SEXUALITY AND SEXUAL DYSFUNCTION AMONG WOMEN WITH BREAST CANCER: A QUALITATIVE STUDY IN KELANTAN, MALAYSIA

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ABSTRAK

Pengenalan: Seksualiti wanita menjadi kompleks selepas rawatan kanser payudara dan kesihatan seksual seringkali diabaikan dalam rawatan kesihatan. Disfungsi seksual diketahui sangat lazim berlaku kepada wanita yang menghidap kanser payudara di Malaysia akan tetapi ianya tidak diberi perhatian sewajarnya sepanjang tempoh rawatan.

Matlamat: Untuk mengkaji kesan dan cara mengatasi berkenaan seksualiti dan disfungsi seksual di kalangan wanita yang menghidap kanser payudara di Malaysia.

Metodologi: Kajian kualitatif ini dijalankan berpandukan analisa fenomena. 14 wanita berkahwin yang menghidap penyakit kanser payudara dan memenuhi kriteria disfungsi seksual wanita di Hospital USM dan Hospital Raja Perempuan Zainab 2, Kelantan telah mengambil bahagian dalam temubual secara mendalam dan fotosuara dalam tempoh Jun 2018 sehingga Disember 2018. Temubual tersebut telah direkod suara, ditranskrip dan dimasukkan ke dalam perisian analisis computer NVivo® bagi tujuan pengurusan data. Transkrip tersebut dianalisa menggunakan analisis bertema berdasarkan 'sexual script theory' dan 'meaning-making theory'.

Keputusan: Hasil kajian menunjukkan rawatan kanser payudara telah mengganggu kitaran tindakbalas seks wanita yang menyebabkan perubahan maksud seksualiti daripada hubungan intim perkahwinan kepada tanggungjawab yang lebih mengutamakan kemesraan fizikal daripada persetubuhan. Wanita ini diselubungi perasaan kekurangan dalam peranan berdasarkan jantina. Ada sesetengah wanita menyedari perubahan prestasi seksual suami dan cuba ditempuhi bersama- sama dengan sentimen kelemahan diri sebagai isteri. Perasaan cemas

dan bersalah muncul dalam perjalanan hidup mereka diiringi emosi suami samada kekecewaan ataupun keprihatinan terhadap mereka. Untuk mengatasi masalah seksual dah disfungsi seksual, wanita ini berusaha menerima masalah ini menggunakan kekuatan kepercayaan terhadap agama dan menghadapinya dengan cara mengubahsuai aktiviti seks. Mereka mencari jalan penyelesaian secara positif melalui konsultasi kesihatan, mengubahsuai penampilan diri, perbincangan secara terbuka dengan pasangan dan mendapatkan sokongan daripada wanita lain yang menghidap kanser payudara. Sebahagian daripada mereka menghadapinya secara pasif dengan mengelak hubungan intim ataupun memberi kebenaran kepada suami untuk mengamalkan poligami.

Kekuatan dan Had Kajian: Kekuatan kajian ini adalah kerangka fenomena menggunakan temubual secara mendalam dan penceritaan melalui gambar untuk membantu mengkaji topik seksualiti yang sensitif secara mendalam. Had kajian adalah hanya melibatkan wanita Melayu yang berkahwin daripada kalangan sosio-ekonomi yang rendah-sederhana melalui kaedah persampelan bertujuan menyebabkan hasil kajian tidak dapat diumumkan kepada populasi yang lain.

Kesimpulan: Kajian ini menunjukkan bebanan kanser payudara dan rawatannya terhadap kesihatan seksual pesakit dan pasangan maka kenalpasti dan tangani masalah tersebut akan memberikan pengalaman hidup sebagai pejuang kanser payudara yang lebih baik. Wanita yang menghidap pesakit kanser payudara di negara ini menggunakan pelbagai strategi yang menekankan kepercayaan agama dan kesejahteraan hubungan sebagai kunci utama untuk menghadapi masalah seksual.

Kata kunci: kanser payudara, disfungsi seksual wanita, seksualiti, kesan, cara menangani

Abstract

Background: Women's sexuality becomes complex after breast cancer treatment and sexual health often being neglected in medical care. Sexual dysfunction is highly prevalent among women with breast cancer in Malaysia however it remains invisible in clinical management of the illness.

Aim: To explore the consequences and coping strategies on sexuality and sexual health among the women with breast cancer in Malaysia.

Methods: This qualitative study was conducted within phenomenological framework. 14 married women with breast cancer that fulfill the criteria for female sexual dysfunction (FSD) from Hospital USM and Hospital Raja Perempuan Zainab 2 in Kelantan participated in in-depth and photo elicitation interviews between June 2018 until December 2018. The interviews were audio-recorded, transcribed verbatim and transferred to analytic computer software NVivo® for data management. The transcriptions were analysed using thematic analysis based on the sexual script theory and meaning making theory.

Results: Finding shows that breast cancer treatments had disturbed the women's sexual response cycle leading to changes in direction of meaning of sexuality from marriage intimacy to obligation that preferred physical affection rather than penetrative intercourse. The women struggled with feeling deficiency in gendered role. A few even noticed changes in husband's sexual performance and these were in battling with inadequacy sentiment as a wife. Fear and guilt surfaced within the journey accompanied by the spouse's emotion of either exposing frustration or becoming more attentive towards the women. To overcome sexual problem and sexual dysfunction, the women strived to accept the illness using religious belief and conform

by altering sexual practises. These individuals positively look for 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 towards polygamy.

Strengths and Limitations: The strength of this study includes phenomenological framework using in-depth and photo-elicitation interviews helps to explore delicate and sensitive issue about sexuality thoroughly. The limitations are only Malays, heterosexually married from low to middle socioeconomic background using purposive sampling were enrolled causing the finding cannot be generalised to other population.

Conclusion: This study highlights the burden of breast cancer and its treatment on the sexual well-being of the patient and spouse hence recognising and addressing the sexual health will improve the overall survivorship experience. Women with breast cancer in this country embraced various mechanism that emphasised the pivotal role of religious belief and relationship context as key factors in the coping strategies.

Keywords: breast cancer, female sexual dysfunction, sexuality, consequences, coping

Chapter 1
INTRODUCTION

1.1 BREAST CANCER AND SEXUALITY: MY INITIAL JOURNEY

My interest in breast cancer and sexuality began during my internship training in surgical department in Northern East Malaysia. I came across a few patients that refused treatment by giving excuse of marital concern. This intrigued me as unmarried lady at that time about the real issue underneath the refusal because early intervention in cancer treatment is lifesaving. However, the busy schedule as an intern did not permit me to look up further for information so it was left unanswered.

My undergraduate experience had exposed me to holistic approach in providing care to an individual and driven me to pursue in Masters of Family Medicine in 2016. This specialty emphasised on biopsychosocial model that is cultural and value-based in order to provide comprehensive and personalised care in the community. Sexual health was one of the core topics in our syllabus and as shy I was as a Malay lady despite being married at that time, I had to put on a game face and probed into this private issue with my patients.

Coincidently, one of my cousins was diagnosed with breast cancer and raised her concern about possible side effects of the surgery and adjuvant therapies. It was at this juncture, it struck me that perhaps my previous patients with breast cancer actually struggled with their own sexuality and sexual dysfunction hence refusing the treatment option. I knew then that I had to move out from my comfort zone and immersed into understanding about sexuality and sexual dysfunction from the women with breast cancer's perspectives.

1.2 SEXUALITY AND SEXUAL DYSFUNCTION: MEANING AND SIGNIFICANCE

Understanding the meaning of sexuality and its position in illness is crucial before I embark into the research on sexuality and female sexual dysfunction (FSD). Referring to World Health Organisation, sexuality is defined as "a central aspect of being human throughout life and greatly influenced by the interaction of biological, psychological, social, culture, religious and spiritual factors".(1) It embraces the physical and mental practices either with oneself or another in order to obtain sexual pleasure; involves in integration of the personal identity and contributes to procreation.(2) Sexuality directly relates to experiences of oneself as sexual being and integral aspect of total human personality.(3)

Sexuality is a basic need and an essential aspect for many women.(4) Therefore, it has been incorporated into quality of life assessment for each person inflicted with illness. In order for a person to have a good sexual health, it involves positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences without any coercion, discrimination and violence.(5)

According to latest revision of DSM-5, FSD is categorised into three groups which are female sexual interest/arousal disorder, female orgasmic disorder and genito-pelvic pain/penetration disorder.(6) The criteria include distress as the consequences of painful sexual activities, disruption in orgasm, arousal and desire. A Consensus Statement from the Fourth International Consultation on Sexual Medicine 2015 defined female sexual dysfunction (FSD) as the distress associated with sexual symptoms that last at least three months and occur in at least 75% of sexual experiences.(7) There is a growing interest among the main body of research onto this disorder because it is a known predictor for quality of life. The prevalence

of FSD among primary care population in Malaysia is 29.6%(8) and reported to be much higher in population with chronic disease. (9-11)

1.3 BREAST CANCER: FACTS FROM GLOBAL AND LOCAL

My engagement with women with breast cancer occurs because I am a family medicine doctor. I am their first point of contact for clinical diagnosis and further referral to respective surgical team in hospital. Following that, I would maintain the role as family doctor to these women and attend to any health concern throughout their lives.

Globally, breast cancer is the most prevalent malignancy affecting women. According to the estimated statistics from World Health Organization in 2018, approximately 2.0 million women were newly diagnosed with breast cancer that made up to 11.8% of all new cancer cases.(12) It contributed to nearly 6.6% of cancer mortality across the all sexes and all ages worldwide.(12) In Malaysia, it is the commonest type of cancer among women from 2007 to 2011 with total of 18,206 cases that accounts for 32.1% of total cancer cases.(13) Chinese ethnicity has the highest number of incidences then followed by Malay and Indian. Nearly 56% of cases presented at early stage (Stage I and II) due to the introduction of national screening mammogram and heightened public awareness. (13)

Improved survival among women with breast cancer had been attributed to advancement of treatment modalities in the recent years and subsequently led the paradigm to shift from dying to living with the disease.(14-16) Local study showed overall observed survival rates at one, three and five years were 70.8%, 56.9% and 49.4% respectively.(17) The study also showed women in Malaysia were diagnosed at early age whereby nearly 51% of the cases were diagnosed before the age 50 years old. Therefore, breast cancer survivors in Malaysia are relatively young after one to six years of treatment.

Literatures highlighted the prevalence of FSD among women with breast cancer globally ranged between 31-77%.(18-21) ~~In our phase two study, the prevalence is 73% which is lower than prevalence study done by Norley *et al* (22) in 2014 that reported up to 90% women with breast cancer struggled with sexual dysfunction because both used different instruments. Our study also reported three significant associated factors that influenced the FSD score are family history of breast cancer, duration of marriage and frequency of sexual intercourse.(23)~~ Norley et al (22) in 2014 reported up to 90% women with breast cancer in Malaysia struggled with sexual dysfunction.

1.4 VULNERABILITY OF SEXUALITY PROBLEM AMONG WOMEN WITH BREAST CANCER

I learn that breast cancer is a complex traumatic experience with intense impact on all facets of human's life including her self-identity, social relations and psychosexual functioning. Life journey of women with breast cancer is accompanied by shadow of changed in sexuality as they have to die to the old way of being and rebirth with a new way of being by reconnecting and building new relationship with self and significant others.(24)

These women go through the process of exquisite symbol of femininity dismemberment, biopsychological side effects of oestrogen deficiency including poor vaginal lubrication, vaginal atrophy and poor sexual desire; radiation burns that affect their physical appearance and feeling of inadequacy of gendered role in patriarchal ways of society.(24, 25) There is a shift in the recent years among the researchers to move beyond the focus of negative consequences following breast cancer and begin to examine the positive aspect in view of

contention that people can experience positive changes in their lives after traumatic events and illness.(26)

1.5 EXPERIENCES OF WOMEN WITH BREAST CANCER: WHAT ARE THE CONSEQUENCES AND COPING STRATEGIES?

My next question for the literature research is about the experiences of women with breast cancer identified having sexual problem. The women in these studies addressed two elements when talking about experiences with the illness: consequences and coping strategies. (Referring to the literature review, not my research finding)

1.5.1 CONSEQUENCES OF SEXUAL DYSFUNCTION

Literature on Western and non-Western women showed that breast cancer affected all three domains of sexual dysfunction; decreased sexual desire, dyspareunia and difficulty to reach orgasm.(27-31)

In the western literature, majority of these women reported negative adjuvant treatment-related side effects including absence of breast sensitivity following radiotherapy, reduced vaginal lubrication and lacked sexual desire after chemotherapies that disturbed the sexual activities.(32-34) Most of them also remarked surgical procedure was a direct assault to their body via dismemberment of femininity exquisite symbol that resulted in body image mutilation.(3, 26, 33, 35, 36) Another common emerging theme was psychological distress to adjust to the 'new body' that was often associated with pessimistic views and concern about their spouse's reaction.(2, 26, 33) Minority of them described change in the priority as survival issue had superseded sexuality.(33)

Relationship problems as a result of women's sexual problems were reported. A lot of them highlighted reduced intercourse frequency, complicated and less spontaneous sexual activities that contributed to major restraint or even breakdown to the relationship.(35-39) On the contrary, there were a few of them appreciated positive discourse in which breast cancer diagnosis had increased sense of tenderness, heightened gratitude towards the partners and maintained good sexual relationship.(2, 36-39)

Convergent findings were reported in non-Western literature regarding sex paucity due to physical side effects of adjuvant therapies;(30, 40, 41) emotional distress towards the partner's negative response;(41) non acceptance to the disfigurement after surgery and self-identity crisis;(29, 30, 41, 42) marital distress and disharmony.(30, 40) These studies also reported distinct outcome in which majority of these women described negative impact on sexual relations following FSD (30, 40, 41) but a few of them experienced positive appreciation towards the husband and discovered a new meaning of sexuality.(29, 42, 43)

Studies that were conducted among Muslim women reported different findings in view of highly patriarchal family structure and sexuality was viewed as taboo. Dominant male sex drive discourse had obliged them to engage in intercourse despite various sexual problems and their feminine role in the society to sexually attract the husband was severely impaired following breast cancer illness.(40, 44) Whereas minority of Asian women had misconception about sexual activity as the cause of cancer metastasis therefore hesitancy in resuming sex after the diagnosis.(30, 41, 45) One Indian study revealed oppressive stigma towards those who lost the breast due to cancer diagnosis and this cultural value had contributed to the development of FSD.(42)

1.5.2 COPING STRATEGIES FOR SEXUAL DYSFUNCTION

Coping has been defined as "a process, that is efforts to manage stress that change over time and are shaped by adaptational context out of which it is generated".(46) Study showed that passage of time did not erase the 'damage' caused by breast cancer as women continued to use strategies to handle the negative experiences and for self-enhancement beyond treatment completion.(26)

Literature on coping strategies among women with breast cancer to overcome sexual problem is scarce. Western literature reported that women initiated open communication to articulate the needs and feeling of in order to negotiate their sexual life;(2, 16) tried to reduce the discrepancy between their post and pretreatment (ideal) bodies by donning different style of clothing or substitute with brassieres, prosthesis and wigs;(26, 36, 42) seeked assistance from healthcare professionals in order to adapt to sexual life after breast cancer;(2) redefined 'the self' and accepted themselves in a different way beyond appearance throughout the journey of personal maturity;(24, 26, 36, 39) cultural-based social support group to alleviate the sexual concern through illness interpretation and adaptive coping.(25, 30, 35, 47) A few non-Western studies reported that religion and spirituality play pivotal roles in order to minimize sense of helplessness and passive acceptance among women with breast cancer.(48-51)

There was broad spectrum of values in relation to the importance of couple's sexual bond were held which determined the coping style towards the sexual changes. For women who put much importance on the sexual bond with their partner, the changes could be a serious problem leading them to take active measure by assertively seek partner's understanding through open communication but otherwise, those who did not regard the sexual changes as a

serious threat to the couple's integrity would take a -wait-and-see attitude.(41) In the end, those who experienced good support, love and confirmation as direct consequences from coping strategies reported high level of gratification from affective relations even though erotic part was dampened.(30, 36, 41)

1.6 HELP-SEEKING BEHAVIOUR OF WOMEN WITH BREAST CANCER REGARDING SEXUALITY AND SEXUAL DYSFUNCTION

Based on the above-mentioned consequences and coping strategies among women with breast cancer when faced with sexuality problems and sexual dysfunction, my next question for the literature research was about health-seeking behaviour of these women. The increased awareness of sexuality issue in breast cancer illness did not translate into improved sexual healthcare service. Hill *et al* (52) reported that 40% of breast cancer survivors expressed interest in receiving sexual healthcare but only 7% had sought medical help. It was further supported by a French study that concluded sexuality remain insufficiently addressed despite increased attention about quality of life for the survivors.(53) It was postulated that sexuality and intimacy remained invisible in the healthcare setting due to structural influences governing the clinical cultures, invalid assumption; mismatched priorities between clients and healthcare providers.(34, 54) Embarrassment, privacy and confidentiality factor together with perceived lack of understanding from other people's perspectives were the contributing reason for negative help-seeking behaviour.(30, 55)

1.7 WHAT IS MISSING IN THE LITERATURE?

From the literature, sexuality problem and sexual dysfunction is highly prevalent across the regions with multitude associated factors and similar prevalence were also reported in this country. Qualitative analysis revealed that despite the vulnerability of women with breast cancer to the sexual crisis, diverse consequences and coping strategies were identified. Our local studies had focused on various aspects such as social support, body image, quality of life and psychological aspect.(56-59) Qualitative literature highlighted detrimental effects through altering their symbol of femininity and negative psychological state takes place following breast cancer treatment that contributed to strained relationship.(45, 58) However; contrary to high prevalence of FSD, sexual supportive need among women with breast cancer in this country were reportedly low which was posited due to underreporting of sexual needs as Asian community preferred to discuss it behind closed door.(60) This converged with recent exploration of breast cancer experiences among Malaysian women that revealed no sexual problem among them.(61)

The conflicting evidence between high prevalence and low supportive need strengthened my aspiration to explore on the consequences and coping strategies of women with breast cancer in regard to sexuality and sexual dysfunction in this country. Malaysia is multi-ethnic region and sexuality is fundamentally bounded by socio-religious values; hence I believe this study will provide essential baseline information regarding the consequences and coping strategies of sexual dysfunction among these vulnerable women.

1.8 THEORETICAL FRAMEWORK: UNDERSTANDING AND EXPLAINING THIS RESEARCH

It is important to explore any relevant theoretical underpinnings that can help me to understand the lived experiences of women with breast cancer identified having sexuality problems and sexual dysfunction. Based on literature research, I decided to adopt sexual script theory to explain the consequences and meaning-making theory to understand the coping strategies of the women.

1.8.1 SEXUAL SCRIPT THEORY

Sexual script theory contends that human use scripts to guide their sexual conduct in similar ways the actors use scripts to guide their performances and communication within a theatre.(4) It was first theorised by Simon and Gagnon (4) in 1973 that sexuality and sexual behaviour are social process rather than biological imperative. Simon and Gagnon further argued that most of social life must operate under the guidance of an operating syntax and scripts are metaphor for conceptualising the production of behaviour within social life.(62) The aim of this theory is to recognise the determinants (experiences) that encourage individuals to participate in certain sexual activities.(4)

Scripting exists at three distinct levels in order for behaviour to occur: *socio-cultural scenario, interpersonal scripts* and *intrapsychic scripts* that transect in static or dynamic way but not necessarily equally relevant in all situations.(62, 63) The static direction can be illustrated from the shared *socio-cultural* context among members of the society involving media, local authority, government and religious bodies that acts as "instructional guides" to regulate acceptable sexual conduct.(4) On the other hand, the dynamic aspect of *socio-cultural* context conjectures that the scripting may vary across the place, generation, socio-demographic background and *interpersonal* determinants.(4) In my study, *socio-cultural* perspective

involving Malay *Adat* and Islamic religious belief dominated the script of women with breast cancer when faced with sexuality and sexual dysfunction.

The *interpersonal* script determinant takes place at the level of social interactions when actors (individuals) cognitively convert the scripts they have learnt from sociocultural scenarios to be adapted into specific relational circumstances.(4, 62, 63) They represent the dyadic process whereby partners act as social actors and became partial scriptwriter by negotiating appropriate conduct and making it congruent with desired expectations.(63) In my study, I would like to explore the communication between breast cancer women with the spouse and healthcare providers within the specific circumstance of sexual dysfunction. It is important to understand the scripts these women use to explain the situation they are in and how they adapt within the relationship when FSD hindered them from meeting the desired expectations.(4)

Intrapsychic script represents 'internal rehearsal' when alternative outcomes are available in the circumstances of highly taxing *socio-cultural* and *interpersonal* scenarios. It occurs when complexities, conflict and/or ambiguities became endemic at the level of *socio-cultural* scenario and much greater demands are placed on the actor that cannot be met by *interpersonal* scripts alone.(62) In the literatures, differing assessment were reported whether breast cancer experience has enriched or worsened the sexual life that illustrated the dynamic process of *intrapsychic* scripts depending on individual's personal experiences and meanings.

1.8.2 MEANING MAKING THEORY

I use meaning making theory to explain the coping strategies in order to overcome sexuality problem and sexual dysfunction among women with breast cancer. Park and Folkman (64) theorised that destructive and traumatic life events lead people to question why it happened to them and they will make 'meaning out of the event' in the process of looking for explanation.(51)

For this study, I apply the modified meaning making theory that posit coping strategies are primarily driven by type of 'approach' and 'focus' as reported in a grounded theory analysis on Chinese women with breast cancer.(65) These two conditions are the discriminating factors in describing the distinctive outcomes of psychological adjustment among women with breast cancer - *Fighter*, *Follower*, *Struggler* or *Bearer*. Those who focus on finding solution and prefer active approach will *fight* and seek help and treatment. Fighters usually settled the actual problem by trying their best to control it. Women who *follow* the natural cause usually focus on the coping but rather simulate yielding approach and would only accept help when offered. On the contrary, individuals who *struggle* with their life event often focus on the problem and assimilate active approach which often contributed to anxiety and depression. Similarly, those who focus on the problem but use yielding approach with *bear* the situation as they assumed it is unmanageable and lead to rumination.

1.9 FIGURES

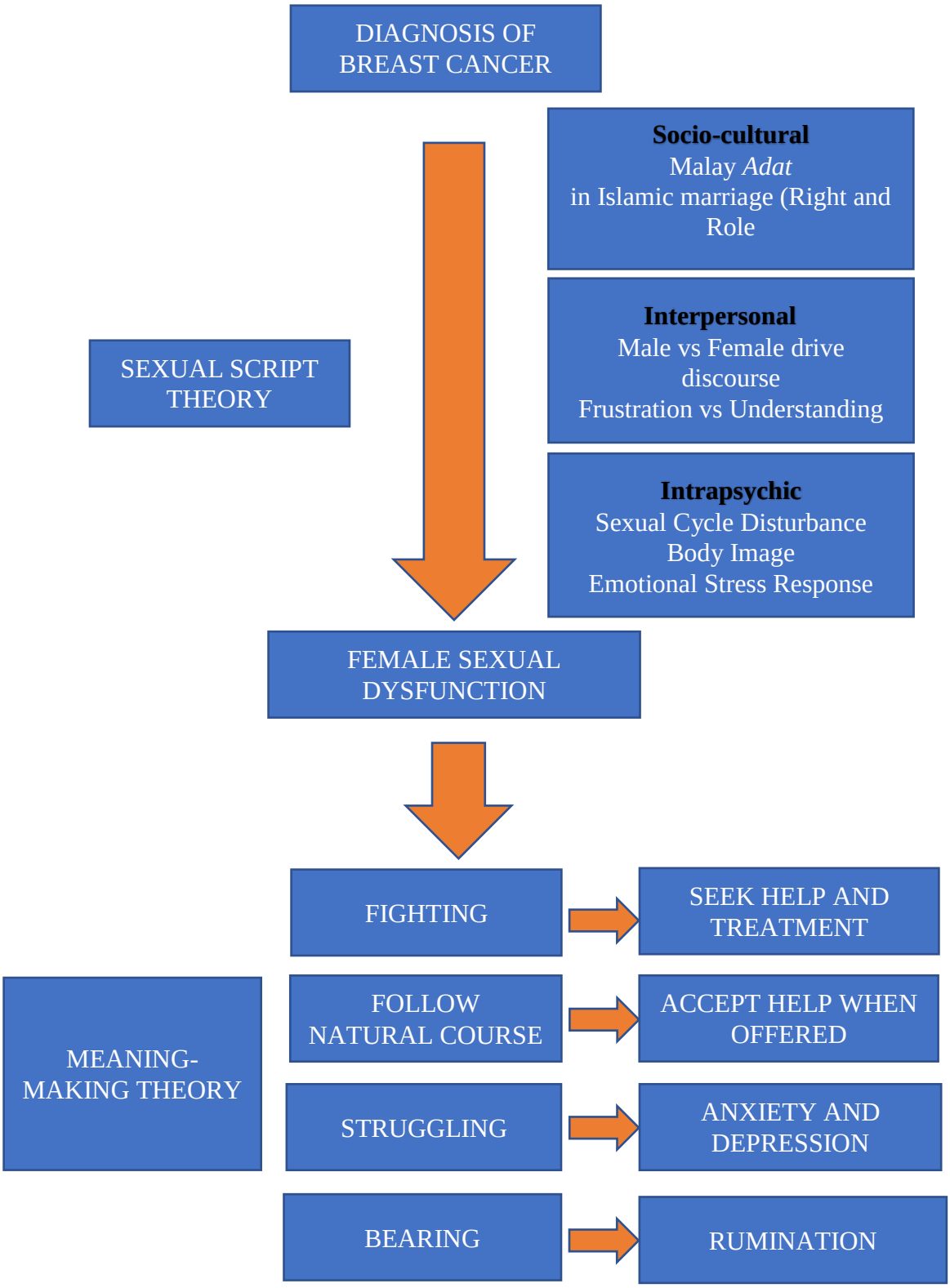

FIGURE 1: Sexual script theory adapted from Simon & Gagnon (62) and meaning-making theory for women with breast cancer adapted from Ching (65)