

Qualitative Exploration of Sexual Health Among Diverse Breast Cancer Survivors

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Abstract Although the physical and emotional impact of surgical removal of partial or complete removal of the breast as well as effects of breast cancer treatment on the individual have been well documented, little research is available on sexuality and sexual health of breast cancer survivors in a relationship context. Sexual health concerns of breast cancer survivors remain an unmet need for many. The present study consisted of qualitative interviews with 135 racially diverse, female breast cancer survivors who completed treatment to better understand their perspectives on sexual health and management of sexual problems in their potential and existing relationships after breast cancer. Key thematic findings include that breast cancer survivors have to (1) adapt to the physical and emotional traumas of breast cancer surgery and treatment, (2) navigate complicated sexual communications with potential and existing partners, and (3) negotiate intimacy and closeness without sexual intercourse with existing partners. This study demonstrates the need for healthcare providers to discuss sexual health after breast cancer with all of their patients as it is a concern that faces single and partnered breast cancer survivors months and years after treatment.

Keywords Breast cancer · Sexual health · Racial/ethnic minorities

Introduction

Over their lifetime, about 1 in 8 women in the USA will develop breast cancer. With advances in surgery and treatment, early detection through screening, and increased awareness, 89 % of women affected with breast cancer survive more than 5 years after diagnosis [1]. Survivorship refers to a range of cancer experiences and trajectories. For example, breast cancer survivors (BCS) may be living cancer-free for many years but experiencing one or more serious, late complications of treatment such as problems with sexual health [2].

Sexual Health of BCS

Sexual health is “a state of physical, emotional, mental and social well-being in relation to sexuality” [3]. In Western culture, the female breasts symbolize sexuality [4] which is defined as a central aspect of human life, encompassing sex, eroticism, pleasure, and intimacy [3]. This central aspect of life for BCS is affected by breast cancer treatment and the course of a disease that exerts devastating effects upon women’s sexual function. For BCS, the most uncomfortable topic to talk about is probably their sexual life and the changes that have transpired due to the illness [5]. The meaning of the body and thus sexuality is redefined. There are visible and invisible changes affecting sexual health. The visible physical changes may include weight gain, hair loss, and loss of skin elasticity, scars, and/or missing or asymmetrical breasts. The invisible changes resulting from chemically induced menopause may include vaginal dryness, painful coitus, and low libido [6]. In a prospective study of 79 BCS age 23 to 70 years,

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sexuality-impairing factors that were reported included loss of libido and weariness, changes in body image, and other chemotherapy-induced menopausal symptoms such as hot flashes and sleeplessness [7].

The sexuality-impairing factors persist during remission for the majority of women with hormone receptor-positive breast cancer who need adjuvant endocrine treatments, specifically aromatase inhibitors (e.g., arimidex) and selective estrogen receptor modulators (e.g., tamoxifen) intended to deprive cancer cells of estrogen. Arimidex inhibits estrogen biosynthesis by blocking the action of the enzyme aromatase used by the body to make estrogen while tamoxifen blocks the effect of estrogen on breast and other reproductive organ tissues [8]. In a cross-sectional study comparing the prevalence of urogenital symptoms and vaginal atrophy in 97 postmenopausal breast cancer patients on adjuvant endocrine treatment to 105 age-matched control women, the study found 57.6 % of aromatase inhibitor-treated and 32.4 % of tamoxifen-treated breast cancer patients rated at least one vaginal atrophy symptom which was significantly more common than in control subjects ($p < .01$) [9]. Vaginal atrophy symptoms consisted of vaginal itching or irritation, vaginal dryness, and pain or discomfort with intercourse. Compared to other women in the study, women on aromatase inhibitors reported moderate or severe vaginal atrophy more often ($p < .05$) [9]. In another study of 83 BCS living cancer-free for 3 or more years (median 7 years) after cancer treatment, the authors assessed four self-reported sexual morbidity domains (sexual function, sexual distress, body change stress, and body satisfaction) [10]. The findings indicated that 77 % of all participants experienced sexual dysfunction, 1 out of 4 participants reported either always or frequently feeling bothered by low sexual desire, and most participants experienced relatively high stress about body change and overall lower body satisfaction [10].

Sexual Health of Diverse BCS

Few studies have directly focused on the sexual health of racially/ethnically diverse breast cancer survivors. A study of African American BCS showed that women experienced high risk for reproductive health problems, including menopause symptoms, sexual dysfunction, and distress about cancer-related infertility [11]. In a qualitative study about the psychosocial impact of breast cancer on women from diverse ethnic and socioeconomic backgrounds, Ashing-Giwa and colleagues found that discussing body image and sexual concerns were most needed among Asian American BCS [12]. In another study comparing Hispanic and White women breast cancer survivors, all women reported a general lack of sexual desire, but compared to non-Hispanic White women, Hispanic BCS had significantly less sexual desire, greater difficulty enjoying sex, and more difficulty with getting sexually aroused and having orgasms [13]. While there is literature

on sexual health of BCS from specific racial groups, there remains a need for more studies examining sexual health issues of racially diverse BCS samples. The purpose of this study is to qualitatively explore the sexual health experiences among racially diverse BCS.

Methodology

This sample is a subsample of a larger study of spirituality, quality of life, mood, and social support among breast cancer survivors in the San Francisco Bay Area. To be eligible for the overall study, the participants needed to (1) have had a diagnosis of breast cancer (stage 0, I, and II) within the past 4 years; (2) have completed primary treatment; and (3) speak and/or write in English, Cantonese, or Spanish. An initial interview was conducted and a follow-up, qualitative, in-depth interview and quantitative surveys were conducted 2 years after. Only respondents who had completed both an initial interview and a follow-up interview with questions on sexual health were included in this sub-study. The research team conducted interviews at the participant's home or at a public place convenient to her. Tape-recorded interviews were conducted in English, Spanish, and/or Cantonese and lasted approximately 1.5 to 2 h. The women were asked open-ended questions on (1) sexual activity after surgery and treatment and (2) relationship with partner after surgery and treatment.

The analysis was based on a grounded theory approach with the focus on a core category: sexual health following a breast cancer surgery and treatment. Following the procedures for grounded theory analysis, open coding was first utilized to identify types of categories and domains based on the emerging themes found repeatedly throughout the data [14]. The codes that emerged were not forced or fixed. Investigators independently reviewed transcripts for commonalities and differences. Text within a coding category was evaluated to determine whether it accurately fit the definition of the code. Verification of the accuracy of the coding scheme (conceptual categories, their definitions, and the observations coded within each category) occurred using both inductive and deductive methods.

Results

One hundred thirty-five ($n = 135$) women were interviewed about their sexual health (Table 1). These women were early stage (stage 0 to stage II) BCS with a mean of 23 months past their breast cancer diagnosis. The majority of participants were married/partnered (55.6 %) and forty-four percent (44.4 %) were single, divorced or widowed. The age of participants ranged from 33 to 83 years with the mean age of participants at 58 years old. Our racially diverse sample included participants who identified as African Americans (26.7 %), Asian

Table 1 Background of respondents (*n* = 135)

	<i>N</i> (%)
Age range	33–83 (mean 58.3, SD 11.5)
Months since diagnosis	4–48 months (mean 23.7, SD 10.1)
Race/ethnicity	
African American	36 (26.7)
Asian American	48 (35.6)
Latina	15 (11.1)
Whites	35 (25.9)
Mixed	1 (0.7)
Marital status	
Single	22 (16.3)
Married/partnered	75 (55.6)
Divorced	20 (14.8)
Widowed	18 (13.3)
Stage of disease	
Stage 0	7 (5.2)
Stage I	66 (47.8)
Stage II	62 (5.2)
Type of treatment	
Radiation	97 (71.9)
Chemotherapy	72 (53.3)
Hormonal therapy	87 (64.4)
Type of surgery	
Lumpectomy	90 (66.7)
Mastectomy	45 (33.3)

Americans (35.6 %), Latinas (11.1 %), Whites (25.9 %), and mixed (0.7 %). Two thirds (66.7 %) of the participants had a lumpectomy, while one third (33.3 %) had a mastectomy. In terms of the treatment, 71.9 % received radiation, 53.3 % received chemotherapy, and 64.4 % received hormonal therapy.

In reviewing these transcripts, three major themes emerged about their sexual health as a BCS. A major theme was that BCS had to adapt to the physical and emotional traumas that resulted from surgery and treatment. Another theme was that due to changes in the body, communication about sex with significant others or potential partners was complicated and thus required considerable navigation. Finally, the last theme that emerged from the data was that in addition to adapting to changes in the body and navigating sex communication, many BCS negotiated a closeness and intimacy without sexual intercourse in their existing relationships.

Adapting to the Physical and Emotional Traumas of Breast Cancer

The impact of surgery and cancer treatment on women’s bodies was mentioned as the primary factor affecting their sexual health. Most of our participants had either a lumpectomy or a mastectomy in addition to radiation, chemotherapy, and/or

hormonal therapy. After lumpectomy, which conserves the breast and leaves most of the tissue in place, the look and feel of the breast could change; the breast might have red discoloration and numbness around the surgical scar, reduce in size, and/or become firmer. Mastectomy removes the entire breast and could cause permanent numbness across the chest. Breast surgery, whether lumpectomy or mastectomy, was a shock to many participants and had profound effects on their sexuality.

Several respondents discussed how their body had changed in ways that were not only physical but also emotional. For some BCS, partial or full removal of the breast also seemed to signify the loss of their sexuality, leading some to withdraw from intimate acts that might expose their breast. One respondent, a partnered 51-year-old Chinese American, discussed how she was dealing with the emotional shock of undergoing surgery and treatment and the impact it had on her sexual health 1 year post-treatment:

“We’re talking about the breast... Our sexuality comes from our breast so that in itself was an emotional shock. The treatments may affect that but I think emotionally, that has maybe even a more impactful distortion or detriment to how we feel of our sexuality. For me, it took me a while to even be felt. I didn’t want anyone touching me, especially on my breast. Especially my left breast that I had the lumpectomy.”

Chemotherapy treatment may be given before to reduce the size of the tumor or after surgery to reduce the risk of cancer recurrence. Women with hormone-sensitive breast cancer may undergo hormonal therapy with or without chemotherapy to treat and then to prevent cancer recurrence. While the surgical removal of the breast affected women’s body image and sexuality, the side effects of chemotherapy and hormone therapy resulted in physical and emotional barriers to sex. Some of the physical side effects include hair loss, fatigue, weight gain, and menopausal symptoms. Menopausal symptoms such as vaginal dryness, pain during sexual intercourse, and decrease in libido, lessened desire for sex among BCS. A 38-year-old Korean American respondent discussed the different sexual experiences for her and her partner after receiving chemotherapy and radiation. She stated, “I was pretty dry. We tried the best we could but it wasn’t always pleasant for me. But for him, it was fine.”

Despite efforts to address vaginal dryness with lubrication and medication, sexual intercourse was painful for many BCS. For example, one married, 50-year-old White woman remarked:

“My major problem is with vaginal dryness... so painful to have intercourse now... very bothersome and painful. And I’ve tried, I’ve tried the Estroting. That didn’t work. I tried Astrogel. That didn’t work. It just feels like it’s atrophied in there. It just feels awful.”

For one married, 59-year-old Chinese American woman, sexual intercourse is painful and she lost interest in sex even though she could achieve orgasm:

“I haven’t had any trouble with orgasm, but I do have trouble with lubrication...I had problems right after my mastectomy and the surgery... and so I lost interest in sex for a while and he kind of backed off. And so our sex life has gotten down to almost zilch right now. And I wish it were different.”

In addition to the physical side effects from surgery, chemotherapy, and hormone therapy, decrease in sexual desire proved to be a tremendous loss to the sexuality and sexual health of BCS. The sense of loss due to changes in sexual relations extended to the partners of BCS as well. One 57-year-old White woman described how her lack of sexual desire due to the side effects of treatment was a shared loss with her husband:

“I found that is really a loss. A loss for myself. A loss for my husband. So here’s the thing about sex... It’s become alienated. I’m very sad. It’s an enormous loss... He also talks about feeling loss of how it’s changed our life but we are still very close. We cuddle a lot.”

Like other respondents, despite her own lack of sexual desire and the differential experience in sexual pleasure, she still tried to have a sexual relationship with her husband: “I still make sure he’s still taken care of. He’s not in bad shape as I am. As least he can feel it. He can have orgasms and I just, no. That’s really a problem.”

Accepting that these bodily losses and changes to their sexual health proved to be difficult for some. For BCS who regarded sex as an important factor in their intimate relationships, sexual limitations resulting from breast cancer treatment could leave BCS feeling helpless. One respondent, a 62-year-old White woman with stage I breast cancer stated:

“The feeling that I am letting my husband down...We always had a good sex life. Sometimes when nothing else was going well, that was the only thing that was going well. I’ve talked to friends about this who said this would not be significant for them because that was never important. Unfortunately for us it was [important] so yea it’s not been fun. I don’t know to fix it either.”

Not only do BCS experience drastic changes to their bodies after undergoing surgery, they also have to adapt to the side effects that chemotherapy and hormone therapy had on their sexual health. These side effects of vaginal dryness, pain during sexual intercourse, and decrease in sexual desire all contribute to the decline of sexual health and feeling of

tremendous loss among BCS. Yet, despite these physical and emotional traumas from surgery and treatment, some BCS continue to try to continue having a sexual relationship with their partner.

Navigating Sexual Communication

As mentioned in the previous theme, BCS already have to make additional efforts to try to find pleasure in sexual intercourse, if any. However, BCS have to put in extra work even before having sexual intercourse. In addition to adapting to the physical changes to their body and the emotional trauma of breast cancer treatment, respondents also described challenges in navigating the sexual communication with potential and current partners.

For single BCS, the complications in sexual communication were often grounded in the pressure and extra burden they feel in having to disclose the effects that surgery and treatment had on their bodies with a potential new partner. They might also feel anxious about how the potential partner would react to their bodies. One single, 46-year-old White woman noted that her mastectomy and hysterectomy had prompted her to think more consciously about her sexuality and body. Prior to treatment, this respondent had felt at ease with herself and she never had to explain herself. However, after surgery and treatment, she feels burdened by sexual communication while also feeling like sex is not something for her:

“And now if I met someone I have to explain a lot of stuff and I also just feel sort of exempted myself from the sexual arena... it certainly is quite a change in my life. It’s a big impact actually... it would be quite nice to have a twinkling of a romantic interest and something.”

One respondent, a 36-year-old Chinese American woman, discusses how the potential partner must be accepting and understanding of her health condition if they were to have sex. Meanwhile, she pondered whether she could accept rejection once she disclosed her condition:

“In terms of the sex life, the other person would need to know about my health. Ultimately if I found a person that likes me and I feel that I find him okay, I’ll definitely tell him. This issue though would involve our communication. If he can’t accept it, I don’t know if I can accept it.”

Another respondent, a 50-year-old, single White woman, described the devastating effects of a potential partner’s mixed messages regarding seeing her body. This respondent was self-conscious about how her body looked because surgery and radiation made her breast red and swollen. She was reluctant to let the potential partner see her body at first even

though he insisted that he would not mind. However, it seemed that this person ultimately could not meet the respondents' needs:

“Of course every woman wants a partner who is going to find them beautiful and sexual whether they have one breast or two breasts or a marred breast or what. And here I was only partially involved with someone who really couldn't commit or meet my needs... It felt like he couldn't handle it when I was ready... It was very devastating... I felt like he's a very looks conscious person. And that's not the kind of person I needed to be with... It was really hard with this guy because it made me feel sexually unattractive.”

Anxiety around sexual communication also extended to BCS who were in a relationship. For some partnered BCS who are uncomfortable with the topic, they may avoid communication about their sexual needs with their current partner altogether. Similar to other BCS who had no sexual desire but who wanted to please their sexual partner nonetheless, a 56-year-old Latina woman described her avoidance in communicating with her partner about her sexual problems out of fear that he may receive the message poorly:

“Well, I have no sex drive at all. I do have a relationship because the person I have been with has always been there for me in the good and bad moments. I try not to let him know... I'd rather he doesn't know because he is going to take it the wrong way. He's going to think that I don't love him, that I don't want to be with him, because that's the character of Latin men.”

For some BCS, sexual communication was not always direct with partners who had been with the BCS since before the cancer diagnosis. With long-term partners, there was a shared understanding that their sex lives would be altered after surgery and treatment. One married, 60-year-old African American respondent discussed how it seemed normal to not talk about sex after cancer, but a loving connection was what she valued with her partner:

“I don't think we ever talked about [sex]. It seemed perfectly normal to me... It was a traumatic period. It made sense to me that I felt a distance between myself and my husband. We weren't having sex during that period... Caring and loving and being close and having that connection is a different matter. If that had changed, I would have been scared.”

Sexual communication could be a difficult subject for many people to approach in general. For single BCS, sexual communications could be burdensome and complicated by

the need to disclose the effects that breast cancer surgery and treatment had on their bodies to potential new partners. Depending on individual circumstances, BCS who are in a relationship could also have difficulty bringing up their sexual problems to their partner due to concerns over how their partner might react, while others may have reached a shared understanding with their partners that their bodies had changed.

Negotiating Intimacy and Closeness without Sexual Intercourse

Many of our respondents reported difficulties with having sexual intercourse. While some BCS continued to have sex out of the desire to please their partners, some negotiated and came to terms with having an intimate and close connection with a partner that did not involve sex. As a way to cope with their bodily changes and physical barriers to sex, some respondents reported accounts of displaying affection and love through cuddling, hugging, kissing, and holding hands.

Intimacy and closeness without sexual intercourse was prominent among BCS who had been with their partners or spouses for a long period of time. After trying to remedy her sexual problems, a 68-year-old African American woman who had been married for 48 years, commented on the shift of intimacy with her spouse and their new way of being with each other that was comfortable:

“We have discussed it a little bit and certainly we've tried to remedy the situation... but what we have found is that we are intimate in a different kind of way. He's much more willing to have PDA (public displays of affection). I mean we kiss a lot and hug a lot and touch a lot ... it's just that we don't get to intercourse.”

Intimacy after breast cancer mostly involved the simple romantic gestures of hand holding, hugging, and kissing. With these actions and the reminder of their loving connection, BCS and their partner maintain a supportive relationship, in which a BCS could feel safe despite undergoing the traumas of cancer. As one respondent, a Filipina 52 years of age, remarked:

“For me, sex has different meanings. Sex is not only having an intercourse... my husband and I never miss kissing at night. We never miss saying “I love you” to each other and even though we don't always have physical contact, but we sleep close together at night time and we always hold hands before we sleep and I think I'm ok.”

Respondents reported a sense of acceptance that they as a couple had experienced a changed intimacy. A 50-year-old White woman described having a solid relationship with her

husband that is more than just sex and how her cancer diagnosis actually strengthened her marriage:

“We have been married 27 years. So our relationship is actually stronger. So I think we are mature adults that the physical aspect is one entity but there is a lot of other stuff to a relationship. So I think we really focus on that because we are around each other all the time. We work together. 24/7. So it’s a different relationship than most people. So yeah. We both accepted it.”

It seems that when BCS are already in a relationship when they were diagnosed with cancer, their partner might be more understanding of the sexual issues that come about after surgery and treatment. Sexual intercourse was not necessary for having a close and meaningful relationship. While some may regard sex as an essential part of a relationship, we found that BCS who were in long-term relationships came to acceptance of having intimacy with their partners that did not involve sexual intercourse.

Discussion

In exploring BCS perceptions and management of their sexual health after surgery and breast cancer treatment, we found that there were no racial/ethnic differences. We found that BCS had to adapt to dramatic changes to their bodies and deal with tremendous loss regarding their sexuality. BCS also had to navigate complicated sexual communications with potential and existing sexual partners due to disclosure of their sexual health problems. Lastly, we found that despite all the negative impact breast cancer had on their bodies and sex life, BCS and their partners negotiated ways of being close and intimate with each other that involved display of more romantic gestures and de-prioritization of sex. In turn, these BCS felt secure and loved in supportive relationships where partners understood the effects of surgery and cancer treatment.

Accounts of how the physical changes from surgery and treatment negatively affected our respondents’ emotions and sense of self are in congruence with existing literature on sexual issues reported by BCS [15]. As breasts are often associated with a woman’s sexuality and femininity, partial or complete removal of the breast deeply affects body image of BCS. While these sexual issues among BCS are well documented, less is known about BCS sexuality in a relationship context [15]. Our study adds to the literature in demonstrating that BCS and their partners have differential sexual experiences wherein BCS do not always find pleasure in sex but have sex anyway to please their partners. For BCS who lack sexual desire, the sense of loss regarding their sex life is a shared loss with their partner.

Researchers have shown that the quality of the relationship is a predictor of sexual health in BCS [15]. What is missing in the literature though is how single and partnered BCS communicate about sex after treatment. A major finding in this study is that respondents felt that they needed to navigate sexual health communication that was more complicated due to the physical changes related to cancer treatment. Sexual communication was difficult for both single and partnered BCS. People who were single hesitated to have sexual relations with new partners due to body image issues, feelings of unattractiveness, and having to explain how their body had changed post-treatment. Others who are partnered have to negotiate how to manage the changes of their sexual relationship; but for some BCS, they prefer to not approach the topic at all with their partners.

Our final finding of negotiating intimacy and closeness without sexual intercourse among partnered individuals is also in concordance with current literature. Gilbert and colleagues found that partners of cancer survivors who were successful in renegotiating sexuality and intimacy attributed this success to good communication and positive relationship context [16]. However, successful renegotiation of intimacy may be limited to only a fraction of BCS. Hawkins and colleagues found that only 19 % of women and 14 % of men who were partners with someone with cancer were able to renegotiate sexuality and intimacy in their relationship. Moreover, only 17 % of women and 16 % of men described positive feelings of understanding or acceptance of sexual relationship changes due to the effects of cancer [17]. We add that successful renegotiation of intimacy may be more available to BCS who were already partnered before breast cancer diagnosis, and hence, their partners already knew what to expect in terms of the impact of breast cancer on their sexual relationship. Our findings affirm the need for healthcare providers to address the sexual health needs of BCS in a relationship context.

Couples can benefit from open discussions of how to cope with the barriers to sex experienced by BCS. Healthcare professionals could play an essential role in helping patients explore sexuality post cancer treatment by employing strategies that normalize discussions regarding sexual health. Hill and colleagues found that few BCS seek help from their healthcare providers even though many would like to discuss their sexual health issues [18]. Even when BCS want to consult their healthcare providers on sexual health problems, their providers might not be comfortable in addressing the topic. Hordern and Street found that healthcare professionals in cancer settings avoided topics of sexuality and limited discussions with patients to medical topics such as fertility, contraception, and menopause [19]. While sexuality might be viewed as secondary to “life or death” circumstances around cancer, people living with cancer should, nonetheless, be able to feel comfortable in discussing sexual health issues with their healthcare providers to improve their quality of life after

cancer treatment. Resources are needed for both healthcare providers and patients to engage in conversations regarding sex and intimacy after breast cancer.

Although we have respondents from diverse racial and ethnic backgrounds further affirming findings from other researchers on sexual health after breast cancer [12], there are several limitations to our study. While most of our respondents answered questions about their sexuality, some answered more in depth than others. Those who chose to answer in more details about their sexuality may have been more open and comfortable in discussing their sexual health issues in general. In addition, our open-ended questions about sexual activity and relationship after surgery and treatment focused on participants' experience only. It would be desirable to explore healthcare providers' perspectives.

Conclusion

In terms of the breast cancer continuum, there has been much research on quality of life and breast cancer among women of color. However, there is little information on sexual health of BCS in a relationship context. Our study adds to the body of literature regarding unmet needs for sexuality and intimacy among BCS and brings in additional perspectives from diverse racial/ethnic groups. More research is needed to know if patients feel comfortable discussing sexuality with their healthcare providers. Past research on patient-provider communication among racial/ethnicity minority women with breast cancer show that barriers and challenges exist in discussing concerns regarding breast cancer treatment and side effects [20]. This study demonstrates the need for healthcare providers to discuss sexual health after breast cancer with all of their patients as it is a concern that troubles single and partnered BCS months and years after treatment. As this study demonstrates, sexual health is an important part of quality of life for BCS, regardless of relationship status.

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