ABSTRACT

Introduction: Women’s sexuality becomes complex after breast cancer diagnosis and sexual health is highly neglected in the management of the illness.

Aims: To explore the coping and strategies to overcome sexuality problems and sexual dysfunction among women with breast cancer.

Material and Methods: Using the in-depth and photo-elicitation interview methods, this qualitative study following phenomenological analysis was conducted on fourteen married female respondents with breast cancer and had the positive result for female sexual dysfunction (FSD) screened by Female Sexual Function Index (FSFI-6 items) from Kelantan, Malaysia. The interviews data were audio-recorded, transcribed verbatim and managed in analytic computer software NVivo11 Pro. The transcriptions were analyzed using thematic analysis by referring to the meaning-making theory.

Main Outcome Measures: We identified overlapping themes of coping and strategies among women with breast cancer to overcome sexual problems and sexual dysfunction which correspond with meaning-making theory.

Results: Three themes have emerged. Women with breast cancer that developed sexuality problem and sexual dysfunction strived to accept the illness using religious belief and conform by altering sexual practices. These individuals positively look for a solution by seeking formal healthcare advice, modify their physical appearance, active discussion with the husband and support from other survivors. A few of them passively struggle with the subject by averting the intimacy and receptive toward polygamy.

Conclusion: This study highlighted the various mechanisms that emphasized the pivotal role of religious belief and relationship context as key factors in the coping strategies among women with breast cancer in Malaysia. The finding may not be generalized to other countries.

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Key Words: Breast Cancer; Mental Health; Qualitative; Sexual Dysfunction; Sexual Health
INTRODUCTION

Cancer is a critical turning point in life that permeates all dimensions of a person’s health and wellbeing. Sexual health is a central determinant of quality of life; it is multifaceted and changes during different stages of life. Sexuality is a human dimension that is best characterised in a biopsychosocial manner that extends beyond genitality. Women’s sexuality can be especially complex after a diagnosis of breast cancer, which can have serious physical and emotional side effects that may persist years after successful treatment.3

A review of existing literature reveals that female sexual dysfunction (FSD) is very common among breast cancer patients worldwide; its prevalence ranges from 31-77%, and it has been reported across cancer types, treatments, gender, age, and relationship statuses. A recent study found that breast cancer is a predictor for FSD and the body of scientific research on the impact of diagnosis, treatment modalities, and clinical stages of cancer on sexual function is growing.4

It is postulated that the negative impact of breast cancer treatment on sexual health is multidimensional — physical, psychological, and interpersonal. Physical consequences relate to the side effects of adjuvant therapies, either chemotherapy, radiotherapy and/or combination with hormone therapy. They may include fatigue, loss of breast sensation, and induced menopause due to oestrogen deficiency, which increases the likelihood of thinning and drying of the vagina (severe atrophy), decreased vaginal lubrication and decreased sexual drive. Intrapsychic predicaments often include a feeling of being “less a woman,” a loss of femininity, negative body image, and a feeling of sexual unattractiveness as a result of breast surgery due to scars, asymmetrical shape, and sensory changes. Negative emotional effects, including depression and anxiety, have also been associated with these changes. It is noteworthy that, despite major sexual changes, the impact of these changes on the quality of patients’ relationships may vary: Some women report persistent sexual problems that lead to complicated sexual activities and marital conflict, while a few describe positive increases in non-intercourse intimacy and manage to restore satisfactory sexual relationships after their diagnoses.5

Qualitative studies on quality of life have found that breast cancer treatments can have detrimental effects on sexual health by altering women’s symbol of their own femininity and due to negative psychological states, which can strain relationships. Despite the high FSD prevalence among breast cancer patients (up to 71%−90%), it is reported that the need for psychological supportive care with regards to sexual health among women with breast cancer is low. This may not fully reflect the actual status in a conservative society like Malaysia, where sexuality is seen as embarrassing and open discussion is discouraged, making sexual health a low priority for many women.

In relation to coping, Herzberg (2013) suggests that coping mechanism refers to a range of ways that individuals (with their couple and people surrounding) potentially interact when they experience any stressors. The individuals usually react focusing on their emotion and problems they tend to solve. Along the journey of coping, breast cancer patients have described various impressions: the death of their sexuality and intimacy; a rebirthing process in which they welcome early menopause; and disruptions to their relationships and a loss of self-esteem and confidence in their womanhood due to dismemberment of the breast. However, little research has been done in Malaysia on the coping mechanisms used by women with breast cancer to handle sexual health issues. Thus, in this paper, we explore the coping and strategies to overcome sexuality problems and sexual dysfunction among Malay women with breast cancer. Thus, in this paper, we explore the coping and strategies to overcome sexuality problems and sexual dysfunction among Malay women with breast cancer.

METHODS

In this study, a phenomenological approach and a qualitative study design were employed to facilitate interpretations and understandings of the coping strategies women with breast cancer use to overcome sexual problems and sexual dysfunction and to determine the significance of those strategies. Taking into account the importance of respondents’ actual words as essential sources of information, a qualitative model using interpretative (hermeneutic) phenomenological framework is used here as a platform to allow these women to fully describe the meaning of their internal experiences in their responses to the interview questions and to allow them to freely tell their stories in their own words capture.

We identified 64 eligible participants from the second phase of the larger study that matched the inclusion criteria of this research: 18−65 years old, married, sexually active, scored ≤19 in a validated Malay version of the Female Sexual Function Index-6 (FSFI-6) with the problem self-reported as newly developed after the diagnosis of breast cancer, no known psychiatric disorder or previous history of pelvic surgery excluding Caesarean section and partners do not have male sexual dysfunction. Using purposive sampling and data saturation principles, letters of invitation to participate in the study were given by hand to who were identified through two main public hospitals in Kelantan. There were 15 who agreed to participate then signed a written consent form indicating their agreement and appointment was made for the semi-structured interviews. The semistructured questionnaires guide used in this study were (i) How do you deal with your sexual problem(s)? (ii) Describe how your sexual problems have affected your life? In what way(s)? (iii) How do you seek help or healthcare for your sexual problems? (iv) If not, how do you cope? The study (the third phase of the larger study) was conducted over 6 months, from January 2019 to June 2019. The enrolment process ended once recurring patterns emerged in participants’ data. During the study, one respondent withdrew...
as she was unable to continue because she felt emotionally disturbed and unable to proceed with the interview session; subsequently was offered a referral to a physician or psychiatrist.

To acquire a full understanding of respondents’ life experiences, the interview sessions were conducted in person and in the participants’ mother tongue (Kelantanese dialect) to enable the authors to observe subtle or hidden meanings in the participants’ discourses. The interviewer was a female medical provider but does not treat these women. Meetings were scheduled via telephone, and most of the women opted for interviews in the clinic following their clinic appointments; some requested meetings at their homes. The arrangement for location was made based on patient’s preference. For both locations, one room was allocated for the interview sessions to ensure privacy. Prior to the actual interviews, a pilot study was conducted to determine key questions relevant to the respondents’ experiences for use in the interviews; possible photos for use during photo-elicitation were also identified if the participants have difficulties to produce their own. Total of 30 photos were generated and used for all participants with varied subject with regards to their emotions, consequences and strategies dealing with sexual dysfunction. The photo-elicitation method was used to develop better communication between researcher and interviewee; and to stimulate the respondents to share their experience that lie beyond the initial information shared in the first interview. Respondents took an average of 45 minutes to an hour to answer all the questions.

Two interview sessions were scheduled with each participant. In the first session, demographic and clinical information was obtained from the informants. Additional questions addressed respondents’ coping strategies for overcoming sexual problems and sexual dysfunction related to their journeys of living with breast cancer. A second interview was scheduled a fortnight following the first interview; this provided the researchers ample time to identify any incomplete data and allowed the respondents to think of other important information to address in the next interview. The second interview aimed to visualise the respondents’ experiences and understand their perceptions of images related to sexual dysfunction. This interview used the complementary method of “looking at” and “looking behind” photo-elicitation or drawings. All participants preferred the photo-elicitation method to drawing for elaborating on their descriptions of these issues. The first author also prepared fieldnotes after the interview. However, her own point of view on the issue was not included in the analysis to maintain the study’s objectivity.

The next step in data analysis involved ensuring that the interview responses could be analysed thematically. All interviews were audio-recorded, and the recordings were transcribed verbatim and entered into NVivo11 Pro (Qualitative Research Computer Analysis Package). Prior to that, 2 researchers (S.N. and N. H.Z.) read the first five transcripts multiple times to get a sense of the participants’ “whole stories.” Based on this, the two researchers coded these transcripts independently and created an initial list of codes in NVivo11 Pro. The codes were re-evaluated and finalised in consultation with the other researchers (R.M. and I.I.H.). During this process, new codes were continuously added into NVivo11 Pro as they appeared in subsequent transcripts. The coded items include passages, insights and thoughts relevant to the topic of this study. Similar codes in the participants’ words and the researchers’ interpretation were clustered to develop subthemes, and interrelated or connected subthemes were then grouped together as main themes. To ensure the study’s rigor, the main themes were agreed on by all researchers, 4 of whom are experts in qualitative research models (R.M., N. H.Z., P.L., and L.W.Y.). The main themes are presented in a master table (Table 2). The study not only highlights themes and patterns but also includes the “contradictions, ambivalence, and paradoxes” that emerged from the data on the participants’ lived experiences. The saturation of themes occurred when there were no new themes observed in our data particularly in the last 4 participants. In order to ensure the study’s credibility, the participants were contacted after the interviews via email to check and confirm the transcripts and emerged themes. All participants concurred with the study findings that reflected their lived experiences about coping mechanism and keen to share the outcomes to the community.

The study was granted ethical approval from the Clinical Research Centre, Ministry of Health, Malaysia; KKM/NIH-SEC/P18-547(11) and Human Ethics Committee, Universiti Sains Malaysia; USM/JEPEm/17090387.

RESULTS

The participants consisted of 14 women with breast cancer with various sociodemographic and clinical backgrounds (Table 1). These women aged an average of 51 years, married for average 22 years, and diagnosed with breast cancer an average of 3 years. All of them were on chemotherapy and radiotherapy. Only one fifth of women were also on hormonal therapy. All women had dyspareunia in combination with other domains of sexual dysfunction.

Three main themes emerged in the coping strategies Malay women with breast cancer use to overcome sexual problems and sexual dysfunction: (i) ‘Redha,’ or acceptance of the illness; (ii) Searching for help; and (iii) Avoidance of intimacy (Table 2).

“Redha,” Acceptance of the Illness

Prayers for Strength. Most of the participants use spirituality as a coping strategy for handling the consequences of breast cancer, including sexual problems. They said they view cancer as a trial from God to test their faith and patience. Most stated that their bodies and body parts belong to God and that they must accept it if He chooses to take part of their body back through cancer. They also believe that there is a disguised blessing in every hardship in life and that they will be repaid in the hereafter,
as life is only temporary. Some said that adversity is a gift to cleanse them from sin.

One participant stated that she would often pray for the strength to participate in sexual intercourse because she believed that it was her duty to satisfy her husband’s sexual needs (see Figure 1):

The excruciating pain lingered afterwards, and I would be wide awake, in agony. I always pray to God to give me good health so that I can fulfil my duty towards my husband. I particularly ask Him for help to give me strength to at least have intercourse without so much pain.

Another participant noted that, upon realising her sexual dilemma, her husband played his part by praying as well:

He comforted me a lot, encouraging me not to worry about my problem, and he was very accepting. He even shared with me that he always prayed to God to decrease his sexual desire because this is his partly a test for him, too.

Keeping a positive attitude towards their illness and sexual dysfunction gave participants the strength to move forward. A few chose not to dwell on issues of body image and allowed time to heal their negative emotions. One described the inner strength that has helped her handle the issue:

I believe every illness comes from God, so it is beyond me. We must be brave through life’s hardships, and I always remember God.

However, some patients struggle to accept their fate. One used Figure 2 to depict her struggle, especially during the early phases of treatment:

It was hard for me initially. I had too much on my plate. I needed to worry about my illness, my recovery, my family and the sexual issues, too.

Altered Sexual Practices. Some women deal with their sexual difficulties by altering their sexual practices. Many participants reduced the frequency of intercourse. Mrs E described her husband’s request for alternative sexual positions. One woman often resorted to quickie sex:

After my breast cancer treatment, I often refused intercourse in a respectful way, and he was receptive. The act required energy, and if it took too long, I would have body aches and leg cramps. I always asked him to finish quickly.

Other women became passive and engaged in undesired but consensual sex to avoid marital conflict:

I told him it (intercourse) was very painful for me, and he seemed to understand. However, whenever he approached me for it, I would just comply because I did not want him to hold a grudge against me.

Searching for Help

Following Health Professionals’ Advice. A few participants recalled that some healthcare providers had explained the possible sexual side effects of adjuvant treatments. One woman tried to follow medical advice about resuming normal life, including sexual activity:

The doctor told me that, as a cancer patient, I should resume daily activities as usual when my pain levels were very low. My main priority was my husband, so on certain days when I felt a lot better, I would signal to my husband that I was ready for intercourse. I could not expect to wait for pain-free days to meet my husband’s sexual needs. I believe I have to compromise.

Only one participant formally asked about her sexual concerns during medical consultations:

I told the doctor that intercourse was very painful, so he suggested buying lubricants. I did feel embarrassed, but, thankfully, the conversation was brief.

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**Table 1. Profile of women with breast cancer involved in the study, n = 14**

| Variables                  | Range / Mean (SD) | n (%) |
|----------------------------|-------------------|-------|
| Age                        | 39-65 51 (7.903)  | -     |
| Education level            |                   |       |
| Primary                    | 1 (7)             |       |
| Secondary                  | 5 (35)            |       |
| Tertiary                   | 8 (58)            |       |
| Occupation                 |                   |       |
| Housewife                  | 5 (35)            |       |
| Government servant         | 8 (58)            |       |
| Private sector             | 1 (7)             |       |
| Years of marriage          |                   |       |
| 1-10                       | 1 (7)             |       |
| 11-20                      | 8 (58)            |       |
| 21-30                      | 2 (14)            |       |
| 31-40                      | 3 (21)            |       |
| Years of breast cancer     |                   |       |
| 1-5                        | 13 (93)           |       |
| 6-10                       | 1 (7)             |       |
| Stage of breast cancer     |                   |       |
| I                          | -                 |       |
| II                         | 9 (64)            |       |
| III                        | 4 (29)            |       |
| IV                         | 1 (7)             |       |
| Treatment                  |                   |       |
| Lumpectomy                 | 3 (21)            |       |
| Mastectomy                 |                   |       |
| Unilateral                 | 10 (72)           |       |
| Bilateral                  | 1 (7)             |       |
| Reconstructive surgery     | 1 (7)             |       |
| Chemotherapy               | 14 (100)          |       |
| Radiotherapy               | 14 (100)          |       |
| Hormonal therapy           | 3 (21)            |       |
Modified Physical Appearance. Body image was a major concern for these women. Some took the initiative to wear a prosthesis, head covering, and brassiere so that their bodies looked almost the same as before treatment. This modification helped them regain their self-confidence:

I don’t want my breasts to look saggy to my husband, so I put on a sponge bra.

Only one participant underwent reconstructive surgery; she described how much this improved her self-esteem:

I am glad about my decision to do reconstructive surgery; it was the right thing to do because it strengthened me a lot psychologically. Even though it doesn’t function like a normal breast, at least I do not feel that half of them is missing.

A few participants used lubricants, such as jelly or organic oil, for vaginal dryness; they said that this helped relieve pain during sexual intercourse:

It (intercourse) was painful because of the dryness, similar to premature menopause. I did not tell my husband, but he...
might have noticed it, and he bought virgin coconut oil as a lubricant. I was ok with it because it reduced the pain.

Seeking Understanding From Husband. Most of the participants highlighted the importance of open communication with their husbands to handling their sexuality and sexual problems. They believe that explaining the consequences of breast cancer on their sexual lives helped their husbands be more considerate and understanding of the situation. Many expressed gratitude for husbands who were accepting of these sexual changes:

I told my husband that I have a problem with low sexual drive. I wanted him to understand that I was sick and I did not want sex as much. He was empathetic and started giving me longer foreplay and more stimulation.

One participant chose Figure 3 to illustrate her husband’s support following her honest revelation of her sexual issues:

I told him that I would meet his sexual needs even though I was tired because I did not want to commit a sin. He never commented on my flaws, and because of that, I am determined to take good care of my husband.

Another woman was grateful for her husband’s understanding and chose Figure 4 to illustrate her feelings:

This is how we are. My husband accepts me as who I am now. He can communicate his (sexual) needs and what he expects me to do differently during intercourse. I can feel his love and appreciation.

However, for some participants, sexuality in the form of penetrative intimacy was no longer the main focus in their lives, so they refrained themselves from discussing these issues with their husbands. They change sexual intercourse activities to other forms of intimacy and focusing more on the gendered role (Figure 5):

I felt that both of us struggle to enjoy sex at this age. We simply stopped doing it without any discussion; neither of us even brought up the topic for discussion.

Support From Other Survivors. Because sex is a culturally sensitive issue in Malaysia, few participants said they had sought help for sexual problems in real-life support groups. Only a handful had ever raised their concerns with group members in person, and acknowledgment that it was a common problem
gave them reassurance. The other participants said they prefer online support groups that allow them to remain anonymous:

I joined a local online breast cancer support group, and whenever I read that some other patients have also experienced sexual pain, I feel relieved, since I experience this, too. Some people do discuss this sensitive issue openly, but not me. I would just read and privately message the person for more information.

Avoidance of Intimacy

Avoidance of Sexual Intercourse. Many of the participants handle sexual difficulties through various avoidance tactics. Some said they had tried to refuse intercourse in subtle ways, such as not responding to foreplay, to avoid misleading their husbands into penetrative sex. They may also sleep facing away from their husbands, minimise cuddling, or occupy themselves with household chores to avoid going to bed at the same time as their husbands:

I often gave my husband excuses to avoid sex. I said I was tired; I have a lot of housework to do. After a while, he just let it go.

However, a few of them were straightforward and refused it bluntly:

It is too painful to have intercourse, so I told him not to. He complied.

Offers of Polygamy. While some participants expressed fears that their husbands might abandon them, a few were receptive to the idea of their husbands marrying another woman because they felt that they were incapable of fulfilling their husbands’ sexual needs:

I told my husband if he wanted to marry a second wife who could satisfy his (sexual) needs, he had my permission to do so. I know my inadequacy.

One woman recalled her willingness to share her husband with another woman out of guilt:

I felt sorry for him; I was not able to give him my best. I asked him to just marry another wife.

DISCUSSION

This study has explored how women with breast cancer cope with sexual transition using a meaning-making framework. We use a version of meaning-making theory that was adapted to apply to women with breast cancer.29 Meaning-making is a dynamic process that may change over time and depends on person’s broad outlook on life and the event’s personal significance for her (Figure 6).30 This theory provides insights on the adjustment process with the aim of liberating people from being passive victims of their circumstances and helping them become active participants in their lives via heightened mindfulness and accountability.30

Ching et al posit that coping strategies are primarily driven by a person’s “approach” and “focus”; these factors define the possible outcomes of a psychological adjustment. Based on approach and focus, people can be classified as fighters, followers, strugglers, or bearers.30 Those who focus on finding solutions and prefer an active approach will fight and seek help and treatment. Fighters usually resolve a problem by trying their best to control it. Women who follow the natural cause usually focus on coping but take a yielding approach and only accept help when it is offered, rather than seeking it out. In contrast, individuals who struggle with their life event focus on the problem but take an active approach; this often contributes to anxiety and depression. Similarly, those who focus on the problem but use a yielding approach will bear the situation, which they view as unmanageable; this leads to rumination. Most participants in the present study adopt the roles of followers or strugglers; only a few emerged as fighters.

Almost all the participants in this study cope with sexual issues by following the natural course through accepting the changes and modifying their sexual practices. These followers made positive meanings out of their sexual problems using their spiritual beliefs; they perceive God as powerful, compassionate, and fair, and this helps them accept their illness. A positive relationship with God and full reliance on Him evokes a sense of hope and helps them avoid resignation. They focus on solutions and use conforming approaches by altering their sexual practices to cope with their husbands’ sexual demands throughout their journeys. This finding converges with other non-Western literature, which has reported spirituality and religion as means for coping strategies that enable patients to follow the natural course of their illness.29,31–32

Although most participants in this study accept and follow the natural course of their illness, a few struggles to make meaning out of difficult sexual experiences; these focus on the problem and adopt a yielding approach. These strugglers are unable to accept the problems of FSD and prefer to avoid intimacy. This finding is in line with another study that found that Asian participants valued avoidance of conflict and marital harmony as signs of respect for one’s partner, in contrast to the traditional Western goal of emotional intimacy in marriage.32 Healthcare providers need to work within this framework of harmony, which undermines direct communication; they must focus on the nonverbal cues that these women frequently use to avoid intimacy. The other significant finding of this study is that several participants suggested polygamy to their husbands, which is permissible in Islam although it is not the way of avoiding sexual intimacy.

A few of the study participants adopt the role of fighter by searching for help and treatment. They accept their illness and focus on coping, using an active approach. The significant
finding of this study is that women rarely seek formal advice from health professionals on sexual issues; this aligns with previous studies finding that breast cancer patients are very unlikely to seek consultation regarding sexual issues. The main concerns of most breast cancer patients include whether sex is safe during chemotherapy or after surgery, questions about bodily changes due to chemotherapy, and methods for coping with sexual distress. This study also found that physical modifications using female accessories are essential to handling disruptions to body image and are key to improving breast cancer patients’ self-confidence and helping them feel “normal”; this aligns with previous studies. A positive body image enables self-compassion and self-acceptance, whereas a poor body image may lead to negative marital and social coping strategies, specifically avoidance, self-blame, or cancellation of social engagements.

Most of the fighters in the study try to find solutions by actively seeking understanding from their husbands. They believe that intimacy issues deserve open communication between the partners with the goal of mutual understanding and cooperation in addressing problems; this finding also aligns with previous studies. Support, love, and confirmation through communication between the partners resulted in participants’ gratitude and higher relationship satisfaction, despite limitations to the erotic aspect of their relationships.

The other fighters in this study acknowledge the role of social support groups in their pursuit of treatment and solutions for sexual problems; this finding is similar to those of previous studies. Although Asian women in general are less likely to discuss sensitive issues with their families and friends due to a desire for privacy and a wish to avoid burdening significant others, other studies in this region report that social support helps women feel comfortable sharing their problems during illness, improves their self-esteem, and increases their optimism.

Our study provides insight into why some women with breast cancer are distressed about their sexuality and problems with sexual dysfunction while others are not. The keys to coping strategies amongst Malay women are their religious beliefs and the context of their partnerships — that is, how much they value their relationships with their spouses similar to what had been
Coping Strategies for Sexual Problems and Sexual Dysfunction Amongst Malay Women

need to initiate open communication about sexual dif
ers, and available support in detail. Only then can healthcare
journey. Providers should explore patients’ embedded religious
with Malay women by performing detailed assessments in order
to identify the meaning-making patterns in each patient’s life

The findings of this study imply that healthcare providers
need to initiate open communication about sexual difficulties
with Malay women by performing detailed assessments in order
to identify the meaning-making patterns in each patient’s life

The strength of this study lies in its use of a phenomenological
analysis involving face-to-face, in-depth interviews including photo-
elicitation in order to gain profound insights into this sensitive topic.
The data from this first qualitative model in Malaysia on breast can-
cancer patients’ coping strategies for addressing sexual problems and
sexual dysfunction can expedite assessment and management in
clinical settings while enabling healthcare professionals to provide
holistic, personalised care to women with breast cancer.

The limitations of this study include the small sample size led
to no stratification for types of dysfunction, menopausal status,
procedures, alternative practices and treatments among the
women with breast cancer, which may limit the discussion and
generalizability of the findings to the entire Malay population.
This study only involved women of Malay ethnicity with various

CONCLUSION

In conclusion, the findings of this study highlight the various
coping and strategies adopted by Malaysian women with breast
cancer when faced with sexual problems and sexual dysfunction.
These strategies are predominantly based on the participants’
religious beliefs and relationship contexts. Motivational and hin-
dering factors in handling these private issues must be individu-
ally evaluated to provide personalised care to improve patients’
quality of life. Healthcare providers also should offer opportuni-

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