


Experiences of Women in Sierra Leone Relating to Accessing Breast Cancer Treatment

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Abstract

The lack of consistent access to breast cancer care and treatment remains a significant problem for women diagnosed with breast cancer in Sierra Leone. The instability of the political structure has created an environment with a high level of illiteracy and financial hardship among the female population, resulting in a significant deficiency in information relating to symptoms and the detection of breast cancer. To study the lived experience of women living in Sierra Leone who were diagnosed with breast cancer, I [the first author] used a descriptive phenomenological approach. I conducted semi-structured interviews based on Andersen and Newman's healthcare utilization model, identifying predisposing, enabling, and need factors (Andersen & Newman, 1973). I recruited 10 participants by placing flyers in two organizations supporting breast cancer patients and used snowball sampling. Findings from the study showed that participants were aware of breast cancer and the risks associated with delayed cancer treatment. Social structures were identified as the main contributors to accessing breast cancer screening and selecting a health facility for treatment. Perceptions of affordability, quality of services, and recommendations by previous clients simultaneously influenced the selection of a health facility. The findings may assist health systems with addressing access to breast cancer care and treatment for women in Sierra Leone. Government officials may utilize the findings from this study to develop healthcare policies regarding access to breast cancer treatment.

Keywords: *breast cancer treatment, breast cancer diagnosis, Sierra Leone, phenomenology, qualitative research*

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Introduction

The need for a comprehensive plan to promote access to care for breast cancer treatment is of the utmost importance in developing countries; limited health resources and poor infrastructure could affect access to health care, such as breast cancer treatment (Silumbwe et al., 2018). Like most women in Africa, women from

Sierra Leone have many issues affecting how they function daily, including inequality among genders, diminished social standing relating to education and employment, sexual violence, and female genital mutilation (Denney & Ibrahim, 2012). Improving access to care in Sierra Leone is critical to ensuring that women with breast cancer receive proper treatment. Women in Sierra Leone encounter a considerable disparity compared to women in Western countries regarding breast cancer treatment access (Shepherd & McInerney, 2006). Since the 1900s, there has been a comprehensive understanding of the difficulties encountered by women with breast cancer, but limited information exists on the experiences of women from Sierra Leone regarding access to treatment for breast cancer (Travers, 2016).

Cancer is an ongoing health problem in Africa, particularly when compared to other countries. Kantelhardt et al. (2015) noted that breast cancer prevalence and susceptibility among the African female population has continued to increase compared to developed countries. The key cause, according to Kantelhardt et al. (2015), was a lack of timely access to breast cancer diagnosis and treatment. Late diagnosis is an issue in Africa compared to Western countries. A study conducted in East Africa by Daramola et al. (2015) concluded that over 70% of the patients were diagnosed with Stage III or IV breast cancer because of late detection. These late diagnoses were due to the lack of proper medical services—particularly in far-off provincial areas—and to destitution because medical services are not free in many nations, compared to most European nations with a universal health insurance infrastructure (Jedy-Agba et al., 2016). These research studies demonstrate the challenges for African women in obtaining access to breast cancer diagnostic and treatment services compared to their Western counterparts.

African women have little knowledge of breast cancer and experience negative socioeconomic lifestyles that affect the timely detection of breast cancer. Breast cancer awareness and knowledge are the first defenses against this disease (Nyante et al., 2014; Qian et al., 2014). The absence of a clear understanding of breast cancer's symptoms and progression and how it is detected could make it difficult to implement efforts geared toward improving the survival rate.

According to Olayide et al. (2017), the number of females in Africa with limited knowledge about breast cancer far outweighs females who possess some form of knowledge. A lack of breast cancer education presents a risk factor for the disease (Olayide et al., 2017). Both Clegg-Lampthey (2017) and Shepherd and McInerney (2006) identified addressing this inadequate knowledge of breast cancer as the best avenue toward timely detection of breast cancer and seeking medical attention. Recent researchers have found, though, that insufficient information on breast cancer symptoms and access to care still exists. This lack of information leads to fear, fatalism, and high mortality rates for breast cancer.

Breast cancer is the most prevalent cancer in Sierra Leone, accounting for up to 25% of all new cancer cases and 35% of all cancer-related deaths in Sierra Leone (WHO, 2018). In Sierra Leone, the female population with breast cancer who succumb to the disease account for about 40% (International Agency for Research on Cancer & WHO, 2018). Additionally, Sierra Leone has a high incidence of breast cancer at 43.6 per 100,000 and a mortality rate of 25.4 per 100,000 (International Agency for Research on Cancer & WHO, 2018). The exceptionally high breast cancer mortality rate in Sierra Leone indicates the need for research to understand access to breast cancer treatment for women living in Sierra Leone.

Low educational levels and poor living standards may contribute to the existing beliefs about breast cancer in Sierra Leone, where in 2015, 52% of its population were women who suffered from a lack of employment and a low education level, making them more susceptible to poverty than their male counterparts (Bayoh, 2019). In a study in Sierra Leone, 50% of the female respondents identified cancer as a fatal disease if not detected and treated early. Of the remaining half, approximately 42% outlined key symptoms of breast cancer, and less than 3% had no knowledge and awareness of breast cancer (Shepherd & McInerney, 2006). Being uninformed

about breast cancer, in addition to having insufficient financial means to seek medical attention, are barriers to early diagnosis.

There is limited literature surrounding the availability and accessibility of breast cancer diagnostic services in Sierra Leone, as well as a lack of qualified healthcare personnel who specialize in treating and managing non-communicable diseases such as cancer and a lack of available medication to treat these diseases (Witter et al., 2020). In addition, the absence of a healthcare policy prioritizing cancer puts the lives of women at risk—specifically, Sierra Leone fails to recognize breast cancer as a menace (Shepherd & McInerney, 2006). Sierra Leone also lacked appropriate radiotherapy care centers to treat breast cancer (Daramola et al., 2015; Shepherd & McInerney, 2006). Lack of access to breast cancer treatment centers, as well as a shortage of qualified healthcare staff, show that patients face challenging odds if diagnosed with breast cancer.

Conceptual Framework

Andersen and Newman's (1973) healthcare utilization model guided this study. The first factor, predisposing factors, includes the sociocultural factors of race, age, education, health beliefs, and attitude, as well as living conditions a person was exposed to before becoming sick (Andersen & Newman, 1973). The enabling factors (the second factor) look at a person's financial ability to pay for care, what care is available at a reasonable distance, and the quality of care a facility provides (Andersen & Newman, 1973). The third factor, the need factor, examines how people perceive their health status, as well as what creates a need to seek care (Andersen & Newman, 1973).

Methods

Purpose, Research Question, and Research Design

The research question for this study was:

Based on their lived experiences, what are the predisposing, enabling, and need factors of women in Sierra Leone when accessing breast cancer treatment?

Qualitative data were gathered through semi-structured interviews with 10 women in Sierra Leone who were diagnosed with breast cancer. A descriptive phenomenological tradition was used in this study to answer the research question. Developed by Husserl, descriptive phenomenology focuses on connecting the thought of one's experience (the "what") to the perception of one's experience (Sloan & Bowe, 2014).

The descriptive phenomenological approach in this study employed bracketing, which required me to forego my personal experience or any predisposition about the phenomena under study to understand how the phenomenon emulates participants rather than how I [the first author] would comprehend the phenomenon (Elkatawneh, 2016). Bracketing allowed me to set aside personal biases and rely on the raw data to describe the participants' experiences.

Participants

I recruited 10 Sierra Leonean women between the ages of 35 and 50 who resided in Freetown and the surrounding rural areas and who were diagnosed with breast cancer. Although breast cancer diagnoses in women under 40 represent only about 7% of cases worldwide (Anders et al., 2009), I chose to expand the sampling age group to 35 years of age because statistics show that most women in West Africa will have their first child by 18 (Avogo & Somefun, 2019).

I used criterion sampling for participant selection, which requires that every participant in the study share a common experience of the phenomenon being studied (Palinkas et al., 2013). The two primary criteria for inclusion in this study were that each participant must (a) fall within the preset age group of 35–50 years of age and (b) have a diagnosis of Stage I, II, III, or IV of breast cancer. I sought at least two participants from each breast cancer diagnosis stage or upon recurrence for inclusion in this study. Recruitment continued until the data saturation was reached.

Data Collection

Data were generated using in-person, semi-structured, in-depth interview questions about the participants' experiences relating to accessing breast cancer treatment. The interviews were recorded using audio equipment, and a journal was used as secondary data for data triangulation (Noble & Heale, 2019). At the end of each interview, I thanked the participant for their time and reminded them of the importance of their contribution to the study. I asked if they had any questions, provided them with my contact information should they have any follow-up questions or future participants' recommendations, and gifted them a prepaid cellphone recharge as a thank-you.

Data Analysis

I conducted a thematic data analysis guided by Braun and Clarke's (2006) six steps of inductive thematic analysis, which include data familiarization (Step 1), initial coding (Step 2), searching for themes (Step 3), reviewing the themes (Step 4), naming the themes (Step 5), and presenting the findings (Step 6). In this study, I used Steps 1–3. My reasoning follows.

Data Familiarization

Step 1 of the data analysis process was data familiarization. This step provided an overview of the interview data set (Braun & Clark, 2006). Data familiarization aims to find patterns of meaning across participant responses and interview transcripts (Braun & Clarke, 2006).

Initial Coding

In Step 2, I identified initial codes that supported the research question and the conceptual framework. Coding refers to grouping excerpts from the transcripts with similar meanings (Braun & Clarke, 2006). I assigned the same code to various excerpts that had a similar meaning.

Searching for Themes

Step 3 involved searching for themes. I reviewed the initial codes to identify related ones, categorizing them and developing themes (Braun & Clarke, 2006). Related codes were identified when the meaning of the data assigned to them converged by displaying different aspects of the same overarching idea (Braun & Clarke, 2006). I then identified categories from the converging codes. Similar categories were further refined until six major themes and seven subthemes were identified. Table 1 indicates how initial codes and categories were clustered to form themes.

Table 1. *Codes, Categories, and Themes*

Code	Categories	Theme
Education on the effect of breast cancer	Patient education	Quality of health care
Explanation of type of treatment	Adequate communication	Quality of health care
Lack of options for breast cancer treatment	Inadequate communication	Quality of health care
Type of treatment	Treatment received	Quality of health care
Church members encouragement to receive breast cancer care	Spiritual support	Social life & networks
Culture plays a role in health decision	Family & friends influence	Social life & networks
Dealing with stigmatism	Experienced stigma	Social life & networks
I survived	Spiritual support	Social life & networks
Neutral experience with breast cancer care	Family & friends influence	Social life & networks
Encouragement of family to get screening/treatment	Family & friends influence	Social life & networks
Encouragement from friends to get treatment	Family & friends influence	Social life & networks
Faith in God's healing power (prayer)	Faith in God	Social life & networks
Religion played a role in health decisions	Belief in God's healing	Social life & networks
Geographical location	Location	Sociodemographic characteristics
Marital status	Marital status	Sociodemographic characteristics
Level of Education	Education	Sociodemographic characteristics
Source of income	Income	Sociodemographic characteristics

Results

In this section, findings are presented to respond to the study research question, which explored predisposing, enabling, and need factors of women accessing breast cancer treatment in Sierra Leone. The following five themes were found to respond to the research question.

Theme 1: Attitudes and knowledge of breast cancer

Theme 2: Access to health services

Theme 3: Affordability of treatment

Theme 4: Coping with breast cancer symptoms, diagnosis, and treatment

Theme 5: Quality of healthcare

Quotations in the sections below explain and illustrate each theme.

Theme 1: Attitudes and Knowledge of Breast Cancer

Participants' attitudes and their knowledge of breast cancer were discussed in Theme 1. Knowledge of breast cancer was the first aspect explored to see what information participants learned. Two participants discussed risk factors associated with breast cancer; one was unaware, whereas the other named three risk factors.

Participant 1 indicated that they were unaware of the risk factors for breast cancer: “I do not know the reason why people get breast cancer.” Participant 2 reported that breast cancer was caused by smoking, excessive alcohol consumption, and failure to breastfeed children. The second aspect to be explored was participant knowledge of the effect of delayed breast cancer treatment. Many ($n = 5$) participants knew that delayed breast cancer treatment increased a woman’s chance of cancer death.

A summary of Theme 1 indicates that participants knew about breast cancer, and they discussed factors predisposing a woman to cancer, including smoking, excessive drinking, and failure to breastfeed. Participants were also aware of the risk of death from delayed breast cancer treatment.

Theme 2: Access to Health Services

Participants’ experiences accessing health services for breast cancer screening and treatment were discussed in Theme 2. Disclosing symptoms of breast cancer to friends, neighbors, family members, or healthcare professionals prompted them to seek screening. Participant 8 reported telling a neighbor and their mother about a lump in their breast and was encouraged to seek breast cancer screening.

Participants indicated that their choice of a healthcare facility was influenced by advice from the non-profit organization they initially sought help from ($n = 4$), family ($n = 4$), friends ($n = 2$), religious leaders ($n = 2$), community members ($n = 1$), and social media advertisements ($n = 1$). Participant 8 stated, “I chose that clinic because it is well known that this clinic is good at dealing with breast cancer. I always hear the adverts on the radio where enough women are going there.”

Support structures were vital in encouraging participants to take up breast cancer treatment. For some respondents, this meant family members, including parents, children, siblings, and extended family. For example, Participant 5 stated: “I decided (to seek treatment) because my sister advised me about this sickness.” Participant 10 noted, “My children were the ones that encouraged me to go for breast cancer treatment.” Religious leaders and individuals of similar faith were instrumental in encouraging participants to seek treatment as well. Participant 6 reported their Islamic faith leader’s advice: “My Imam talked to me and advised me to go to the treatment.”

The next aspect related to access to health services was transportation to the healthcare facility for treatment. All participants indicated that they used public transportation from their residences to the healthcare facility. Using public transportation also impacted the affordability of treatment.

Theme 3: Affordability of Treatment

The affordability of healthcare treatment is the focus of Theme 3. With regard to affordability, participants indicated they had to bear the following costs associated with breast cancer: screening, treatment, and transport costs to the treatment center. Participants also reported that the cost of treatment for breast cancer was of high concern. Affordability of treatment caused delays in seeking screening, diagnosis, and treatment for most participants.

Treatment delays of more than 1 month for cancer were prevalent for many participants ($n = 7$), ranging from 1–4 months. Six participants reported a delay in treatment and relied on financial support from friends, family, and sponsors (non-profit organizations). For instance, Participant 3 reported: “For 3 months, I had to wait until the non-profit organization found a sponsor to help pay for the treatment.”

In addition, participants reported that they also required financial support to cover living expenses during the time of illness and treatment. Participant 5 indicated she had no income since she had no energy to work: “Right now, I am not working, and I do not have a business. My family helps me with money to live because I

am not well right now, so I do not have the energy to work.” Participant 2 stated: “I know when you do this operation, you have to stay in the hospital for some time, and I would not be able to sell my market and feed my family.”

Theme 4: Coping With Breast Cancer Symptoms, Diagnosis, and Treatment

Theme 4 described participants’ experiences with a breast cancer diagnosis, treatment, and coping mechanisms as being difficult. Participants described their experiences by using the following words and phrases: “I was scared,” “stressful,” “It (diagnosis) is not true,” “discouraging,” and “disappointed.” Additionally, Participant 2 stated: “I felt like I had done something wrong, and God was punishing me.” Other participants were in denial when they received the diagnosis.

Participants also reported harrowing experiences and fears during breast cancer treatment. Most participants ($n = 7$) were afraid that cancer would lead to death. For instance, Participant 4 stated: “The doctor told me breast cancer is a sickness that kills people, and my kids are very young. I did not want to die and leave them.”

Several factors enabled the participants to cope despite the difficult experiences during diagnosis and treatment. Religion was a source of hope and strength during breast cancer treatment. The common idea among the participants was that God had the power to heal, giving them hope to endure the treatment. The next enabling factor was support from family and friends. Participant 1 noted: “I lost my hair, my family counseled me, and said: “This is a sickness for some time. It will not be like this forever.”” Participants also reported that healthcare workers were an essential support structure during breast cancer diagnosis and treatment.

Theme 5: Quality-of-Care

According to participants, the quality of health care was inconsistent, which made the quality of care a key focus of Theme 5, specifically, the breast cancer treatment plans. Participants reported having varying experiences in their treatment plans and receiving different levels of care. Participants also indicated that their relationship with healthcare providers was crucial in encouraging them to take up breast cancer screening and treatment. When seeking treatment, positive experiences with healthcare providers contributed to a good experience with breast cancer care for participants.

Participants also reported that communication about cancer treatment options from their healthcare provider was essential. Four participants stated that they were not offered treatment options. Participant 3 stated: “They told me to take chemo, but they did not give me options. They told me if I took the treatment, I would start feeling better because it was good for me.” Patient education about the treatment plan by healthcare providers was not always adequate. Participant 3 stated: “Honestly, I did not understand all about the sickness or the treatment, but the doctors went to school, and they knew when they told me to take the treatment I did.”

Discussion

Integration Into the Current Literature

The absence of a clear understanding of breast cancer’s symptoms, progression, and detection significantly affects the survival rate of the disease, so the participants’ knowledge and attitude about breast cancer was a key finding in this study. Breast cancer awareness and knowledge are considered the first defenses against the disease (Nyante et al., 2019; Qian et al., 2014).

Sliva-Dos Santos et al. (2017) stated that knowledge of early detection methods for breast cancer among African women is still low. Though research in Africa continues to demonstrate a low level of knowledge and attitudes regarding breast cancer, this study showed that some women do possess an understanding of breast cancer diagnosis and treatment.

Participants indicated that their choice of a health facility was influenced by advice from the non-profit organization from which they initially sought help, as well as family, friends, religious leaders, and community members. The Tesfaye et al. (2018) community-based, cross-sectional study identified aspects that enabled or hindered healthcare utilization where social relationships—especially with other women—were a significant predisposing factor in accessing healthcare in the case of breast cancer.

Socioeconomic factors also affected access to health care (Ward et al., 2004), as illustrated by the transportation (i.e., public transport) that all participants used from their residence to the health facility. The influences of support systems and socioeconomic factors in accessing breast cancer treatment were present in this study and confirmed the literature and the utilization of the healthcare model.

The high cost of breast cancer treatment affected access to treatment as participants required financial support. Bayoh (2019) estimated that a mammogram's cost ranged from \$50 to \$70, which most women could not afford. Although participants indicated they were worried after the breast cancer diagnosis, they did not know how they would afford the treatment.

According to Foerster et al. (2019), financial help is needed for most breast cancer treatment. Participants noted receiving financial support from nonprofit organizations, family members, friends, and neighbors. Participants also stated that they had no income source since they could not work during their illness, which made the high cost of breast cancer treatment even more of a concern. According to Shepherd and McInerney (2006), the high cost of treatment and a lack of finances contribute to avoiding treatment. In this study, delays of more than 1 month occurred before the start of cancer treatment for many ($n = 7$) participants.

Participants described how they received their initial breast cancer diagnosis, and they reported the experience of going through treatment as scary, disappointing, in denial, stressful, and discouraging. To cope with their diagnosis and treatment, participants provided the common idea that God had the power to heal, giving them hope to endure the treatment. Mehrabi et al. (2016) came to the same conclusion: Religious and spiritual beliefs were a strong coping strategy used to deal with the diagnosis of breast cancer. According to Mehrabi et al. (2016), healthcare workers need to acknowledge and consider a patient's religious and spiritual beliefs when providing care or advice on breast cancer treatment decisions. For women diagnosed with breast cancer in Sierra Leone, the diagnosis was scary, but they chose to endure surgery and chemotherapy and turn to God for strength.

Participants had varied experiences with the quality of health care for their breast cancer treatment in Sierra Leone. In this study, positive experiences with healthcare providers when seeking treatment contributed to a good experience with breast cancer care and treatment. Emphasis should be placed on the fundamental role of seeking quality detection, breast cancer care, and treatment from healthcare professionals (Clegg-Lamptey, 2017). Participants reported that the healthcare providers' patient education about the treatment plan was not always adequate. Literature showed a strong correlation between under-diagnosis and under-utilization of health care related to breast cancer and limited knowledge and awareness of breast cancer exhibited by healthcare professionals (Kantelhardt et al., 2015).

Limitations

Although I invested sufficient time to familiarize myself with the study setting and participants, telephonic interviews acted as a barrier to observing and interpreting participants' body language, which would have

conveyed hidden information. Through body language, I would have observed the participant's willingness to share personal information and determine whether there was more information than what was being shared. Therefore, I solely relied on the participants' verbal responses, since all interviews were conducted by phone; conducting face-to-face interviews was a challenge due to the COVID-19 pandemic.

Implications for Social Change

Positive social change can be ensured through education, the promotion of social structures, and the support and encouragement from healthcare workers. The presence of social structures makes it possible for individuals to disclose any symptoms or anomalies they might observe or discover during a self-examination. The disclosure can prompt individuals to seek treatment or undergo screening, thereby potentially minimizing the effects of breast cancer. The findings of this study showed that information and advice about breast cancer treatment can be shared through personal relationships when healthcare needs arise. This setup for information sharing can facilitate accessing breast cancer treatment by allowing a friend or family member to be accompanied to the same hospital for breast cancer screening.

Conclusion

This study's findings demonstrate that a woman's knowledge of breast cancer can ensure that she will seek treatment; the significance of support structures in accessing health services and coping with the diagnosis and treatment; the need to provide financial support for breast cancer diagnosis and treatment; and the need to enhance the quality of breast cancer care in Sierra Leone. These findings can be used by health systems, the government, and faith-based organizations to enhance healthcare services for women in the diagnosis and treatment of breast cancer.

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