

Life Experiences and Coping Mechanisms among Breast Cancer Patients in an Urban Malaysian Hospital: A Qualitative Study

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ABSTRAK

Kanser payudara adalah antara kanser tertinggi yang menjejaskan kualiti hidup dalam kalangan wanita di Malaysia. Walaupun sangat sukar untuk menentukan kualiti hidup (QoL) dengan tepat, ia mempunyai konsep yang luas dalam mempengaruhi kepuasan hidup secara global, yang merangkumi kesihatan yang baik, perumahan yang mencukupi, pekerjaan, keselamatan peribadi dan keluarga, interelasi, pendidikan dan riadah. Dalam kajian ini, kami berhasrat untuk membincangkan perubahan kehidupan apabila pesakit didiagnosis dengan kanser payudara dan persepsi mereka terhadap sokongan sosial yang diterima. Kami juga membincangkan faktor kerohanian sebagai mekanisma pesakit untuk mengatasi keadaan kesihatan mereka. Kajian ini dijalankan dengan menggunakan kaedah persampelan yang purposif. Persepsi sokongan sosial, kualiti hidup, dan faktor keagamaan dibincangkan melalui perspektif sembilan orang pesakit kanser payudara dengan temu bual yang terdiri daripada soalan separa berstruktur. Metodologi asas kualitatif interpretasi telah digunakan untuk menganalisis persepsi sokongan sosial dan faktor keagamaan sebagai mekanisma adaptasi pesakit. Keputusan menunjukkan bahawa semua pesakit kanser payudara melaporkan sokongan sosial yang baik daripada keluarga dan rakan-rakan kecuali seorang pesakit. Lima tema telah dikenalpasti iaitu corak kehidupan, suasana sokongan, pembuatan keputusan dan orang yang dipercayai dan tempat mengadu, harapan, dan pertahanan psikologi serta kerohanian. Tujuh daripada sembilan pesakit melaporkan bahawa agama membantu mereka untuk menghadapi penyakit ini dengan mengekalkan harga diri, memberikan rasa makna dan tujuan, memberi keselesaan emosi, dan memberi harapan. Kesimpulannya, sokongan sosial dan faktor keagamaan adalah sangat penting dalam kehidupan pesakit kanser payudara dalam menangani keadaan kesihatan mereka.

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Kata kunci: kanser payudara, kerohanian, kualiti hidup, sokongan sosial

ABSTRACT

Breast cancer is top-ranking cancer that affects the quality of life among women in Malaysia. Although it is very difficult to define the quality of life (QoL) precisely, it has a broad concept that affects global life satisfaction, which includes good health, adequate housing, employment, personal and family safety, interrelationships, education, and leisure pursuits. In this study, we aimed to discuss the life changes upon being diagnosed with breast cancer and their perception of social support. We also discussed the spirituality factor in patients' coping mechanism with their health condition. This study was carried out using a purposive sampling method. The perception of social support, quality of life, and religiosity factor is discussed through the perspectives of nine breast cancer patients with an interview consisting of semi-structured questions. Basic interpretive qualitative methodology was applied to analyse the perception of social support and religiosity factor as a coping mechanism. The results showed that all the breast cancer patients reported good social support from family and friends except for one patient. Five themes were identified, namely patterns of life, supportive atmosphere, decision making and confidence, expectation, as well as psychological defences and spirituality. Seven out of nine patients reported that their religion helped them to cope with the disease by maintaining self-esteem, providing a sense of meaning and purpose, giving emotional comfort, and providing a sense of hope. In conclusion, social support and religious factor are very important in the lives of breast cancer patients in dealing with their health condition.

Keywords: breast neoplasms, quality of life, social support, spirituality

INTRODUCTION

The Malaysian National Cancer Registry (NCR) 2012-2016 reported that the three most common cancers among Malaysian residents were breast cancer (19.0% of all cancer cases), colorectal cancer (13.5%) and lung cancer (9.8%) (National Cancer Institute 2019). Breast cancer accounted for 34.1% of all cancer among females in Malaysia, with as much as 21,634 cases. The incidence and cumulative

risks of breast cancer was highest among Chinese, followed by Indian and Malay. The overall lifetime risk was 1 in 30 in Malaysia with the most breast cancer patients presented at the ages of 45-69 years.

The diagnosis of breast cancer is a significant stressor that may be overwhelming and negatively affect the patients quality of life (QoL). The QoL is the measure of the patient's perception of self-well-being. It is comprised of psychological, physical,

cognitive and social functioning (O'Neil et al. 2013). QoL is important to everyone and although it is difficult to define it precisely, QoL has an innate meaning to most people. Over time, the survival rate among breast cancer patients has improved with early detection and advances in cancer care. Nevertheless, the current focus in cancer treatment does not only centre on the disease control but also the general well-being of the patients.

In the context of health care, QoL applies to life concerns that are most influenced by health or disease, thus the term "health-related quality of life" (HRQL) (Karimi & Brazier 2016). According to Cella and Stone (2015), HRQL is defined as the extent to which one's QoL, or one's usual or expected physical, emotional, and social well-being are affected by an illness or its treatment. Every person has different expectations and coping abilities regardless of the severity of their illness. Even patients with similar objective health status may experience different HRQL. As a result, the measurement of HRQL should be from the individual's perspective whenever possible. The importance of obtaining HRQL reports from patients themselves is highlighted by a substantial literature reporting different estimates of symptoms and HRQL between patients and their physicians (Sharif 2017).

A life-threatening disease such as breast cancer has caused significant life experience to the patients and their spouses. Patients' QoL and overall survival are predicted by the psychological symptoms. When compared to normal populations,

many breast cancer survivors were diagnosed with mild to moderate level of depression (Reich et al. 2008). In contrast, a cohort study by Ng et al. (2015) concluded that Malaysian female breast cancer patients had relatively better QoL and lower level of anxiety and depression which reflects the importance of social support for these patients. Besides social support, health literacy and access to health information also improve QoL by decreasing the levels of depression and anxiety (Kugbey et al. 2019).

Although social support from family and friends has been extensively studied, little is known about how social support received by the patients really helped them in dealing with the illness. Research in psycho-oncology probes into the psycho-social and emotional aspects of cancer and their relation to health and overall patient care. Coping with cancer is a prime focus for researchers in view of its impact on patients' psychological well-being and life in general. Studies have revolved around quantitative study designs such as questionnaires to study the coping strategies used by breast cancer patients and their quality of life.

Few studies have used qualitative designs such as semi-structured interviews to investigate coping mechanisms of patients diagnosed with breast cancer. By using qualitative research design it allows a profound understanding of the reasons, processes and strategies that patients use to cope with cancer. Hence, this study aimed to discuss the life changes upon being diagnosed with breast cancer among

patients in Ampang Hospital and their perception of social support. We also examined the spirituality factor in patients' coping mechanism with their health condition.

MATERIALS AND METHODS

Study Design

This study was conducted over seven months from September 2018 to March 2019. Study approval was obtained from the National Medical Research Register (NMRR), Ministry of Health Malaysia (Number: NMRR-162853-31908). Ampang Hospital, a premier secondary-care and tertiary-level government hospital was selected to recruit eligible subjects, which includes both inpatients and outpatients.

Respondents were picked based on purposive sampling. Saturation was used to establish adequate data from the study to establish a justifiable and valid understanding of the study phenomenon (Saunders et al. 2018). Inclusion criteria for subjects were as follows: (i) they were recently diagnosed with breast cancer regardless of stage; (ii) waiting to receive treatment; (iii) receiving or had received all or any three modalities of clinical treatment (surgery, radiotherapy and/or chemotherapy); and (iv) currently undergoing follow-up appointments after the primary clinical treatment of cancer, with breast cancer diagnosis confirmed in the hospital records. Those unable to converse in Malay or English were excluded.

Data Collections

Patients were approached in the surgical ward or the surgical outpatient clinic, where they were briefed regarding the purpose of the research and signed a consent form upon agreement to participate. In-depth individual interviews were conducted by two researchers to avoid bias. The qualitative approach used in this study aimed to gain in-depth understanding on the life experience of breast cancer patients. The data were collected using semi-structured and in-depth individual interviews which were all audiotape-recorded. The interviews were done in an isolated room to ensure the patients' comfort and safety.

The semi-structured questionnaires were developed as guidance during the interview. The questionnaires were in English and Malay language and was pre-tested for content validity among breast cancer patients and survivors. The questions were prepared after an extensive literature review (Streubert & Carpenter 1999; Berterö & Chamberlain Wilmoth 2007; Gurm et al. 2008; Cebeci et al. 2012; Phenwan al. 2019). The interview session were divided into general and specific questions as presented in Table 1. Probing questions were also asked during the interviews to achieve maximum variation, richness, and depth of interviews. The average time for the interview process is 40 minutes.

Data Analysis

Each recorded interview was transcribed verbatim for qualitative analysis. The basic interpretive study using thematic analysis was used in

Table 1: Semi-structured interview questionnaires

Sections	Items
General question	1. Can you describe (or tell more) about your life experience upon being diagnosed with breast cancer? [Probing]. 2. How do you feel right now? 3. What do you need the most at the moment? 4. Do you think religion helps you in facing breast cancer?
Specific questions	1. What do you think of social support from family and friends that you've received? [Probing]. 2. How would you rate the social support that you received from 1 until 10? [Probing]. 3. Who is the closest person that you would share and discuss with when making decisions? 4. Do you think this is a test from god or misfortune (bala)?

this qualitative methodology as it is the best approach for the individual to construct the reality in interaction with their social worlds. In addition, this approach is applicable when the interviewer wants to explore the meaning of a particular phenomenon (Merriam & Grenier 2019).

RESULTS

In total, nine patients consented to the interview comprising four Malays, four Chinese and one Indian. They were between 45 to 71 years with a median age of 60 (IQR: 55-69). The monthly household income ranged from RM200.00 to 4000.00 (USD 48.64-972.76), with a median of RM1800.00 (IQR: 400-2000). Their demographic details are as illustrated in Table 2.

Theme 1: Pattern of Life

Most patients described that they were trying to keep their life as normal, as they could do the same life that they had prior to the diagnosis.

However, patient 4 who underwent chemotherapy admitted that she felt lethargic especially after chemotherapy thus she had difficulty doing her routines especially heavy activities.

“After chemotherapy, I always feel nauseous and unable to do heavy activity. Otherwise, I can still do house-chores and ride my grandchildren to school” - Patient 4

All of them admitted that they had emotional disturbance upon being diagnosed but with time and the help of their respective coping mechanisms, they were able to accept it. Such a description can be seen in patients' narration as follows when they were asked about the life changes they went through upon diagnosis of breast cancer.

“I feel sad, but I never tell the kids that I feel sad as I don't want the kids to be sad as well.” -Patient 2

“I feel slightly worried but I believe God is with me all the time.”- Patient 8

It was observed that some of the patients with late stage breast cancer experienced activity limitation but

Table 2: The socio-demographic data of the respondents patients

Patients	Age	Race	Religion	Marital status	Highest level of education	Occupation	Monthly household income	Breast cancer stage
Patient 1	65	Malay	Muslim	Married	Secondary	Housewife	RM200	Stage 3
Patient 2	55	Malay	Muslim	Widow	Secondary	Hawker	RM400	Stage 4
Patient 3	69	Chinese	Buddhist	Married	Secondary	Housewife	RM4000	Stage 1
Patient 4	45	Malay	Muslim	Widow	Secondary	Babysitter	RM1800	Stage 3
Patient 5	60	Chinese	Buddhist	Married	Secondary	Housewife	RM2000	Stage 2
Patient 6	49	Chinese	Buddhist	Married	Primary	Housewife	RM300	Stage 1
Patient 7	60	Indian	Hindu	Married	Secondary	Housewife	RM900	Stage 1
Patient 8	69	Chinese	Christian	Married	Primary	Housewife	RM2000	Stage 2
Patient 9	71	Malay	Muslim	Widow	Secondary	Housewife	RM2000	Stage 2

some patients with early stage claimed that they have no significant changes in their life.

"I think nothing much changes in life. Of course, I was thinking about my family, but they said don't worry. They said do not worry so much because it is just a small lump and early stage. I still go to the market and everywhere else. No need to stay in the house all the time. If you think negatively, you will get scared more." - Patient 7

"I was a bit surprised. But there is no change in my life. I still can cook for my husband and my son. I love cooking. I still go to church, clean up the house. But not heavy activity because I easily get tired. Because of that, I need to sleep to regain my strength. I pray more after knowing about the diagnosis." - Patient 8

Theme 2: Supportive Atmosphere

Supportive atmosphere is a common theme narrated by almost all patients in this study. When they were asked what they need the most in their life

at the moment, all of them answered they needed support from family and friends. Their family was always there for them when needed. Patient 7's family always gave her motivation and moral support to be positive with her life and illness.

"They said do not worry so much because it is just a small lump and early stage. I went to market and I go everywhere. No need to stay in the house all the time. If you think negative, you will get scared more." - Patient 7

The patients were also asked about the social support that they received from their family and friends and how much they would give the score for the support from 1 until 10. Most of the patients gave full marks of what they think of the satisfaction of social support given by family and friends.

"I am really satisfied with the support that I have now. I enjoyed socialising with friends. My kids always bring me to karaoke." - Patient 2

"I got full support from my family. They always said, 'Don't worry, be cheerful, take precautions'." - Patient 7

Patient 8 gave half of the scores as she felt that she did not receive much support from the family as they are very occupied and busy with other commitments such as work and studies. The patient also hid her breast cancer diagnosis from her son due to the fear of burdening him.

"I give 5 over 10 because sometimes they are too busy, come back late at night. My husband works in insurance company and meet clients at night. I let all of my children know, except my youngest child overseas so he won't worry but I wish he was here beside me." - Patient 8

Patient 4 was worried about balding following chemotherapy but was grateful to have her supportive and encouraging husband.

"I am worried about becoming bald after chemotherapy. I am fortunate my husband supports me no matter my condition. He (the husband) also encourages me to continue my treatment in the hospital." - Patient 4

Additionally, patient 6 stated that connecting such cancer patients to the non-governmental organisations (NGOs) may prove to be beneficial in terms of social support and compliance to treatment.

"There are breast cancer NGOs that can provide wigs for patients like me and sessions for the patients to support each other." - Patient 6

Theme 3: Expectation

Most of the patients described that they need the company and comfort from family and friends when they were asked what they need the most

at the moment. However, based on responses from the patients, it is very difficult to differentiate what patients really want and what they are actually experiencing in their life.

"I need company. I do not want to be left alone. Whenever I am left alone, I will feel sad and cry. My kids always accompany me." - Patient 2

"I need comfort from family and to be surrounded by them. "Don't worry, we are here to help you, we are going to look after you," my siblings said. I am very happy" - Patient 7

"My family is always with me; they gave their full support especially my eldest son. He said, "Mom, do take care of yourself first, don't worry about me" - Patient 8

Theme 4: Decision Making and Confidant

The patients were asked about the closest person that they would share and discuss things with when making decisions. Most of the patients tend to share and discuss their life with those closest to them who are able to listen and respond appropriately to their concerns.

"My kids, especially the second child." - Patient 2

"I usually discuss with my eldest daughter to make decisions. I got full support from my children and I like to share with them." - Patient 3

When asked about their spouse role in decision making and confidant, Patient 5 said that she preferred to share with her daughter and sisters compared to her husband as the husband does not listen to her and the

husband sometimes does not respond much to what she is saying.

"He listens but he doesn't know how to respond to me. Sometimes I know he was listening, but his mouth didn't say anything." - Patient 5

Whereas patient 8 will share with her husband and also the trusted church member as she narrated,

"I usually make decisions by myself. My husband will just be fine with whatever I have decided. My husband is the closest to me. I love to share with church members and my husband." - Patient 8

Theme 5: Psychological Defenses and Spirituality

Spirituality plays an important role for breast cancer patients to alleviate psychological distress. Elements such as acceptance, optimism, and comparing self to the those who are less fortunate may help the patients to defend or shield themselves from detrimental psychological aspects that may worsen their well-being.

"When I try to compare myself with other people, I am luckier than those who don't have any family members or shelters to live in. I am grateful for who I am and able to accept this fate." - Patient 1

"I was initially feeling depressed, disappointed, and sad. Over time, I was able to accept my fate. I live my life for my children." - Patient 9

Seven out of nine patients shared that their religion helped them cope by maintaining self-esteem as well as providing a sense of meaning and purpose, consolation, and a sense of

hope.

"I feel calmer and closer to God. I follow the advice from Ustaz Kazim Alias (Islamic preacher) to recite certain verses of the Quran after prayer. I feel that this is a test for me to expiate my sins. I accept my fate." - Patient 2

"Breast cancer makes me feel a deeper connection and closer to God. When I get sick, I will seek help from Him. So, if anything happens to me (i.e. if I die), I will be with Him. If I run away from Him, where can I go to? who else should I turn to? His (God's) words encourage me more and strengthen me. It makes me feel secure." - Patient 7

"I improved a lot in my worship. I do my prayer early, right after the adhan (call to prayer). I also do additional prayers like solat Hajat and solat Taubat. I assume this is a test for me to be stronger and as kafarah [expiation] of my old sins." - Patient 8

DISCUSSION

The qualitative data obtained in this study provide preliminary insights into the experiences of Malaysian women with breast cancer. The results show the multidimensional effects of breast cancer on women's health in multiple dimensions. Although various studies have been done to understand the psychosocial aspect of breast cancer, only a small number of studies have touched on the living experience of women diagnosed with breast cancer. Throughout this study, the present knowledge was added by portraying the living experience of breast cancer patients. The patients

described their life experiences by means of their emotional reactions, fight for fulfilling life expectations with current illness, psychological defenses, and struggle for normal life as well as making decisions and having the best confidant that can listen and respond appropriately. Eventually, all these themes will ultimately aid in increasing the QoL of breast cancer patients.

Physical and mental issues arising from various breast cancer treatment modalities as well as issues with social life, future uncertainties, and spiritual problems affect the well-being of the patients (Julkunen et al. 2009; Oh & Cho 2020). In our study, patients highlighted the importance of family support to help them brave through their breast cancer journey. This includes physically and psychosocial support. Various supportive behaviours that were described by the breast cancer patients include psychological, emotional, and instrumental support (Kugbey et al. 2019). Furthermore, aside from spouses, family members giving support were mostly comprised of women. In fact, one of the patients in this study preferred to share her problem with her sisters instead of her own spouse. This is unsurprising as women are generally the primary caregivers. Family and friends, especially women, tend to strongly support women with breast cancer (Berterö & Chamberlain Wilmoth 2007). However, support from both the spouse and other family members are equally important for the breast cancer patients to best cope with their illness (Julkunen et al. 2009).

Social support is crucial in handling

cancer cases (Cheng et al. 2013). Most cancer patients that received and wanted social support from their friends and family perceived it as helpful in dealing with their condition (Finck et al. 2018). The outcome of this study supports this observation; Some patients claimed to experience a lack of social support and expressed that they do not want to be left alone and wanted to be accompanied by their family and friends. The need for support from family members were also expressed by patients who claimed to have enough social support. They wanted to be seen, listened to and understood by those who were closest to them. This suggests that patients who felt they received “inadequate support” had troubles to adjust and increased feelings of stigmatisation, which were expressed as feelings of isolation, avoidance, feeling “branded” and “abnormal” (Else-Quest & Jackson 2014). Lack of social support may be damaging to breast cancer patients as those who perceived high level of satisfaction of social support reported better emotional stability and decreased depressive symptoms (Ernst et al. 2017; Thompson et al. 2017).

Moreover, the stigmatisation of cancer often leads to withdrawal of support and avoidance behaviour among family members and friends towards breast cancer patients (Ernst et al. 2017). This occurs because the family members and friends were uncomfortable with the notion of death and dying, and may wrongly view cancer as contagious and bringing shame to the family (Yeung et al. 2019). These group of people were also

unsure of the appropriate ways on how to act towards breast cancer patients. This includes not knowing the right thing to say or even accidentally saying the wrong thing to the breast cancer patients. Cancer stigma showed the strongest association with the degree of psychosocial adjustment among cancer patients (Kang et al. 2020). Thus, healthcare professionals should assess for stigmatisation among these group of people towards breast cancer patients, and also self-stigmatisation among the patients themselves in order to address the issues and develop patient-tailored stigma management programmes.

Based on the responses from the patient, it is very difficult to differentiate what patients really want and what they are actually experiencing in their life. Health-related QoL is the gap between patients' expectations and our experience of health. It cannot differentiate between changes in the experience of disease and expectations of the disease (Carr et al. 2001). Perception of QoL has interindividual variability and is dynamic in nature. Individuals with different expectations will experience different QoL even though they have the same clinical conditions, and those whose health has changed may report the same level of QoL with repeated measures. Thus, further studies and more concise questions should be constructed to achieve the objective.

Most of the patients in this study reported that their religion helped them cope with their illness by maintaining self-confidence, providing consolation and a sense of hope. This was consistent with a systematic review

that provided evidence of spiritual or religious coping conferring such benefits to cancer patients (Thune-Boyle et al. 2006). Positive religious coping is viewed as a manifestation of a secure relationship with a benevolent God. Negative religious coping is seen as a manifestation of a less secure connection with God who is distant and punishing, or as a religious struggle to search for meaning (Pargament et al. 1998). Therefore, any form of religious coping may serve multiple purposes. For instance, meaning in a stressful situation can be sought in various ways; redefining the stressor as a chance for spiritual growth or as a punishment from God (Pargament et al. 2000).

Religious and spiritual beliefs are one of the most important elements in assisting patients to cope with illnesses. For Muslims, prayer is an individual obligation on a daily basis. Previous study showed that 62% of cancer survivors used prayer for health when their perception of illness-related morbidity and mortality increases (Mao et al. 2007). Spirituality, on the other hand, plays an important part in assisting women to overcome thoughts of mortality and help them cope with their illnesses (Vachon 2008). Interestingly, the patients claimed that after the diagnosis, they tended to perform additional prayers such as the repentance prayer, or *solat Taubat*, and the prayer of need, or *solat Hajat*. They would also supplicate to Allah (God) after performing their prayers asking to be cured. Some would also recite the holy Quran and some verses that are believed to be curative. This study suggests that prayer and

spiritual healing have a positive impact on patients' emotional states and physical symptoms. In one study done among Malay Muslim breast cancer patients in Malaysia, the more spiritual respondents reported a better QoL and being less stressed (Sharif & Ong 2019).

This study was done to explore female breast cancer patients' perceptions of their care and needs. The results of this study challenge health care providers and educators to be more mindful of the challenges faced by these women and to ensure that the best possible care provided for these patients. Social support needed by breast cancer patients arise at various stages of the disease and treatment. Social support is indispensable in health care and identification of the shortcomings of support from the patient's perspective may enhance the delivery of more appropriate health care. Since family and friends are the pillars of the cancer patients' social support, it is very important that they be well-versed on the patients' concerns.

Several limitations were identified. Firstly, this study was done in a tertiary hospital in the capital city of Malaysia. The respondents may not represent the general population in Malaysia. Future research should focus on a bigger group of patients in various other centres. Secondly, qualitative study allows better comprehension of patients but a quantitative method with a standardised method is needed to improve the reliability of data collection. Thirdly, all our patients were either married women or widow

thus their primary focus mainly on their family relationship which is relatable to Asian's culture. Lastly, the time between their cancer diagnosis and the interviews varied from one patient to another. Some of the breast cancer patients may record different adjustments level to one another. We should consider the long term impact of the disease and treatment on the psychological well-being of breast cancer patients. Despite these limitations, the results of this study contributes to an ongoing effort to fill the gap in the literature and to comprehend the life experience of Malaysian women with breast cancer.

CONCLUSION

No illness exists in a vacuum. To healthy people, cancer is one of the scariest diseases which strikes unexpectedly. It is imperative to not only treat the patients but also to improve their QoL as it is the ultimate goal in every individual's life. Improving social support for breast cancer patients can improve their QoL while having inner strength via religion can help patients overcome their fears towards the disease. Social support is required by breast cancer patients and the need may arise anytime throughout their breast cancer journey. Social support is very important in health care and it is crucial that patients' family and friends be well-versed in the patients' true needs. Health care providers may play a crucial role to increase awareness and explain to the patients' family members and friends regarding the importance and impact of their

support.

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