

Body Image and Psychosocial Distress: Implications for Breast Cancer Patients' Quality of Life in Nairobi County

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Abstract

Patients with breast cancer undergo invasive treatment and surgical procedures, which could result in temporary or permanent body changes. How breast cancer patients and others react to their altered bodies influences psychosocial distress, their quality of life and treatment efficacy. This study examined body image, psychosocial distress, and quality of life in breast cancer patients. This study used a phenomenological approach to examine the experiences of breast cancer patients. Using probability and expert sampling, 32 breast cancer patients were selected from a target sample of 763, along with five nurses and three physicians. In-depth interviews and focus group discussions were used to collect the data. The interview transcripts were coded, and inductive method was used to generate themes of significance. Four sub-themes emerged from the analysis; namely, altered appearance, diminished self-esteem, the meaning of the breast, and sexuality after breast cancer. The study found that poor body image and psychosocial distress were prevalent among breast cancer patients but inadequately understood and managed. Widespread but unaddressed were impaired body image and sexuality issues. Additionally, the patient's environment mediated body image and subjective wellbeing. Psychosocial distress also negatively affected emotional, social, sexual, and role-function quality of life. The study recommends provision of breast prostheses as well as creation of individual and couple counselling services and support groups. Policymakers and hospitals need to adopt a patient-centred approach that takes breast cancer patients' disease and body image concerns into account.

Keywords: *Breast cancer; body image; psychosocial distress; -quality of life; qualitative study.*

1.0 Introduction

Breast cancer (BC) is a prevalent disease in Kenya, that accounted for 16.1% of all 42,000 cancer cases diagnosed in 2020 (International Agency for Research in Cancer, 2020). Surgical interventions and other breast cancer treatments are detrimental to women's body image, causing losses on multiple fronts, which affect their psychosocial wellbeing and quality of life (QOL). Body image (BI) in breast cancer patients is a multifaceted concept that includes breast cancer patients' cognitions, feelings, and consequent behaviours towards their appearance. BI also includes altered role functions such as motherhood, as well as social function which may be curtailed by self-consciousness (Mokhatri-Hesari & Montazeri, 2020). Body image has been found to impair emotional, social and sexual domains of quality of life, yet it is neither well understood nor accounted for in Kenyan BC care. This study examined the complex nature of body image following breast cancer, psychosocial distress and quality of life.

Statement of the Problem

Breast cancer diagnosis and treatment can have a significant impact on a woman's quality of life (Aamir et al., 2022). Scarring, breast loss, and asymmetry are all side effects of surgical procedures that can impair a woman's body image, sexuality, and perceptions of femininity and beauty. Adjuvant therapies can also have side effects such as hair loss, skin discoloration, and infertility. These changes in appearance and roles are predictive of psychosocial distress, which has been shown to impair the affective,

social, sexual, and role function domains of quality of life (An et al., 2022). Psychosocial interventions include information about breast cancer's clinical course and treatment alternatives, psychosocial counselling, mitigation of altered appearance, and family and social support. However, little is known about body image and psychosocial distress among breast cancer patients in Kenya. This study examined how body image and psychosocial distress influence prognosis and quality of life. The study aims to inform the transition to a patient-centered cancer treatment model that incorporates monitoring and mitigation of psychosocial distress.

"Men view women who have undergone a mastectomy as unattractive, sexually inactive, and expensive to maintain"

Purpose of the study

This study aimed to determine if breast cancer patients' body image influences their psychosocial distress and ultimately their quality of life.

Research Question

Does body image predict psychosocial distress, and does distress influence the breast cancer patient's quality of life?

Theoretical Review

Pearlin et al.'s (1981), Stress Process Model (SPM) and Bandura's (1998) Social Cognitive Theory of Health Promotion (SCTHP) explained body image, psychosocial distress, and QOL. The SPM proposes that stressful events are rooted either in a social context or personal challenges. The SCTHP proposes a complex, dynamic and reciprocal interplay between outcome expectancies, perceived environmental barriers, and facilitators as determinants of body image, psychosocial distress, and quality of life.

Overview of Literature

Breast cancer treatment can lead to temporary or permanent losses, such as hair loss, eyelash loss, and nail discoloration, as well as permanent losses such as breast loss and asymmetry. Additionally, women with breast cancer may develop lymphedema, which causes arm discoloration and deformity in addition to swelling. As such, body image concerns and subsequent psychosocial distress have been found in women with breast cancer due to changes in their physical appearance and roles (Guedes et al., 2018). The cognitive component of body image reflects breast cancer patient's attitudes towards their physical self, satisfaction with their appearance, and attractiveness, while the affective component reflects a breast cancer patient's perceived loss of physical integrity, dissatisfaction with asymmetry, hair loss, skin discoloration, and insecurities regarding femininity and attractiveness. Due to their appearance, these patients may engage in isolating behaviours (Melissant et al., 2018).

Breasts are both functional and sentimental organs, and a breast loss following mastectomy, as well as other conditions such as lymphedema, have an effect on a woman's body image.

Empirical research suggests a link between women's satisfaction with their appearance (body image), which influences their self-esteem and has an impact on their emotional, social, and sexual QOL domains (Paterson et al., 2016). A Turkish study by Kocan and Gursoy (2016) found that after mastectomy, women expressed unfavourable feelings about their appearance, using terms such as "abnormal," "deformed," and "ugly." Brandão et al. (2017) found that having a negative body image can lead to low self-esteem. Grogan and Mehan (2017) discovered that breast loss diminishes women's body confidence, leading to isolating behaviours. These studies suggest that women with a tendency to view their bodies as objects for others to observe and evaluate should receive counselling as part of their treatment to help them cope with changes in their appearance, body image, and self-esteem.

In an unpublished qualitative study, Nmoh (2019) paints a bleak picture of Kenyan women who have had mastectomy and other alterations to their bodies. According to the study's key informants, men view women who have undergone a mastectomy as unattractive, sexually inactive, and expensive to maintain. Advocates for BC have reported observing the "half-person" syndrome in many of the women with whom they interact

(Nmoh, 2019). Body image as a predictor of psychosocial distress has not been incorporated into the cancer treatment and management vocabulary in Kenya, according to Ndeti et al. (2018).

2.0 Materials and Methods

An exploratory phenomenological cross-sectional research design was used to investigate 763 female breast cancer patients. Using opportunity sampling, 20 cancer patients were chosen for in-depth interviews, 12 for two 6-person focus groups, and 5 on-call nurses from each treatment facility. Three physicians were chosen using expert

sampling. Data was gathered through face-to-face interviews and focused group discussions (FGDs). The inductive method was used to develop themes of significance from interview transcripts.

3.0 Results and Discussion

Response rate

The response rate was 100%, where all the sampled twenty women participated in the in-depth interviews, twelve participated in two focus group discussions consisting of six participants each, while four nurses, one lay navigator, and three physicians were interviewed.

Table 1

Socio-demographic Characteristics of Respondents

Participants (individual interviews) n = 20			
2 FGDs of 6 participants each n =12			
Total n = 32		n	%
Age	32-39	8	25
	40-49	10	31
	50-59	7	22
	60-69	<u>7</u>	<u>22</u>
Marital status	Single	6	19
	Separated	4	13
	Divorced	1	3
	Married	<u>21</u>	<u>66</u>
Surgery	Lumpectomy	5	16
	Mastectomy	14	44
	Yet to undergo chemo	4	13
	Breast reconstruction	2	6
	Metastatic disease	<u>7</u>	<u>22</u>
Treatment type	Chemotherapy	7	22

Both chemo & Radio	9	28
Chemo/radio/hormonal	12	38
chemo/radio/antigen	1	3
<u>Treatment planning stage</u>	<u>3</u>	<u>9</u>
<u>Lymphedema</u>	<u>9</u>	<u>28</u>

Table 1 lists participants' socio-demographic and clinical characteristics. The average age of participants was 48 years, with 56% of the population being under 48 years old. This result is consistent with previous findings that low- and middle-income nations have a higher incidence of breast cancer among young women than high-income nations (Bidoli et al., 2019). 14% had not yet undergone mastectomy, 16% had undertaken a lumpectomy, and 6% had undergone breast reconstruction. All of the women received chemotherapy, with variations in radiotherapy, hormone, and antigen treatments. The results demonstrate prevalence of appearance-altering experiences. The thematic analysis yielded four sub-themes; namely, altered appearance, meaning of the breast, diminished self-esteem and sexuality.

Global Theme: Body Image and Sexuality

Sub-theme 1 - Altered Appearance

When asked about their appearance after BC, twenty-six of the thirty-two women interviewed were dissatisfied and self-conscious about their appearance. They expressed unfavourable feelings using terms such as "stooped", "unbalanced", "one does

not look good", and "shameful". The most typical description of their looks was that they felt incomplete because they did not have breasts. Self-consciousness is a precursor to self-isolation, as evidenced by the participants' accounts.

P-D1: I am self-conscious; I self-isolate as a result of mobility challenges and the leaky, smelly wound. Even coming to the hospital is stressful and challenging. Often, when I get into a "matatu" ("public transport"), the other passengers step out. I feel ashamed and stigmatized.

P-T8: I am self-conscious; I am unable to relax around people, and "sometimes I question if this is my body. Going before people has become difficult.

P-T5: My appearance has changed; I lack balance as a result of breast loss; I do not look good; I must choose my dress carefully, but I still do not look good (tone of voice changed).

The patient's feelings were validated by the medical professionals:

N1-Palliative Nurse: Patients with mastectomy, skin

discoloration and hair loss often cover their affected parts with clothing, such as trousers, long sleeved garments, wigs, headscarves and caps. They also volunteer information on how treatment side effects are affecting their body image, sharing a lot about what is distressing them.

When asked collectively about their contentment with their appearance in relation to hair loss, breast loss, and skin discoloration, majority of the participants in the FGD responded:

There is no reversal with breast loss; it will never grow back! (tone of voices sad). Moreover, when a woman has lost her breasts, every person she meets appears to be staring at her.

Sub-theme 2: Diminished Self-esteem

For a number of women, altered appearance has affected their self-esteem negatively.

P-T10: "Loss of breast and hair and other changes in my appearance have really affected me. I feel so bad, and I ask God, why did you allow me to lose my breast? During treatment, I once looked at myself in the mirror and I looked so ugly; I looked older than my grandmother. I hated myself so now I never look at myself in the mirror when I am undergoing treatment, but now that my skin has improved and some hair has grown, I look at myself in the mirror as I comb my hair."

P-F9: "I do not like myself. My appearance has changed due to

change in skin colour, hair loss, and weight loss. Even worse, the wound makes me self-conscious and humiliated in social places."

A health care professional echoed these sentiments:

N3-Oncology Nurse: Ulcerating wounds are a threat to body image, the women's self-esteem and relationships; we hear stories of rejection and abandonment by spouses; "my husband moved away, or he has married another woman, he has no breasts to touch or I smell all the time.

Narratives indicate insensitivity of others and exacerbate the shame and low self-esteem of a number of participants who also experience stigmatization:

P-F3: I struggle with lack of balance; I do not look good, and I am troubled and discouraged by questions such as, "Where did the flesh on the left side of your chest go?" or "Why are you stooping on one side?"

This participant had accepted her altered appearance, and consequently, she did not struggle with diminished self-esteem. However, she would not mind a breast prosthesis.

P-T1: My appearance has changed greatly; I lack symmetry, and my hair has just begun to grow back, but I am unconcerned. I don't mind not having breasts; I have children; from the bottom of my heart, I chose life over beauty.

P-F1: My appearance has changed completely, but I am not bothered, I have shifted my focus to God and getting well.

Some women's body image and self-esteem improved. According to a participant who has undergone breast reconstruction surgery, surgery came with benefits.

P-F3: From my perspective, surgery has been beneficial. Before surgery, I did not like my breasts; I had even considered undergoing cosmetic surgery to reduce the size; but you know what, God works in mysterious ways; the disease has given me the small breasts I always desired; I am more satisfied with my appearance now than I was before; I feel more attractive these days; I am slaying.

Some women were at peace with their altered appearance.

P-F4: I do not have one breast now, but that has not changed how I feel about myself. I feel confident, attractive and desirable.

Healthcare professionals interviewed validated these sentiments:

N4-Palliative nurse: For these women, usually they have a disturbed body image and low self-esteem. These women are labelled; they are given names by the community: (Fene, whose breast was cut). They self-isolate because of the labelling and stigmatisation. They even stop going to church.

Sub-theme 3: Meaning of the breast

For many of the women interviewed, the breast represents femininity, beauty, attractiveness, desirability and motherhood; it is an organ that completes a woman. The

participants' statements demonstrate that the breast is not only an organ but also a symbol with numerous meanings and with many stakeholders.

P-T10: Loss of breast has affected my confidence as a woman and my feelings of being a complete woman who is desirable. You know breasts are the organs that please men, I do not know why, so I really feel terrible that I lost my breast.

The breast as a sentimental organ with many stakeholders was evident as a number of women shared about the effect of their breast loss on their children.

P-FG10: My five-year-old daughter often checks my scar and asks, "Mama, will the breast grow again?"

Another participant shared that her young son keeps asking:

P-FG11: Mum, when will your breast grow back?

Another participant shared of her 13-year old son's reaction to her breast loss:

P-FG12: My 13-year-old son was so distressed and kept asking, "mum now you will just stay like that, or when stepping out, he would ask, "now you are going before people like that?"

Some participants experienced abandonment by their spouses because for them the breast defines a woman:

P-FG12: My husband told me he has no use for a woman without a breast and abandoned us.

Some participants attributed normal disagreements with their spouses to their altered appearance:

P-FG8: When I disagree with my husband and he takes off, I feel it is because of my loss of breast, that he does not find me as shapely as other women”, that bothers me a lot.

Many women shared that their husbands have never looked at their scar:

P-FG3: After the prosthesis, I regained my confidence and self-esteem, I am now so confident. In fact, I have no problem showing my scars to people. However, my husband has never looked at that part of my body.

Some female BC patients exhibit symptoms of half-woman syndrome, according to the health care professionals.

S1-Lay Navigator: Women who have undergone mastectomy feel like they are less of women due to the loss of a feminine organ. This half-woman syndrome is often discussed during support group talks, but wholesome support should include moral support, prosthesis, and psychological interventions to mitigate the feelings.

The clinician's observations revealed that age plays a role in the significance of the breast:

O1-Clinical Radio-oncologist: Women in a 20s or 30s are usually more apprehensive about what diagnosis means, treatment decisions like mastectomy or breast conserving surgery. BC diagnosis is loaded with concerns in relation to not only

body image, but also other issues like fertility, dating and choices of partner and other developmental milestones linked to this stage.

Sub-theme 3: Sexuality

Literature establishes a connection between negative body image and sexuality, and sexual difficulties in women with poor body image (Sebri et al., 2021). However, the current study found that cancer, treatment side effects, stigma, fear of conceiving and fungating wounds have more influence on their sexuality than dissatisfaction with their appearance.

P- D2: I lost desire due to pain and stress; my relationship with my husband went bad because he used to think I was pretending to be unwell as a disguise for rejecting him.

P-T10: My husband withdrew; he lost all interest in me as a woman even though I was desirous. This disease has affected intimacy with my husband, all those years since I was diagnosed with breast cancer; he lost interest in me as a woman. (demeanour reflective of pain).

Following chemotherapy, a few participants' libido improved, but their spouses treated them asexually.

P-FG2: My experience was different from other participants; my sexual desire increased, my body was burning with desire, but my husband, could not touch me. Up to this day, my husband still avoids me.

Health care professionals (HCP) validated these sentiments.

N3 Clinical Navigator: Fears of the husband hurting the wife, the woman's fear of conceiving, or myths of disease transmission all affect sexual intimacy after breast cancer. Patients also say their sexuality is affected by low libido, pain when they engage, or husbands relating to them in a non-sexual manner, which affects the women's feelings of desirability, which they perceive as rejection.

N4 Palliative Care Nurse: Treatment affects their sexual desire, but rejection and emotional pain also affect their sexual feelings and desirability.

Discussion

The study's in-depth exploration of the women's experience with BC revealed novel experiences across the disease trajectory. Moreover, most of the participants had body image concerns due to physical changes caused by the disease or treatment.

Altered Appearance

Participants reported discontent with their appearance and increased self-consciousness. Further, after a mastectomy, participants in this study reported feeling incomplete. These findings corroborate Aitken and Hossan's (2022) conclusion that breast loss and other physical changes cause dissatisfaction with one's appearance, self-consciousness and social withdrawal. Further, this study established affected aspects of body image such as sense of wholeness, femininity, attractiveness, desirability, self-confidence

and esteem. Participants also felt labelled and stigmatised by society.

This was compounded by self-stigma leading to social withdrawal. In this study, young BC patients and survivors struggled managing expectations, adjusting to their altered bodies, and always having to explain these changes to others. This led to isolating behaviours. Moreover, dissatisfaction with appearance was associated with women's relationships and QOL. Consistent with An et al. (2022), the findings established a link between women's satisfaction with their appearance and their emotional, social, sexual and role function QOL domains.

Meaning of the Breast

For many of the women interviewed, the breast is a symbol of femininity, beauty, attractiveness, desirability, and motherhood, as well as the organ that completes a woman. Consistent with previous findings by Álvarez-Pardo et al. (2023), the participants' statements indicated that the breast is not only an organ but also a symbol with multiple connotations and numerous stakeholders.

This study confirmed the findings of Varez-Pardo et al. (2023) that the breast is a symbol of femininity, attractiveness, desirability, motherhood, and the organ that completes a woman. In addition, current findings corroborated Nmoh's (2019) conclusion that some women were abandoned by their husbands because they were deemed insufficiently feminine, while others were unable to reconcile with the deformity and could not even look at the scar. This study did, however, establish a novel finding; that

is, children's grief over the loss of their mother's breast and ensuing desire to regain it.

Diminished Self-esteem

The physical losses and changes inherent in BC interventions equally alter women's cognitions about self. Self-esteem is based on BC patient's perceptions about their bodies (Morales-Sánchez et al., 2021). Consistent with literature, this study found that negative perceptions influenced low self-esteem. However, unlike other studies, most participants in this study also attributed diminished self-esteem to societal reaction to their losses including negative reactions from significant others. Hence, significant others' and society's responses serve as risk and protective factor for self-esteem.

Sexuality

Negative body image is linked to sexual problems in women (Hoyle et al., 2022). This study found that disease, treatment side effects, stigma, fear of conceiving, and ulcerating wounds affect sexuality more than body dissatisfaction. The study also found that spouses stigmatised and rejected women even when their desire increased.

4.0 Conclusion

The most prevalent psychosocial manifestations of disease adaptation were dissatisfaction with appearance, low self-esteem, isolation, impaired intimate relationships, and psychosocial distress. Half-woman syndrome, social anxiety, depression and social isolation all contributed to psychosocial distress. This demonstrates that BI informs psychosocial functioning and

QOL. From the current investigation, a number of conclusions were derived. Body image informs psychosocial distress. The emotional support of a spouse buffers self-esteem. At all phases of the disease, body image and psychosocial distress are significant issues for women with breast cancer, impairing their emotional, social, sexual, and role functioning. Lack of psychosocial support in the treatment model may lead to unresolved psychosocial issues over time, thereby negatively influencing treatment outcomes and quality of life.

5.0 Recommendations

The study recommends provision of breast prostheses as well as creation of individualised and couple counselling services and support groups. Finally, policymakers and oncology settings need to adopt a patient-centred approach that takes breast cancer patients' disease and psychosocial concerns into account.

Contribution to Theory, Policy and Practice

Consistent with the Stress Process Model (SPM), this study determined that a breast cancer patient's body image is determined by their perceptions of their bodies, their context, and the social responses to their alterations. Bandura's Social Cognitive Theory of Health Promotion (SCTHP) provided an explanation for self-efficacy, societal reactions, and their influence on patients' body image by proposing a dynamic and reciprocal interaction between outcome expectancies and perceived environmental barriers that facilitates influencing psychosocial distress and quality of life.

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