education, screening, counseling, advocacy, research, treatment and improve the quality of life of women at risk with breast cancer through community outreaches and education can only make significant impact if accompanied by real-life and actual alleviation of the underprivileged conditions that create the lack of access to hope.

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