HUSBANDS' EXPERIENCE OF LIVING WITH SURVIVORS OF BREAST CANCER WHO HAD SEXUAL DYSFUNCTION, IN KELANTAN, MALAYSIA

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ABSTRAK

Pengenalan: Disfungsi seks adalah berleluasa dikalangan perempuan yang mengidap cancer payu dara. Mengalami disfungsi seks di samping kanser payudara memberi kesan bukan sahaja kepada isteri, malah juga kepada suami. Mengambil tahu tentang masalah hubungan keluarga dan masalah seksual dapat mengurangkan kesan negative dan dapat memberi kebaikan untuk kesihatan kepada pasangan suami isteri. Suami merupakan tulang belakang utama untuk memberi sokongan kepada isteri yang mengidap kanser payudara.

Matlamat: Untuk mengetahui pandangan suami tentang seksualiti dan pengalaman mereka menghadapi masalah isteri yang mempunyai disfungsi seks selepas kanser payu dara

Metodologi: Satu kajian kualitatif yang menggunakan pendekatan fenomenologi, melalui temu ramah yang telah dijalankan dengan 14 orang suami yang masih aktif melakukan seks bersama isteri yang mengalami disfungsi seks selepas mengidap kanser payudara di Kelantan. Pesakit yang dipilih menyertai temuduga pada selang masa September 2019 sehingga Mac 2021 mesti lah tidak mempunyai masalah mati pucuk dan mendapat markah >11 dalam ujian indeks fungsi antarabangsa disfungsi erektil. Temuduga yang dijalankan akan direkod dan ditranscripsikan kepada tulisan.

Transcripsi akan di pindah untuk dianalisakan menggunakan aplikasi komputer NVivo® untuk mengurus data dan menganalisa. Tema yang dianalisa akan diaplikasikan dan dimasukkan ke dalam teori 'meaning-making'.

Keputusan: Terdapat empat tema yang terbentuk bagi memahami pengalaman suami: Pemahaman seks yang sempit, seksual emosi, penyesuaian keintiman, dan penyaluran kehendak seksual.

Kesimpulan: Kajian ini menekankan tentang beban yang ditanggung oleh seorang suami untuk menghadapi isteri yang mengalami kanser payudara dan mempunyai masalah disfungsi seks selepas mengidap kanser payudara. Suami menunjukkan pelbagai respon dan cara mengatasi dengan menggunakan kepercayaan agama dan mengalihkan perhatian daripada mekikirkan hubungan seks kepada perhatian terhadap kesihatan isteri atau melakukan aktiviti lain.

Kata kunci: kanser payu dara, akibat, mengatasi, suami, seksualiti, disfungsi seks

ABSTRACT

Background: Sexual dysfunction is prevalent among Malaysian women with breast cancer. Having sexual dysfunction on top of breast cancer cause consequences not only to the wives but also to their husbands. Understanding about our clients' sexual and relationship issue may reduce negative consequences and provide better health outcome for both parties since husbands or partners act as the main supporter for our patients.

Aim: To explore husbands' view on sexuality and their experiences when dealing with the wives' sexual dysfunction after diagnosed with breast cancer.

Methods: This qualitative study was conducted within phenomenological framework among sexually active husbands of wife with sexual dysfunction after breast cancer in Kelantan. Husbands who did not have erectile dysfunction following sexual screening using International Index of Erectile Function (IIEF-5) with the score of >11 were purposely encouraged to participate in in-depth interviews between September 2019 and March 2021. The interviews were audio-recorded and transcribed verbatim. The transcriptions were then transferred to analytic computer software NVivo® for data management and analysis. The thematic analysis was done by placing meaning making theory in to the consideration.

Results: Four themes were developed to understand the experience of the husbands: Narrow sexual understanding, emotional sequela, intimacy adaptation, channelling sexual needs

Conclusion: This study highlights the experience of husband dealing with wife sexual dysfunction after breast cancer. Husbands embraced various respond and coping strategies that emphasised the religious belief and self-distraction pivoting sex to health concern and other activities.

Keywords: Breast cancer, consequences, coping, husband, sexuality, sexual dysfunction

CHAPTER 1
INTRODUCTION

Female sexual dysfunction had been defined by a Consensus Statement from the Fourth International Consultation on Sexual Medicine 2015, that it is the distress associated with sexual symptoms that last at least three months and occur at least in 75% of sexual experiences (McCabe *et al.,* 2016). According to American Psychiatric Association (2013), female sexual dysfunction general term containing several sexual health concerns that can be distressing for female patients and it is categorised into three groups which are female sexual interest/arousal disorder, female orgasmic disorder and genito-pelvic pain/penetration disorder. Breast cancer is the highest among the ten most common cancers in Malaysia from 2012 to 2016. The total number of breast cancer patient is 21,634 cases were diagnosed for the period 2012 to 2016 which account for 34.1% of cancer cases. Chinese had the highest incidence in Malaysia followed by Indian and Malay. As for the incidence among different states in Malaysia, Penang has the highest incidence of breast cancer cases with 55.2% while Kelantan has third lowest at 20.8% per 100,000 as reported (Malaysia Ministry Of Health, 2019).

The prevalence of female sexual dysfunction (FSD) among women with breast cancer after receiving treatment in the North-eastern part of west Malaysia was 73.4%. Among the significant factors that associate breast cancer survivors are family history of breast cancer, duration of marriage and frequency of sexual intercourse (Ooi *et al*.,2021). Other study done in Malaysia also shows that prevalence of sexual dysfunction among 100 patients with breast cancer in University Malaya Medical Centre (UMMC) as assessed by the Female Sexual Function Index (FSFI) with the cut-off score of ≤ 26.6 was 90.0% (Norley, 2014). In a study done in USA among 83 long-term breast cancer survivors, 77% of the participants were considered to have sexual dysfunction based on FSFI. While 37% and 51% of them qualified for female sexual dysfunction based on two Female Sexual Distress Scale-revised (FSDS-R) clinical cut offs (Raggio *et al.,* 2014). There is one prospective study from Iran assess the sexual function of 277 breast cancer patients attending the Cancer Institute of Iran using FSFI before

and after treatment. The report showed significant drop in sexual function after their treatment as the pre and post treatment sexual dysfunction was found to be 52% and 84% respectively (Harirchi *et al.*, 2012). Another study which was done among 150 women with genital and breast cancers in Iran was done, they reported 47% of the women have sexual dysfunction with mean (SD) age of 47 (7.7) years (range from 25 – 65-year-old) (Fahami *et al.*, 2015). For prevalence in a younger group of patients, a study was conducted among female aged 25-45 years with breast cancer using FSFI, also done in Iran. The study compared with a control group of female participants. From 186 patient with breast cancer, most common sexual dysfunction that developed after breast cancer are lubrication disorder (57%), followed by satisfaction disorder (53.8%), desire disorder (42.5%) and arousal disorder (37%) (Safarinejad *et al.*, 2013). Research among western women found that disturbance to sexual functioning following breast cancer included dyspareunia, fatigue, vaginal dryness, decreased sexual desire, decreased sexual arousal, numbness in previously sensitive breast, difficulty in achieving orgasm and lack of sexual pleasure (Emilee *et al.*, 2010). Studies in Chinese, Iranian and Turkish population also yielded similar results (Can *et al.*, 2008; Zee *et al.*, 2008; Alicikus *et al.*, 2009). Ganz *et al.* (2003) reported that younger women faced greater challenges in the form of sexual dysfunction, loss of reproductive opportunity and premature menopausal symptom especially vaginal dryness.

Consequences of breast cancer had been studies involved non-White woman with breast cancer showed negative experiences including psychological distress, sexual and marital concern and fatalistic view (Taib *et al.*, 2011; Norsaadah *et al.*, 2012). Nonetheless, other studies had shown that some individuals developed positive personal growth because of personal relationship experiences (Ashing-Giwa *et al.*, 2004; Ahmad *et al.*, 2011; Tighe *et al.*, 2011). Tighe *et al.* (2011)reported there was evident need for sexual health and relationship counselling because breast cancer is a complex feature of survival that impacts and reflects

upon the quality of interpersonal relationship. Relationships had been shown to experience substantial stress during breast cancer, with 25% reported to suffer from relational strain, 35% felt that their partners to be emotionally unavailable and 12% reported a separation (Walsh *et al.*, 2005).

Sexual assessment or counselling on sexual matter is not routinely provided to breast cancer patients in oncological settings. Several studies had been conducted on breast cancer patients in Malaysia focused on various aspects such as social support, body image, quality of life and psychological reactions (Hwa *et al.*, 2011; Yusuf *et al.*, 2013a; Yusuf *et al.*, 2013b; Lim *et al.*, 2015). Another study in assessing supportive care needs among breast cancer women in Sarawak concluded that sexuality domain score was low due to underreporting of sexual needs as it was an intimate matter and not for discussion within Asian community (Fong and Cheah, 2016). Recent qualitative study done to look for the perspective of healthcare providers at North East Malaysia in managing sexual dysfunction for woman with breast cancer shows that healthcare providers and patient felt embarrassed to talk about sexual problem. Healthcare providers also confess that they have never or only minimal training on sexual health issue. Thus they tend to focus more on their specialty and never or only small part of counselling talk about sexual health and female sexual dysfunction with their patients (Chanmekun *et al.*, 2021). A study in Australia reported that only 30% of women who was diagnosed with breast cancer had discussed about sexuality with their health care professionals, indicating that this is an aspect of quality of life which is often neglected (Hawkins *et al.*, 2009). Comparative study in Korea also revealed the unwillingness of breast cancer patients to talk about sexual problems, thus giving challenges to healthcare provider in giving counselling or information (Kim *et al.*, 2009). Montazeri (2008) highlighted the importance of discussing and emphasizing sexuality aspect during follow up to improve the quality of life among breast

cancer patients. In a study by Hordern and Street (2007), the authors reported about the unmet patients' need in communicating about intimacy and sexuality among cancer patients.

Partner of breast cancer patient respond with the new changes and how they cope with their life affect their relationship. When patient have declined in sexual function, it will affect their partner. Partner support is one of important factor that can affect patient emotional and physical problem (Stenberg *et al.,* 2010). We should treat breast cancer patient not only the disease, but also their mental and social wellbeing as stated by World Health Organization that health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (Callahan, 1973). Family oriented healthcare is one of core concept of family physician where by treating the family as the unit of care because individual and family are inseparable (Buckingham *et al.*, 2013). Thus, husband health condition must be considered because living with wife with breast cancer also give negative effects on husband. Many studies indicated that husbands or partners also experienced difficulties since the day their spouses were diagnosed with breast cancer (Marshall and Kiemle, 2005; Loaring *et al.*, 2015). Support from a partner can play a key role in a woman's emotional adjustment to breast cancer (Kinsinger *et al.*, 2011). Depression and anxiety are among the significant emotional difficulties for both patient with breast cancer and their partner have experienced (Marshall and Kiemle, 2005; Gilbert *et al.*, 2010). This is because husbands or partners are unprepared for this phenomenon (Zahlis and Lewis, 2010), and felt burden related to the increased role and responsibility demands (Stenberg *et al.*, 2010).

Husbands or intimate partners are key support for breast cancer women. Many literatures argue that husbands still unclear of what they should do to support their wives. In fact, they really need comprehensive information related to disease, treatment, prognosis, the consequences of cancer to quality of life of both sides which include their sexual well-being and relationship (Adams et al., 2009; Fletcher, Lewis, & Haberman, 2010). Female sexual

dysfunction is seldom discussed during consultations either patient or partner (Moreira *et al.*, 2005). Initiating a conversation on sexual health matters is very difficult due to the sensitivity, complexity, and constraints of time (Marshall and Kiemle, 2005)

Studies related to consequences of living with FSD and breast cancer wives unfortunately are very limited. Marshall and Kiemle (2005) explored the consequences of breast cancer to sexual functioning of 12 women, three years post mastectomy and their partners (10 men). They found that all women experienced some degree of sexual change and sexual anxiety, and a few felt loss of their sexual self. While many partner experienced mainly sexual anxiety. Breast cancer has led many partners to change their sexual focus to their spouses' health during the initial phase of the treatment (Zahlis and Lewis, 2010). This issue, however, still deserve an exploration among the Malaysian population. There is lack of published qualitative data and only have published data from other countries regarding husbands dealing with sexual dysfunction wife after breast cancer. Breast cancer has also led many husbands to change their roles, responsibility and sexual attention (Zahlis and Lewis, 2010). Thus, this issue deserves an exploration among Malaysian population since sexual relationship is one of important factor to have a marital satisfaction (Tavakol *et al.*, 2017).

This study will use meaning making discourse theory to explain about lived experience of husband and wife with breast cancer. The meaning making was theorized by Park and Folkman (1997) within the broader framework of stress and coping theory. We propose that individuals are required to make meaning of their life circumstances in order to deal with adversities in life. The meaning making is a psychological process which elucidates how people construe traumatic and potentially destructive incidents that occur to them (Park and Folkman, 1997).

Shocking and stressful experience often lead the patients to question 'why it happened to me?' In the process of looking for underlying explanations, people "make meaning from the event". Meaning making can be different individually and may change over time depending on

the person's broad outlook towards life and personal significance of the event. This process is essential in equipping people with stressful life changing events specifically sexual problem and marital relationship in coping with their problems. Those who cannot make meaning out of specific experiences would face difficulties dealing with them (Park and Folkman, 1997). Meaning making discourse will assist us to understand how individuals handle the situations of living with their illnesses (Plattner and Meiring, 2006). The theory highlighted that meaning-making can be perceived as both "part of coping" and "an outcome of the coping process" in the course of dealing with stressful incidents (Park and Folkman, 1997).

MEANING MAKING THEORY FOR HUSBAND LIVING WITH WIVE OF BREAST CANCER AND SEXUAL DYSFUNCTION

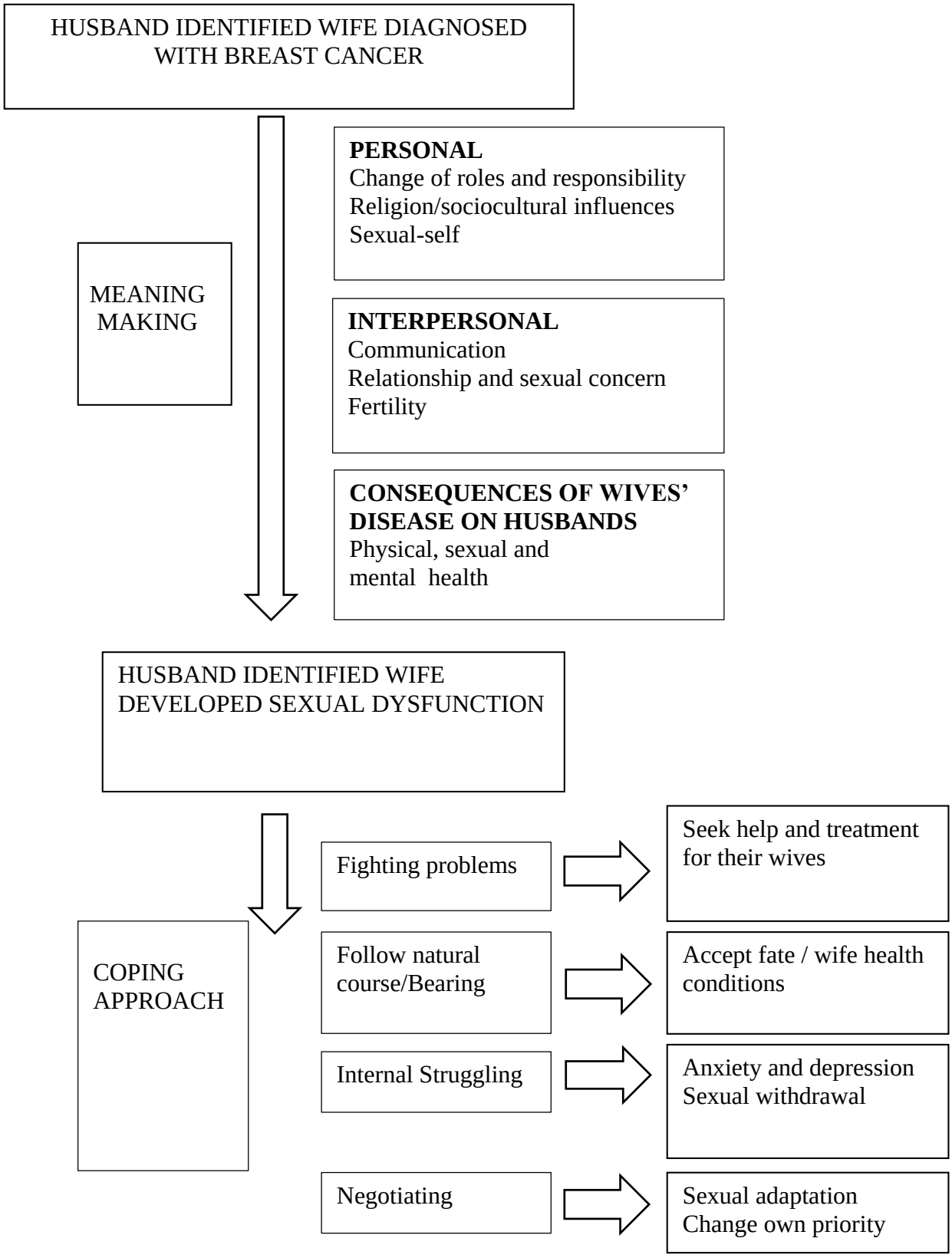

Figure 1 Conceptual framework adopted from meaning making theory (Adapted from Park and Folkman. (1997))

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CHAPTER 2
OBJECTIVES OF THE STUDY

2.1 GENERAL OBJECTIVE

To explore husbands' view on sexuality, sexual dysfunction, experiences and their coping mechanism in dealing with sexual dysfunction among those with breast cancer wives.

2.2 SPECIFIC OBJECTIVE

1. To explore husbands' understanding of sexuality.
2. To explore husbands' experiences of living with breast cancer patients complicated with sexual dysfunction.
3. To explore the consequences of female sexual dysfunction on husbands and their relationship.
4. To explore the coping strategies adopted by husbands to overcome this problem.

CHAPTER 3
MANUSCRIPT

3.1 TOPIC

"SEXUAL SACRIFICE": HUSBANDS' EXPERIENCE OF LIVING WITH SURVIVORS OF BREAST CANCER WHO HAD SEXUAL DYSFUNCTION, IN MALAYSIA

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3.2 ABSTRACT

Background: Sexual dysfunction is prevalent among Malaysian women with breast cancer. Having sexual dysfunction in addition to breast cancer, results in substantial consequences not only for the wives but also for their husbands. Understanding about our clients' sexual and relationship issues may reduce negative consequences and provide better health outcomes for both parties as husbands or partners are our patients' main supporters.

Aim: To explore husbands' views on sexuality and their experiences when dealing with wives' sexual dysfunction after being diagnosed with breast cancer.

Methods: This qualitative study was conducted within the phenomenological framework among sexually active husbands of wives with sexual dysfunction after breast cancer diagnoses in Kelantan. Husbands who did not have erectile dysfunction following sexual screening using the International Index of Erectile Function (IIEF-5) with a

score >11 were encouraged to participate in in-depth interviews between September 2019 and March 2021. The interviews were audio-recorded and transcribed verbatim. The transcriptions were then transferred to analytic computer software NVivo® for data management and analyses. Thematic analyses were conducted by considering meaning making theory.

Results: Four themes were developed to understand the experience of the husbands: Narrow sexual understanding, emotional sequela, intimacy adaptation, channelling sexual needs

Strengths and Limitations: The strength of this study includes the phenomenological framework using in-depth interviews to explore delicate and sensitive issues about sexuality thoroughly. The limitation was that the majority of husbands were Malay, thus we are unable cover the three main ethnicities in Malaysia and other limitation was sensitive of sexuality topic and respondent may not be open to full disclosure of their feelings and coping strategies.

Conclusion: This study highlights the experience of husbands dealing with wives' sexual dysfunction after breast cancer. Husbands embraced various response and coping

strategies that emphasized religious belief and self-distraction, pivoting sex to health concerns and other activities.

Keywords: Breast cancer, consequences, coping, husband, sexuality, sexual dysfunction

3.3 INTRODUCTION

Female breast cancer has become the most common type of cancer worldwide, and surpassed lung cancer in 2020. A total of 2.3 million new cases of female breast cancer were diagnosed in 2020, making it the most frequent type of cancer among women [1]. This report is parallel to the occurrence of cancer in Malaysia, where breast cancer is among the most commonly reported type of cancer between those aged 25 and 65 years [2]. In Malaysia, the prevalence of female sexual dysfunction (FSD) among women with breast cancer after receiving treatment was 73.4%. Among the significant factors that associate survivors of breast cancer with FSD are family history of breast cancer, duration of marriage, and frequency of sexual intercourse (SI) [3].

Managing cancer should treat not only the patient but also the partner or husband of the patient. Pauwels et al. (2013) found that the relationship with one's partner is an important factor involved in the care required after breast cancer treatment [4]. A partner's support is significantly affected if the wife develops sexual dysfunction as sexual difficulties reduce relationship satisfaction [5]. This is because partners respond to the new changes and how they cope with their life will affect their relationship. Partner support is an important factor that can affect patients' emotional and physical problems [6]. Taking good care of the couple during follow up offers better health outcome for the couple's relationship.

Breast cancer has led many partners to change their sexual focus to their spouses' health during the initial phase of the treatment [7]. Marshall and Kiemle (2005) explored the consequences of having breast cancer to sexual functioning women, three years post mastectomy and their partners and they found that all women experienced some degree of sexual change and sexual anxiety, and a few felt loss of their sexual self. While many partner experienced mainly sexual anxiety [8]. Studies related to s of living with female sexual dysfunction and breast cancer wives unfortunately are very limited.

Many studies indicated that husbands or partners also experience difficulties since the day their spouses were diagnosed with breast cancer [8,9]. Support from a partner can play a key role in a woman's emotional adjustment to breast cancer [5]. Depression and anxiety are among the significant emotional difficulties both patient and partner have experienced [8,10]. This is because husbands or partners are unprepared to this phenomenon [7], and felt burden related to the increased role and responsibility demands [6].

Unfortunately, FSD is seldom discussed during consultations with either patients or their partners [11]. Initiating a conversation on sexual health matters is difficult because of their sensitivity and complexity, and time constraints. The main reasons why patients and partners refuse to discuss sexuality are that this topic is too personal or private, and they are not comfortable discussing their general and sexual relationship [8]. Therefore, this study aimed to understand the meaning of sexuality among husbands and their experiences living with wives who suffered from FSD after breast cancer.

This study will use meaning making discourse theory to explain about lived experience of husband and wife with breast cancer. The meaning making was theorized by Park and Folkman (1997) within the broader framework of stress and coping theory. We propose that individuals are required to make meaning of their life circumstances in order to deal with adversities in life. The meaning making is a psychological process which elucidates how people construe traumatic and potentially destructive incidents that occur to them [12].

Shocking and stressful experience often lead the patients to question 'why it happened to me?' In the process of looking for underlying explanations, people "make meaning from the event". Meaning making can be different individually and may change over time depending on the person's broad outlook towards life and personal significance of the event. This process is essential in equipping people with stressful life changing events specifically sexual problem

and marital relationship in coping with their problems. Those who cannot make meaning out of specific experiences would face difficulties dealing with them [12]. Meaning making discourse will assist us to understand how individuals handle the situations of living with their illnesses [13]. The theory highlighted that meaning-making can be perceived as both "part of coping" and "an outcome of the coping process" in the course of dealing with stressful incidents [12].

3.4 METHOD

Phenomenology is one of the most common methodologies used in qualitative studies [14]. The phenomenology study involves the exploration of lived experiences, lived phenomena, or changes occurring in a person or people. In this study, phenomenology helps to describe experiences of the husband's viewpoint, what they go through physically, how they feel emotionally, and what influences their thinking. It covers various possible aspects of experience so that husbands can reflect and take meaning from living with the phenomena [14, 15].

Setting:

The study conducted in Kelantan, located in the north-eastern corner of the peninsula Malaysia. Interview was held at participants' home or at consultation room in the hospital. To maintain privacy , interview was done between participant and interviewer only.

Participants:

This study is a continuation of Che Ya et al., (2021) sexual problems and sexual dysfunction amongst malay women with breast cancer. Their Index case is a woman with a breast cancer patient who is known to have sexual dysfunction according to Malay Version of Female Sexual Function Index-6 (MVFSFI-6) with the score ≤ 19 and married for at least 1 year. We collect our case from their participant's husband. Among 50 husbands who agree to be contacted, only 14 husbands agree to participant in our study. Some of them refuse to participate due to personal reason and sensitive issue. All participants must be aged 18 years old and above, currently married to index case, heterosexually active, able to communicate well in Malay, not practice polygamy before wife diagnosed breast cancer and not known case of psychiatric disorders such as depression, anxiety or schizophrenia. They were screen for sexual dysfunction based on Malay version International Index of Erectile Function (IIEF-5). All of them score IIEF-5 >11 and included in the study.

Procedure:

After ethical permission from the Human Research Ethics Committee of Universiti Sains Malaysia (USM), the researchers wrote a letter to the respected hospital to seek permission to conduct research.

After obtaining the approval from the hospital's director, participant were identified based on inclusion criteria. Researchers received the contact number of patients from their wife as index case. Written consent obtained. Subsequently, a face-to-face, in-depth interview (IDI) was held by the first author. The interviews were held in Kelantanese Malay dialect and it was recorded using two digital voice recorders. The average duration of the interview was around one hour.

Participants were asked to complete the socio-demographic information (**Appendix A**) before interview began. Participant were informed of this study's aims, the dissemination of results, and their confidentiality. The first author conducted semi-structured interviews based on semi-structured questionnaire in Malay. They were asked about their understand of sexuality, experience and consequences living before and after their wife diagnosed breast cancer and developed sexual dysfunction and how they cope with it. For each interview, the field notes were written based on our perception, experience, and interaction with the interviewee during the interview sessions. This note was necessary to help us better understand the phenomenon. Each documentation has been transcribed verbatim. Member checking was done by giving back the transcribed to the participants to check. All participants agreed with what have been transcribed.

The interviews were first piloted by the first author among first three participants under the supervision of our senior researcher who was well trained in qualitative research. The pilot study was conducted to ensure the suitability and comprehensibility of the semi-structured