



Lived Experiences of Women Who are Long-Term Breast Cancer Survivors in Lagos State, Nigeria

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Abstract

Introduction Breast cancer (BrCa) survivors have increased globally with the continued improvement in cancer management. Despite this, there are significant issues experienced by these women during BrCa treatment. It is therefore important to explore the unique experiences of women who are long-term BrCa survivors. **Objective:** This study aimed to explore the lived experiences of 22 women who are long-term BrCa survivors in Lagos State, Nigeria. **Methodology:** A phenomenological approach was used to carry out one-on-one unstructured interviews with the participants, who were selected purposively using a snowball sampling technique. The interviews were analysed using Nvivo 14 to identify themes and subthemes. **Result:** The participants were 5 years or more, post-treatment for BrCa, with an average age of 43 years at the time of diagnosis. Four themes emerged: (i) In the very beginning, (ii) Going through difficult times, (iii) Becoming a survivor, and (iv) Living as a survivor. Sixteen subthemes were also identified. The participants had a self-identification pattern as survivors, and an interpretation of their experiences which were influenced by a cascade of factors including spirituality, family support, financial burden, counselling and emotional support which differs from one participant to the other. **CONCLUSION:** The study highlights the unique experiences of long-term BrCa survivors and the challenges they face on their journey to survivorship. Early diagnosis, inner strength, family support, faith, and quality treatment were identified as important factors in fighting cancer and reaching survivorship. The findings have implications for nurses and other healthcare providers, who should acknowledge the distinct experiences of these women to provide appropriate support and care.

Keywords: Breast Cancer, Lived Experience, Survivorship, Long-term breast cancer survivors

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Introduction

Breast cancer (BrCa) is the most common cancer among women worldwide (Chiarani, Chularee & White, 2020). Advancements in biomedical technology and medical care have led to improved survival rates for BrCa patients, especially those who are diagnosed early (World Cancer Research Fund International, 2020). However, 2,261,419 new cases of BrCa were diagnosed among women globally in 2020, making it the most common cancer worldwide, accounting for 12.5% of

new cancer cases (World Cancer Research Fund International, 2020). In Africa, BrCa is the most common cancer, accounting for 25.8% of new cancer cases (World Cancer Research Fund International, 2020). In Nigeria, BrCa is the most common cancer among women, accounting for 11.6% of new cancer cases and 6.6% of all cancer-related deaths (Adeniji, *et al.*, 2020). Unfortunately, many cases are diagnosed at advanced stages, with 39.6% at the regional (stage III) and 16.9% at the distant (stage IV) stage, and the

median age at diagnosis being 49 years (Adeniji, *et al.*, 2020). Survivors of BrCa are those who have been diagnosed with this disease and survived after treatment. This term is socially constructed and is considered more acceptable than the traditional term "Cancer Patients," which can connote victimization and self-pity (Costa *et al.*, 2019). While survival rates have improved in developed countries due to improved treatment modalities, they remain poor in developing countries (Mohammed *et al.*, 2018). The 5-year survival rate after diagnosis ranges from more than 90% in high-income countries to 66% in India and 40% in South Africa (Bjerkeset *et al.*, 2020). In Nigeria, the disease-free survival at 2 and 5 years was 66.6% and 60.3%, respectively (Musa, *et al.*, 2021). For many cancer patients, receiving a cancer diagnosis and undergoing treatment can be an extremely stressful experience that can leave individuals vulnerable to long-lasting negative psychological outcomes. This is due in part to the increasing incidence of cancer and the overstressing of already limited healthcare resources and equipment (Nwozichi *et al.*, 2017). This experience as explained by several scholars based on caring theories that care providers and Patients live with the experiences even after the treatment (Nwozichi, 2019). Although BrCa survivors of different ages might experience common treatment side effects, younger women reported low levels of quality of life (Ngan *et al.*, 2022), including psychological distress, sexual functioning and body image concerns, as well as relationship problems (Rosenberg *et al.*, 2022).

BrCa survivors may also face negative social experiences, particularly from family members and the larger community. Their lives are marked by altered relationships and social suffering, as well as a failure to fulfil societal and familial duties (Almegewly, 2017). Gorman (2018) and Almegewly (2018) stated that BrCa patients struggle to recognize and capitalize on business opportunities, complete unfinished business with important people in their lives, and spend time with

loved ones talking about past pleasures and tragedies, which can be therapeutic for some patients and family members. Another element of the story of BrCa women is their economic circumstances. BrCa survivors' fiscal experiences may not all be positive. Many of them may suffer from financial depletion, inability to carry out enterprises, and a lack of access to other economic rights due to aches, chronic sickness, and the financial consequences of medical expenses. Many BrCa patients have experienced financial difficulties at one point or another.

Earlier studies have found that BrCa women use various coping techniques, including decision-making, to confront their life-threatening disease and the lengthy and rigorous therapy (Pérez *et al.*, 2014). Emotional support was the most commonly used coping style among newly diagnosed cancer patients. However, when people are diagnosed with a terminal illness, they often engage in denial, which can be beneficial or detrimental to their health. Denial is the first step in dealing with a life-threatening illness, allowing individuals to adjust to the situation (Calderon *et al.*, 2021; Nipp *et al.*, 2016).

Several cancer treatment clinics have been established to help BrCa patients lead longer and healthier lives. Moreover, coping strategies have been proposed to improve BrCa patients' physical and psychosocial well-being (Nwozichi *et al.*, 2017). Clinically, adaptive coping behaviours such as acceptance, seeking emotional support, and positive reframing have been found to enhance quality of life and happiness in patients who correctly recognize their poor prognosis (Nipp *et al.*, 2017). Additionally, various coping strategies were used to manage the diagnosis and subsequent challenges, including dietary adjustments, exercise, meditation, spirituality, and cognitive strategies (Levesque *et al.*, 2020).

As BrCa survival rates have improved, the discourse surrounding the disease has become more complex. In reference to the Western

cultural understandings of BrCa, the discourse of survivorship may replace the beliefs and fears of cancer as a deadly disease (Yufe *et al.*, 2021). The shift in cancer representation, using traditional metaphors such as 'cancer victim' or 'cancer patient', indicates that the latter is often being replaced by the term 'cancer survivor'. These messages about cancer survivorship could likely influence the process of making sense of cancer. However, the phenomenological literature on BrCa often describes the formation of personal and life events without referencing the survivors' stories and their interpretation of life after surviving BrCa (Haiderali *et al.*, 2021).

Method:

A qualitative approach was employed in this study, specifically, a phenomenological study design was used to explore the lived experiences of breast cancer (BrCa) survivors in Lagos State, Nigeria. The phenomenological method involves the use of interviews, observations, and surveys to gather information and describe how a participant experiences a specific event (Naderifar *et al.*, 2017). The participants included a sample of women who are long-term survivors of BrCa, and snowball sampling was used to recruit participants who met the inclusion criteria. The sample size was 22, determined based on the attainment of saturation. Unstructured interviews lasting 40-60 minutes with open-ended questions were conducted to collect data from participants in a manner that allowed them to narrate their stories without being influenced. All interviews were recorded with a device after obtaining permission from the participants, who were required to fill out consent forms. Nvivo 14 qualitative software was used to analyze the data from this study. Participants' descriptions were read and reread in their entirety to obtain a better understanding of the whole. Statements,

including phrases and sentences directly related to the phenomenon being studied, were separated into cohesive meaning units to enhance manageability. Words containing the same or similar thoughts were eliminated. Finally, greater understanding was articulated by extracting the meanings from the phrases and statements.

Rigour

The principles of the hermeneutic arc proposed by Ricoeur (1991) were followed in this study, which includes concepts of naive reading, structural analysis, and in-depth interpretation of meaning. According to Ricoeur (1991), interpretation moves forward from naive understanding, where the interpreter has a superficial grasp of the whole of the text, to deeper understanding, where the interpreter understands the parts of the text in relation to the whole and the whole of the text in relation to its parts. In this way, Ricoeur's theory of interpretation provides researchers with a method of developing inter-subjective knowledge. To ensure accuracy, verbatim transcription of interview data was carried out.

Ethical Approval

Ethical approval was obtained from the Babcock University Health Research Ethics Committee (BUHREC)

Findings

The majority (86.4%) of the women were younger than 50 years. Except for one participant who did not know the stage of her BrCa at the time of diagnosis, most of the women (77.3%) reported being diagnosed with stage II BrCa. The shortest length of time that a participant had been a BrCa survivor was 5 years, while some had been survivors for up to seven years. A summary of the demographic characteristics of the participants is presented in Table 1.

Table 1: Participants’ Demographic Characteristics

Participant code	Age in years	Year of Diagnosis	Stage at diagnosis	Year of treatment completion	Educational Qualification	Marital Status
Participant O	30	2015	2	2017	BSc	Married
Participant J	27	2015	2	2016	BSc	Single
Participant E	49	2016	3	2017	HND	Married
Participant W	41	2015	2	2017	BSc	Married
Participant A	38	2014	2	2016	BSc	Married
Participant L	49	2015	2	2017	BEdu	Married
Participant Q	36	2016	2	2017	HND	Married
Participant K	47	2015	Unsure	2017	MSc	Married
Participant V	36	2016	2 grade 1	2018	MSc	Married
Participant U	47	2017	2	2018	BEdu	Married
Participant T	40	2016	2	2018	HND	Married
Participant Z	39	2015	2	2016	MSc	Married
Participant S	61	2017	3	2018	SSCE	Widowed
Participant I	49	2016	3	2017	BSc	Married
Participant B	50	2017	2	2018	BSc	Married
Participant C	35	2016	2	2018	BSc	Married
Participant D	31	2015	2	2017	MSc	Married
Participant F	45	2015	2	2016	SSCE	Divorced
Participant G	49	2017	2	2018	BSc	Married
Participant H	50	2017	2	2017	BSC	Married
Participant M	39	2016	2	2017	BSc	Married
Participant N	49	2015	2	2017	SSCE	Married

N=22

Themes and Sub-Themes

The interview provided a medium for the participants to share their lived experiences, and four themes emerged from the interview transcripts as root codes. Twenty sub-themes were identified from the derived concepts. These themes include: (i) In the Beginning, (ii)

Going Through Difficult Times, (iii) Becoming a Survivor, and (iv) Living as a Survivor. These themes were carefully analyzed to explain the lived experiences the participants had during their survivorship journey. The themes and sub-themes are presented in Table 2.

Table 2: Themes and Sub-themes of the Study

Themes	Sub-themes
Experience at the beginning of the journey	Detection and diagnosis Being distraught Accepting treatment
Getting through difficult times	Finding comfort in religion Joining BrCa support groups Harnessing family support Being resilient
Becoming a survivor	Dealing with treatment side-effects Reality of financial toxicity Coping with fear of the unknown Adhering to orthodox treatment Overcoming self-esteem issues
Living as a survivor	Making Significant life changes Identifying as a survivor Managing anxiety and fear daily A second chance at life.

Theme1

Experience at the Beginning of the Journey

The importance of understanding the survivorship journey of the participants cannot be overstated, as it provides detailed insights into the unique experiences shared by the survivors. The "In the very beginning" theme indicates the starting point of how these women were able to navigate through the difficult times of their lives. This theme is further categorized into three sub-themes: detection and diagnosis, being distressed, and accepting treatment.

(a) Detection and diagnosis

The participants in this study described their experiences of detecting the lump in their breasts and seeking a medical diagnosis. Commonly, they found the lump while performing self-examination during showering, and sought medical advice for confirmation. The doctors then performed a check and ordered tests such as mammogram and biopsy for diagnosis. One participant shared her disbelief upon discovering the

lump as she never thought that a breastfeeding woman could have BrCa.

"I woke up one morning and noticed a tiny lump in my left breast. I thought it was milk accumulation because I was actively breastfeeding. A few weeks again I checked because my mind had gotten carried away even. I noticed the same lump and I decided to speak out and look for help. I was curious. Although I had heard about BrCa, but I would never have believed that was me and cancer then. I would never have believed it! my dear that is how my battle with cancer started o" (Participant C).

The trend of discovery started with lump detection in the bathroom for most participants. Another participant described how a diagnosis was reached was for her.

"I discovered the lump in my bathroom, that was early 2015 and after a month or two, I decided to check up on my doctor, then it was like a hard peanut. It was very little but hard

to touch. I would be the one to tell the doctor that it is there because you will have to massage. He now sent me for different tests and scans and I came out that there was indeed a lump there and there were clusters of malignant cells, it was suspicious..." (Participant J).

One participant described the need for her to get a second opinion outside of Nigeria because the lump was not detected on palpation.

"The doctor touched it and did all the examination, and he said, "Oh, there is nothing". But of course, I felt I should get a second opinion. So, I travelled out of the country and saw a general practitioner and he too said he couldn't really tell if there was anything but he would send me for a test. So he sent me for a mammogram and ultrasound. When I did the mammogram was where the lady said that I shouldn't wear my clothes yet that she wanted me to do a biopsy. When I did the ultrasound was when they told me they noticed two spots under my armpit and my left breast so they need to do a biopsy to check what it is" (Participant O).

(b) Being distraught

This sub-theme conceptualized the significant reactions of women after being told they had cancer. All of the participants stated that they experienced unpleasant feelings, including "shock," "anxiety," "fright," "hopelessness," "emptiness," "worry," "sadness," "fear" and "uncertainty." The emotional impact of receiving a breast cancer diagnosis was significant for most of the participants. Despite some having a premonition due to self-detection of a breast lump, they were not emotionally prepared for the news. Most of the women reported being continually crying and depressed, with many describing the diagnosis as devastating, and shocking, and asking why me. Others expressed worry about their mortality, and anger, or walked aimlessly. This period was a dark and challenging time for most of the participants. One participant

expressed the feeling as a very bad experience that she would not wish on her enemy.

"Kaiiii! I felt bad, I was crying, I keep asking God why me. Kaiiii! If not for the intervention of Dr. xxxx, I would have killed myself" (Participant L).

For another participant, it was shock and fear. *"I was shocked because at the stage they divulged the news to me, it was already at stage two. So I was shocked and so fearful because whenever you hear cancer, it's death that people will be thinking about. So I was so fearful"* (Participant E).

The emotional impact of receiving a diagnosis of BrCa was significant for the participants, as expressed in various ways. Uncontrollable crying was a common response, and several participants likened the confirmation of their diagnosis to receiving a death sentence.

"I felt very bad. I broke into tears. After I left the hospital I was thinking and thinking on the road that I was almost hit by a car. Nobody receives cancer news and is happy, even the strongest of all. It is like a death sentence. That was exactly how I felt. I was shattered and kept on wondering what I must have done wrong to deserve this. My mental state was affected. My work was affected in spite of being a government worker. I was depressed for a very long time. But thank be to God" (Participant Z)

(c) Accepting treatment

In the face of their cancer diagnosis, the participants were initially distraught but gradually accepted their situation and sought treatment. They became more determined to tackle the disease and sought help and information from various sources, including literature and medical professionals. This increased knowledge helped them to make informed decisions about their treatment options. For instance, one participant recounted how she made a well-thought-out decision to undergo treatment after gathering sufficient information on BrCa and the treatment options available.

"It was when I now went back to the clinic, they told me to come back in two weeks and that was when I was told I had cancer...then he said I needed to do a bone scan and another scan just to check it hadn't spread because it was already in my lymph nodes. Like I said it was just too much of information for me and they gave a lot of literature to take home..." (Participant K)

One of the participants who accepted treatment recounted doubting the treatment because she believed it was a means for the doctors to extort her.

"...and the treatment started... I was full of doubt. But I was like let's see what they are doing or trying to say. In fact, at a time I said maybe these people just wanted to collect money from me, they thought I looked like someone that has money to give and all that until they sent me to the oncology department (Participant J).

For other participants, there was no clear description of how they came to accept the BrCa treatment, but they mentioned just summoning the courage to go ahead. One participant described just encouraging herself that every problem has a solution.

"I remember it was on a Tuesday. I cried all through the night. I was around (referring to the hospital) till 6.30 p.m. I cried.... and cried in the doctor's office before going home...all through. After that, I felt that when there is a problem there must be a solution..." (Participant U).

THEME 2

Getting through difficult times

The participants defined going through difficult times as encountering life circumstances and treatment-related effects that have significant physical, emotional, social, and economic effects. Physically, all the participants experienced signs and symptoms while under the treatment. The side effects of their treatments included pain, physical weakness, burning, nausea, vomiting, black nail, and hair loss. Psychological

manifestations include depression, distress and anxiety. The participants described what it feels like to go through BrCa treatment and how they were able to weather the storm during this period. Thus, this theme was further categorized into four sub-themes: (i) Being resilient, (ii) Finding comfort in religion, (iii) Joining BrCa support groups, and (iv) Harnessing family support - which described their ways of coping.

Being resilient

The participants in this study reported that they had become stronger individuals, both physically and mentally, after going through the traumatic experiences of BrCa diagnosis and treatment. They used terms such as "winner," "passed," "rebirth," and "beat it" to describe their feelings of triumph over the disease. For instance, they acknowledged how challenging it was to navigate the period of diagnosis and treatment, but they remained determined to overcome the difficulties by choosing to live, especially for their young children. One participant highlighted how her resilience grew stronger when she thought of her young children.

"I have three young children and I want to stay alive for them and myself... Nobody wants to die, nobody knows what will happen the next minute...that's why I give every day the things I can give" (Participant V).

(a) Finding comfort in religion

Religion was identified as a significant source of comfort for many of the participants. While each participant had their own way of describing the comfort they received through religion, a common aspect was access to prayer support. In some instances, they also received financial and emotional support from fellow church members and clergy. The participants found inner strength and encouragement to persevere through their treatment side effects through their religious beliefs. One participant described the role of religion as faith-strengthening, stating that it provided her with the strength to cope with her illness.

"It depends on the aspect you see the leadership of where you are worshipping. My own helped me because it made my faith stronger. As well I got support from my church. There is some support they gave although not big but it still counts for me" (Participant Q).

The participant in question attributed her survival to her personal relationship with God, as she had not experienced any symptoms of BrCa. This participant regarded her survival as a result of divine intervention.

"So, for me, because we are very religious people, what I will say religion played for me is that, and this is what I share with people. I am not a churchgoer, I hardly go to church, but I am a believer, and I don't joke with my prayers but I don't go to fellowships. The role it played for me was that I knew that God was the one that made me" (Participant K).

The participants reported that they learned to accept life and became mentally stronger individuals by sheer force of will. They described techniques such as "putting the mind at ease," "focusing on the moment," and "having faith in God" as helpful in their journey. Additionally, many participants expressed how prayer support from friends, family, and religious communities helped them navigate through the difficult times. One participant described how prayers helped her through the challenging times of her treatment, stating that "prayers are a source of comfort and strength that can help one to overcome anything."

"I have a lot of faith in God. I prayed and got prayer support too, I however didn't joke with my orthodox medicines because I knew there was a place for prayers and another place for medical science. They both worked hand-in-hand for me" (Participant U).

(c) Joining BrCa support group

One participant stated that the primary reason for joining a BrCa support group was to share experiences with others who had gone through

similar situations. The participant found the support group to be a valuable source of emotional support and felt that connecting with others who had faced similar challenges was helpful in navigating the difficult experience of BrCa treatment.

"Yes, I belong to One in Lagos, they just do counselling, but what I really needed was financial support because the illness made me poor" (Participant V).

One participant stated that the primary reason for joining a BrCa support group was to share experiences with others who had gone through similar situations. The participant found the support group to be a valuable source of emotional support and felt that connecting with others who had faced similar challenges was helpful in navigating the difficult experience of BrCa treatment.

"Yes, I am on this platform (RFPA). We discuss about the cancer, whatever is bothering us and people that have gone through it to share their experience and encourage us" (Participant E).

The amount of help gotten from support groups was limitless as one participant described.

"Yes, and they were very very helpful. If I had any challenge I said it out and they helped me." (Participant L).

(d) Harnessing family support

In the context of cancer and its treatment, patients often experience various unpleasant symptoms and situations that render them unable to work and earn funds to finance their treatment. Therefore, most patients rely heavily on family and relatives for financial support. However, support from family and relatives goes beyond financial aid and also extends to physical and emotional support. While many of the participants in this study found comfort in religion and encouragement from support groups, they also enjoyed significant support from family members including spouses, children, and siblings, as

well as friends. For instance, one participant described having all the family support she needed throughout the course of her treatment and post-treatment.

"...my friends and family were there for me. They tried and over tried. They would say "Ino [not real name] eat whatever you like, don't say because you have cancer, whatever you feel you want to buy or eat, please eat it; we can do that for you". Someone will give me money and will "please call on me for anything. Not because I gave you this one, if there's any need for anything please let me know". So that's why I didn't solicit for any group. I was even richer than I was before. (Participant J).

Even when I was going to market, though I was making it but I discovered that after my treatment and everything, I could still afford half a million naira. I will just sit down like this and someone will just call me and give me money. I thank God for that. Send me your account number. How are you managing? This and that.." (Participant W).

THEME 3 **Becoming a Survivor**

This theme in the study of breast cancer (BrCa) survivors featured three sub-themes that aimed to harness the lived stories and experiences of the participants. The sub-themes were developed to explain how the participants dealt with various challenges during their treatment and aftercare. The first sub-theme focused on the participants' approach to dealing with the challenges of their treatment and financial difficulties. The second sub-theme described how the participants dealt with their fears and self-esteem issues during their cancer journey. The final sub-theme highlighted how the participants' adherence to orthodox treatment helped their survival. The sub-themes were presented to provide a comprehensive understanding of the challenges and experiences faced by the participants, as well as their resilience and coping mechanisms.

a. Dealing with treatment side-effects

Treatment regimes for breast cancer consist basically of surgery, radiation therapy, chemotherapy, hormonal therapy, and targeted therapy (Gek *et al.* 2020). These treatment options have been claimed to be effective. However, many of these therapies cause immediate, residual, latent, or late side effects (ElSharkawy and ElSharkawy. 2014) Treatment-related side effects are mostly acute, but some can be long-term (Fallowfield, 2015). This is very similar to the finding in this study, where participants reported they dealt with the downside of chemotherapy (acute side effect) including nausea, vomiting, hair loss and change in skin colour, amenorrhea, and low libido.

"My greatest challenge is the crisis of the chemo. It was not palatable at all. I thank God though, that despite all the crisis. I took 10 rounds of chemo. I first did four then later my doctor said he is going to increase it and that one is more powerful than that one. So the four chemo I had taken before they need to be changed and it is more powerful than the one I have been taking. So I took it and also did my radiotherapy" (Participant L).

The long-term effect of BrCa treatment was also felt by these participants as reported by them.

A participant had to deal with bone issues which may be one of the long-term complications of BrCa treatment. Another recounted how she made use of a prosthesis to cover up for the loss of her breast.

"...After my mastectomy, I got my prosthetics, when I pack myself, nobody knows. During the chemo I lost all my hair, my complexion changed, and I had to buy different kinds of wigs, short, long, curly etc. I have regained everything I lost though but each time I remember, it's not a good experience" (Participant U)

b. financial challenges

The participants in this study experienced various challenges related to their cancer

treatment and the management of its side effects, and they often relied on the support of others to help them cope. Financial difficulties were a common challenge, with some participants receiving support from family and friends, support groups, or non-governmental organizations recommended by their healthcare providers. Others had to pay for treatment out of pocket or use their savings. The love that participants recalled most vividly was the kindness and support they received from healthcare facilities, support agencies, and individuals who helped them finance their treatment.

"The money for the treatment was never my challenge... Someone will give me money and will say, "Please call on me for anything. Not because I gave you this one, if there's any need for anything please let me know". So that's why I didn't solicit for any group. I was even richer than I was before. Even when I was going to market, though I was making it but I discovered that after my treatment and everything, I could still afford half a million naira. I will just sit down like this and someone will just call me and give me money. I thank God for that. Send me your account number. How are you managing? This and that. I really thank God for that. Before I met you today my brother just called and I told him I wanted to chicken and he sent me fifteen thousand naira. I really thank God" (Participant W).

c. Coping with fear and self-esteem issues

In the face of the challenges experienced by participants, fear was identified as a major concern for some, particularly related to the unknown and treatment outcomes. Coping strategies for fear included avoidance and resignation to fate, while others relied on their faith in a higher power to overcome their fears. One participant also described struggling with self-esteem but received support through counselling services to maintain a positive self-image. This experience was remembered as a particularly helpful and positive one.

"My biggest challenge during the treatment was getting people not to call me. I didn't want anybody to project their fear. I don't want that "eyah" stuff, I am not that kind of person. And I didn't want any pity party or anyone talking to me without facts. You know how people can be, they will just say "Ha, this one happened to that one etc". That was my biggest challenge so I would not pick up any call if I saw it because I knew that I had to face my treatment, I knew I had to be in a good place. It is very important to be in a good place and I didn't want any naysayers or anybody to tell me chemo this, chemo that etc. For me that was the biggest challenge" (Participant K).

"Initially, it was the fear of the unknown...it's that fear of the unknown. What will come out of this? Am I going to make it?... I decided that let me go to these people who are helping me in prayers...So, the fear, the fear, there was a time that I was actually fearful. Very very fearful. Fear of cancer, because this cancer is not something like malaria. It is a deadly disease and it is life-threatening. So I was afraid. Little by little God is taking Control" (Participant W).

d. Adhering to orthodox treatment

Participants expressed their gratitude for the encouragement they received, which helped them adhere to and complete their orthodox treatment throughout their journey with BrCa. Interestingly, none of the participants mentioned the use of traditional medicine either as a sole treatment or in combination with orthodox medicine. In fact, many of the participants encouraged other women with BrCa to prioritize orthodox medicine for their treatment. The participants explained that the various forms of support they received during treatment helped them to adhere to the months of orthodox treatment required for BrCa. Although one participant identified funding as a challenge, she was also quick to note that the lack of it has caused many people to drop out of treatment or not seek orthodox treatment altogether.

"People that have received treatment should do their treatment very well. They shouldn't skip their treatment. Thankfully I didn't listen to those who said chemotherapy is bad, else I wouldn't be where I am today. My doctor used to encourage me to concentrate on my treatment" (Participant L).

"The main important thing is to listen to your doctor, follow their instruction" (Participant A).

"I have three young children and I want to stay alive for them and myself... Nobody wants to die, nobody knows what will happen the next minute...that's why I give every day the things I can give" (Participant V).

THEME 4

Living as a survivor

In the context of breast cancer (BrCa) survivorship, the realities of living as a survivor involve finding ways to adjust to the daily demands of survivorship. For the participants in this study, the daily struggle begins with identifying as a survivor and continues with managing the anxiety and fear that arise daily. To adjust to life as a survivor, all the participants had to let go of their old lifestyle and embrace a new one by making significant lifestyle changes.

(a) Identifying as a survivor

In this study, the participants' understanding of survivorship varied, which influenced their willingness to identify as survivors or make their survivorship public. Fear of stigmatization from society was also a reason for some participants' hesitation to identify as survivors. However, some participants identified as survivors and found purpose in their survivorship by creating online support groups. These online groups provided a source of love and care for participants, as evidenced by one participant's success in using them.

Ha! It depends on the gathering o. You know the environment we are in. Even when I want to start my treatment I know some people that tell me that chemo can kill you and that I

should not do it o. so it depends on the gathering. I don't like being stigmatized. if it is outside, some people can start saying rubbish about someone outside" (Participant E).

(b) Managing anxiety and fear daily

In the context of BrCa survivorship, participants in this study revealed that dealing with the possibility of cancer recurrence was a significant challenge. However, through their determination and resilience, most of the participants were able to overcome this fear by blocking, avoiding or managing it. Notably, participants reported that this daily struggle eventually faded away as they passed the estimated years for BrCa recurrence.

"I don't give in to fear as regards breast cancer. I have other aspects of my life and projects that I focus on and dwell on, thereby giving no room for fear. Yes! I have built myself up like that... Naturally, Yes, But I don't dwell on it. You know we live in a world full of negativity and these are being broadcast on a day-to-day basis. But I don't allow that to get to me. In the same way, there are negativities, there is positivity" (Participant I).

(c) Making significant lifestyle changes

The participants in this study reported that their experience of surviving BrCa required making significant lifestyle changes. Specifically, they had to modify their diet, engage in regular exercise, and prioritize their mental and emotional health. The participants believed that these changes were critical to maintaining their health and preventing cancer recurrence. As they navigated this new way of life, the participants sought support from loved ones to find peace and cope with the stress and anxiety that often accompany survivorship. One participant emphatically said, thus:

"It has to change. Before cancer comes and after cancer, your body is not the same and it can never be the same. Cancer is a chronic

illness that brings changes in the body, even in the cells of the body. My diet will change. My body has gone through a lot, so I don't need to overstress my body. So I need my time to rest. I need to adhere to my check-up routine and maintain a balanced diet and healthy life. I eat a balance diet and exercise. I am always happy and have a positive mindset and I maintain good relationships with people" (Participant Q).

Discussion

In this study, the focus was on women who had been diagnosed and completed treatment for breast cancer (BrCa) for up to five years or more. The women shared their lived experiences as long-term BrCa survivors. From the study, it was shown that the majority (86.4%) of the women were younger than 50, with the youngest being 27 years old and the oldest being diagnosed at 61 years old. The mean age of the respondents was 42 years, and most (77.3%) of the women reported being diagnosed with stage II BrCa at the time of diagnosis. Some of the participants have been living as BrCa survivors for about seven years, with the shortest being five years of survivorship. However, the experiences shared by these women were different, depending on their socio-demographic characteristics such as marital status, highest educational level, occupation, stage of cancer at the time of diagnosis, and years of survivorship. The information provided based on their experiences was analyzed using a qualitative phenomenological approach.

The initial signs of change noticed by the participants were often accompanied by minimal pain and fear of a cancer diagnosis. Consequently, many of the women were initially reluctant to explore further to confirm their suspicions about changes in their breast(s). This finding is similar to the results of Benson *et al.* (2020), who identified delayed presentation to healthcare as a coping strategy adopted by some women with breast cancer to avoid potentially distressing news about their health status. In Nigeria, women tend to present for diagnosis and treatment at

a more advanced stage of breast cancer compared to women in developed countries, resulting in higher mortality rates from breast cancer in Nigeria (Olayide *et al.*, 2017). However, the findings of this study suggest that despite initial fear and hesitation, the participants gathered the courage to seek necessary medical investigations for early diagnosis. Early diagnosis was found to be a significant factor contributing to their survival, as the majority of the participants were diagnosed with stage II breast cancer.

In this study, immediate commencement of treatment was reported among the participants. The women embraced all the treatment options made available, including chemotherapy, surgery, and radiotherapy, and most had more than one type of treatment. During treatment, financial, emotional, and physical concerns were the topmost challenges reported. All of the participants underwent a mastectomy, which had a negative impact on their physical appearance and social acceptance. While the women felt a sense of hope related to being alive, mastectomy elicited negative emotions and thoughts for many of them due to the loss of a breast. The women expressed worries about their self-image, but this feeling was masked by the supportive use of prostheses and padding to achieve a feminine look. This finding is consistent with the study by Sema and Ayla (2016), which suggested that mastectomy as a surgical treatment for breast cancer may negatively affect a woman's body image and self-image.

The second theme of the current study was "Getting through difficult times." The finding of this study is consistent with prior research on cancer patients (Dsouza *et al.*, 2018; McConkey & Holborn, 2018; Smit *et al.*, 2019), which reported shock, disbelief, anger, fear, sadness, and anxiety as the most common reactions of patients with cancer. The diagnosis and treatment of cancer can have a significant impact on an individual's quality of life. Cancer is often perceived as an

incurable disease that leads to a painful shortened life span and eventual death, making it a major stressor in the lives of those affected. Having cancer can be incredibly jarring and can turn a patient's world upside down. This theme is comprised of three sub-themes: finding comfort in religion, joining BrCa support groups, and harnessing family support. These themes and subthemes describe what it is like to go through BrCa treatment and the difficulties that patients must overcome during this experience.

In this subtheme, "Finding comfort in religion," the participants recounted how they found comfort in religion and spirituality during their BrCa treatment. There was a common variable among all the participants, which was access to prayer support, financial assistance, and emotional support from fellow religious group members and clergymen. These findings are consistent with prior studies by Benson *et al.* (2020), which reported that religious coping was one of the most commonly adopted active coping strategies by BrCa survivors. While the participants could not physically explain how religion helped them cope, they reported that their experiences of body weakness, fatigue, immobility, nausea, vomiting, hair loss, and change did not frighten them because of the inner strength and encouragement they received from their faith. This finding was from the character and belief perspectives of the participants which were further described as *hope-giving and faith-strengthening*.

Secondly, joining BrCa support groups was another way the participants found peace and persevered through difficult times in the journey through survivorship. Most of the participants in this study joined BrCa support groups and all recounted that they enjoyed the experience of sharing with others about BrCa. This experience by many was tagged under the sub-theme "*Joining BrCa support groups*". The demand for financial support was among the top reasons behind the poor treatment and early screening for BrCa in most recent research findings, particularly in developing

countries, due to the constant increase in exchange rates and economic meltdown not in favour of developing countries. This has increased the disease burden due to the cost of drugs and treatment of breast cancer (Dsouza *et al.*, 2018).

In addition, family played a vital role in helping the participants get through difficult times in the course of treating BrCa (*Harnessing of family support*) in this study, the participants mentioned that the roles played by their spouses, children, and siblings can not be over-emphasised. Apart from the comfort found in religion and encouragement from support groups, they also enjoyed robust support from family members. The report from a study also supported the fact that the significance of family support cannot be overemphasized. The study explained that patients described how their families helped them forge ahead in their cancer care journey. This support came in the form of providing funds for treatment and other emotional benefits (Nwozichi *et al.*; 2020). According to (Annina & Josef; 2019), family and friends may assist cancer patients in processing their cancer-related traumatic experiences and may be involved in meaning finding, efforts that could lead to improved interpersonal relationships. Therefore, family members provide a wide range of support to enable the BrCa survivor to scale through these difficulties that come with In this study, financial support was found to be a crucial means through which BrCa survivors can share their burden of the disease. For instance, whenever people gifted them money as support, it went a long way in reducing the stress of having to work and earn such an amount, which in turn could be channelled into their treatment (Bosire *et al.*, 2020). This finding is similar to the experiences recounted by most of the participants in this study who depended on family members for care or financial assistance to lessen the disease burden. It is important to note that financial support is essential in ensuring that BrCa patients have access to the necessary treatment options, particularly in developing

countries where the cost of drugs and treatment is high (Dsouza *et al.*, 2018). The financial burden of cancer care can have negative implications for the quality of life of patients, and therefore, there is a need for interventions to alleviate this burden, particularly for those who lack adequate financial resources.

Becoming a survivor is an important milestone for breast cancer (BrCa) patients. While many women are relieved to have finished with treatment, they often worry about the cancer returning. This study showed participants were faced with various challenges, including; physical, psychological, social and financial burdens. Overcoming these challenges played a crucial role in their survival. According to Laura *et al.* (2021), the high survival rate of BrCa is achieved at the expense of multiple treatment modalities, such as surgery, chemotherapy, radiotherapy, and hormone therapy, which can have significant side effects and impact patients' quality of life. Additionally, uncertainty surrounding prognosis can affect patients psychologically, impacting their ability to tolerate treatment and affecting their social relationships and self-esteem. Furthermore, Rahimeh *et al.* (2023) reported on the practical needs of BrCa survivors, including financial distress, healthcare costs, life insurance, and managing problems at work or in education. The majority of participants in their study reported issues with work or education, such as making plans for activities, dressing, and bathing. However, all participants reported financial problems.

In this study, the majority of participants sought information on secondary prevention of BrCa to prevent recurrence and improve their overall health. They primarily employed lifestyle modifications and routine medical checkups. Making positive lifestyle changes can also have psychological benefits for BrCa survivors by empowering them to overcome the feeling of loss of control. Some participants reported starting their own gardens to enable them to eat healthy meals,

while others recounted avoiding or reducing their intake of junk food. This was achieved by reading literature on healthy eating habits, which provided information on replacing junk food with healthier options such as vegetables and grains. Other lifestyle changes included engaging in regular exercise.

None of the participants in the study reported having a history of smoking or drinking alcohol. However, physical activity was reported as a major lifestyle factor, which has a robust effect on breast cancer outcomes. It is recommended that engaging in 150 minutes of moderate to vigorous exercise or 75 minutes of vigorous exercise per week, along with two to three weekly sessions of strength training, can help reduce the risk of breast cancer recurrence and mortality (Julia & Ellen, 2017).

On the other hand, although, the participants in this study would not like to identify as a survivor in public, they still make an effort to look out for others by expressing their stories to help healthy people and people recently diagnosed with BrCa navigate treatment and survive BrCa. This is discussed by advocating for early testing, activating faith, treatment resolution, and for people living with BrCa to protect their sanity. When breast cancer is identified early, the treatment is highly effective, achieving survival probabilities of 90% or higher (HPA, 2022; World Health Organization, 2021). HPA (2022) reported that the five-year survival rate for Stage zero breast cancer was 97.7%, Stage I breast cancer was 95.7%, Stage II breast cancer was 89.1%, Stage III breast cancer was 72.3%, and Stage IV breast cancer was 25.7%. In addition, the result from (Fan-Ko Sun *et al.*; 2023) path analysis indicated that individuals with religious beliefs and less disease severity have better social functioning and good social functioning reduces the level of depression.

The diagnosis and treatment of BrCa is very cumbersome and challenging. That is why it is recommended to support people diagnosed with this deadly disease. This can be achieved

through BrCa survivors reaching out to people to create awareness of the disease. Referencing their own BrCa journey experience, the participants of this study have the understanding that BrCa can occur in women at a young age and in some men. They recommend early testing without any fear, shame, or guilt. They were quick to note that the difference between a BrCa survivor and someone who did not survive BrCa mostly depends on how early it was detected. Early-stage cancer detection could reduce breast cancer death rates significantly in the long term (wang, 2017). This study also suggested that women should consistently do a self-breast examination because early detection saves lives. The American Cancer Society (2013), recommended three screening options: mammography, clinical breast examination (CBE), and breast self-examination (BSE). Despite the fact that mammography is the most effective tool for early breast cancer detection, it is prohibitively expensive in developing nations. Therefore a lot of citizens from these countries such as Nigeria rely on BSE.. Furthermore, Kenzudin, (2022) agreed that the impact of early detection of breast cancer on morbidity and mortality is significant. If this cancer was detected early, a 95% chance of survival could be achieved.

On the issue of spirituality, due to the religious stance of the participants in this study, activating and putting one's hope in a supreme being (God) was a common advice that the BrCa Survivor in this study had to give to people who have been recently diagnosed with BrCa. This method they believed worked for them during their journey to Survivorship and claim would work for anyone on the road to BrCa Survivorship. Spirituality is an important resource at the time of diagnosis and treatment decisions(Diva *et al.*,2021). This is in tandem with the option of the participants in this study stating the importance of trusting God through the journey. Furthermore, participants reported that spirituality was a positive coping

strategy, providing support, comfort, and hope throughout the journey.

The participants in this study also encouraged people to be compliant with their treatment regimen. The participants considered being resolute about treatment including the type of treatment and following through with the treatment an important thing for BrCa patients. They explained that focusing on the treatment provided by the doctor and adhering to the regimen despite the side effects and other challenges usually results in beating BrCa. One participant implored those in treatment not to skip their treatment. The use of herbal treatment was also discouraged

Finally, it was suggested that people diagnosed with BrCa should as much as possible, protect their sanity as this is very crucial to surviving BrCa. The participants in this study explained that fear kills than cancer and allowing negative people in one's circle while on the road to surviving BrCa can be detrimental to the journey. One participant explicitly stated that the people in one's circle while on this journey can determine how much fear you can have and another participant encouraged other women to be in a happy place always because it aids healing. Meanwhile, for another participant, breaking the culture of silence when people with BrCa need help is important as much as believing they can overcome the disease.

Conclusion

The conclusion of the study suggests that survivorship is a subjective process that involves both positive and negative life changes. BrCa survivors must possess inner strength and resilience to overcome cancer, with the support of family, religion, and comprehensive treatment plans. The study also highlights the importance of staying positive, making dietary changes, exercising, and going for regular medical checkups for BrCa survivors. Finally, the article concludes that BrCa survivors can reach out to BrCa patients in the treatment phase by sharing their experiences and offering hope to them.

Overall, this study provides valuable insights into the challenges faced by BrCa survivors in defining themselves as survivors and offers recommendations for managing survivorship.

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