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Lived experiences of breast cancer survivors at the General Hospital Ilorin Kwara State Northcentral, Nigeria

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Abstract

Breast cancer is a debilitating disease with severe physical, psychological, social, and financial consequences. A phenomenological approach was used in this study to investigate the lived experience of twenty-one (21) breast cancer survivors who were purposefully chosen until saturation was reached. Tesch's data analysis method was employed. The participants' ages ranged from 30 to 70 years old, with the majority (16 out of 21; 76.2%) diagnosed within the previous two years and many describing the treatment experience as unpleasant and painful, with numerous side effects including nausea, insomnia, sore throat, and hair loss. The majority of participants (16 of 21; 76.2%) reported financial hardship as a result of treatment costs. The disease's socioeconomic impact includes poor human relations, negative perceptions of breast cancer diagnosis, poor sociocultural roles, and negative effects on patients' livelihood. Breast cancer counseling should be expanded, government and other stakeholders should also consider subsidized breast cancer management. (*Afr J Reprod Health* 2023; 27[6s]: 90-98).

Keywords: Breast cancer survivors, quality of life, lived experience, coping strategies

Résumé

Le cancer du sein est une maladie débilante aux conséquences physiques, psychologiques, sociales et financières graves. Une approche phénoménologique a été utilisée dans cette étude pour étudier l'expérience vécue de vingt et une (21) survivantes du cancer du sein qui ont été délibérément choisies jusqu'à ce que la saturation soit atteinte. La méthode d'analyse des données de Tesch a été employée. L'âge des participants variait de 30 à 70 ans, la majorité (16 sur 21; 76,2 %) ayant reçu un diagnostic au cours des deux années précédentes et beaucoup décrivant l'expérience de traitement comme désagréable et douloureuse, avec de nombreux effets secondaires, notamment nausées, insomnie, mal de gorge et perte de cheveux. La majorité des participants (16 sur 21; 76,2 %) ont signalé des difficultés financières en raison des coûts de traitement. L'impact socio-économique de la maladie comprend de mauvaises relations humaines, des perceptions négatives du diagnostic du cancer du sein, des rôles socioculturels médiocres et des effets négatifs sur les moyens de subsistance des patientes. Les conseils sur le cancer du sein devraient être élargis, le gouvernement et les autres parties prenantes devraient également envisager une prise en charge subventionnée du cancer du sein. (*Afr J Reprod Health* 2023; 27[6s]: 90-98).

Mots-clés: Survivantes du cancer du sein, qualité de vie, expérience vécue, stratégies d'adaptation

Introduction

Breast cancer has been termed the most commonly occurring cancer in women worldwide and the most prevailing cancer overall¹⁻³. Breast cancer represented 24.45% of all cancer types in Nigeria⁴. Breast cancer is a disease that causes significant physical, emotional, social, and economic difficulties for those who are affected and their families. Furthermore, women newly diagnosed with breast cancer get emotional, humiliated, and

disheartened as a result of societal attitudes toward them⁶. Research has revealed that women who are breast cancer survivors may face a variety of long-term physical changes, symptoms, and therapeutic side effects⁷. Treatment of breast cancer may cause physical changes in appearance, scars, hair loss, menopausal symptoms, reproductive issues, lymphedema, muscular pains and weight loss or gain⁸⁻¹⁰. Also, most individuals that have undergone breast cancer treatment have also reported anorexia, decreased libido, fatigue, sleep

disturbances, poor concentration, low energy and cough^{11,12}.

In addition to physical challenges, breast cancer survivors may have to struggle to execute basic personal care tasks such as shaving, applying cosmetics, and clothing themselves¹³. Women diagnosed with breast cancer may also undergo other psychological experiences that are debilitating such as the experience of fear of death or abandonment, distress, high levels of emotional and social problems, as well as feelings of hopelessness, worthlessness, doom, and guilt^{6,10}. Similarly, breast cancer survivors may also encounter embittered social life experiences especially, from the family members and the community. Their lives are reported to be characterized with altered relationships and social hardship, inability to perform societal and family functions^{9,14}. The role performance of women diagnosed with breast cancer is also severely altered, as inconveniences from the treatment (surgery, chemotherapy or radiation therapy) hinders them from performing their designated roles in the family¹⁴. Individuals living with breast cancer may also experience financial drain and hardship due to the high cost of accessing treatment services. Moreover, most of the treatment services are not covered by health insurance⁷.

Several types of cancer management practices have been developed to assist patients with cancer to enable them live better and longer, while coping strategies have been suggested to improve psychosocial and physical well-being of breast cancer patients. Adaptive coping behaviors such as positive reframing, acceptance, and seeking emotional support have been found in clinical studies to improve quality of life and mood in patients^{15,16}. Hence, this study explored the lived experience of breast cancer patients at the General Hospital, Ilorin, Kwara State, Nigeria.

Methods

Research design, setting and population

The research design was phenomenological and contextual using qualitative strategy. This study was conducted at the surgical out-patient clinic of the General Hospital Ilorin, Kwara State, Nigeria. Breast cancer patients receiving treatment in the

selected hospital were the target population of the study. Clinic records for October, 2021 showed that 12 patients with breast cancer visited the surgical outpatient clinic.

The inclusion criteria for the study were patients with breast cancer, age 30 and above, have completed the initial treatment (extended survivorship), fully completed treatment (permanent survivorship) and willing to participate in the study.

Sample size and technique

Sample size for the study was determined by data saturation while paying attention to the scope of the study, quality of data gotten, nature of the research topic, the study design and the presence of shadow data. Data saturation was achieved when 18 participants had been interviewed. However, 3 more interviews were conducted to ensure referential adequacy. This was done to ensure that there are no new or lost information.

Purposive sampling technique was utilized to select participants who fit the inclusion criteria and were willing to participate in the study.

Instrument and data collection

A probe was used to collect data on the experiences of breast cancer patients. Data was collected from participants between December 2021 and February 2022. Interviews were conducted at the surgical out-patient department consulting room of General Hospital Ilorin Kwara State on Tuesdays. Each interview lasted for about 30-40 minutes per participant. The interviews were written and audio-recorded with participants' permission and field notes were taken to complement the information recorded. Participants were assured that their identity will not be released at any point of the research process. Also, the researchers meet with the participants to discuss the content of the study, this allowed for questions to be asked, clarifications made, and feedback solicited prior to continuing with the interview process. Once all questions had been answered and the participants agreed to move forward with the interview.

After participants signed written informed consent form, a time was agreed upon by both parties in which to complete the interview.

Data analysis

Data was analyzed according to Tesch's content analysis approach using open coding.¹⁷ Themes were generated from the data obtained from interview with participants. Furthermore, sub-categories were generated from the themes. The quantitative data collected for the study were firstly checked for errors, cleaned and analyzed using the Statistical Package for Social Sciences (SPSS), version 25. Frequencies and percentages were calculated for demographic characteristics and responses of study participants.

Trustworthiness

To ensure trustworthiness, strategies including using only participants that fit the inclusion criteria, prolonged engagement with the data during data analysis, presenting direct quotations from the participants, peer examination, interpersonal relationship and trust building were employed.

Ethical considerations

Prior to the commencement of the study ethical approval was obtained from the research and Ethics Committee of General Hospital Ilorin (GHI/ADM/134/VOL.II/ 394). Written informed consent was obtained from the participants before the interview commenced and permission was taken from the participants to record their responses during the interview in order to ensure proper data analysis. Participants were informed that they were not compelled to participate in the study and their refusal to participate will not put them at any disadvantage.

Results

Demographic profile

The socio-demographic profile of participants is displayed in Table 1. Majority (38.1%) of the participants were aged 61-70 years. In terms of occupation, 42.9% (9 of 21) were civil servants. Almost all (81%) of the participants were married and 42.9% of them were educated up to a tertiary level.

Table 1: Socio-Demographic profile of participants (n=21)

Variables		Frequency	Percentage
Age	31-40	6	28.6
	41-50	6	28.6
	51-60	1	4.8
	61-70	8	38.1
Gender	Female	21	100.0
	Full housewife	1	4.8
Occupation			42
	Civil servant	9	.9
	Artisan	1	4.8
	Unemployed	0	0
	Private organization	1	4.8
	Others	9	42.9
	Marital status	Single	1
	Married	17	81.0
	Divorced	0	0.0
	Widow	3	14.2
	Separated	0	0.0
Educational Level	Non-formal	2	9.5
	Primary	4	19.0
	Secondary	6	28.6
	Tertiary	9	42.9

Medical history of the participants

Details of the medical history of participants are summarized in Table 2.

Table 2: Medical history of the participants

Variables	Categories	Frequency n =21	Percentage
Family history of breast cancer	Yes	3	14.3
	No	18	85.7
Duration of living with breast cancer	Less than 2years	16	76.2
	2-4years	5	23.8
Type of treatments	Chemotherapy	17	81.0
	Radiotherapy	Nil	0.00
	Mastectomy and chemotherapy	4	19.0

Majority (85.7%) of the respondents denied having a family history of breast cancer. As regards duration of living with breast cancer, 16 of 21 (76.2%) of the participants had been living with

breast cancer for less than 2 years while 23.8% have been living with breast cancer for a duration of 2-4 years. Also, majority (81%) of the participants were undergoing chemotherapy.

Qualitative findings

The qualitative findings from the study are presented according to the themes and categories generated from the data (Table 3). Each theme is described with its corresponding category.

Table 3: Main themes and categories generated from the data

S/N	Main Themes	Categories
1	Treatment Experience	General experience Financial implication of treatment
2	Quality of Life	Physical changes caused by treatment Effect on functioning and social relationship Reaction when informed of breast cancer
3	Psychological impact	Psychological distress
4	Coping Strategies	Emotional focused coping (family support, social support, and distraction such as music "Gist" or chatting) Problem focused coping (Endurance, spiritual intervention, dietary advice, medical advice)

Theme 1: Treatment experience

General experience

Majority (20 of 21; 95.2%) of the participants described the treatment experience as unpalatable and painful, with many associated side effects like nausea, insomnia, sore throat, and loss of hair. Also, some of the participants' reported experience of frequent stooling, and restlessness. Some of the observed responses are as follows:

"Well... actually the experience is not easy because taking chemo.... hmm... the first one that I took, it was so terrible although I did not vomit but I used to feel as if I will vomit. I lost my appetite, I could not drink water, I preferred drinking hot water" (P8, 46 years, Married)

"It was a very bad experience that I had, at times I used to feel weak and dizzy any time I took the treatment and at times I feel like vomiting. So, it gives me a very bad experience" (P 10, 34 years, Married). Since, despite most of the participants reporting negative experiences they had as a result of the chemotherapy treatment, a participant associated her chemotherapy sessions with positive experience such as a relief from the pains.

"Before I started chemotherapy, the affected breast (left) was swollen and I do experience severe pain in it. But immediately I started chemotherapy, I was greatly relieved. My pains and some of the discomfort subsided" (P19, 47 years, Married)

Financial implication of treatment

In response to the question "how has breast cancer treatment affected your income?" Almost all (19 of 21; 90.4%) of the participants reported that breast cancer treatment has affected their income greatly. Participants reported spending large portion of their income or saving on their treatment.

"Most of the money I was using for treatment every three weeks affected my business. I spent close to twenty-five thousand naira on the treatment every 3 weeks. I was nearly started begging for alms. I was supported by my siblings. Presently I don't have a penny for subsequent chemotherapy" (P1, 66 years, widow)

"It really affected my finances, I cannot be recounting my ordeal, I look for money from any avenue in order to continue with my treatment. Even to carry out test it is difficult, but I believe that everything would be better" (P3, 65 years, Married)

"Yes, it has affected the family finance badly. I cannot run my business at the moment which means we only have my husband's income for the family. So, I took unexpected loan for the treatment and am paying back without making profits on it" (P8, 46 years, Married)

Theme 2: Quality of life

Physical changes caused by breast cancer treatment

Majority of the participants (17 of 21; 81.0%) indicated that they were healthy and strong before

the breast cancer disease condition. However, after the diagnosis, there were reports of noticeable loss in weight and strength. This could be indicator for a shift in body image pre, intra and post treatment. Some responses are:

"I was strong and healthy before the sickness, after all these treatments I became lean because I was not eating well, though I was not too fat before, but my stature was very alright compared to now" (P2, 64 years, Widow)

"I was not too fat, but I was bigger than this and I was very pretty looking then Sometimes, I looked at my old album and I could see how chemotherapy had affected my life. I refused to have my picture taken during treatment. Oh, I missed my long hair" (P5, 32 years, Married)

"I lost my hair completely, but I was encouraged that after the sickness my hair would grow again ...my skin at times becomes black. I have to buy some creams to mix up with the cream I'm using because it used to be so black." (P6, 62 years, Married)

Alteration in sleeping pattern

It was also found that one of the changes experienced during treatment was alteration in sleep pattern. About one-fourth (6 of 21; 28.6%) of the participants complained that they could not sleep at night due to body pains, restlessness, and anxiety.

"I just started treatment last week, I could not sleep throughout the night and even the following day I could not sleep also, my eyes were opened till daybreak and I was feeling uncomfortable but I hope to endure for the period of treatment, God help me" (P7, 32 years, Married)

Alternation in body image

Participants reported some changes in their body functioning which later affected or impacted on their body image. Example of such changes includes change in movement or speed, facial appearance, body weakness and scar formation:

"Since I started treatment, I have lost weight, I have been very light while walking, then it makes me to look older than my age The chemotherapy experience was really tough. I was weak... I couldn't move or walk. I was depending on my

sister to help me and take care of my children" (P19, 47 years, Married)

"I cannot move fast again that's why I said I'm looking older than my age. I can't walk fast as I used to do. I'm a bit somehow sluggish; and my hairs are going off" (P8, 46 years, Married)

Effect on functionality and social relationship

This sub-theme explains how their experiences have affected their functionality and their social relationship with friends, family, neighbors, and others. Majority (16 of 21; 76.2%) of the participants affirmed that their functionality as daughter, sister, mother, wife, friend, career women or members of the society had been affected by the nature of their health condition. Some responses are as follows:

"It brings fear; I don't have time to cater for my children. I cannot provide for my children. I failed in my responsibilities to them. it makes me to be sad and discouraged... (sobbing)" (P21, 64 years Married)

"The weakness often experiences each time of treatment could not allow me to do home chores. I am a teacher I cannot go to school because of my physical changes, and it affects me a lot, though I am being paid my monthly salary but there are some benefits I am deprived of, such as gifts from parents and lesson money (allowance) shared by participating teachers" (P10, 34 years, Married)

Reaction when informed of breast cancer diagnosis

While some accepted their fate, others reported showing signs of lingering on the denial and depression stages for quite some time. A few (3 of 21; 14.3%) of the participants reported being calm, nine (9 of 21; 42.9%) of them reported feeling of sadness, three (3 of 21; 14.3%) reported acceptance of fate almost immediately after they were diagnosed while (5 of 21%) participants reported that they wept and were embittered.

"When I was first diagnosed, I felt so sad because it's a bad ailment. Whenever I'm alone I used to think a lot and cry a lot too. I felt like it was the end of the world for me" (P10, 34years, Married)

"I accept my fate, I accepted God's verdict because I don't know how it happened to me but I know God

will see me through. I believe he is aware of my condition and there is nothing God cannot do” (P3, 65 years, Married)

Theme 3: Psychological impact of breast cancer diagnosis and treatment

Psychological distress

In response to the question “How has been your well-being since you are diagnosed with breast cancer”, more than half (12 of 21; 57.1%) of the participants reported that the diagnosis and treatment procedure of breast cancer has made them experience low mood or signs of depression. They also indicated that sometimes the thought of a possible loss of life makes them feel helpless and sad. Some also experience signs of anxiety for varied reasons. Those that reported experiencing anxiety symptoms were almost half (9 of 21; 42.9%) of the participants, while 6 participants (28.6%) said that they experienced a combination of stress, low mood, and anxiety symptoms simultaneously.

“Psychologically at times I will go into depression, I can use the whole day thinking about my health status. At times I would be thinking that one day I would die just like that, and this scares me. I put all my faith in God because I know my God is able” (P9, 62 years, Married)

“I am depressed. Yes, I am, because I was told that breast cancer used to kill its victims. Although some people counsel me to be strong and not allow it to weigh me down and I should not kill myself with worries and anxieties, that people do survive it. I have fear that I might not escape the death” (P17, 34 years, Married)

Theme 4: Coping strategies

The study also examined the coping strategies employed by the participant. It was noted that majority (15 of 21; 71.5%) of the participants made use of spiritual interventions such as prayers, attending church programs, receiving spiritual counseling, use of holy water and anointing oil. Supports from the family members were found to be adopted by more than half (13 of 21; 61.9%) of the participants. Dietary restrictions and adherence

to medical advice were employed by seven of the participants. About one-third (6 of 21; 28.5%) of the participants mentioned the use of self-encouragement as their adopted coping strategy while four of the participants indicated endurance and tolerance as method of coping strategy used. Exercise, strolling, and adequate rest were also employed by three of the participants (14.2%). Two of the participants used social support in form of chatting and spending quality time with friends as a means of coping. Distraction as a coping strategy such as watching of television and listening to music were each used by participants to take their mind of their health condition.

Emotional focused coping

The varieties of emotion focused coping strategies employed by the breast cancer survivors include family support, social support in form of gist or chatting with friends, and distraction such as listening to music. Some responses include:

“My family members used to come around me during weekends to make me happy; when they come, they make me to laugh and forget my sorrows; some of my friends do visit me too.” (P19, 47 years, Married)

“I do exercise like walking round my compound...I do a little exercise not too stressful, walking round the compound. And I visit my sister at least once in a month while she would come to my house at least once in a week.” (P13, 43 years, Married)

Problem focused coping

The problem focused coping strategies employed by the breast cancer survivors were; spiritual intervention which was employed by the majority (71.5%) of the participants, followed by adhering to dietary advice (28.6%), and adherence to medical advice, and taking adequate rest.

“I put my trust and faith in Jesus Christ. I look up to Jesus on the cross of Calvary. I do not believe in any other thing so that I would not be discouraged. I don't discuss my health issue with anybody except this interview I granted you” (P1, 66 years, Widow)

“I have been using the drugs am given, if it finishes, I will make sure I buy another one of the same

products. Since I was strongly advised not to stop the medication” (P4. 69 years, Widow)

Discussion

The study was conducted to explore the lived experiences of breast cancer. Only three of the twenty-one participants (3 of 21) said they had a family history of breast cancer. Research findings revealed that although around 70% of breast cancers are not hereditary, family history is a substantial risk factor for the illness¹⁸. This indicates that the closer the familial relationship with the family who has had breast cancer in the past, the higher the chances of developing the condition¹⁸. Breast cancer treatment like many other cancers has been associated with side effects such as excruciating pain, nausea, vomiting, insomnia, sore throat and frequent stooling¹⁹⁻²¹. In agreement to the findings of this study breast cancer survivors go through physical, social, economic, and psychological challenges such as; fatigue, osteoporosis, early menopause, traumatic stress, distress, depression, fear of recurrence, low libido and infertility.

In this study survivors mentioned that they noted marked differences in their physical appearance after the diagnosis of breast cancer and whilst receiving treatment. Good quality of life has been linked to positive self-esteem which can be reduced by the physical alterations caused by breast cancer^{22,23}. Research has shown that individuals with breast cancer experience altered perception of their body image, leading to self-consciousness in their physical appearance¹⁴.

Cancer-related fatigue is described as a persistent, subjective experience of exhaustion that interferes with normal functioning and is caused by cancer or cancer therapy²⁴. Majority of the participants complained of fatigue caused by the illness and its treatment. This finding was similar to previous studies^{20,21,23,24}.

Survivors reported that they were unable to actively perform their roles as a member of a family unit or society. The illness also prevented them from maintaining social relationships with friends. This is in unison with findings that suggests that the physical and bodily changes experienced by patients with breast cancer prevents them from

functioning in their roles and responsibility, and leads to a change of lifestyle^{14,25,26}. Also, majority of the participants reported having poor relationship with family and friends after the diagnosis of breast cancer. Similar findings were noted in previous studies where participants noted that relationship between spouse or families were affected by issues such as poor communication and caregiver’s burden which in turn bred negative emotions and strained relationships^{14,15,19}.

In this study, it was found that the breast cancer survivors displayed different emotional behaviors such as; sadness, acceptance of fate, bitterness and crying when informed about their health status. The predominantly negative emotions could be linked to the fact that in Sub-Saharan Africa, late diagnosis or detection is most common and is often associated with poor prognosis such as death. It is easy to suffice that when individuals are faced with the diagnosis, they take it as a death sentence. Similar findings were also noted in a study conducted in Ghana where participants resorted in emotional breakdown upon diagnosis of breast cancer²⁷.

Some participants in this study reported having difficulties concentrating properly on tasks they could do with ease previously. This is in tandem with research which reported that women with breast cancer experience some impairment such as trouble with their short-term memory, poor concentration, and attention²⁸. These changes could be as a result of fatigue, and poor sleep which naturally affects memory, concentration and attention^{28,29}.

Breast cancer survivors in this study experienced financial burden due to breast cancer treatment. The financial hardship caused by treatment costs could potentially lead to poor quality of life as many survivors have mentioned that they had to exhaust their savings in order to procure treatment. Furthermore, job loss due to ill health also prevents survivors from having a stable source of income^{14,20}. The result is in agreement with a study in Kenya, where participants established that most households in Kenya cannot afford the financial demands of cancer treatment with their current income hence, they usually resort to selling of their properties, fundraising and borrowing after all their savings have been

consumed³⁰. However, this is contrary to another study conducted on Danish breast cancer patients, where treatment of breast cancer had only a minor effect on the family income even three years after diagnosis³¹.

The reason for this might be the government health insurance scheme and high compensation of welfare of cancer patient in Denmark which are non-existent in Nigeria health sector.

The emotional focused coping strategies used by breast cancer survivors were discovered to be support from the family; distraction techniques such as gist or chatting with friends and listening to music or singing. Breast cancer patients can adopt coping strategies such as: emotion focused strategies; strategies focused on relieving the emotions associated with the problem, and strategies focused on making meaning of the situation^{19,20,23}. However, the flip side of using predominantly emotion-focused coping is that it brings immediate and temporal relief, but does not take the problem away. Subsequently, the most predominant problem focused coping strategy utilized by participants in this study was spiritual intervention. Findings suggest that patients who formed physical and spiritual resilience to deal with their condition and accept their diagnosis maintained an optimistic attitude and anticipation to participate in their medical decision in order to fight against the disease¹⁴. Furthermore, a problem-focused strategy can assist survivors in managing specific difficulties by attempting to actively adjust the problematic conditions that cause pain, such as searching for information and resolving outstanding problems, among others²⁰.

Limitation

Despite the fact that the study's goals were met, it may still have some limitations because the purposive sampling technique used in this study is frequently linked to responder bias. Also, the study was contextual thus, the findings may not be generalised to other areas.

Conclusion

Findings from this study showed that participants found the general treatment experienced to be

unpalatable, with side effect like nausea, insomnia, sore throat and frequent stooling. Also, the participants experienced a low quality of life with a wide range of physical, psycho-social and financial issues.

Recommendations

Counseling should be provided to patients and families prior to and throughout each appointment to increase social support and treatment adherence. Health care facilities should also take the necessary steps to alleviate any pain and discomfort that patients with breast cancer may experience while undergoing treatment. Finally, the government and other stakeholders should provide financial support for treatment options such as surgery, chemotherapy, and radiation.

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