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Effect of Socio-Cultural Beliefs on Late Stage Presentation of Breast Cancer among
Ghanaian Women

A Thesis Submitted to the
Yale University School of Medicine
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by
Yehoda Marteki Martei

2011

ABSTRACT

EFFECT OF SOCIO-CULTURAL BELIEFS ON LATE STAGE PRESENTATION OF BREAST
CANCER AMONG GHANAIAAN WOMEN. Yehoda M. Martei; Verna Vanderpuye; and Beth A. Jones.

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New data emphasizes the increasing burden of cancer in the developing world, which has led to an increasing move to prioritize cancer care on the global health agenda. Breast cancer is the leading cause of cancer mortality among women globally. In Ghana, most women present with advanced stage breast cancer. There is currently no national screening program, and insight into why women present late stage is limited. The aim of this study is to characterize why women present with advanced stage breast cancer in Ghana.

We used a Qualitative study based on in-person and in-depth interviews with 31 breast cancer patients seen at the Korle-bu Teaching Hospital in Ghana. The interview data was transcribed, and coded based on the Grounded theory method. Data was organized using NVivo 9 software.

Five recurrent themes emerged from our study with four explicitly related to late stage at presentation: 1) Study participants expressed some awareness of breast cancer, but with varying depths of knowledge; 2) most patients present late because they do not associate a “painless” breast lump with possible breast malignancy; 3) women with a confirmed breast cancer diagnosis, delay treatment because of the fear of mastectomy; 4) religion plays an important supportive role for breast cancer patients. 5) A fifth factor was not explicitly related to delayed presentation. Breast cancer treatment presents a significant financial burden but was not stated as an explicit reason for delayed presentation. We concluded that despite efforts to increase awareness, there are still significant knowledge gaps, and social and cultural factors that need to be addressed to enable patients translate this information to their personal health. The church’s current role can be leveraged to augment current efforts to increase breast cancer awareness and utilization of the current services available. Successful design and implementation of cancer programs hinge on attention to socio-cultural influences on advanced stage presentation.

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- Yehoda Martei.

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INTRODUCTION

The International Agency for Research on Cancer (IARC)'s most recent cancer statistics indicate that the majority of the 12.8 million new cancer cases (56%) and the 7.6 million cancer deaths (63%) worldwide occurred in developing countries. In developing countries, more people develop (7.1million) and die from cancer (4.8million) each year than are affected or die from HIV/AIDS throughout the world (an estimated 2.7 million and 2 million respectively in 2008) (1, 2). These new data emphasize the increasing burden of cancer in the developing world, which has led to an initiative by significant global health players to move cancer on the global health agenda (3). However, there is still a ring of silence surrounding cancer diagnoses in the developing world and preliminary studies are needed to examine the perceptions of cancer in order to design culturally appropriate and effective cancer control programs in the developing world.

Breast Cancer in Ghana

Breast cancer is the leading cause of cancer mortality among women globally. 1.1 million women in the world are diagnosed annually with breast cancer, which accounts for more than 10% of all new cancers diagnosed per year (4). 410,000 women die of breast cancer every year, which represents more than 1.6% of all female deaths worldwide (5, 6). The IARC estimated WHO age-world standardized-incidence rate (ASR (W)) for breast cancer in 2008 among women in the United States is 76.0. For the

same year, the age-world-standardized mortality rate for breast cancer in the United States was 14.7. The IARC calculates the ASR (W) by dividing the number of cases within a specified age-group with the corresponding population at risk and is expressed per million person-years. The IARC estimates for Ghana were ASR(W) incidence rate of 25.8 and ASR(W) mortality rate for breast cancer of 15.2 in 2008 (7). These data underscore the fact that despite the significantly lower incidence rate of breast cancer among Ghanaian women relative to American women, the breast cancer mortality burden of the two countries are comparable.

In most developing countries, including Ghana, the incidence rate of breast cancer is comparatively low compared to western countries. Consequently, breast cancer and other cancers are not traditionally recognized as public health problems in these countries. Infectious diseases are the main focus and target of public health interventions in a majority of these countries (1, 3). In recent years however, the incidence rate of breast cancer in developing countries has been increasing at approximately 5% per year (8). The earliest study of breast cancer in Ghana revealed that breast cancer accounted for 7.45% of all cancers treated from 1972 to 1977 at the Korle-Bu Teaching hospital (KBTH), one of the two main teaching hospitals in Ghana (9). Ghana does not have a national tumor registry, so these data represent only breast cancer cases that come to medical attention at the KBTH and cannot be extrapolated to represent the incidence of breast cancer in Ghana. These data are useful for evaluating trends in cancer cases seen at KBTH. The most recent data showed an increase in the relative proportion of breast cancer cases, with breast cancer accounting for 15.4% of all malignancies seen at the KBTH (10). A 10 year review (1991-2000) of autopsies and hospital mortality carried out

in Ghana showed a parallel increase in breast cancer mortality - 17.24% of cancer deaths among women were attributable to breast cancer (11). All these point to an increasing burden of breast cancer in Ghana, which is consistent with current statistics that show an increasing trend in breast cancer incidence and mortality in developing countries globally (7).

Despite the relatively lower incidence of breast cancer among Ghanaian women, the mortality rates for breast cancer are comparable or even higher in the Ghanaian population compared to the US population (7). This observation can be explained by several factors. Majority of the breast cancer patients in developing countries present with advanced stage cancer, and consequently have a poor prognosis when they are initially diagnosed (8, 12). Studies indicate that women who attend annual screening mammograms present with smaller size tumors, which in the long-term accounts for improvement in survival (13, 14). It can be accurately inferred that a significant fraction of the high mortality rate in Ghana can be explained by the underutilization of mammography screening and other screening modalities among Ghanaian women. Recent studies have also compared breast cancer presentation and mortality patterns between African Americans and Africans. In both populations, the breast cancer mortality is disproportionately higher than the incidence. Similarly, the average age at presentation for Africans and African Americans, was 10 years younger than the average age at presentation of breast cancer patients in western nations. Data available for African American breast cancer patients, show a stage shift toward more advanced disease, which resulted in higher breast cancer mortality. New data has also shown the genetic predisposition to more aggressive disease in the African American population. Whether

this contributes to advanced stage presentation and increased breast cancer mortality in Sub Saharan Africa remains uncertain (15).

Breast Cancer Mammography Screening

The commonest screening technique used in the detection of breast cancer globally is screening mammography (16). Previous studies in the US and other Western countries have shown that a significant fraction of the decrease in the breast cancer mortality in the last couple of decades can be attributed to mammography screening. In the US, approximately 48% of the decline in breast cancer mortality experienced from 1975-2000 can be accounted for by screening mammography (13). Similarly in the UK, about a third of the overall 21% decrease in breast cancer mortality from 1990-1998 is estimated to be due to screening (14). The recent controversy surrounding the revised screening guidelines by the United States Preventive Services Task Force (USPSTF) does not dispute the mortality benefit of mammography screening, but instead, they recommend against screening for women younger than 50 years and older than 75 years, because there is insufficient data to support mortality benefit in these age groups (17). Despite the net mortality benefit of mammography screening, research preceding these new screening recommendations show that most women in the US do not adhere to the screening guidelines (18-22).

There is no national mammography screening program instituted in Ghana. The main modalities of screening are the Clinical Breast Examination (CBE) and Breast Self-Examination (BSE). Previous studies show no mortality benefit of the BSE and there are

currently no randomized trials of the CBE (23). Currently, the USPSTF does not endorse both modalities of screening (17), but in the absence of routine screening mammography in Ghana, most breast cancers are picked up by the BSE and CBE. There has been a recent surge in public education programs about breast cancer and available screening options, as well as organized mass CBE screening outreach programs organized by both the government (national teaching hospitals) and non-governmental organizations (NGOs) (such as Mammocare Ghana and Reach for Recovery). The KBTH is located in Accra, the capital city of Ghana, and organizes free CBE a couple of days within the year. Mammocare Ghana is an NGO that promotes breast cancer and screening awareness. This NGO organizes free CBE screening through outreach programs. Reach for Recovery Ghana is an NGO that provides a network of support for breast cancer patients and survivors. They also organize annual breast cancer information sessions to promote breast cancer awareness and early detection. In spite of these provisions, mammography screening and CBE continue to be significantly underutilized among Ghanaian women (12). The average tumor size at presentation among breast cancer patients in Ghana is 6-7cm (12), compared to an average tumor size of 1.4cm and 1.9cm among US women aged 50-60years and <40years respectively (24). This raises the concern that women are not getting screening mammograms and CBEs. It further indicates that although the Ghanaian government and NGOs are making screening more accessible and available, the actual uptake of screening services by the population remains poor. Successful implementation of any screening intervention necessitates an assessment of breast cancer awareness within the population and an analysis of the factors that explain why women present with advanced stage breast cancer. Current

research also suggests that even in instances where women have a confirmed diagnoses of breast cancer, treatment follow-up is poor (25). The reasons for this remain unclear, but are most likely socio-cultural and socioeconomic-related, and have yet to be described.

Previous Studies

A Pubmed search for publications related to Ghana and breast cancer yielded limited results. Few studies have looked at the knowledge of breast cancer and breast cancer screening among women in Ghana (25). Studies in other parts of sub-Saharan Africa have looked at perceptions of breast cancer and the depth of breast cancer knowledge among women in Africa. The results revealed that women knew very little about breast cancer (26-30). Additionally, less than half of family physicians and nurses surveyed, said they regularly carried out or recommended breast cancer screening to their patients (27, 31).

Although evidence indicates several obstacles to diagnosis and management of breast cancer in Ghana, information to characterize the socio-cultural phenomenon is lacking. The goal of this study is to understand the degree of breast cancer awareness among a subset of women diagnosed with breast cancer. This study also aims to allow participants to describe how their knowledge of breast cancer and socio-cultural factors influenced their decision to present with symptoms and to follow up with breast cancer treatment. The importance of this study is underscored by the fact that despite the wide acceptance of breast cancer screening and the extensive public awareness of breast cancer

among the American public, many women do not receive regular mammograms according to screening guidelines (32-34). A significant body of research related to mammography screening in the US has been directed towards understanding the screening patterns specific to different ethnic groups (35-38). Similarly this study will shed light on the specific factors associated with late presentation of breast cancer symptoms and play a pivotal role in the future design and implementation of educational tools for breast cancer screening and management in Ghana.

METHOD

Study Design

This study used qualitative methodology as a preliminary vehicle for investigating the above research question, because qualitative methods are well suited for studies for which there is a paucity of prior research (39). Few studies have explored the knowledge, attitudes and beliefs of breast cancer patients in Ghana. While previous investigators have used a questionnaire based approach, we believe the qualitative method is more effective in revealing salient insights into socio-cultural and socioeconomic factors that impact breast cancer, and specifically their impact on late breast cancer presentation (40). The qualitative approach also employs open-ended questions which allow the interviewer to re-word and re-order questions to explore topics introduced by the respondent (41). In this particular study, the qualitative method allows the respondents to explain their understanding of breast cancer using their own vocabulary. The results of this qualitative study will be useful for generating hypotheses that can be tested with quantitative research design (39). We believe this fund of knowledge will inform the design and implementation of educational programs to address the diagnosis and management of breast cancer in Ghana (40, 42).

Patient Population

The research protocol was approved by the Human Investigation Committee of the Yale University School of Medicine, New Haven, CT (HIC Protocol # 0804003745).

The study setting is the outpatient breast clinic at the KBTH staffed by a team of surgeons, radiation oncologists, oncology nurses, a clinical psychologist and a clinical pharmacist, who meet every Tuesday to discuss self-referred patients. The clinic also serves as a follow-up center for patients with confirmed breast cancer diagnosis undergoing treatment.

31 study participants were selected using purposive sampling (39). Women with a confirmed breast cancer diagnoses, who were attending routine follow-up appointment at the clinic between June 2008 and August 2008, were approached in-person by one of the authors (VV), who is a radiation oncologist at the clinic, and asked if they would participate in research to study the perception of breast cancer among Ghanaian women. In order to address the goal of the study, we selected women with confirmed diagnoses of breast cancer. All the study participants had been previously seen at the clinic, and were presenting for follow-up. Of note there was variability in the timeline of breast cancer management in order to inform a broader understanding of factors that influence screening and follow up at different stages of treatment. All the women who were approached agreed to participate in the study, and were then introduced to the interviewer (YMM), who explained the study in detail. Participants were reluctant to give written consent, so verbal consent was obtained for all study participants, and consenting patients were interviewed at the clinic.

Interview and Data Collection

The interviews were conducted in English and three local Ghanaian languages – Twi, Ga and Ewe. There were no third parties present for any of the interviews, except for one interview in which the study participant's daughter was present and served as an English-Ewe translator. The interviewer (YMM) was fluent in the other languages – Twi and Ga. The study participants were asked a series of open-ended questions about their general health and wellbeing, previous encounters with the healthcare system, knowledge of breast cancer, screening, presentation and treatment course, as well as their feelings about their diagnosis, and religious and socio-cultural influences relevant to their recent breast cancer diagnoses. The iterative process was used for this study. Preliminary data analysis of earlier interviews occurred concurrently with data collection, and the interview questions in subsequent interviews, were modified based on emerging themes (42). Questions were optimized during this process in order to retain only questions that were effective in eliciting the necessary information. A mix of both planned and unplanned follow-up questions were carefully considered to continue the conversation and were primarily directed by the respondent's knowledge and interests (40). In this setting where the vocabulary for breast cancer is not directly translatable to the local languages, the translations during the interviews were descriptive and the meanings of the questions were clarified by allowing the respondents to first express the understanding of the question in their own words before answering the question. Questions were paraphrased as many times as needed to ensure a uniform understanding among the study participants. No repeat interviews were carried out. Figure 1 shows the semi-structured interview guide. All but three interviews were anonymously recorded using a digital tape

recorder. Three participants objected to taped interviews, so the interviewer took notes during these interview sessions, including verbatim quotes. The interviews lasted an average of 45 minutes. Recorded interviews were then transcribed by an independent transcriptionist. Interviews conducted in English were transcribed verbatim. Interviews conducted in languages other than English were translated and transcribed. The transcriptions were translated, back translated and reviewed by the interviewer (YMM) to establish accuracy of the data. The interviewer was fluent in Twi and Ga, but not Ewe.

Data Analysis

Data were analyzed according to principles of Grounded Theory methodology (39), with the aim to generate hypotheses from the data. All transcribed interviews were entered and organized using NVivo 9. Each interview was coded by two independent coders – the interviewer (YMM) and two independent coders. The data were coded using ‘open coding.’ The interviews were coded line by line and a theme was assigned based on the understood meaning. In order to determine the accuracy of the code assigned, throughout the analyses the coders compared the segment pertaining to a certain code with previously coded segments with the same code and analyzed whether they reflected the same theme, in a process called “constant comparison” (42). The independently coded interviews were then compared for agreement of the coding assigned. Where there was a disagreement, the code assignments were discussed between the two coders and the interviewer, to establish an accepted agreement. All coded interviews were uploaded into Nvivo 9, and we used the query tool to compare the level of agreement between coders

for each of the interviews. There was at least 80% agreement between coders for each of the interviews (42). We sought to ensure the credibility and reliability of the data by providing an “audit trail” to the other researchers that is by monitoring and reporting data collection and analytical processes and procedures fully (39). Reliability was established by using more than one coder and by review and discussion of the codes among the three coders, as needed.

RESULTS

Study participants represented a range of ages, geographical locations and different stages of breast cancer management (Table 1). Five recurrent themes characterized the knowledge, beliefs and attitudes about screening mammography and four were specifically related to why women delay with breast cancer presentation. A summary of the major themes is presented in Table 2: 1) Most of the women in our study expressed some, but variable degrees of breast cancer knowledge and screening recommendations but were unable to translate this information to their personal health; 2) Symptomatic women often delayed with presentation because they did not associate a breast lump with breast cancer, often mistaking the lump for a common “boil;” 3) When diagnosed with breast cancer, most of the study participants failed to follow up for timely treatment because of the fear that a mastectomy would lead to death and diminished sexuality; 4) Although not directly associated with late presentation of breast cancer, the church plays a pivotal role in dissemination of information on breast cancer screening, referral to oncologists, and provision of emotional and spiritual support during breast cancer diagnosis and management. For some women the church aided in their decision to present for breast cancer management; 5) When specifically asked about the influence of financial limitations on delayed presentation, the study participants discussed the high cost of chemotherapy treatment. Only two of the respondents explicitly stated treatment costs as a reason for late presentation. Most of the women in our study had purchased into the National Health Insurance Scheme (NHIS) introduced by the Ghanaian

government, and stated that this insurance covered part of the cost of surgical management, diagnostic imaging and laboratory work, but not chemotherapy and radiation, which they believed were the most costly aspects of breast cancer management. We provide verbatim quotations to illustrate each theme.

Theme 1:

Most of the women in our study expressed some, but variable degrees of breast cancer knowledge and screening recommendations but were unable to translate this information to their personal health.

Prior to their diagnoses, all but two of the study respondents had heard some information about breast cancer. The main sources of information identified were the media (i.e. television or radio) and church-organized health outreach programs. When asked about knowledge of breast cancer and screening recommendations prior to diagnosis, one of the study participants said, “I even saw it on a TV program, “Mmaa Nkomo.” They said women should check every morning for lumps. But when I wake up, I don’t even think there will be anything there... so I don’t’ check.” Another said, “I heard an announcement on the radio that all women should go to Korle-Bu [the teaching hospital where this study was conducted] to have their breasts checked. It was announced on Peace FM.” Some of the respondents identified church-organized programs as their source of information, “they come and tell us in the church, before I know that there is something like that [breast cancer] to check the breasts.”

The women in our study expressed some awareness of breast cancer but showed significant variability in their knowledge. A 77-year old grandmother had this to say, “they usually say that when you put money in your brassiere, you can develop it,” while a bank executive had this to say, “my knowledge is scanty... all I know is that you can have some cancerous cells developing, that can start with a lump or something and then it grows into something else. And then if they detect the lump quickly enough they remove it and you’re ok, but if it has spread then you have to have another form of surgery. Sometimes people lose their breasts and they go through chemotherapy and if they’re able to detect it early enough, it’s treatable, but once it’s advanced there’s no cure for it, you probably have to be given medication to slow down the rate at which it spreads.” A few women assigned spiritual causes to the disease. One of the study participants who had sought interim treatment from a traditional herbalist was told that her breast cancer was a result of a spell: “he said my husband fought with somebody and that, that person [cast a spell]... so the spell was meant for my husband but it did not get him so it attacked me.”

Regardless of the depth of knowledge about breast cancer, the study participants explained that breast cancer is not discussed in social circles. This silence is further perpetuated by current breast cancer patients and survivors, who refuse to discuss their diagnoses. One of the study participants explained that, “I had heard about it [breast cancer] but I had not seen it with my eyes. I didn’t know anyone who had it...” Another participant explained that, “I was shy because people would have said that I had brought a curse on the family especially because it had never happened to anyone. That’s why I didn’t tell anyone.” The women in our study also commented on the fact that discussing

their diagnosis inspires gossip. One participant explained, “for some people [breast cancer patients]... there are spiritual forces [causes] too so you shouldn't talk about it;” and another explained, “if I should tell them [network of friends], they would be consumed with fear and there will be too much gossip. I don't want things to spread.”

Theme 2:

Symptomatic women often delayed with presentation because they did not associate a breast lump with breast cancer, often mistaking the lump for a common “boil.”

Despite some knowledge of breast cancer and screening, most women did not present with early with breast cancer symptoms. All study participants presented with a lump and/or some other breast symptom, which most mistook for a “boil.” A boil, which is a “a localized swelling and inflammation of the skin resulting from usually bacterial infection of a hair follicle and adjacent tissue, having a hard central core, and forming pus—called also *furuncle* (43),” is a fairly common occurrence among Ghanaians (across the entire population) and it usually resolves spontaneously or after a couple of applications of western or traditional/herbal topical treatment. One of the participants who presented five years after noticing her lump said, “It was long ago, about 5 years ago. But all that while, it was not painful so I used to say it's just a boil, it will go away eventually,” and another expressed a similar opinion, “I thought it was a boil and so I was applying the medicine for boils but it wasn't going away.”

All study participants expressed shock at their diagnosis, and it was inconceivable to them that what had initially started out as painless breast lump turned out to be breast

cancer. To summarize, one patient said, “it [the breast lump] was just there, it wasn’t painful, and no fluid came out of it. So I became surprised because it didn’t seem to match with any of the breast cancer symptoms that you hear, such as fluids coming out of the breasts, the color of the breast changing, etc.”

Theme 3:

When diagnosed with breast cancer, most of the study participants did not follow up with timely treatment because of the fear that a mastectomy would lead to death and diminished sexuality.

A recurrent theme that emerged in our study was that when women presented to the hospital and saw an oncologist, who established their breast cancer diagnosis, most of these women, did not adhere to timely management or absented themselves for varying lengths of time, before re-presenting at the hospital. This was attributed to the fear of mastectomy. When probed directly about the fear of mastectomy, women explained that they believed mastectomy was associated with death. One woman explained, “I thought because our breasts were next to our chest, one will die when one’s breast gets cut off.” Another study participant said, “I understand when you do the surgery you will die... so when I was at the surgical ward, they even booked me for that surgery and I run away.”

Another fear of mastectomy which women expressed very passionately was the diminished sexuality a woman experiences after mastectomy. An 85 year old widow, who consented to a mastectomy with little protest, had this to share about the implication of a mastectomy for younger patients, “I saw young ladies like you who had it [breast cancer]

and it was very sad because I was thinking there is no way they will get anyone to marry them. Some of them had one breast. If you have one leg, or one hand you get someone to marry you but without a breast, you won't get anyone to marry you! If you don't have a husband it is very difficult. That is why the doctor said it is so bad to get the sickness [breast cancer] at a young age." One woman in our study whose final decision was to forgo mastectomy expressed her concern in this way, "a woman's glory is her breast, so what is your use if one of your breasts is not there? I will rather die with my two breasts than live with one." There was one case in which a woman who had initially consented to a mastectomy expressed regrets about the procedure because of the impact of the surgery on her marriage. She reported, - "my husband even wanted a divorce because he said I had been maimed."

Theme 4:

Although not directly associated with late presentation of breast cancer, the church plays a pivotal role in dissemination of information on breast cancer screening, referral to oncologists, and provision of emotional and spiritual support during breast cancer diagnosis and management. Some respondents stated that the church aided in their decision to present for breast cancer management.

All of the women in our study identified with a religious group. All but one, who was a Muslim, identified as Christians. Most of the respondents attended church/mosque on a regular basis. Although the women in our study did not directly mention the church (or their faith) as reason for delayed presentation, a recurrent theme was the influential

role of the church during various stages of their diagnosis and management. For most participants, the church was aware of their breast symptoms and involved in some aspect of their disease prior to presentation to the hospital. For some of these women, a church leader, or an individual in church encouraged them to present to the hospital with their symptoms or recommended them to an oncologist at the KBTH clinic. One of the study participants stated that part of the reason why she eventually presented to the hospital with the breast lump was, “when I showed it to the nursing sister at church, she even told me that it wasn’t really anything and that the doctors could operate on it and have me come back home right away but the tests showed that it was cancerous even though it was small.” Another study participant stated that: “I told my pastor and then he recommended Dr. X.” And even for those who independently arrived at the decision to seek medical follow-up, they still turned to the church for support before presenting to the hospital. One of the study participants said, “I told my superintendent minister and my pastor, who prayed for me before coming to Korle-Bu [the teaching hospital where this study was conducted].”

Although the study participants had expressed their reluctance to discuss their diagnoses publicly or within social circles, our study reveals that women diagnosed with breast cancer felt confident in discussing their diagnosis with church affiliates. One study participant when specifically asked about this said, “Only the pastor knows. I’ve told other people I’m sick but only the pastor knows exactly what is going on.”

Theme 5:

When specifically asked about the influence of financial limitations on delayed presentation, the study participants discussed the high cost of chemotherapy treatment. Only two of the respondents explicitly stated treatment costs as a reason for late presentation. Most of the women in our study had purchased into the National Health Insurance Scheme (NHIS) introduced by the Ghanaian government, and stated that this insurance covered part of the cost of surgical management, diagnostic imaging and laboratory work, but not chemotherapy and radiation, which they believed were the most costly aspects of breast cancer management.

Given that Ghana is a resource-poor country, the study participants were asked directly how cost of care influenced delayed presentation. Only two of the study participants identified this as a reason for absenting themselves or delaying treatment. One of the study participants expressed this financial barrier as such: “Immediately I went to the lab and came here, they immediately scheduled me for surgery. I didn’t have money so I went home and never came back because I didn’t have money... I run away because of the money.” One of the study participants, a trader, explained the difficult financial choice she had to make, which subsequently resulted in her delayed presentation: “...at the time I discovered this lump in my breast, my daughter had just been accepted into Legon [one of three main universities in Ghana] to study nursing... I didn’t come [follow up with treatment] because I wouldn’t have been able to work to provide [financially] for my child and I would have destroyed her life... so I wanted to her to go because I knew that even if I had passed away, she would have entered the University.”

Most of the study participants however, discussed the enormous financial burden of cancer management and specifically remarked that chemotherapy drugs were too expensive. Majority of the study participants who were in low-income jobs received significant financial assistance from the church. When probed about the extent of financial assistance offered by the church, one of the study participants said, “so they gave me my bill [for chemotherapy] and I gave it to the church so they appealed for funds and that is what I used to pay it off. I paid 425 GH¢ cedis [~\$300]”

Almost all the women indicated that they had purchased the NHIS, however they expressed frustration regarding the limited coverage of this insurance plan. To summarize the general theme, one study participant said, “I have health insurance but it doesn’t cover much. It covers x-ray and it covers lab. But it doesn’t cover anything here [i.e. chemotherapy and radiation therapy].

Specific questions with regards to transportation revealed that 25.8% of study participants traveled from outside of Accra, to seek treatment at the Korle-Bu Teaching Hospital, which is located in the capital city, Accra (Table 1). Consequently, these patients had to make arrangements for home care and also arrangements for housing while in Accra for treatment. However, this was not explicitly stated by any of the women in our study as a reason for delayed presentation and management.

DISCUSSION

We found that all respondents had some prior knowledge of breast cancer through the media (i.e. television and radio) and church outreach programs. However, none of the study participants attended screening (either screening mammograms or clinical breast exams) and consequently these patients presented with late stage disease. An interesting fact to note is that 41.9% of the patients in our study were diagnosed before age 40 (Table 1), and would not have met current recommendations for screening. In all cases patients had a palpable lump or other breast symptom at the time of presentation. 96.8% of study participants presented with at least a breast lump (Table 1). We found that lack of familiarity with the association between a breast lump and breast cancer, and fear of mastectomy, were the main reasons why women delayed with breast cancer presentation and timely management respectively. Although a previous study (25) had documented reasons why women report late or do not return for treatment, our findings provide further insight into the complex ways in which social factors and cultural beliefs interact and result in delayed presentation and follow up for surgical and medical management of breast cancer.

Our findings suggest there is some breast cancer awareness. The fact that women delay with presentation indicates that the information received does not accurately translate into action with respect to their personal health. The recurrent belief that a painless breast lump is unlikely to be breast cancer, suggests a need to improve knowledge about breast cancer symptoms in this population. Our findings also suggest

that despite the availability of information, there is no talk of breast cancer in social circles, with most women stating that they have never seen anyone with breast cancer. This lack of an informed social network may contribute to the knowledge deficit, particularly the tendency to think of breast lumps as relatively harmless rather than a symptom of breast cancer. This could explain the gap between some breast cancer awareness and the inability of study participants to translate this awareness into meaningful health benefit (i.e., with respect to early detection) on an individual level.

This study also provides important insights as to why mastectomy is not widely accepted and may contribute to delay in presentation when symptomatic and avoidance of surgical management once a diagnosis of breast cancer has been confirmed. To our knowledge, no study has described the role of sexuality as a prominent barrier to diagnosis and treatment of breast cancer within this population.

Given the recent reports of interest in cancer in developing countries, and new efforts to put cancer management as well as other chronic diseases on the global health agenda, our findings have important implications for the design and implementation of sustainable and effective breast cancer control programs. Specifically for Ghana, this research provides information that may identify the deficits in the existing breast cancer education, screening and management efforts by the government and NGO's. Our findings suggest that the church has a positive influence on women's decisions to present and follow up with breast cancer management. The church is also a safe space for breast cancer dialogue. Although most women were uncomfortable discussing their breast cancer diagnosis with extended family and friends, some of them shared information about their diagnosis with their religious leaders. It is therefore perceivable that women

would benefit from a network of breast cancer patients and survivors who are members of their religious group. Although only a few women mentioned an association with a survivor's support group, a religious-centered survivorship program may be well-utilized and could aid in diffusing some of the myths and silence surrounding breast cancer. This set-up will augment current efforts to provide support for breast cancer survivors. Additionally, spiritual, emotional and financial support can continue to be concurrently offered by the church for these women with breast cancer.

Our study also reveals that most participants had purchased the NHIS, introduced by the government of Ghana in 2003. The premium for this insurance scheme ranges from GH¢7.2 (~\$5) to GH¢48 (~\$34). Based on the information gathered, patients depend on the insurance coverage of laboratory tests and diagnostic scans, but continue to express concern about the financial burden of chemotherapy and radiation management of breast cancer. We believe these findings inform future studies of larger populations, with the aim to understanding health insurance needs relevant to breast cancer management.

Although several novel themes emerged from this study, our findings should be interpreted in light of the fact that the qualitative study has some limitations: We employed purposive sampling to specifically identify women who would inform our research question. We only interviewed women seen at the self-referral clinic at KBTH, which also represents another level of selection bias. Additionally, the attitudes, knowledge, and experiences identified from the patients we studied may not be generalizable to the entire population since these are women who, despite delays, eventually did present for follow up and management of their breast lump. There is likely

an unquantifiable group of women who do not present at all, thus these results cannot be extrapolated to the general population. Specifically for non-participants, financial hindrance to presentation and management could be even more significant than that reported here. Future quantitative studies of larger populations would provide a more representative picture of the breast cancer experience of Ghanaian women.

Our research has several strengths. In person, one-on-one in-depth interviews facilitated an open and candid discussion. Additionally, we used several recommended strategies to ensure reliability, including audio-taping of almost all the interviews, independent development of coding scheme and follow up comparison between coders and maintenance of an audit trail to document analytical processes and procedures (39, 44).

With new global emphasis on moving cancer care and funding up the global health agenda (1, 3, 45), our research highlights that understanding and addressing the social and cultural influences on the breast cancer experience of Ghanaian women, and presumably women in other sub Saharan countries, will aid in the design of effective cancer control programs.

Figure 1: Semi-Structured Interview Guide

1. What do you know about breast cancer and screening?
2. What do you believe is the cause of breast cancer?
3. Tell me about your breast cancer experience?
 - a. Probe about screening habits, symptoms at presentation, and time course of their diagnosis and treatment.
 - b. How long did you wait to see a doctor? Why is that?
 - c. How did you feel when you were initially diagnosed, and what were your major concerns? Explain what influenced your decision to pursue management?
4. Did you tell others about your breast cancer diagnosis? What exactly did you tell them? How has your diagnosis changed the way people perceive you?
5. What support systems of groups of individuals influenced your decision to present and pursue treatment?
6. How did the cost of care influence your time course of presentation to the clinic and your management decisions?
7. Is there anything else that you can share with me that might better help me understand the factors that influenced your delay in presenting and seeking care for breast cancer?

Table 1:

Descriptive Data among Recently Diagnosed Breast Cancer Patients Seen at Korle-Bu

Teaching Hospital, Accra, Ghana between June to August 2008.

N = 31 (unless otherwise noted)

CHARACTERISTIC	n (%)
Age	(years)
Age Range	25 - 85
Mean Age (SD)	47.12 (31.86 – 62.38)
Median Age	48
Age Groups (years)	(n)
<= 30	4 (12.9)
>30- 40	10 (32.3)
>40-50	6 (19.4)
>50-60	6 (19.4)
>60-70	2 (6.5)
>70	3 (9.7)
Breast Cancer Symptoms at Presentation	(n)
<i>(of note, some patients reported multiple symptoms; only the first symptom reported is recorded)</i>	
Breast lump	30 (96.8)
Nipple discharge	3 (9.7)

Swelling	1 (3.2)
”Heavy breasts”	1 (3.2)
Rash	1 (3.2)
Burning sensation in breasts	1 (3.2)
Breast Cancer Treatment <i>(self-report)</i>	N = 31 (%)
Neo-adjuvant Chemotherapy	4 (12.9)
Adjuvant Chemotherapy	13 (41.9)
Lumpectomy	5 (16.1)
Mastectomy	11 (35.5)
Surgery (extent unknown by patient)	1 (3.2)
Therapeutic Radiation	8 (25.8)
Awaiting treatment plan	3 (9.7)
Occupation	N = 31 (%)
Hotel clerk/Secretary	2 (6.5)
Nurse’s assistant/nurse/pharmacy attendant	4 (12.9)
Farmer/Fish monger	3 (9.7)
Trader/Retailer	8 (25.8)
Banking executive/Marketing manager	2 (6.5)
Retired/Unemployed	8 (25.8)
Caterer/Seamstress	2 (6.5)

Teacher	2 (6.5)
Patient commute to KBTH, Accra	
Participants living in Accra	23 (74.2)
Participants living outside of Accra	8 (25.8)

Table 2: Summary of Major Themes

1	There is some awareness of breast cancer, but with varying depths of knowledge.
2	Participants present with late stage breast cancer because of the lack of association between breast lump and breast cancer.
3	Delayed breast cancer treatment is because of the fear of mastectomy.
4	Religion has a positive influence on breast cancer presentation and treatment. It also plays an important supportive role.
5	Financial reasons were not explicitly related to delayed presentation and treatment.

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