

## Changed Body and Marital Intimacy among Women with Breast Cancer in Korea

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### Abstract

**Purpose:** Difficulties relating to changes in sexuality are common as a result of breast cancer and its treatment. Little is known about the changes in sexuality and the emotional intimacy and relationship with husbands, after alterations in the physical and psychological functioning of breast cancer survivors in Korea. This study undertook to explore the changes in life and marital intimacy for Korean women after breast cancer treatments.

**Methods:** This was a qualitative descriptive study using focus group interviews. A total of 11 women who had undergone breast cancer treatments, participated in audio-taped focus group sessions. Qualitative descriptive analysis identified the themes that portrayed their experience.

**Results:** The three themes that portrayed the changes were: (1) Changed body causes changes in marital intimacy, (2) I am still sick (non-supportive intimate partner), and (3) Sorry, but I love you.

**Conclusions:** The negative cancer experience of the patient influences the multidimensional and dynamic relationship they share with their husbands. The possible impact of this study is the knowledge gained that an important aspect in the care for breast cancer survivors by health care professionals is to provide support services for couples to reduce their concerns surrounding the changes in body image and sexuality.

**Keywords:** Sexuality, breast cancer, body image, Korean women, focus group

### INTRODUCTION

Although the incidence of breast cancer has globally increased in women, survival rates have improved largely due to advances in medical technology and aggressive adjunctive therapy. The five-year survival rates for breast cancer in the U.S. have increased to 89.4%; in South Korea, it has risen by 3% – from 88.5% to 91.5% (Center, 2016). Increase in the survival rates have resulted in a corresponding increase in survival times, which underscores the importance of addressing the issues regarding the quality of life among breast cancer survivors (Emilee, Ussher, & Perz, 2010).

Beyond surviving the initial diagnosis and treatment, the post treatment phase is conspicuous in that cancer patients experience a spectrum of late and long-lasting life changes subsequent to the illness and its treatment, which has a

tremendous impact on the quality of their life (Cheng, Sit, & Cheng, 2015; Rosenberg et al., 2013). Hence, evaluating issues regarding the quality of life of the woman is crucial in clinical practice, for detecting physical and psychosocial problems provoked by the disease and/or its treatment (Garrusi & Faezee, 2008; Mackenzie, 2014).

Studies of women who have undergone a mastectomy report that these women experience adverse effects due to body image changes and subsequent changes in sexuality, and experience a loss of womanhood (Garrusi & Faezee, 2008; Ussher, Perz, & Gilbert, 2012). These studies highlight the women's concerns regarding their body image, and perceived alterations in the relationship with their partner or spouse, revealing an underlying apprehension about their sexuality and sexual relationships (Boquiren et al., 2015; Vieira, Santos, Santos, & Giami, 2014).

These concerns are complicated by the fact that women with breast cancer often regard their spouse as a primary source of support (Mosher et al., 2013), and the psychosocial adaptation of the women to breast cancer is significantly related to various aspects of relationship functioning with their husband or primary partner (Emilee et al., 2010). Various findings associating the substantial changes to the body and relationships as well as the intrapsychic consequences, cannot be disregarded by discursive constructions of illness, femininity, sexuality, and marital relationship in understanding the emotions that heighten these negative changes (Ussher et al., 2012). Unfortunately, these subjects, and exploring alternatives for promoting effective sexual intimacy between the woman and her husband or partner, are rarely the topics of an open discussion (De Araújo Ferreira, De Oliveira Gozzo, Panobianco, Dos Santos, & De Almeida, 2015; Ussher et al., 2012). Even though these concerns are recognized as problems that are an intrinsic part of the care, many nurses ignore or do not focus in practice, due to the unrevealed relationship and insufficient knowledge. A broader focus is therefore required to circumvent these drawbacks, so that the experiences of the women can be evaluated and considered in nursing care practices.

Until recently, most studies examining the impact of breast cancer on marital relationship and intimacy focused only on the women's ability to engage in satisfying sexual activity (Emilee et al., 2010). However, a good couple relationship and a supportive intimate husband or partner is known to assist women cope with cancer and improve their quality of life

(Ussher et al., 2012). Hence, it is necessary to focus on the internal conflicts of the woman and the psychological changes regarding the relationship quality, which can be strong predictors of sexual health after breast cancer. Moreover, exploring and identifying these concerns and fears can raise an awareness of the most relevant subjects in the post-treatment phase, since sexuality and intimacy-related issues are fundamental to maintaining the well-being and self-esteem of women affected by breast cancer.

When sexuality reflects the socio-cultural context of an individual experience, multiple changes can occur, especially in the woman's cultural orientation. Therefore, living with women having breast cancer requires a set of interpersonal and cultural outcomes. The purpose of this study was to explore the changes in body and marital intimacy for Korean women after breast cancer treatments. We employed the exploratory qualitative approach and studied the effects of treatment within a given social-cultural context with regards to both personal and sensitive issues.

## METHODS

### Study design

Similar to a large intervention study that developed a sexual life reframing program and evaluated its effect on marital intimacy, body image, and sexual function among breast cancer survivors (Jun et al., 2011), we used focus group discussions to address post-treatment responses to body change and marital intimacy among women. This research questioned changes perceived in sexuality after breast cancer, in a sample of South Korean women breast cancer survivors. In-depth interview were conducted for focus group discussions, with three groups of 3-4 participants each, to collect their opinions and sentiments on a certain topic. The focus groups took place in a secluded room at a cancer centre for women. Potential participants were informed about the study procedures and purpose; it was

believed that in the absence of their husband/primary partner, this environment would foster willingness among the participants to openly share with others facing similar concerns and fears.

### Ethical considerations

This study was approved by the Institutional Review Board of the general hospital's cancer centre for women. Participants were informed about the purpose of the study and the procedures taken to protect their confidentiality. All interview data and record files were stored on the hard drive of a password-protected computer shared solely by the authors. Backup document files were secured in locked file cabinets in the offices of the authors.

### Participants and data collection

Participants were recruited from a women's cancer center associated with a general hospital in Seoul, South Korea, who participated in a group program for breast cancer patients, and who agreed to understand and participate in the purpose and contents of this study. Inclusion criteria included women who had been previously diagnosed with breast cancer stages 1-3; had completed their treatment within 1-5 years since breast surgery, but have not made a complete recovery (as per their doctor); married, between 30 and 59 years of age; and living with their husband. They were selected because of their willingness for participating in group discussions regarding psychosexual and marital concerns. They were recruited by referral from nurses at the Breast Cancer Centre, and were undergoing a breast cancer rehabilitation service.

Eleven women agreed to be interviewed; their experiences were very similar and data saturation (no new information emerging during analysis) was quickly reached. Demographic characteristics of the participants are displayed in Table 1.

**Table 1.** General and Disease-related Characteristics of Patients (N=11)

Case	Age (yr)	Stage	Method of surgery	Time since surgery (mo)	Menstrual status	Religion	Education
A	39	II	Unilateral Mastectomy	36	Irregular	None	High school
B	38	III	Unilateral Mastectomy	18	Menopause	Protestant	High school
C	47	I	Lumpectomy	56	Menopause	Catholic	High school
D	42	II	Unilateral Mastectomy	52	Irregular	Buddhist	College
E	55	I	Unilateral Mastectomy	30	Menopause	Protestant	High school
F	49	II	Double Mastectomy	60	Menopause	Buddhist	High school
G	39	III	Unilateral Mastectomy	27	Menopause	None	College
H	59	I	Lumpectomy	32	Menopause	Protestant	High school
I	42	III	Lumpectomy	17	Menopause	Catholic	High school
J	57	I	Unilateral Mastectomy	45	Menopause	Protestant	High school
K	53	I	Lumpectomy	45	Menopause	Catholic	Elementary School

All the women were invited to contribute in the focus group. A total of 11 women in three focus groups participated, with 3-4 individuals per group. One of the benefits of using focus groups is that the subjects are comfortable and participate frankly, and are encouraged to share their ideas and opinions within the 'comfort zones' (p33) (Stewart & Shamdasani, 2014).

Discussions were held in a small-secluded meeting room at the women's cancer centre, and each of the three focus groups lasted about 1 to 1.5 hours. The discussions began with the researcher asking a broad, open-ended introductory question used as a prompt to encourage women to share their experiences with one another: 'Please tell me how your life has changed since your breast cancer treatment'. This probe was followed by other open-ended questions: 'What physical and psychosocial factors did you experience as a result of the impact of cancer on your sexual life'? and 'How has cancer and its treatment affected your marital intimacy'? Focus group discussions were recorded and the data was fully transcribed, constituting the corpus of analysis. General demographic and disease-related data were collected in individual conversations with participants and/or extracted from medical records.

### Data analysis

Data analysis followed the general approach of focus group discussion analysis put forth by Krueger (Krueger & Casey, 2014). Two researchers read each transcript several times to familiarize themselves with the content, and to understand the entire interview. Primary coding was performed with a low level of inference by each author, and initial codes and the preliminary codebook was created during this stage. Emerging themes from the two analyses were compared and contrasted, and reviewed by another author to achieve consensus and resolve any differences or disparities. To improve inter-rater reliability, the authors re-reviewed the codes and categories to reach a consensus on creating and matching themes, data rearrangement, mapping and interpretation during the process of several meetings (Krueger & Casey, 2014; Nyamathi & Shuler, 1990). To illustrate the themes that emerged during the focus group discussions, verbatim passages are provided in Italics in the results section of this paper.

## RESULTS

Three key themes emerged from the interviews: (1) Changed body causes changes in marital intimacy, (2) I am still sick (non-supportive intimate partner), and (3) Sorry, but I love you. These three themes detail the various aspects of women living with breast cancer, and also highlight the experiences of these women regarding the changes in marital intimacy as a consequence of their treatment.

### Changed body causes changes in marital intimacy

Participants shared negative consequences of body changes due to cancer treatments such as surgery, radiation, and chemotherapy. A number of women expressed emotional trauma related to their altered body image, and expressed loss of confidence in their appearance.

*It was more serious problem than I had expected when I came back home from the hospital. As I undressed, I saw that there's no breast, and I was no longer a woman. It's getting serious since then.... (D, 42)*

Most participants also experienced changes in their genital organs, such as vaginal dryness, rashes, and pricking sensation.

*After chemotherapy, I have experienced vaginal dryness after my period. If I have rashes around the vaginal area, there is a pricking sensation. (I, 42)*

Participants reported that sexual intercourse (coitus) was altered by physical changes after cancer treatments. The altered body worked as an emotional barrier in a sexual relationship, preventing the couples from resuming sexual intimacy.

*I try to not show the surgical scar when I have sex with my husband after the surgery. I was not quite comfortable with him looking at my breast even though my husband told me he understood. (A, 39)*

In addition, participants experienced emotional distance as a result of infrequent sex while undergoing the treatment. They worried about the loss of their femininity and sexual drive. They further stated that distance in sexual relationship resulted in changed marital intimacy with their spouse.

*As diminishing vaginal fluid, I kept avoiding sex and being touched by my husband involuntarily because I lost my breast ... And my husband seems to have lost interest in me. I thought it wouldn't be a problem with sex if I opened myself even after a surgery; however, after the second surgery, my body is not cooperating. (F, 49)*

*My sex drive came back gradually after chemotherapy, but it is a bit awkward to have sex after a while we have been sleeping in separate bedrooms. I don't know how to express my sexual desire... Then, I easily become cranky and upset about a petty remark. (I, 42)*

### 'I am still sick (non-supportive intimate partner)'

'I am still sick' was the second subject. Women defined themselves as cancer patients who still require care and support after termination of the treatment. They continued to experience sickness, felt unwell, and were lacking in energy. Participants expressed disappointment for the indifference and ignorance of husbands regarding what women experience after cancer treatment.

*Pain does not seem to be visible. I still have pain on my arm, and I am still having a hard time. I kept a stiff upper lip even though it is hard. My husband seems to think that I am all right and healthy. That was a lot of disappointed (J, 57).*

*Breast cancer requires constant care and attention even after the surgery. It did not seem easy for my husband to keep it in mind. While I was getting chemotherapy, he paid a lot attention to me and cared about me; however, he seems to overlook and missed symptoms from that I still suffer. (F, 49)*

Participants had a feeling of regret that husbands did not pay much attention to the wife's symptoms and ignored them.

Women experienced a change in marital intimacy, and detected coldness and distance after the treatment had ended.

*It has been 2 years since I underwent a breast cancer surgery. ... I am sometimes disappointed of what he says. It feels like he has already forgotten that I am still a breast cancer patient... ... I hope he cares about me a little bit more... I guess he forgets that I am still sick. He seems to treat me as like I just took a cold medicine and recovered from a cold. (G, 39)*

#### **Sorry, but I love you**

Although participants experienced alterations in their body, a sense of distance, and changed marital intimacy, they also reported existent love and trust from their husbands, and expressed guilt and appreciation toward their husbands. Relationship difficulties and changed intimacy seems to be a transition for couples who have faced breast cancer.

*My husband doesn't usually express himself even though he has a hard time; however, I deeply sympathized with my husband recently when I saw him sleep in a petite build and looking pathetic. He used to look confident and powerful... I was sick as well as he was... I feel sorry for him, and I realize how small he is now when I see him from behind (E, 55)*

*Ever since I was diagnosed with breast cancer, I got annoyed easily and complained a lot about my husband; however, I started understanding that it must have been hard and painful for my family as well to accept my illness. In a movie, there was a husband crying secretly by the window, and the scene reminded exactly of my husband who must have had a hard time without expressing what he went through because of me. I felt deeply sorry for my husband. (B, 38)*

The women experienced new intensities of sympathy and a connection with their husbands that they had not felt before the illness. They were more deeply involved in marital intimacy.

*Before I was sick, I was told formally that I would marry you if I were born again. But when I am sick, I look at my husband who has careful care and care for my two children and now I really want to marry my husband even if I am truly born again. (A, 39)*

*I was disappointed by my husband and I hated him. But when I was separated from my husband for the health management, I missed my husband. No ardent love of my husband but I think he is the only my man. (J, 57)*

#### **DISCUSSION**

Although breast cancer and its treatments result in major shifts in the physical and psychological well-being of patients and their husbands, the consequences on a woman's sexual health and their intimate relationship with spouses is less recognized. When interacting with cancer survivors, health professionals need to fully be aware of the patient's experiences, in order to improve their overall quality of life.

The participants in this study described a poor body image after surgical treatment. Body image related issues have been consistently important from the early through late stage breast

cancer (Mackenzie, 2015; Mosher et al., 2013; Rosenberg et al., 2013). Study participants expressed that their body was disfigured by cancer treatments, and also experienced feelings of rejection by their husbands due to their altered body. A poor body image and negativity of attractiveness as a woman are reported in literature, particularly in western societies (Boquiren et al., 2015; Emilee et al., 2010). In Asian culture, female breasts are perceived for mothering and childbearing, and are not an indication of femininity (Cheng et al., 2015; E. E. Lee, Tripp-Reimer, Miller, Sadler, & Lee, 2007). However, recently published studies in Korea have acknowledged the importance of changed body as a loss of femininity and its psychological impact on women, including feelings of depression and anger (Byun, Chung, & Park, 2011; G. Lee & Lee, 2011; Yi & Son, 2010). Our study participants also expressed that their altered breasts resulted in changed feelings regarding their femininity, and they felt these changes impacted their marital intimacy. This implies that the impact of an altered body image is undergoing a change in Korean culture.

Participants also expressed experiencing sexual barriers such as vaginal atrophy and dryness. Participants in our study described gynaecological symptoms such as pain and vaginal dryness, and also tiredness, all of which impacted their ability to have comfortable sex and enjoy sexual intimacy. These changes have a negative impact on marital intimacy (Emilee et al., 2010; Gilbert, Ussher, & Perz, 2011). Physical difficulties and challenges in coital intercourse during early cancer treatment results in women to altogether avoid sexual activity with the partner. It appears that women avoided sexual intercourses for long periods, which worsened marital intimacy. It also resulted in changed intimacy between a sick wife and a healthy husband. This is consistent with the study of Ussher et al., wherein they reported that when women neglected their partners, it could lead to a breakdown in their relationship.

The literature describing sexual behaviour among breast cancer women and their partners is not only limited to the corporeal dimensions, but also to social and relational issues (Ussher et al., 2012). Avoiding sexual intercourse influences feeling of intimacy negatively. The quality of marital relationships and intimate partner support are important factors for patients to cope with cancer and its treatment (Archibald, Lemieux, Byers, Tamlyn, & Worth, 2006; Garrusi & Faezee, 2008). Participants in this study expressed a tendency to avoid sexual intercourse after treatments due to both physical and psychological reasons, such as tiredness, decreased vaginal discharge and dyspareunia. From a medical perspective, some of these symptoms could be treated; psychological issues however may be more difficult to assess and treat. In our study, it was not clear whether women were seeking further medical assistance or education to cope. It was also unclear whether these women attempted to renegotiate sexual activity when they encountered painful and difficult coitus. This is also consistent with previous research reporting that couples do not try to renegotiate sexual activity, such as relying on non-coital sexual practices (Ussher et al., 2012). Deteriorated sexual life and related marital crisis have been described as 'a precarious situation for pending divorce' (G. Lee & Lee, 2011), and 'dangerous marriage due to no sexual life' (Yi & Son, 2010) for Korean patients. This highlights the importance of active communication and the need for

professional advice and support for couples in the process of adapting to sexual changes (Emilee et al., 2010; Ussher et al., 2012). Multidisciplinary professional teams, including those who are trained to assess and manage both medical and psychological issues, are required to counsel couples early on in order to increase their ability to plan for and solve barriers they may experience.

Spousal support plays a fundamental role in the quality of life of cancer patients and ultimately, cancer treatment outcomes. Our data indicate that participants continue to view themselves as sick women requiring support and care while surviving cancer. Although some critics warn against creating the situation of 'sick role' where patients become dependent and helpless (Zebrack, 2000), participants in this study revealed their need to have continued support after the treatment had ended. It could be that breast cancer women may need more time, especially since their efforts are influenced by the lack of energy and time during and after active cancer treatment. The self-concept as a sick woman seems to be related with their interaction with family members (Zebrack, 2000). This is consistent with recent research that breast cancer women have a strong gender identity indicating that family needs, especially children, are the first priority, often more than their own health (Mackenzie, 2014, 2015). In the Lethborg et al. study, describes the different expectations and experiences between breast cancer patients and their partners (Lethborg, Kissane, & Burns, 2003). At the point of treatment completion, spouses desired a return to a pre-cancer life described as 'normal', but patients continued to experience difficulties. Although there are contradictory perspectives on 'normality', the meaning of normality which is new and discontinuous from the past for cancer patients were presented (Baker et al., 2015). The concept of normality after treatment may be different between patients and partners. In the cancer trajectory, breast cancer patients may experience continuing struggles with ongoing personal health issues and social roles as a wife.

Although participants reported neglecting the sexual needs and relationship difficulties of their partner, they also expressed guilt and appreciation toward their husbands. Relationship difficulties and changed intimacy should be considered as transitional difficulties which couples with breast cancer experience. Literature has reported that communication issues resulted in relationship conflict, which further leads to relationship breakdown (Badr & Taylor, 2006; Ussher et al., 2012). Lack of sexual desire, physical pain, and fear for women living with breast cancer are important factors that result in unmet sexual needs in their partners. Since women may experience feelings of guilt and appreciation, delicate personal and interpersonal need assessments, and interventions promoting open communications, are important. Mutual constructive communication between partners and patients seems critical in increasing marital intimacy and quality of life in women (Manne et al., 2006).

Our study has certain limitations. First, the focus group interviews were conducted with a relatively small number of participants from a single hospital. Additionally, we were unable to comprehend whether the specific group dynamics influenced what the women reported. Therefore, these findings cannot be generalized for all Korean women who have

undergone breast cancer treatment. For example, women from a different age group may not report similar consequences from breast cancer treatment. This may especially be true among older women who may not value sexuality so highly, or for whom sexual intimacy has less importance. Also, our study participants were recruited from a breast cancer rehabilitation service; these women had greater access to information about breast cancer and the consequences of treatments on women's sexuality compared to other women cared for in other outpatient services.

## CONCLUSION

Breast cancer impacts the lives of the patient as well as their husband or primary partner. Our study described the experiences of women with regards to body changes, and their feelings about the impact of cancer treatment on sexual intimacy. These women were clearly affected by various factors, and openly shared the negative aspects of breast cancer and its treatment. This study also revealed another important factor: the subjects continued to describe themselves as 'a still sick person' even after termination of treatments. Although women experienced body changes and altered sexual intimacy, they also expressed feelings of guilt and appreciation toward their husbands. These findings, along with previously published studies, highlights the importance of the role of health care professionals in supporting couples who are undergoing numerous changes brought about by breast cancer and its treatment, and which might have a prolonged impact on the patients' perceptions of themselves and their sexual intimacy.

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