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Black Women's Body Image, Breast Cancer, and Post Traumatic Growth

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Introduction

According to researchers, Black women's incidence of breast cancer was slightly lower (126.7 per 100,000) than those for White Non-Hispanic Women (135.2, per 100,000). Although the incidence rate for breast cancer is lower for Black women, the breast cancer mortality rate is higher for Black women, 28.7 compared to 20.8 per 100,000 for White Non-Hispanic women (Noone et al., 2017). There are other health disparities between Black American and Caucasian breast cancer patients (Jatoi et al., 2022; Sajal et al., 2022). These disparities include mastectomy and breast reconstruction, as well as barriers to health care access, financial distress, and small numbers of referrals to reconstructive surgeons for minority patients. Breast cancer is a worldwide health problem. Pilevarzadeh et al (2019) investigated the global presence of cancer. They found breast cancer patients had the highest prevalence of depression at 32.2% worldwide.

Black Women, Body Image, and Identity

When a disease state visibly affects the body and the treatment has side effects, that impacts the body and body image (Alderman et al., 2011; Kang et al., 2018). Body image concerns affect 67% of breast cancer survivors (Fiser et al., 2021). Common psychological symptoms of adjusting to breast cancer is a change in body image and a reduction in self-esteem (Morales-Sánchez et al., 2021). Breast cancer can also impact a woman's view of sensuality and sexuality (Bray et al., 2018; Nardin et al., 2020; Tat et al., 2018). To assist, a few studies (Fisher et al., 2018; Fiser et al., 2021) offer breast cancer survivors psychological and lifestyle interventions to prevent or improve a negative body image.

Women's physical bodies are critiqued more often, and women tend to have a negative

body image more frequently than men (Green et al., 2018). Adolescents are especially susceptible to media exposure and negative body images. Jiotsa et al., (2021) suggested that the influence of social media on the body images of teens and young adults, especially when designing treatment plans which may affect a change in their body image should be considered. Richard, A. et al., (2019) examined the effect of beauty care treatment on younger breast cancer survivors. Reported was this type of treatment had a positive effect on their self-esteem and body image. Likewise, the *Look Good, Feel Better* program (Look Good Feel Better Foundation, 2019) has subscribed to that philosophy for a long time. The program provides breast cancer survivors many things from spa days, lotions, cosmetics to showing survivors how to style hair, wigs and apply makeup. Women who are not satisfied with their bodies are at a higher risk for higher levels of dissatisfaction as negative media images bombard them daily (Patton, 2018).

However, Black women's body image may not be influenced as much as we may think by mainstream culture (Rodgers et al., 2019). Graham (2018) wrote society often incorrectly assumed women of color defined beauty the same way White women do. The same can be said for body image. Therefore, how Black women define themselves is what matters, not an arbitrary assignment of body image, beauty, or attitude by mainstream culture. Few studies examine African American women regarding breast cancer, body image and self-esteem in the United States. Even then the women were usually young adults or a college aged population. Melissant et al. (2019) study had a mean age of 57. Patients were older, higher educated, and found appearance not important during illness and were less concerned about social media.

Black Women and Mastectomy

Reconstructive surgery can result in a positive body image (i.e., carrying oneself confidently, dressing stylishly, etc.). Post-mastectomy reconstruction has also been linked to an improved quality of life (improved emotional, physical, and social wellbeing (Schumacher et al., 2017; Carreira et al., 2021). However, although Black women have a lower rate of breast reconstruction after a mastectomy compared to White women (Rubin et al., 2013), Black women are less likely to receive reconstruction immediately after surgery and less likely to talk to a plastic surgeon prior to the mastectomy (Alderman et al., 2011). In some cases, reconstruction may be delayed, not discussed, or discouraged even in light of the 1998 legislation that mandated insurance companies cover reconstruction after a mastectomy (US Department of Labor, n.d.).

In addition to the issues mentioned above, Black women have higher reconstruction complication rates than White women. Connors et al. (2014) suggests this is additional evidence for reconstruction disparity outcomes by race. Even when collecting research data, it matters whether the mastectomy was conducted on an outpatient basis. Most earlier research studies did not include outpatient services in their statistics since it does not count as a hospital stay. So important data may be unavailable, such as discussions regarding reconstruction and other vital information (Husain et al., 2019). Vanderburgh (2018) indicated this disparity may begin with the physician's diagnosis and the belief that the provider has all the “right answers” which could be negatively affected by the patient’s race or ethnicity. Specifically, the doctor may not discuss options such as reconstruction or even discourage such treatment for a Black female patient. That

could be the beginning of the Black woman's first experience with a medical system that may not respect her choices.

Deciding to have implants is less likely for Black American women (Living Beyond Breast Cancer (LBBC), 2015). Likewise, according to LBBC, Black Americans were more likely to have tram flaps than their White counterparts who opted for breast implants. A tram flap is skin and/or fat from the transverse rectus abdominis ("6-pack") muscle used to reconstruct the breast (Breastcancer.org, 2022). Most Black women prefer to use their own body instead of having a foreign substance permanently placed inside their body. With a decision not to have implants or the "flap" procedure, there are other options such as a prosthesis.

Breast Reconstruction

Women often chose reconstruction to feel whole or to look normal; they hoped that reconstruction will bring some sense of femininity, sexuality, or normalcy, without the hassle of the prosthesis (Cromptvoets, 2006; Hoyle et al., 2022). The reasons for not having breast reconstruction were often the same as in other studies, i.e., pain or wanting to avoid more surgery or concerns about implants. The women in an earlier study (Richard, 2016) indicated a commitment to their decision. This was like the Zeigarnik effect where some people stay with their decision despite the consequences. In the case of breast cancer, we see participants follow through to the end with their decision, regardless of the obstacles (Zaveri et al., 2022). This is the same result (Richard, 2016) discovered when looking at the persistence of breast cancer survivors waiting for their breast reconstruction, despite medical complications. This information is noteworthy because it indicates how not communicating options and not following the

standard of care procedures such as consulting with a plastic surgeon can result in a poorer outcome for the patient (Schumacher et al., 2017; Gonzales et al., 2019).

Post-Traumatic Stress Disorder (PTSD) and Post-Traumatic Growth (PTG) Theory

Post-Traumatic Stress Disorder (PTSD) is defined as recurrent and intrusive distressing recollections of what happened, upsetting dreams, detachment and emotional numbness, difficulty sleeping, concentrating, and feeling of being on edge due to a traumatic event (American Psychiatric Association, 2022). For Cancer survivors, PTSD symptoms can include recurring thoughts about cancer, reminders of cancer-related events and anxious feelings not felt before the traumatic event. These symptoms can result from a breast cancer diagnosis and as well as treatment. Body image and sexuality issues can include managing lymphedema after post-surgery treatments for those affected by breast cancer (Hoyle et al., 2022). Regardless of the type of surgery, cancer survivors have health and body image concerns that generic quality of life instruments do not capture. That view leads to Post Traumatic Growth (PTG).

Post-Traumatic Growth is a theory defined as “surpassing levels of functioning than those which existed before a traumatic event” (Calhoun & Tedeschi, 2006; Hefferon, 2012). Sudden tragic or trauma producing event, such as breast cancer and all that it entails, may move a person to a state of post traumatic growth or as Naughton et al. (2018) called it “meaning making and promoting well-being”. Studies have demonstrated their assessment and evaluation of Post-Traumatic growth and noted decreased depression and anxiety in breast cancer survivors (Wang et al., 2022; Yastibas & Karaman, 2021).

This theory can be applied to individuals who experience diseases, natural disasters, or situations that invoke prolonged stress. It is not always necessary to have a repeated incident of

terror to experience PTG, it can manifest itself with a single exposure. This phenomenon has roots in understanding the culture (based on the individual) and nature of an experience then and now.

Post Traumatic Growth (PTG) can occur in the life of breast cancer survivors. For instance, in 2016 in a Living Beyond Breast Cancer teleconference entitled “*Love Sex and Relationships: Body Acceptance after Diagnosis*”, experts and breast cancer survivors discussed surgery during the cancer journey. Hefferon (2012) studied 83 females in a qualitative longitudinal study, in which she examined Corporeal Posttraumatic Growth (PTG). The Hefferon study cited a critical need for a measurement tool that included an incremental charting related to body image after trauma. There was such a tool used in the Michalczyk et al. (2022) study. They successfully found psychological resilience and PTG (personal resilience and social competence) using the PTG assessment test in their research on 100 breast cancer patients.

The Hefferon (2012) study highlighted the question breast cancer survivors begin with – “What do you see when you look in the mirror?” This starts the process of examining and evaluating the body as transformation /reconstruction that takes place in the survivors’ life. The PTG theory expanded the superficial analysis of scars and offered a way of analyzing movement toward a better way of talking about seeing oneself. In Akbar’s (1984) seminal study of African American people, they experienced positive improvement and flourished after their health improved. Surprisingly, growth came in part from the struggle with trauma.

Purpose of the Present Study

This is a qualitative study that examined a small population of Black women who involuntarily experienced trauma as they went through breast cancer, mastectomy, and breast

reconstruction. This study sought to examine these Black American women's breast cancer survivors' view of their body image in their own words from cancer diagnosis to post-mastectomy through post-reconstruction. Additionally, purpose was to gain insight regarding whether they experienced an alteration in their perception and body image.

Method

Due to the nature of the questions and participants, a descriptive, interpretative, culture approach was utilized for this qualitative research study. Questions focused on post-mastectomy appearance and breast reconstruction. The responses were the participants recollections about their experiences immediately after their mastectomy, post-op visits, and after reconstruction.

Study Participants

The recruitment effort using the snowballing technique through Facebook, a predominately African American church cancer support group, a hospital rehabilitation group, and contacts with friends identified 23 women. The age range was between 35 and 64 years of age, with all participants living in Charlotte, North Carolina except one person living in Ohio. From this group, eleven women were excluded due to not answering the complete questionnaire, not being Black, not having a mastectomy, or not having reconstruction surgery. The final sample for this study consisted of 12 Black women who had breast cancer and had a single or double modified radical mastectomy (breast tissue and axillary lymph nodes removed) following diagnosis, and reconstruction. All participants were over 50 years of age except one. The mean age was 55.

Instrument

Self-reported responses to a 16-item IRB approved questionnaire were collected. In addition to questions about their breast cancer experience, demographic information was collected for this pilot study. Occupational status, number of children, and other SES measures were not collected.

Procedures

The lead author, a Black, female, three-time breast cancer survivor, conducted all the face to face/individual and group interviews. After two of the participants in person cried, the remaining interviews were conducted by the researcher on the phone or online after completing informed consent documentation. The average interview time was 30 minutes. Due to the traumatic nature of the subject matter, the authors believed it was critical to give participants time to say all they wanted to say. All data was housed in a locked file cabinet and on a password protected computer at a small Historically Black College and University (HBCU). Participants were only known on paper by a number. No incentives were offered.

Some questions on the questionnaire posed were if they had a mastectomy, their initial body image after the surgery, their current body image, and what moved their thinking from post-mastectomy to post-reconstruction, how long did that take. These questions were gathered from previous breast cancer research studies (Hefferon, 2012). These statements were then reviewed by two researchers and placed in themes (post-mastectomy and post breast reconstruction) using Dedoose Version 6.1.18 (SocioCultural Research Consultants, 2015). At the end of the interview participants were also asked for insights about their breast cancer journey.

Data Analysis

Dedoose's analytic tools were used to gain independent agreement of the participants' audio verbatim transcripts. This resulted in eight overall themes. Transcripts of the interviews were analyzed with words and phrases highlighted. Each word or phrase was coded and placed in a group with other similar words and phrases. These groups were given a category name and placed under a particular theme. The last key question, "What brought about the change in thinking from the initial view of your body to now?" was conducted in the same theme-seeking way. The percentages are based on the degree to which a specific theme was a percentage of total responses for the question. Participants could give more than one answer to any question and elaborate on anything they deemed important. Dedoose analyzed the qualitative interview data, coding protocols and computed inter-rater reliability using Cronbach's Alpha ($\alpha=.84$).

Findings

The themes that emerged from the first look in a mirror after breast reconstruction were positive and negative. At that time, participants had a more negative view of the breast/self (60.5%)- "Scars." "Imperfect." "Different than what the doctor said." than a positive view of breast/self (39.5%)- "A pretty sexy girl." "I see someone strong." "My breasts never really defined me.". Participants were asked to recall when their view of themselves changed from their initial mirror reflection after surgery.

Most of the Black women had delayed reconstruction due to medical issues such as blood clot, cancer spread to other areas, or infection. The following are sample quotes from the participants. There were more positive quotes (96.1%) "It's just a physical body." "I have a healthy life." "Look at me." while a small percentage viewed their appearance negatively (3.8%) "I feel I should look better." "Healing problems." "I would love for my breasts to look good."

Participants were asked when and what changed their mind regarding their post-mastectomy body image. The time frame was 1.5 to 2 years after seeing the initial mirror view. The theme “Reason for Change” framed these three categories: Declaration of Identity (61.3%)- “I am alive.” “My marriage.” “I knew who I was before this.”, Sense of Self (19.4%)- “So many women are living and not enjoying life.” “I don’t care what the doctor said about negative stuff.” “I am not defined by society.”, and Acceptance (19.4%)- “I am not my body.” “I don’t think about cancer.” “And I stopped feeling sorry for myself.”

Lastly, an open-ended question asked what insights participants gained through their breast cancer experience. One quote from a participant was particularly striking. She said, “I have to stop letting cancer (like a bowl of yeast) take over my life.” The themes which emerged were: Emotional Upheaval- “It affected my mental health.” “I had always had large full breasts that were a nice physical feature for me.” “This experience changed how I looked at myself and how I thought others viewed me.”, How I Look- “I want a specially designed bra.” “It changed how I thought others looked at me.”, and Personal Growth- “Don’t change your life because of it.” “A mastectomy is not like losing a limb or eyesight.”

Discussion

This study is unique in many ways. The participants were Black women, a population which is often a small part of the participant pool the area of cancer research or any medical issue. Moreover, the age of the participants in this study is higher than most breast cancer survivors who have had reconstructive surgery due to breast cancer. Lastly, there are very few studies of this nature which use the exact words of African American participants. Researchers often paraphrase or provide a check list for participants to check an answer. One recent study, Mushonga et al. (2021) on post-traumatic growth in African American women used participant

quotes. Although the traumatic event in that study was not disease nor surgery, post traumatic growth was a basic tenant of the search on intimate partner violence (IPV). The findings of resilience and positive growth on the other side of trauma in younger African American participants appear to be similar in our findings. The richness of stories and the weight of sentiments come to life when you hear the participant's actual words.

Normally, the question of how participants felt later is sometimes not asked at all, asked immediately after the surgery, or a week later at a follow-up doctor's visit. There has not been sufficient time for the individual to process all that happened and is happening as one may be experiencing PTSD. Often symptoms of depression are masked such that the breast cancer survivor does not recognize she/he/they have feelings of depression until someone points it out.

Immediately after reconstruction most participants, based on the themes, recalled a negative view of the body while having a lowered positive view of self. This view could have been the result of scarring on the breast. That first negative body image appeared to lead to strategies to activate changes in one's physical appearance. Participants began to reconnect with their bodies and see it in a more positive light one and a half to two years post-surgery. Some began changes in diet, increased exercise, or took on more challenges that helped them move to a more positive body image. Our finding was in line with other studies (Husain et al., 2019; Michalczyk et al., 2022). After the passage of time, participants were more appreciative of life, their relationships with others, and their self-image.

The participants' answers regarding what changed their thinking illustrated a shift from a physical/body consciousness toward a positive self-perspective. This was a clear shift in body image from their responses upon seeing their body for the first time after surgery. Initially, the view focused on the body, the superficial body image - "Scars" and "I cried".

However, after approximately two years or more, participants recalled their post-reconstruction body image was more internally focused. Responses were “I feel great” “I love myself”. Regardless of the scars (outside or inside) approximately two years later, their body image was positive i.e., “I see a beautiful girl” “I am more than what’s outside”.

Limitations

Limitations of this study include sample size, location, and age. Like many qualitative pilot research studies, this one used a small population. It was conducted in the southern part of the United States and the population was older than the usual research populations investigating this issue. While those are limitations, they also provide insight into the experiences of African Americans breast cancer survivors.

Future Research & Practice

Future research should focus on finding ways to communicate findings and establish a network that will facilitate interactions with Black women who are cancer survivors. This could improve breast cancer survivors' understanding of the reconstruction process and individual movement toward a positive body image. Fisher et al. (2021) has developed culturally appropriate and environmental risk messaging to about breast cancer targeting ethnically diverse mothers. Richman et al. (2020) has developed a community-based breast cancer prevention program for rural and Latina women. As Kroenke et al. (2016) stated, social network groups are critical for a successful prognosis for women of color. After surveying the target population on their use of social media, a closed Facebook group and a blog both entitled ‘Through a Mirror Dimly’ were established in November 2016 to facilitate the sharing of this information. The URL for the blog is <http://hwrichard.info>.

This study supports the inclusion of a psychologist in a hospital’s second opinion clinic.

The inclusion of a psychologist is supported by Yurek et al.'s study (2000), which noted the usefulness of psychological interventions (anxiety reduction techniques and cognitive behavioral strategies) to cope with body changes. Lewis-Smith's 2018 study with participants averaging 52 years of age, also used a Cognitive Behavioral Therapeutic approach. The data indicate the clinical psychologist and breast cancer nurse affected a positive change in participants' body image. Adding a psychologist to the second opinion clinic or consulting with a psychologist during early identification of breast cancer could minimize quality of life disruptions.

There are other additions which could prove useful. A meta-review of faith-based approaches to cancer education and lifestyle show promise by increasing knowledge (Hou & Cao, 2018). Getting faith-based organizations involved in helping African American women know what to expect would be valuable. One of the most comprehensive studies on cancer which included experiences of survivorship from ethnic minorities examined and contained 72% of works published within the last 5 years. Although it examined various types of cancer, the largest percentage was breast cancer. The Laidsaar-Powell et al. (2019) meta-review looked at various factors which included, but was not limited to spirituality, coping strategies, body image, fertility and quality of life. Hopefully, this will serve as a blueprint for the inclusion of ethnic minorities in research leading to a greater understanding of what is needed when facing these challenges.

More conversations need to occur between the doctor and the patient regarding physical changes that may occur (i.e., keloids, new belly button, no feeling in the chest after mastectomy, etc.). This would be helpful in preparing women for what may occur physically and psychologically during the breast cancer experience, which may include PTSD, Post Traumatic Growth, or other experiences.

Conclusions

This study details the experiences of African American women with breast cancer from diagnosis to post-breast reconstruction. It illustrates how research can be enhanced by the actual words of the participants. Their stories, experiences and insights add richness, clarity and raises questions regarding their breast cancer experience. Further research could be examining those factors and choices breast cancer survivors must consider after a breast cancer diagnosis. There may be hope in knowing when you come out on the other side, you may be stronger than you could have ever imagined.

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