



# Challenges Experienced by Breast Cancer Survivors and Thrivers

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## LEARNING OBJECTIVES STATEMENT

By the end of reading this paper, you will be able to:

- Communicate the side effects of breast cancer treatments
- Reach out to those struggling with their body image after a breast cancer diagnosis
- Inform others about the power of advocacy that can help breast cancer survivors and thrivers

## INTRODUCTION

Discussions surrounding breast cancer survivors and thrivers often include the topic “quality of life.” Although the extent of daily tasks and requirements may look different for these individuals, there are numerous similarities that both groups experience and need to be addressed. Understanding the needs of breast cancer survivors and thrivers can drastically improve the care and support they receive from their networks and the healthcare system. This analysis will examine three points. First, the challenges of the physical side effects of breast cancer treatment. Second, the changes in mental health pertaining to body image and self-confidence. Finally, the power of advocacy to eradicate barriers among breast cancer survivors and thrivers.

## SIDE EFFECTS OF BREAST CANCER TREATMENT

When women are diagnosed with breast cancer, they can experience early menopause, osteoporosis, and loss of estrogen due to treatment. When discussing these concerns with Black women, many were unaware of the extent of the side effects on their bodies. Depending on the cancer treatment, some effects may occur immediately or years later (Mollica and Newman 336).

### Chemotherapy

Chemotherapy is a standard treatment for breast cancer. While many women succeed with this treatment, they may find they have a lower bone mineral density (BMD) once treatment is complete (Tigerlily Foundation). These changes are likely due to chemotherapy's effects on the ovaries and organs that produce estrogen. Chemotherapy is associated with ovarian dysfunction. Thus, menopause can begin and arrive earlier in premenopausal women who received chemotherapy treatments. During menopause estrogen levels are reduced, which leads to an increase in the bone breakdown and decreased bone density (Tigerlily Foundation). Chemotherapy effects include fatigue, neuropathy, cognitive impairment often called "chemobrain," heart failure, liver problems, and infertility (Aziz and Rowland 797; Mollica and Newman 336). Quality of life is significantly impacted when breast cancer survivors and thrivers experience one or a combination of these side effects after chemotherapy (Aziz and Rowland 790). In addition, surviving or living with cancer brings about debilitating or life-threatening health concerns that must be addressed (Aziz and Rowland 790). Some types of chemotherapy, specifically anthracycline-based chemotherapies like doxorubicin, may cause heart disease. This is very important since 1) women who have breast cancer are more likely to develop heart disease than women without breast cancer, and 2) older women with breast cancer are more likely to succumb to heart problems than they are to breast cancer.

### Radiation

*Radiation therapy* is a cancer treatment that uses high radiation doses directly onto the cancerous tumor (Tigerlily Foundation). Undergoing radiation therapy can take a toll on bone health by damaging soft-tissue components of the bone, including blood vessels. As a result, radiation may lead to bone loss in the area where radiation therapy was given, as well as an increased fracture risk over time. In addition to bone loss, things like fatigue, pain, and immobility are the long-term physical effects of radiation treatment (Mollica and Newman 336). These concerns drastically impact the quality of life of survivors and thrivers. Issues pertaining to immobility can be distressing for Black women as they try to manage their numerous roles and responsibilities, often requiring them to be constantly on the move. Other health concerns can become more apparent when survivors and thrivers struggle with mobility. Less physical activity can lead to not meeting the suggested amount of daily or weekly exercise (Weathers et al. 175). There is a possibility that breast cancer survivors and thrivers will develop a type of heart disease due to the lack of physical activity (Aziz and Rowland 791).

### Endocrine Therapy

*Endocrine therapy* is a daily oral medication for women diagnosed with estrogen receptor-positive breast cancer (Johns Hopkins School of Medicine). This medication is typically prescribed after the completion of all other treatments. The differences in prescription occur if someone is premenopausal or postmenopausal (Johns Hopkins School of Medicine). The side effects of endocrine therapy, also known as hormone therapy, are menopausal symptoms like hot flashes, night sweats, vaginal dryness, reduced sex drive, and mood changes (Breast Cancer Now). The reality of endocrine and hormone therapy includes more intense menopause symptoms. Other side effects experienced when taking hormone-based drugs include joint or muscle pain, headaches, reduced bone health, and extreme

fatigue (Breast Cancer Now). Weight gain is also a challenging side effect for patients, especially when individuals struggle to find a good balance of diet and exercise that works for them (Cancer Research UK). Although endocrine therapy is a popular medication, patients must understand the side effects and ways to mitigate them when they arise.

## MENTAL STRUGGLES AFTER A BREAST CANCER DIAGNOSIS

Black women breast cancer survivors and thrivers emphasize that the need to communicate with others is integral to thriving post-diagnosis. Healthy communication with romantic partners, family members, primary care providers, or other peer-support networks can improve one's mental state (Mollica and Newman 335). Historically, the Black community has been reluctant to share their thoughts or emotions with professionals like therapists, psychologists, or counselors. With many individuals not trusting institutions to assist them, several Black community members refuse to seek help. Some individuals choose to shame others for wanting to speak with a therapist. As seeking therapy continues to be destigmatized, Black women breast cancer survivors and thrivers recommend finding a therapist as soon as possible after receiving their diagnosis. Meeting with non-bias professionals can help patients create a comfortable plan and mentally prepare for challenges (Mollica and Newman 338).

A breast cancer diagnosis can lead to low self-esteem and confidence in one's appearance. Research Morales-Sanchez et al. (7) illustrates that body image confidence is another struggle for Black women breast cancer survivors and thrivers. Learning how to navigate a new normal with little to no hair, scars, or significant surgical changes such as mastectomies is tough. In addition, due to the association between breasts and femininity, breast cancer survivors and thrivers may feel like their bodies do not fit the stereotypical body that Black women have (Morales-Sanchez et al. 2). To help overcome negative thoughts and emotions about one's physical appearance, Black women breast cancer survivors and thrivers advocate for individuals to get creative with new looks. For example, some recommend experimenting with micro-bladed eyebrows, nipple and areola tattooing, or even trying headwraps or fun wigs. For some, these techniques help restore and boost confidence after experiencing physical changes to their body.

## THE POWER OF ADVOCACY

The breast cancer journey can bring anxiety, depression, and shame, among many others (Trindade et al. 887). Many individuals become vulnerable to feeling isolated when they reduce contact with their oncology team and primary medical providers (Castonguay et al. 467). Feelings of isolation in breast cancer can be overwhelming (Felder et al. 7). If one does not have an outlet to release these feelings, they can negatively impact one's outlook on life, mental state, and physical activity. One of the ways breast cancer survivors and thrivers can learn to manage these feelings is by connecting with others diagnosed with breast cancer. Comradery can turn into finding one's tribe and community of support. Some breast cancer survivors and thrivers decide to make advocacy a part of their mission and find organizations to amplify their voices.

Connecting with organizations like the Tigerlily Foundation creates another pathway for individuals to uplift one another and promote breast cancer awareness. There is something extraordinary about finding support during the highs and lows of the breast cancer experience. It requires being adaptable and, at times, vulnerable with friends and family. Creating a solid support system can help make the experience a bit easier to navigate.

## CONCLUSION

Conversations like these are crucial to understanding the quality of life for cancer survivors and thrivers. Giving individuals time to process and find what works best is essential. Many things will have to be learned, but new opportunities and doors await on the other side of a breast cancer diagnosis. Breast cancer survivors and thrivers must find support that benefits their particular needs.

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# Patient Perspective for Paper 4

## Quality of Life in Long-term Survivorship

Interviewer: Virginia Leach

Patient Expert: Busola Patrick

In addition to the Inclusion Pledge Paper Series, breast cancer warriors have been asked to describe their experience with each topic. Patient advocacy-based organizations should want to increase the literature of breast cancer research and create space for patients to share their experience, inspire others, and build a community of love and support.

**Interviewer:** What has been the biggest lesson and/or milestone since entering the survivorship phase of cancer?

**Busola:** The biggest lesson I have learned is that survivorship, is part of the cancer journey, as a blessing. Not everyone is fortunate to enter this phase. In this phase, there are still diagnostic tests being conducted at intervals; medications that I still take some with undesirable side effects; a care team that is still concerned about the totality of my health with checks on other body systems to ensure recurrence does not occur. There truly is life outside of cancer (the initial diagnosis), which you experience in this phase. The goal is to pursue your dreams despite your journey.

**Interviewer:** What has been the most significant learning curve for you in this experience?

**Busola:** I have learned to cope with my anxiety regarding recurrence. Each time I show up for a follow-up visit with my oncologist or review tests/labs with my primary care physician, I get very anxious about what else might be lurking beneath the surface. Staying informed has helped me to deal with this in my survivorship years. I have kept abreast of breast cancer research primarily within the African/African American community, focusing on lifestyle changes, knowing one's family history, engaging with my care team, and knowing the fine details of my insurance coverage. Music and dance have also helped me cope with experiencing life in this phase.

**Interviewer:** When you reflect on your breast cancer diagnosis to where you are today, what about you has changed the most?

**Busola:** My outlook on life has changed since my diagnosis. My motto is Live, Love, Learn, and Let Go! I live a full life, enjoying every day with my family and friends. I love deeply and demonstrate it through my actions. I'm learning about my entire body. I'm learning about the healthcare systems and the barriers that exist. I'm learning about other people's journeys (Thrivers like myself) and how they stay afloat using different techniques. I'm learning to embrace my speak-up culture- my voice is my weapon. I'm also letting go of all past hurt that has kept me stagnant. Forgiveness is truly a gift from God, and I have formed a habit of addressing issues as they arise and not allowing them to fester. This has really helped me with my relationships.

**Interviewer:** Do you think there are any challenges or barriers that arise in the survivorship phase of breast cancer? If so, what are they?

**Busola:** There are physical and emotional challenges that are associated with survivorship. Hot flashes, weight gain, decreased libido and occasional mood swings are some of the things I am currently experiencing.

**Interviewer:** How do you find encouragement to keep thinking positively and moving forward on the most challenging days?

**Busola:** My faith and my family give me the daily encouragement that I need. I speak positive things about my life. Faith in Hebrews 11: 1 is the substance of things not seen, the evidence of things hoped for. So, I start my day with positive confessions, reinforcing that I am a living and breathing victor. I'm also meticulous about the choices I make. I choose to be happy and execute positive vibes because it is good for my overall health, knowing fully well that stress and anxiety offset my inner equilibrium.

**Interviewer:** How would you describe your role as a breast cancer advocate and warrior?

**Busola:** My role is to emphasize that breast cancer is not a death sentence. It should be viewed as any other chronic disease. This means bringing awareness of the risk factors for breast cancer. Things within our control such as diet, exercise, environment, spiritual and emotional health are essential to keep at the forefront of our minds. In addition, we need to do in-depth research on things outside our control, like genetics and family history. This also means having conversations about the importance of self-breast checks, mammograms, and digital breast tomosynthesis. My role is to empower other women to engage their providers and care team about prevention, diagnosis, treatment, and survivorship. My duty is to support those who feel powerless and tired through research, prayers, and thoughtful conversations. I found solace in my faith and support system in the most challenging times. As an advocate, my aim is to bring some calm in the middle of the storm.

**Interviewer:** Do you celebrate your cancer anniversary? If so, how and why do you celebrate this important day?

**Busola:** I do not celebrate my cancer anniversary. However, every day is a joyous day in my household. I take time out periodically for self-care and self-love activities. This includes weekend book reads, quiet spa days, girls' trips, comedy shows with friends, to name a few. I've also found my voice with my daughter, speaking to her about knowing her breasts enough to spot when there is an abnormality.

**Interviewer:** Is there anything you would like to share with the Tigerlily Foundation readers and warriors regarding the quality of life of breast cancer survivors?

**Busola:** Sometimes I look at my scars and feel upset, ashamed, or depressed, but truth be told, the scars are a reminder of my journey- a journey of how life dealt me a bad curve. Though I was hit hard, I was blessed with the second chance of rising above that moment which is a humbling experience. As such, I choose not only to survive but to thrive.